(Not) The 'Right Kind' of Dementia Story: Re/Presenting Identities in Reality Theatre and Performance

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Abstract

This thesis examines a select group of verbatim and autobiographical theatre productions and applied performance practices which use words and stories about, with and by people living with a dementia diagnosis (older adults in the main). It highlights the many ethical, political and aesthetic issues arising from the paradox of theatres that rely on narratives from 'real' people being coupled with people not generally deemed to be 'real' (or even 'people'). In so doing, this thesis makes a critical contribution to theatre and performance studies scholarship by uncovering the scarcely explored relationship between narrative and the construction of 'reality' as 'normalcy' that determines 'reality theatre' practice and scholarship. It also investigates and challenges the regnant function of the story itself in dementia cultures (with implications for applied theatre scholarship) as well as in 'reality theatre'.

In the progress of one of the diseases of the dementia group, memory, cognitive and linguistic capacities, and narrative fitness will be compromised, at some stages quite severely. Almost from the moment of diagnosis, people become enmeshed in socio-cultural discourses casting them as 'strangers', or the 'living dead' and not as 'real' people, often losing their claim to personhood as a consequence. Using a distinctive set of case studies from Australia and the United States of America, this thesis considers how people diagnosed with dementia are represented to publics, as well as the emerging ways in which people represent themselves, assessing to what extent the 'right kind' of dementia story, one of tragedy, loss of personhood and socio-economic crisis, is told. This thesis further proposes that Richard Schechner's concept of 'performance consciousness' can re-cast people living with dementia in terms of possibility, not just in terms of tragedy and loss, re-framing particular behaviours and actions as creative adaptations rather than just as deficit exemplars of insidious diseases.

Declaration

STATEMENT OF CANDIDATURE

I certify that the work in this thesis entitled *(Not) The 'Right Kind' of Dementia Story: Re/Presenting Identities in Reality Theatre and Performance* has not previously been submitted for a degree, nor has it been submitted as part of the requirements for a degree, to any other university or institution other than Macquarie University.

I also certify that the thesis is an original piece of research, and it has been written by me. Any assistance that I have received in my research work and the preparation of the thesis itself has been appropriately acknowledged.

In addition, I certify that all information sources and literature used are indicated in the thesis.

Janet Louise Gibson

Student No: 41405935

Signed:

Dated: 4th December 2015

Dedicated with love and appreciation

to my mother, Barbara, and my brother, Rod,

who both left this world during the research and writing of this thesis,

to my partner, Julia, and my sister Mary Jane,

thankfully still here, and

to my father, Dr Hugh Gibson: a brilliant physician,

teacher and lover of the underdog, who died far too young.

Acknowledgements

This thesis emerged sideways not head on. There was and is nothing 'straight' about how it took shape, perhaps befitting a thesis with dementia at its heart. I want to thank the many people who have travelled with me along this slow, winding, sometimes torturous, but always exciting path.

My mother, Barbara Gibson, was the inspiration for me to undertake the work contained in these pages. Born into the Great Depression and made tough by it, she was a fighter. When diagnosed with "probable" Alzheimer's disease, her response was: "I'm going to beat this disease you know Janet. Can you tell me what it's called again?" She was an agnostic, a non-conformist with left-wing leanings who believed that if there was a Devil he resided in the hearts of racists and bigots rather than in a place in the nether regions called Hell. Her religion was kindness: her Heaven a piece of chocolate — Lindt preferably. I am truly my mother's daughter in this latter regard. My mother took me to my first theatre show when I was seven or eight and as a consequence a love of theatre and performance has never left me.

My brother Rod Gibson was diagnosed with, and died of, lung cancer during my candidature. Without him, it still feels as if all the lights in the world have been extinguished. Rod was a complex and colourful man, with a wicked and well-timed sense of humour. A few days before he died, about to down a dose of medicine, he paused, waited for quiet, lifted up the vial and said, in the little bit of voice he had left, "Cheers". Rod was a talented poet, playwright and actor, with a big, true heart. During his illness, and from his bed, he would send me texts to see how I was faring with my PhD. Once I was at my desk writing and I texted, "Going to have a cuppa". Soon after I texted "Now back to the books". Rod quickly punned back: "Literally?" Thank you Rod.

I have the best sister in the world, Mary Jane (MJ) Gibson, also one of the smartest people I know. MJ is a very talented writer, with a clear understanding of and interest in disability issues and their relationship to performance. She has sat through some very long sessions listening to me

read out chapters and has always made intelligent suggestions for change while still encouraging me. I thank you deeply darling MJ.

Thanks also go to my principal supervisor, Dr Yuji Sone, who encouraged me to continue when, at the end of my first part-time year of candidature, my mother was diagnosed and I was not sure I would be able to press on. Thank you for supporting me in my decision to turn this thesis around to dementia, and for some great suggestions when I was struggling to make sense of what I had undertaken. Thank you also for your careful and critical reading of my work and your uncompromising drive to make both my arguments and my writing clearer. Thanks also to my associate supervisor Dr Nicole Matthews, whose excitement about my project and perceptive thinking helped me feel that I did indeed have something new to contribute to debates in disability and dementia studies. Dr Kate Rossmanith, my first associate supervisor, I thank you for your unbounded enthusiasm and support. And also at Macquarie University, the kindness and help of Associate Professors Peter Doyle and Robert Reynolds have not gone unappreciated. To Susan Lever, Elaine Hudson and Moisés Kaufman, many thanks for the wonderful references that helped me procure a scholarship for the last few years of this endeavour.

I was privileged to work for a while in the writing group run by Professor Bruce Johnson at Macquarie University. This group was crucial in helping me believe that I could write and that I had something important to say. Thanks to Bruce for all the help and support with ideas, refining my writing and reassurances to keep going. I would also like to thank Bronwin Patrickson for getting the group off the ground and Rachael Gunn for keeping it going. Thanks too Bronwin and Rachael for the valuable and insightful feedback as well as to Julia Scott-Stevenson, Çan Yalcinka and Pat Grant. Pat, I treasure the great cartoons drawn on my drafts. Finally, thanks to Kerreen Ely-Harper for some early and very good advice not only on my writing, but on surviving a PhD when I felt I couldn't. You told me to "get counselling and have a massage as often as you can afford to do so". I did both and it has made all the difference. Sandy Kondos deserves a special mention for sitting with me,

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List of Abbreviations

AD: Alzheimer's disease

LR: Life Review

MBDJ: *Missing the Bus to David Jones*

NGOs: Non-government organisations

NHPF: National Health Performance Framework

NIDA: National Institute of Dramatic Art, Sydney

PTSD: Post Traumatic Stress Disorder

RT: Reminiscence Therapy

RTs: Reminiscence therapies

TfD: Theatre for Development

TWIMC®: *To Whom I May Concern*

Introduction

My Mother's Story, My Story

> I can only answer the question 'What am I to do?' if I can answer the prior question 'Of what story or stories do I find myself a part?'

> Alasdair MacIntyre, *After Virtue* (2011:250)

This thesis has emerged out of personal upheaval, curiosity about how stories act in the world and the world in them, and my hope for the transformative possibilities of performance. I will begin with its deeply personal genesis. My mother, Barbara Gibson, was diagnosed with "probable" Alzheimer's 'disease' (AD)[1] in 2008, in the first year of my PhD candidature. A diagnosis of AD is usually traumatic, both for the person and the family: it was so for my mother, my siblings, and myself. My mother entered the dementia wing of an aged care facility a year later. Decisions around institutionalisation are also not easy. We were told by the nursing staff that at the end of her first day Mum put on yellow washing up gloves and, with a hammer in hand (where had she picked that up?), proceeded to the door of the wing, which could only be unlocked by entering a number code on a key pad, and tried to smash her way out in what appeared to be a (dramatic) bid for freedom. It didn't succeed. She stayed in the dementia wing for over a year, moving to the palliative care wing for the last three weeks of her life. With a bolus of morphine dripping pain relief into her belly, unable to get out of bed, to recognise anyone, and struggling for breath, she finally died on the 4th May 2010. She was 81 years old.

This experience turned both my life and my research around. Although not evident at the time, I now see that, as one of my mother's care partners,[2] I entered a new

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[1] I put the word "probable" into quotation marks for reasons which will be enlarged later in this chapter but which in summary are firstly, to do with the continuing disputes over AD as a 'disease' entity (see Beard, 2004 and Lock, 2013); and secondly, to do with the fact that many diagnoses are accompanied by this adjective because of the difficulties in diagnosing AD. Double quote marks are used instead of single to indicate its use by doctors in diagnostic conversations with patients. I put the word 'disease' in single quotation marks because of the already mentioned disputes over AD as a 'disease'.

[2] I prefer to use the term 'care partner' in preference to the phrase 'care giver' to underscore that in this latter phrasing, people living without a dementia diagnosis are linguistically denoted as the givers and those living with a dementia diagnosis are by default, the takers. I think that the dynamics of the relationship between people living with and without a dementia diagnosis are far more complex than this latter phraseology allows. I also maintain that those living with a dementia diagnosis can often give much more to those of us living without a dementia diagnosis than we can know if we open up to the possibilities of the relationship. The term 'care partner' is currently being used more frequently in dementia care practice

'reality' where affect was the grammar of the communication space, not cognition[3] which, in many ways, I preferred to how we had related in the past. Fact merged with fantasy: I found it was not useful in our relationship to insist on distinctions between them. For instance, when my mother talked as if Aunty Enid was still alive, which she was not, I learned to accept this fiction. Insisting that she was *not* alive only distressed my mother. She was alive for my mother so that was 'the truth'. Many 'liminal' spaces like these emerged in our time together: some between imagination and memory; some between the present and the past (but not quite past); some between the woman who I began to see as "not my mother" and also "not not my mother" (after Schechner, 1985: 110-113).[4] As a result of these encounters, I began to comprehend the 'performativity' of dementia, finding fledgling connections between my mother's communication practices and performance theorist Richard Schechner's notion of performativity. Schechner sees it as "occur[ing] in places and situations not traditionally marked as 'performing arts' … [making] it increasingly difficult to sustain a distinction between appearance and reality, facts and make-believe, and surfaces and depths" (2013: 24).

This experience also affected the direction of a thesis originally interested in the intersection between verbatim theatre and ethics. Soon after my mother's diagnosis, I began to wonder if theatre pieces that worked with verbatim input from people living with a dementia diagnosis existed and if so, what ethical provocations

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[3] In considering how we, as cultural and linguistic subjects, get beyond thinking to affect, the work of philosopher Kelly Oliver (2001), and that of the neurologist, Antonio Damasio (2000, 2012) have been valuable. Oliver's work on witnessing relies in part on research from psychology and neuroscience about the intrinsic receptiveness of human sensory-perceptual systems to their environments; it also incorporates theories of the shared embodiment of all humans. From this base, Oliver conceptualises witnessing as a process, not only connected with vision and discourse, but also with interconnected perceptual and energetic systems. She posits that humans are connected to other people through the biosocial energy of their environs (2001: 198). Her notion of witnessing is one that is interested in working with both what can be seen, but also with what cannot be seen, in encounters of the subject with the other. Damasio's ideas about pre-or non-verbal neural structures can be used to understand the idea of a self below language and not just an effect of it.

[4] The woman who was not my mother displayed many exhibitionist behaviours. When we were out shopping once, she grabbed my breasts and then hers, and asserted that hers were bigger than mine. In a scene befitting *Murder She Wrote*, Mum is found by the nursing staff trying to strangle Mavis, another woman with dementia, who can only say one phrase, repeated ad nauseam, day in and day out: "la di da, la di di". But this woman who was not my mother still exhibited many of the behaviours I connected with the mother I knew over the course of my lifetime. She still loved to dance, to sing, to perform as she did for all her children when we were growing up, and as she did flirtatiously to various men she was attracted to when she was single after my father died. She loved to dance to any of the songs on her Nat King Cole CD, putting her hand on her hips and making her performer's face, a pouting one, at the same time. She spent a week, on and off, in the facility, by the bedside of a dying woman, comforting her by stroking her hands and face.

they would offer. Verbatim theatre normally relies on the life stories of 'reliable' narrators and, in oral history projects anyway, the assumption of the cognitive "competency" of the primary teller (Pollock, 2005: 3). But people with dementia are often 'unreliable narrators'[5] who frequently struggle to remember their life stories or segments of it, and who regularly resort to fabrication in the telling. In part because of this, and because of the (often gradual) decline in many of their cognitive and physical capabilities, they are repeatedly stereotyped as the 'living dead' and not as 'real' people.[6]

Furthermore, in living through this experience, I noticed that 'our' story[7] did not match those popularly available, and this piqued my curiosity. As stated earlier, over time I came to prefer many aspects of my relationship with the 'new' mother to whom Alzheimer's introduced me, which is not to say that I saw AD in any way as a gift. Dementia has always been, and probably always will be, a frightening experience with immense physical and psychological challenges for the person diagnosed and for the friend, spouse, partner or family member of that person (Basting, 2009a: 2). But viewing dementia as sheer tragedy, along with notions of 'losing' the mother we once knew, which was how my siblings and I greeted the diagnosis when we first heard it, is not the whole story either. Narrative sociologist Arthur Frank (2010) contends that, although people very much tell their own stories about their lives, they also do not make these stories up by themselves. There is a limited repertoire of stories to be told from which we then tell 'our' stories, as is very evident in the case of dementia. In sum, I found myself part of a story for which no template could be found, at that time, in the existing repertoire.

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[5] The term 'unreliable narrator' was coined in 1961 by Wayne Booth in *The Rhetoric of Fiction* (pp. 158-159) referring to a narrator, most often in literature, but sometimes in film, or theatre, whose credibility has been seriously compromised.

[6] I have placed the word real in inverted commas to highlight the many debates between certain philosophers and disability studies scholars over the personhood of the cognitively disabled and who counts or not as a bona fide person (Kittay, 2009; Kittay and Carlson, 2010). However, I am aware that the real is not only a philosophically contentious idea but that, especially within theatre and performance studies, it is more problematic and more ambiguous a term than the mere application of inverted commas could underscore; ideas which are taken up in Chapter 1 of this thesis.

[7] All 'personal' stories are born out of interrelationship. They are co-created with and through the stories of significant others in our lives. However, at the same time, I am conscious that the linguistic and communicative encounters between my mother and I were not normative. I am also aware that I am speaking for her in claiming that this story is 'ours', given the non-normative features of our communication. My interest in this research comes out of a personal experience with AD; but although my story is inextricably bound up with my mother's, I am not her. I cannot know what it is like to live with AD, as I have not (yet) experienced it.

This arsenal of narratives I now label the 'right kind' of dementia story. Several strains of this story are in circulation, focusing on catastrophe, loss, despair, failure and/or tragedy, but never on joy, contentment or possibility. I will define the term the 'right kind' of dementia story in more detail in the key terms section of this chapter. My use of the phrase the 'right kind' is borrowed from the phrase "the 'right kind' of refugee story" as deployed by theatre studies scholar Alison Jeffers in *Refugees, Theatre and Crisis: Performing Global Identities* (2012: 44). Despite the risk of collapsing two different subjectivities into one, analogies, though obviously *very* limited, can be drawn between refugees and older adults living with a dementia diagnosis. Leveraging from Jeffers' idea that the stories of refugees are "troubling, troubled and troublesome" (2012:1) to twenty-first century Western ears for various reasons,[8] I argue that 'stories' performed by people living with a diagnosis of dementia are also troubling, troubled and troublesome, depending on the particular dementia and the state of its progression. They are troubling because they may be hard to hear, due to their chaotic structure or content; troubled, because they may be hard to tell, issuing often from severe states of cognitive rupture and disorientation; and troublesome, because as narrative is usually equated with 'real' personhood (Eakin, 2008: 2), non- or part-narrative people could be confined to institutions, and have some of their privileges and rights as citizens removed for not being able to tell their stories in the 'right' way. When dementia stories are told in theatre or used by theatre- makers to create work, their function in upholding or deconstructing certain master narratives (of tragedy, crisis and so on) will most likely be revealed in some way.[9]

The 'right kind' of dementia story presents naturalised and ahistorical cultural messages informed by and informing the dominant fictions of our culture, including theatrical fictions, and affecting the way we respond to those living with a diagnosis. In public theatre sites, as well as in settings like care facilities, attention to how stories are told about, with and by people living with a diagnosis of AD or a

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[8] For Jeffers, refugee stories are troubling, because they are hard to hear from the standpoint of Western privilege; troubled, because they are usually of trauma; and troublesome, because their veracity is checked by state apparatuses that deem the lives of refugees to be dependent on truth claims made in bureaucratic performances (2012: 1-2).

[9] Along with Jeffers, the work of theatre and performance studies theorist Anne Basting (1998, 2001, 2003, 2006, 2009a, 2009b), who has pioneered the integration of both gerontology and dementia studies with performance theory, has been of immense value to this project.

related dementia[10] can open up discursive spaces where the ethical, political and aesthetic ramifications of the telling of these stories can be made apparent, and perhaps altered, for the benefit of those who live with one of the diseases of the dementia group.

It can be seen therefore that this thesis aligns with expectations for theatre and performance practices and sites as possible spaces of (possible) transformation. As theatre and performance both "inhere in material functions (as social practice) and symbolic functions (as representation)" (Cox, 2012: 120), they are "embodied enaction[s]" (Crane, 2001: 171) that constitute the reality-making systems of both theatre practitioners and audiences. It is within these reality-making systems that the transformative capacity of hope in regards to the effects of performance is enmeshed. However, hope needs to be tempered by respect for the many issues at play when any narratives, but especially those of trauma, victimhood, crisis and displacement, are performed. This can be achieved primarily through attention to the people *behind* the story being performed, as well as to its frames of reception. In other words, attention must be paid to questions about who is served by, who is involved with and who is positioned by these performed narratives (or not), and these questions must moderate any naïve or reductionist ideas about theatrical performances as simple sites of transformation.

In this introductory chapter, I first articulate the principal question that has guided my research, moving onto the critical contributions that this thesis makes to theatre and performance studies literature, then defining any key terms not yet addressed. In the subsequent sections of this chapter, I consider the foundational contexts (historical, socio-political and geo-cultural) in which theatrical representations of older adults living with a diagnosis of senile dementia, as well as applied theatre

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[10] The Appendix has a guide to language use in reference to people living with dementia issued by Alzheimer's Australia (AA) 2014 ('Dementia Language Guidelines'). In this thesis, I conflate two of the suggested AA phrases: "people living with dementia" and "people with a diagnosis of dementia" into my preferred phrases: "people living with a diagnosis of dementia"; "people living with a dementia diagnosis"; or "a person diagnosed with dementia". I do this to emphasise that dementia is an "evaluative notion" (Hughes, Louw and Sabat, 2006: 2) which means that in most cases there is no clear boundary between some of the individual components of, for example, AD and normal aging. I also want to stress that clear-cut differences in symptomatology cannot be determined across the various dementias. Moreover, a definite diagnosis of AD cannot be made until post-mortem, which is why many diagnoses are given as "probable" Alzheimer's (Hughes, Louw and Sabat, 2006: 2). I also do it to stress that dementia is a diagnosis that situates it within a bio-medical framework, which has both productive and troubling ramifications for living in the world.

interventions, are materialised. I then look to the disciplinary locations of this thesis, followed by its methodologies, before finally outlining its structure.

Focus and literature review

Overall, this thesis seeks to situate and explore the contributions that theatre and performance can and do make in responding to and representing people living with a dementia diagnosis through pursuing the following question: If, in part, the figure of the person diagnosed with dementia is produced in and through cultural performances, how then can theatrical performances, as cultural artefacts, best act to represent and/or respond to the figure of that person (the older adult in the main)? 'Cultural performance' as used here refers to the ways a culture articulates and presents itself, encompassing not only cultural and artistic performances but also religious, ritual, ceremonial and political practices, as well as stories and so on, as first defined by anthropologist Milton Singer (1972: 7), and later taken up by various theatre studies scholars, including Erika Fischer-Likte (2008) and Jan Cohen-Cruz (2010). The 'right kind' of dementia story, already briefly expounded, is one of these cultural performances. It is also the particular focus of this thesis through the pursuit of the following questions: To what extent does this production/ intervention tell the 'right kind' of dementia story or disrupt it? Why? And how is this achieved? However, within the overarching charters of all the above questions, my paramount enterprise is to drill down to a specific interrogation of the nexus between stories, words, identity and dementia in theatre and performance productions and practices using the verbatim and autobiographical genres as laboratories: a nexus I see as both troubling and productive.

Over at least the last 20 years and across the globe, there has been an 'explosion' of people's stories and words deployed in verbatim, documentary, testimonial and/or autobiographical theatre productions. Many of these performed narratives are tales of trauma, victimhood and crisis giving voice to the socially, economically or culturally marginalised (refugees, victims of war and displacement, and/or indigenous peoples dislocated from their homelands by colonial and imperialist practices, a legacy from preceding centuries). They usually aim to facilitate socio-political change for either the participants, and/or the spectators, as well as change at a broader social level. Some of these productions feature the people themselves;

actors perform in others. The performances may occur in theatre buildings; others take place in community centres or such like. They raise numerous issues and challenges to the theatre-makers creating, and audiences viewing them, which theatre studies scholars in particular have been keen to catechise.[11]

Recently, on top of the emergence of a growing number of professional and semi-professional theatre productions that deal with issues concerning dementia,[12] wherein actors without dementia perform stories about people living with dementia in either pre-scripted or group devised performances to various publics, verbatim theatre productions about dementia have also started to surface. Certain productions have been created using the verbatim textual input of people with dementia (and their families, in some instances). Two examples from Australia are Theatre Kantanka's *Missing the Bus to David Jones* (*MBDJ*) and KAGE's *Sundowner,* examined in Chapters 2 and 3 respectively.

So what are the challenges to the verbatim theatre maker when people can no longer say who they are, or say it in a way accepted by the normalising regimes in which they are situated? As a likely consequence of immense challenges in this regard, little verbatim theatre has emerged from the stories and words of people living with a dementia diagnosis, inferring a problematic link between stories and the representation of identity. Moreover, in a 'Catch 22' situation, this shortage of verbatim theatre productions has meant that there has been little scholarly interest in the challenges raised by verbatim theatre emanating from people living with a dementia diagnosis. Yet the significance of the nexus between performing life stories and various other identities has been well studied.

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[11] Widely discussed to date have been, among other issues, its "paradoxical pairings" (Wake, 2011: 1) including, for example: the personal and the political (Heddon, 2008); replication (reiteration and re-enactment) and addition (formerly excluded stories) (Wake, 2010b); the archive and the repertoire (Wake, 2011); and reality and representation (Tigner, 2002; Reinelt, 2006, 2009; Bottoms, 2006; Heddon, 2008; Martin, 2006, 2010, 2013). Interest has also been shown in trauma, telling and witnessing (Salverson, 1996,1997, 1999, 2001; Stuart Fisher, 2011; Jeffers, 2006, 2008, 2009, 2012; Wake, 2010b; Thompson, 2004, 2005; 2009); the appropriation of life stories by theatre makers (Couser, 2004; Dolan, 2005; Baglia and Foster, 2005; Heddon, 2008; Casey, 2009; Jeffers, 2012); and the ethical and political challenges of dealing with people's stories and the aesthetic challenges of creating interesting theatre from them (Patraka, 1996; Peterson, 1997; Salverson, 1994, 1996, 1997, 1999; Lathem, 2005; Jeffers, 2006, 2008, 2009, 2012;Stuart Fisher, 2011).
[12] Some of these include the Australian productions of *Do Not Go Gentle* by Patricia Cornelius (45 Downstairs, Melbourne 2010), *Daisy* by Terry Mervin (Woodbin Theatre Geelong, Victoria 2011), and *Vere* by John Doyle (Sydney Theatre Company, 2013).

Scholarly interest has leaned towards the production and reception of stories about, with and by refugees and asylum seekers (Jeffers, 2006, 2008, 2009, 2012; Gilbert and Lo, 2007; Burvill, 2008: Hazou, 2009; Schaefer, 2009; Wake, 2010, 2013; Balfour, 2013; Balfour and Woodrow, 2013); trauma victims and other persons displaced by war (Thompson, 2004, 2005, 2009; Thompson, Hughes, and Balfour, 2009; Stuart Fisher, 2011; Cox, 2012), colonialism (Grehan, 2001; Casey, 2009), illness (Park-Fuller, 2000; Howard, 2013), mental health (Kuppers, 2000), or race (García, 2008). There has also been interest in autobiographical performances by those marginalised by their sexuality (Miller, 1995; Taylor, 2000; Heddon, 2004, 2008; Griffin, 2004); gender (Champagne, 1999; Miller, 1995; Nudd, 1995); disability (Sandahl, 2003, 2004; Kuppers, 2003, 2007, 2011); and so on, as well as an interest in 'multi-cultural' subjectivities (Hopton, 2011). Much of the literature acknowledges the intersections between all the 'categories' listed above.

In spite of this attention to the performance of life stories and identity, the links between the production of narrative, dementia and identity, which involves the social recognition of 'reality' as 'normalcy' (that is, what makes human beings 'real' people), have not been closely investigated in theatre and performance studies scholarship to date, with age and dementia performance theorist Anne Basting's (2001, 2003, 2006, 20009a) work still a singular voice in this area.[13] 'Normalcy' in this thesis is not seen as an unchanging property of human beings. As many disability studies theorists have argued (for example, Davis, 1995; Wendell, 1996; Garland Thomson, 1997, 2002; McCruer, 2006), various discursive regimes, such as those of religion, politics, law, education and medicine have designated certain bodies to be normal and others not, with the assignment of 'normalcy' fluctuating according to history and culture. Unlocking the seemingly imperceptible links between 'normalcy', identity and stories is seminal to cracking open the ways in which perceptions of people living with a dementia diagnosis are fortified in this day and age in many Western cultures. In order to show how these links are

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[13] Publications on dramatherapy interventions with people living with a dementia diagnosis are available but they do not specifically look at the nexus between narrative and identity (Jaaniste, 2011; Reinstein, 2004). Innovative work is emerging in the applied theatre literature on care homes (Nicholson, 2011b; Hatton, 2014) but not in regards to performed narratives in particular.

fortified, I will now to turn to the role of stories in the creation and maintenance of identity as 'normalcy', with political and ethical ramifications for people living with a dementia diagnosis.

Autobiographical theorist Paul John Eakin, following Michel de Certeau (1984), maintains that stories enable people to perform acts of self-construction, establishing themselves to others as 'normal' individuals, and embedding themselves in what he has named a "narrative identity system", bound by a rule-governed discourse, "both culture specific and period specific" (Eakin, 2008: 16). This identity regime sets limits to what can be said or written and it also determines the social recognition of people as people. The workings of this system are not obvious as, from an early age, one is inculcated into doing its bidding involuntarily, with the process continuing throughout one's lifetime. It is mainly when memories fail and narrative fitness collapses, as happens with the onset of dementia, that the workings of the system become discernible. When people can no longer say who they are, in an acceptable way, they are diminished or negated as persons within this system. When narrative is seen to be not just "*about* self, but is rather in some profound way a constituent part *of* self (Eakin, 2008: 2; italics in the original), then these non-narrative or part-narrative people are 'de-I-dentified' so to speak, and as a consequence may be ignored, sidelined, marginalised or, in some cases, abused. Lapses in identity narration generate unwelcome consequences including confinement in institutions (for example, in aged care homes and facilities). The power to confine others for infringements to the "narrative identity system" (Eakin, 2008: 16) makes one of the obvious subjects of any analysis of narrative and its related performance practices, politics. Debates about what constitutes 'normalcy' and personhood add ethics to this foundation (for debates in moral philosophy over personhood and cognitive disability, see Kittay, 2009; and Kittay and Carlson, 2010).

People living with a dementia diagnosis rarely take to the stage to perform their own stories in professional theatre settings, as have some refugees or people with disabilities, but they do frequently 'perform' them in the closed worlds of institutions in applied theatre interventions, and occasionally, on the more exposed stages the internet provides and/or in community settings. In applied theatre scholarship, the hegemonic function of the autobiographical story in dementia cultures (that is, the

imperative to tell and remember as memory and cognition fades) has been generally, and paradoxically, overlooked, while closely examined in reference to other cultures and trauma (Thompson, 2004, 2009; Bharucha, 2011; Stuart Fisher, 2011; Jeffers, 2012). When it has been studied, Erving Goffman's theory of the relational self has been used as the principal theoretical lens with which to positively re-frame the older adult living with a diagnosis of dementia as a communal storyteller (Basting, 2001).[14]

In this thesis, it is my intention to rectify the above-mentioned oversights and, in so doing, to make several distinctive contributions to these literatures. The first is my investigation into the relationship between stories and the materialisation of 'reality' as 'normalcy' in relation to how stories constitute selves, which, as stated earlier, has received scant notice to date. Closely related to this is the second input: my use of dementia as a filter through which certain matters in the reality and applied theatre and performance literatures can be passed, and as a result, be catalysed, unearthing novel perspectives to advance current debates and problematising certain areas that have been taken for granted or overlooked. In this way, as yet another cultural product about dementia, my thesis, is constrained from acting out a story of deficit and lack. Instead, within the boundaries of an academic treatise, dementia is allowed some agency.

Some of the issues which a dementia focus productively complicates or extends include: the notion of the self as authentic, unified and real (Heddon, 2002, 2004, 2008); the ontology of performance and its relationship to the performance of identity (Phelan, 1993; Heddon, 2002, 2004, 2008; Schechner, 1985, 2013; Wake, 2013); the relationship between stories and healing (Thompson, 2004, 2009); the relationship between testimony and performance (Park-Fuller, 2000; Rokem, 2002; Salverson, 1996, 1997, 1999, 2001; Taylor, 2003); the role of the actor/performer in disability and performance (Sandahl, 2003, 2004, 2010; Kuppers, 2003, 2011);

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[14] In *The Presentation of the Self in Everyday Life*, Erving Goffman posits that the "self itself does not derive from its possessor, but from the whole scene of his [sic] action "(1959: 252). Using these ideas as a basis, Anne Basting argues that selves with dementia are more dependent on others than some other selves may be, but that this is not necessarily a problem if we picture selfhood to be on a continuum from a state of mythical independence to that of extreme dependence (2001: 79). Basting argues that people with dementia will usually rely heavily on others for their sense of selfhood but that we all do, to some extent.

spectatorship in the theatre along with an "erotics of suffering" (Salverson, 2001: 123); empathy, victimhood, humour, and stigma (Salverson, 1996, 1997, 1999, 2001; Jeffers, 2006, 2008, 2009, 2012); and ethical praxis in community theatre, that is, issues of force, control and intervention (Prentki and Preston, 2009).The third contribution is my investigation of, and challenge to, the regnant function of the story itself in dementia facilities, also an overlooked research zone.

The final distinctive offering made by this thesis is the application of Richard Schechner's theories of "restored behaviour" (1985: 37), "double negativity" (1985: 110) and "performance consciousness" (1985: 6), to people who live with a diagnosis of dementia. Schechner's theories are principally used in the conclusion to rehearse a theory of dementia as performance where 'performance' is understood in terms of its utopian potential rather than as a "mode of power" (McKenzie, 2001: 25). Nonetheless I contend that currently, in the twenty-first century, the overarching performance 'framework' determining the ways in which, and the contexts where, people living with a dementia diagnosis 'perform' their stories and selves is closer to performance theorist Jon McKenzie's "mode of power" (2001:25) than to Schechner's transformative theoretical options. Moreover, performance as a 'mode of power' is, I assert, the dominant framework in which the reality performance projects I consider in this thesis are located. This alternative definition of performance, along with the use of certain other key terms deployed throughout this study, including Schechner's theories mentioned above, will now be clarified.

Key terms

I will start with a definition of 'dementia' and 'AD'. In current medical science parlance, 'dementia' is a general term describing a group of approximately 100 'disorders' associated with a loss of cognition, that is, the impairment of human memory and thought processes (Brodaty and Rees, 2011). Dementia is often divided into early onset (before the age of 65) or later onset (after the age of 65), as well as primary and secondary. Most primary dementia is located in older adults and seen to be produced by AD, also known as senile dementia of the Alzheimer

type, which accounts for approximately half of all dementia diagnosed in people over the age of 65 (Beach, 1987: 327), and is therefore regarded as one of the most common forms of dementia. AD is known as a progressive and incurable type of dementia which irreversibly destroys neurons in the brain, severely impairing memory, reasoning, language, perception, orientation to physical surroundings and behaviour (Ashford, Schmitt and Kumar, 1996; Gilleard, 2000; Nussbaum and Ellis, 2003).[15]

In this thesis I use the terms 'verbatim' and 'autobiographical performance' to distinguish certain types of productions. Each of these terms is defined and refined in further detail later in this thesis but, in brief, I use 'verbatim' to refer to stories or words as textual content, not necessarily in a word for word sense, and not necessarily by actors. 'Autobiographical performance' usually focuses on some aspect of a life story performed by the same person whose life story it is.

The specific practices of verbatim, documentary, autobiographical and/or testimonial theatre are now often referred to as either "reality theatre" (Garde and Mumford, 2013) or "theatre of the real" (Martin, 2013): both of these umbrella terms are useful for this thesis in a field where debates about the particularities of the various practices have tended to dominate. I use both alternately as they have value for the aims of this thesis. For documentary theatre theorist Carol Martin, the phrase the "theatre of the real" identifies "a wide range of theatre practices and styles that recycle reality, whether that reality is personal, social, political or historical" (2013: 5). Martin's term and its definition capture the field's recent sweeping changes and its wide-ranging practices and methods. Any contemporary study of verbatim and autobiographical theatre must therefore be apprehended with reference to these innovations, some of them postdramatic (Garde and Mumford, 2013).

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[15] AD is attributed to two abnormal protein fragments called plaques and tangles. Tangles are twisted fibres of another protein called 'tau' that builds up inside cells. It is quite common for plaques and tangles to develop in ageing human brains. The early symptomatic stage is called ''mild cognitive impairment': damage to the brain, however, is thought to begin as many as 10 to 20 years before symptoms are evident. With the formation and spread of more and more plaques and tangles into different parts of the brain, cells die and brain functions are compromised. It is this spreading which is responsible for the different stages of the disease. At the final stage of the disease, corporeal functions are severely compromised as the disease moves on to attack those parts of the brain controlling movement and breathing (UCSF, 2011).

For Australian verbatim theatre scholars Meg Mumford and Ulrike Garde (cited in Wake, 2010a: 6) "reality theatre"[16] is a continuum of practices (autobiographical, community, verbatim, documentary, tribunal and history) making evident the ways in which various forms of staging reality are related to each other while still retaining distinct differences. Their continuum is based on the distance between the actual person and the writer, starting with autobiographical theatre at one end, where the 'real' person and the writer are one and the same, moving through theatre which involves communities, like verbatim and documentary, and finishing with history plays, loosely based on real events, but usually with no community consultation. Mumford and Garde's separation of practices under the mantle of one term is useful, for while it gathers together affine practices, it also acknowledges that each practice has distinctive features and does different cultural work.[17]

When I use the terms 'applied theatre' or 'applied performance' I do so to cover a wide range of practices from games through to stage plays, all intended to have social impact. Applied performance is discussed in more detail in Chapter 4. I also use the term 'paratheatrical' in this thesis in drama scholar Michael Mangan's (2013: 6) dispensation as an alternative nomenclature for applied theatre to incorporate reminiscence work and therapeutic drama workshops.

I deploy 'story' and 'narrative' interchangeably in this thesis. Certain literary studies scholars define these terms discretely, with 'story' as the events that happen and 'narrative' as the showing or telling of those events involving sequence (movement from beginning to finish), space (detours from the sequence) and time (Cobley, 2001: 5-17). For philosopher Paul Ricoeur (1988), 'narrative' is time; it is about expectation and memory, and not just paying attention to events on a time-line. However, in this thesis, I am guided by Arthur Frank's contention that the words

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[16] In the later parts of this chapter, I will not cite sources for either 'reality theatre' or 'theatre of the real' as their sources have been attributed here.

[17] This is an idea proposed by both Derek Paget (2009) and verbatim scholar Caroline Wake (2010b). Wake argues that, in certain ways, particular theatre practices "do … different kinds of cultural work" (2010b: 21) and therefore still need to be distinguished, or any muscularity in describing differences in the various practices under their mantles will be lost. Writing about asylum plays in Australia from 2000 to 2005, Wake argues that verbatim plays "were often writing a subaltern history of the period (by interviewing those who had been absented from the public record) while documentary plays were writing a subversive history … (by re-reading publically available documents "against the grain")" (2010b: 21).

'narrative' and 'story' overlap so frequently, that sustaining divisions between them in consistent usage is impossible (2010: 200). Frank also refuses a formal definition of stories contending that stories, in their very ontology, constantly evade classification.

Despite Frank's warnings about classifying stories, it is important to define the 'right kind' of dementia story in more detail because it is central to this thesis. As I noted earlier, the 'right kind' of dementia story circulates hegemonic narratives of loss, despair, failure and tragedy. It does not tell of the extant or emergent capacities of people affected by dementia. Instead, it focuses on their pasts, or on futures made grim for us all by the probability of dementia coming to claim and destroy lives and to push governments and societies towards catastrophe. It may also tell a story of poor long suffering carers having to put up with the demands of aggressive, forgetful, dependent loved ones who are draining personal or familial emotional, physical and financial resources.

The 'right kind' of dementia story then has various iterations. A few examples follow. One tells of a global health 'crisis' of epidemic proportions. This 'crisis' will severely impact economies and societies given the mounting numbers of the elderly predicted to swell across the world specifically in 'first world' countries over the next 35 years (see Deloitte Access Economics, 2011; Australian Government, 2010). The extent to which this story is constructed by medical marketing strategies, encouraging views of dementia as a ghastly epidemic coming for all of us, thereby playing on cultural anxieties in order to achieve financial targets for medical research, is explored in more detail later on in this chapter. As medical research is usually focused on slowing the progression of dementia through drug interventions, and not on looking at the bigger picture of the interrelationship between dementia, values, politics, and social psychology, the epidemic story is often fed and shaped by a "politics of revulsion and fear" (Behuniak, 2011:72) to market medical research. This politics relies heavily on certain 'sticky' metaphors unpacked in more detail later on in this chapter.

Another 'right kind' of story is medical. In general medicine frames itself in regards to normal and abnormal bodies (Hickey-Moody, 2009). Abnormality in medicine is a focus on what bodies cannot do as opposed to what they can do. Limits are then

placed on what can be thought about in terms of embodied differences. Stories emanating from this domain therefore can *only* tell of failure. To get a diagnosis of dementia is to have ascertained "a *failure* or dysfunction of 'normal' functioning" (Gillies, 2000:366; my italics): a process of progressive decline that will lead eventually to a *loss* of selfhood. But the loss of selfhood typically associated with the decline of people who are diagnosed with dementia cannot just be ascribed to neuropathology. The person is also 'positioned' socio-culturally as infantile, incapable, zombie-like, the living dead (Behuniak, 2011:71). These characteristics are assigned, not innate and essential. They are assigned in and through a complex range of determinants including, but not just limited to, the power of medical discourse in our culture.

Yet another 'right kind' of dementia story is constructed in the media and through other cultural products, including theatrical and filmic representations. Anne Basting terms these "tightly told tragedies of dementia" (2009:40). These stories are not focused on the search for a cure, as the biomedical and the crisis modes often are. Instead, they usually contrast "who the person *was then* and who the person *is now*" (Basting, 2009:40; italics in the original) with the denouement being a synthesis of the two states in a moment of lucidity as, for example, when the person diagnosed with dementia suddenly recognises her/his partner. Basting also points out that these stories, like Greek or Shakespearian tragedies which tell of the downfall of kings, often involve the fall of a person from a great height: of intellect, talent or status. Two film examples are Margaret Thatcher's story in *The Iron Lady* (2011) and that of the English writer Iris Murdoch in *Iris (2001)*. In theatre, the recent Sydney Theatre Company production of *Vere* by John Doyle (2013) provides a literal example of a fall from a great height to death in order that the fall occasioned by dementia is stemmed.[18]

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[18] *Vere* tells, in part, the story of a physics professor named Vere, about to start work at CERN - the European Centre for Nuclear Research - in Switzerland. Diagnosed with Lewy bodies dementia, he knows his demise will be rapid and that his brilliant career is already over so he takes his life. This part of the story is based on the actual personage of Vere Gordon Childe, an early twentieth century Australian archeologist and political theorist who died at the age of 65 in 1957 in a fall from Govetts Leap, in the Blue Mountains of New South Wales. He died accidentally, although the Australian Dictionary of Biography's entry on Childe says "it seems possible that he took his own life" as Childe wrote a letter to a friend that read like a suicide note (Cleary, 2013, n.p.).

There is also the 'right kind' of story in the academy, where fear of the condition dominates. Meredith Gresham, a senior dementia design consultant with Hammond Care's Dementia Centre, points out that when undertaking a search of academic literature on dementia employing the terms 'dementia' or 'Alzheimer's' plus 'joy' or 'happiness' or 'contentment', she found nothing; however, in perusing book indexes from "an extensive library on dementia", many entries emerged on "continence… helplessness and hoarding" (2013: 1). Gresham concludes that "[i]n the field of dementia, it seems we don't research or write about love, happiness or fun, yet these are the things that make life worthwhile. And what's more they still occur in dementia" (2013: 1).

The 'right kind' of story also includes reminiscence, which is the regnant paradigm emanating from aged care institutions and Alzheimer Associations. Chapter 5 is devoted to analysing this story in more detail. The 'right kind' of dementia story, as I have already intimated, is frequently buttressed by negative stereotypes and metaphors proliferating in popular cultural representations: what these are and how they are deployed will be explored in more depth later on in this chapter.

I frequently refer to the 're-storying' of people living with a diagnosis of dementia. By this I mean that theatre and performance sites can perform as sites of resistance and transformation in contesting the available dominant narratives: this is Frank's "*narrative ambush*" (2010: 58; italics in the original), which involves rethinking the naturalised ways in which stories are told (in this thesis, about people living with a diagnosis of dementia) and creating a space for a newly reconfigured subject (Gilmore, 1994).

I rely on the terms 'performance' and 'performativity' in this thesis, holding them to have separate although related scenes of development, which are connected to the relationship between performativity and theatricality despite the fact that their associated meanings and uses have been questioned (Dolan, 1993; Butler, 1988).[19] My use of the term 'performance' is largely based on Schechner's

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[19] In 'Geographies of Learning' (1993), Jill Dolan rejects the inter-changeability of 'performativity' and 'performance' in order to prioritise the significance of performance itself. As part of this aim she argues that performance is a genre with its own history and she also makes the point that theories of the performative in many other disciplines creatively borrow from concepts in theatre studies to make their claim for the constructed nature of subjectivity (1993: 419). Theatre studies, argues Dolan, has been "raided and discarded, as part of the proliferation of the performative" (1993: 420).

continuum: "a broad spectrum" ranging from ritual, play, sports, popular entertainments, the performing arts (theatre, dance, music) and everyday life performances to the enactment of social, professional, gender, race, and class roles and on to healing (from shamanism to surgery), the media, and the internet (2013: 2).[20] For Schechner, performances "mark identities, bend time, reshape and adorn the body, and tell stories" (2013: 28). His continuum admits differences between theatrical and everyday performances of the self, but asserts that they are "differences of degree not kind" (1985:37). When I refer to 'performativity', it is in feminist philosopher Judith Butler's dispensation with reticulation to dementia and performance theorist Anne Basting's direction of the term.

Theoretical performativity first developed out of British philosopher J.L. Austin's (1976) coining of the term 'performatives' as words that also institute performances of acts in the social world, including contractual or declaratory utterances (respectively, such as when a person takes a matrimonial vow or when a president proclaims war on another nation). John R. Searle (1969), a student of Austin's, extended these ideas by arguing for the performance aspects of *all* language, focusing in particular on the goals of the speaker, the effects on the audience and the particularities of the social context in which the utterance occurs. Other additions and challenges to Austin's ideas came from Mary Louise Pratt (1977) and Umberto Eco (1977).[21] Philosopher Jacques Derrida (1988) was particularly keen to censure Austin's dismissal of the speech acts of actors as a "…parasitic etiolation of language…in a way hollow or void" (1976:22). Critiquing this idea, Derrida insisted that the general condition of language is iteration or what he

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Judith Butler (1988: 527) argues that one of the major differences between theatrical performances and those of everyday life are that "gender performances in non-theatrical contexts are governed by more clearly punitive and regulatory social conventions". To support her point Butler uses the example of a transvestite who may receive applause on stage, but while on the bus, this transvestite's 'performance' will most probably compel violence.

[20] I rely on Schechner's continuum even though many scholars take issue with it: for example see Bert States, (2003), whose ideas I consider in the final chapter; and Jonathan Pitches and Sita Popat (2011), who object to its linearity, instead proposing a flower model of performance perspectives in which six perspectives (body, space, time, technology, interactivity and organisation) work together to shape the notion of performance.

[21] Mary Louise Pratt 's *Toward a Speech-Act Theory of Literary Discourse* (1977) contributed to understanding the performative qualities of various works of fiction as their authors' elaborate speech acts. Umberto Eco in his 1977 essay 'Semiotics of Theatrical Performance' took this idea out of the literary realm by claiming that an interpretive relationship engineered by performative utterances could exist between an audience member and a theatrical performance, where actors would be making speech acts as 'pseudo-statements' within the fictional cosmos of the play.

termed "iterability." In this view, theatrical utterances are not anomalies but instances of the general state of all utterances: that is as iterations of a preceding linguistic structure.

Judith Butler (1988) went on to link Derrida's assessment of Austin to theories of the body and the force of utterance, in order to offer an account of how the norms that govern speech come to occupy the body. Based on Foucault's understanding of power, Butler challenges conceptions of sex and gender as natural categories of human identity, insisting that their production and materialisation in symbolic form in a culture occurs through repeated action: "[g]ender is performatively constituted by the very expressions that are said to be its results" (1990: 25). For Butler, prohibitions and repeated performances of identity both establish and maintain the social order but with the possibility of agency ever present, that is, with the possibility of acting out within the system in ways that are subversive and transformative of it.

Through her work on performativity, Butler has had a huge, if often contentious, effect on theatre and performance studies scholars. On the one hand, her rejection of identity politics, indeed of identity, and the idea of the body as foundational has created uneasiness, especially in disability studies and its affiliated fields, an area of scholarship for which the body and identity are fundamental. On the other hand, her initial focus on gender and sexual identity has been advanced to other identities: Carrie Sandhal's writing on disability is one example (2003, 2004, 2010); Anne Basting's work in age studies is another (1998). For Basting (1998), the concept of performativity offers an illuminating conceptual approach to understanding the actions and behaviours of individuals and groups across the life span. She sees it as of particular significance on the stage, as actors both enact age or dementia while at the same time negotiating behavioral norms associated with their own chronological ages. Theatrical representations of dementia will in turn affect the way audiences and others might understand and consequently 'perform' their own ageing or perceive and respond to the dementia of their loved ones or clients.

Other age studies researchers have also deployed Judith Butler's theories of the performativity of identity. One of these researchers is Bridie Moore (2014: 2) who

argues that age is produced, not as much by nature, as by effects generated by "cultural apparatus[es]" (Butler, 1990: 199), for example, media images, performances of age on stage and so forth. Following Moore, I have coined the term 'normative age-and-dementia-effects' to refer to the effects of discursive representations of older adults living with a dementia diagnosis, and the biases and assumptions underpinning and sustaining these representations.

'Restored behaviour' is a concept fundamental to Richard Schechner's articulation of performance as pertaining to social behaviour, and not just restricted to the performing arts. [22] For Schechner:"[p]erformance means: never for the first time. It means: for the second to the *nt*h time. In this way, performance is "twice behaved behaviour" or "restored behaviour" (1985:36). It is "living behaviour treated as a film director treats a strip of film… [to be] repositioned or reassembled" (Schechner, 1985:35).These "strips of behavior" are free of origins: their creation, development or discovery may be undetermined, deliberately obscured, enlarged, or changed by legend and ritual (Schechner, 1985:35).

'Restored behaviour' is based on the idea that much of daily life consists of repeated physical, verbal or virtual actions (Schechner, 2013: 29) shaped to suit specific circumstances, characteristics consonant with theatre rehearsals and performances. As Schechner argues, it is clear that "making art involves training and rehearsing… [b]ut everyday life also involves years of training and practice" (2013:28). Culturally specific bits of behaviour are learned, adjusted and performed in relation to specific social and personal circumstances. In personal terms, restored behaviour is separate from the 'me' it comes from and yet not separate, as it comes from the self-same 'me'. For example, it might be 'me' behaving as I am told to do or as I have learned, or as if I were someone else, as in a theatre play. It may also be 'me' 'not myself today' or 'me' 'taken over' as in a trance state.

For Schechner, apparently "once –behaved" behaviours like making a new recipe or talking to a friend are all constructed from "behaviors previously behaved"

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[22] In this way Schechner correlated ritual and theatre, as well as games, play and sports, laying down the "programmatic foundation" of the discipline of performance studies (Balme, 2008:91). Schechner first fully articulated his performance theories in the 1966 essay 'Approaches to Theory/Criticism', which was reproduced in his book *Performance Theory*, first published in 1988. It was then revised and expanded in 2003 (Balme, 2008:91).

(Schechner, 2013: 29). Even events that cannot be located in individuals are linked in what Schechner terms a "feedback loop" to the actions of individuals:

> Thus, what people in northern Hindi-speaking India see acted out in Ramlila[23] tells them how to act in their daily lives; and how they act in their daily lives affects the staging of the Ramlila (1985:37).

In Schechner's view then, 'restored behaviour' is performance comprehended in terms of iterability. However, every performance is also different, and Schechner deals with this paradox by acknowledging that fixed bits of behaviour can be endlessly recombined and varied and that no event can exactly copy any other event given variations in mood, tone and voice as well as occasion and context (2013: 30).

Schechner also associates a 'double negative' with 'restored behaviour'. This concept draws on the work of the British psychoanalyst Donald W. Winnicott, who studied the mother-baby relationship to establish how babies finally distinguish between 'me' and 'not me', given that at the beginning of their lives babies do not distinguish between themselves and their mothers. Winnicott determined that in the move towards separation from the mother, some objects functioned as transitional, belonging neither to the mother nor to the baby, such as certain toys. Winnicott argued that through these objects, children are able to dissolve the hierarchies that separate the real as 'real' from fantasy as 'not real' in a non-ordinary world, for the time they are engaged with them, much like what happens in rehearsals or ritual. Schechner saw that these ideas worked well with those of anthropologists Victor Turner and Gregory Bateson whose notions of liminal spaces and "play frame[s]" (Bateson, 1972:177-193 cited in Schechner, 1985:110) respectively identified the potential for "transitional phenomena" to take place (Schechner, 1985:110) for the child at play and later the adult at art and religion.

One of the most widely cited theories in the performance literature (McKenzie, 2001: 8), 'restored behaviour', and its associated 'double negative', has not been extensively used to catechise everyday performances of dementia in either the theatre or the performance literature to date, with the exception of performance

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[23] Ramlila is a cycle play occurring annually in Northern India that tells the story of Vishnu's seventh incarnation, Rama. The Ramlila literally means 'Rama's play'. It takes 31 days to enact and it is believed that the actors actually become the Gods whose roles they play (Schechner, 2013: 114).

and communication scholar Ragan Fox's article 'Re-membering Daddy' (2010: 11). Anne Basting has also used it in *The Stages of Age to* enable "dual readings of the aged body on stage" (1998: 7). [24] Despite its potential, Schechner's concept of "performance consciousness" (1985: 6) has also not been applied in the literature to date in regards to dementia. Schechner defines "performance consciousness" as that which "activates alternatives: "this" and "that" are both operative simultaneously … [it] is subjunctive, full of alternatives and potentiality" (1985: 6). In identifying this state of consciousness, Schechner is not alluding to any one particular person's consciousness. Rather he is isolating what it is that he believes happens when "performers -and sometimes spectators too- are *changed* by the activity of performing" (1985:4; my italics). Schechner argues, referring once again to the 'double negative', that in performance, ordinary people and objects can be transformed as they are simultaneously " "not themselves" and "not not themselves" " allowing "multiple selves to exist in an unresolved dialectical tension" which may either be permanent, such as in initiation rituals, or temporary, as in art theatre (1985:6).

If Schechner's notion of 'performance consciousness' was more widely understood and adopted, it could allow, along with his better known notions of 'restored behaviour' and the 'double negative', for a re-framing of the particular behaviours and actions of people living with a dementia diagnosis as creative adaptations rather than just as deficit exemplars of insidious diseases. It could also allow for an acceptance of the 'reality' people living with a diagnosis inhabit as opposed to their 'reality' having to be remade in a fashion more in accord with general conceptions of what 'reality' is or should be.

Making any claim about the possible change effects of Schechner's three concepts when applied to dementia locates my argument soundly within what performance scholar Jon McKenzie argues is one of the major paradigms of contemporary performance studies, "*the challenge of efficacy*" (2001: 30; italics in the original). This is a transgressive or resistant paradigm, where cultural performance is

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[24] Basting, however, argues that it cannot be used alone to consider aging in performance as it does not account for the complexities of time that make 'twice behaved behaviour' and the ability for people to become what they once were, improbable. Basting is right if we are to interpret 'becoming' in a literal sense but what makes it appropriate for dementia is the realm inhabited by many people living with a dementia diagnosis which exists somewhere between imagination and reality, and the present and the past.

understood "as an ensemble of activities with the potential … to change people and societies … [and] a catalyst to personal and social transformation" (McKenzie, 2001: 30). But another major paradigm in the field, according to McKenzie, and one much less well known, is that of performance as a "mode of power" endorsing what McKenzie terms "the reading machines of Performance Management, Techno-Performance and Performance Studies" (2001: 25). It has been articulated by scholars as diverse as Herbert Marcuse (1955) as "the performance principle" and Jean Francois Lyotard (1984), as "performativity". According to McKenzie, these perspectives advance a much more negative position on performance than those that promote transformative performance paradigms, and they have been largely overlooked in scholarship. McKenzie uses a Deleuzian-Guattarian approach to argue that performance is a "stratum of power/knowledge that emerged in the US in the late twentieth century … [with] discursive performatives and embodied performance [as] the knowledge-forms of this power" (2001: 25). I hold that performance as a "mode of power" (McKenzie, 2001:25) is proliferating in the twenty-first century, particularly in health science knowledge(s) and practices, with resonance for how dementia 'performs' in the twenty-first century, particularly in residential care homes. These ideas are all more fully explicated in the concluding chapter.

Finally, to the term 'discourse' which is employed in this study in the Foucauldian sense, to do with how knowledge is composed alongside the social practices, subjectivities and power relations built in to such knowledges, as well as into the relations between them. More than just ways of thinking and producing meaning, discourses actually constitute the body, mind and emotional lives of the subjects they seek to govern (Weedon, 1987: 108). In this thesis, I temper my acknowledgement of the power of discourses to constitute bodies and minds by acknowledging that biological, material and embodied elements also play a role in the construction of dementia subjectivities. Both post-structuralist and phenomenological insights are useful for theorising dementia personhood. For people diagnosed with dementia, the body speaks, conveying meaning, even if the world in which they live is created, in large part, linguistically (Vasterling, 2003:212).

In the twenty-first century, discourses on narrative, disability, ageing, crisis, identity and performance intersect in a complex layering of thinking and practice, and determine how theatre and performance products about dementia function in the world. These discourses are tied to whether or not performances in dementia facilities are sanctioned or theatre for public stages is funded, impacting in turn whether the story we hear about dementia in these theatrical sites is the 'right kind': a type of story which risks reinforcing the power of a hegemonic and authoritarian politics, an ethics of devaluation, and an aesthetics of aversion and/or tragedy towards those who live with a diagnosis.

In the next section of this chapter, I want to reveal why these types of stories are being produced at this particular time in history, in Western countries specifically. To do this, it becomes necessary both to excavate the way in which senility and old age were viewed in the past as well as to trace a brief history of the 'Alzheimerisation' of senility in Western cultures, underpinned by the growth of the dementia 'industry' (Alzheimer's organisations and the like). In the following, I set out the historical, socio-political and geo-cultural contexts in which theatrical representations of older adults with senile dementia, as well as paratheatrical interventions are materialised. My discussion mainly focuses on Western countries, not non-Western, and more specifically on English-speaking countries such as the United States of America (USA) and Australia. Any efforts to recast senile dementia (or AD) and its peoples on public stages or in institutional spaces require both an exposure of its genealogies and a re-thinking and unsettling of its current popular framings.

Historical and geo-cultural contexts: recasting senility as Alzheimer's disease

Senility began to be remade in the twentieth century, in a variety of ways, but with dementia as its "dominant modern clinical form" (Cohen, 2006: 2) in what has been termed "the Age of Alzheimer's" (Cohen, 2006: 7).[25] In order to trace this

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[25] According to medical anthropologist Lawrence Cohen, senility is the perception of adverse behavioural changes in persons perceived as old in terms of biology. It is also the contexts in which these changes are discerned (such as institutions) and how they are discerned: for example, if they are measured quantitatively or in other ways (Cohen, 2006: 1).

remaking, I will begin my investigation at the end of the nineteenth century, when a jumble of attitudes towards 'the elderly' existed in Western countries at large. In general, the value of old age had diminished (Cohen, 2006)[26] and senility had acquired increasingly negative connotations. In America, it was largely thought that the ageing body and mind could not keep pace with the rapid changes of industrial and post-industrial society (Ballenger, 2006: 107). In medical circles across the Western world, confusion largely reigned as to the normal condition of the "elderly mind" (Beach, 1987: 331).[27] Debates raged as to the relative importance of ageing and disease in triggering illness in old people (see Beach (1987) for an account of the various debates), although many psychiatrists did tend to peg mental psychoses to age.[28] A clear description of senile dementia had been provided as early as 1845 by the Parisian psychiatrist Jean-Etienne Esquirol, but it was difficult to distinguish this kind of dementia from other psychoses possibly present (such as schizophrenia or major affective disorders) and which themselves had not yet been differentiated in the fledgling field of psychiatry (Beach, 1987: 330-331). The relationship between normal ageing and disease remained a central difficulty for nineteenth-century medicos (Beach, 1987: 340).[29] Into this milieu, AD was born.

AD was named after the German psychiatrist and neuropathologist Alois Alzheimer. In 1906, Alzheimer delivered a lecture describing the results of a post-mortem he had done on the brain of a woman, Auguste D., who had demonstrated symptoms of severe memory loss, disorientation, hallucinations, and ultimately death at the age of 55. His examination, using a newly invented silver staining

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[26] In the first part of the twentieth century, senility and, for example, hysteria, were both marked as disorders of memory, but the senile subject lost traction as a vehicle for the exploration of ideas to do with language, memory and the self (Cohen, 2006). For Lawrence Cohen, this situation is just beginning to be rectified in the twenty-first century.

[27] There are, however, disputes as to the status of ageing in Western countries before the nineteenth century. Sociologist Jesse Ballenger argues that old age has always been stigmatised, though not always in the same way (2006: 106), whereas Lawrence Cohen thinks that prior to the nineteenth century, some philosophical value was accorded to the ageing subject: "Dotage [was] the epitome of unreason as a natural state, the epitome of Nature itself" (Cohen, 2006: 4). Medical humanities commentator Margaret Lock, landing on Ballenger's side of the argument, argues that the dominant idea about ageing in Shakespeare's time was of decline and decay. However, the difference was that what was regarded as senile dementia was hardly ever seen as pathology, but instead as a normal part of ageing (Lock, 2013: 28).

[28] For example, the *Textbook of Psychiatry* by Thomas Clouston published in 1898, categorises insanities into adolescent, climacteric and senile although the idea of age-related illness can be traced back as far as Hippocrates (Beach, 1987: 339).

[29] This had also been a question for medicine in the century before and even as far back as the ancient Greeks, according to medical historian Thomas Beach (1987: 340).

technique, detected various abnormalities of the brain: a thinner than usual cerebral cortex, as well as senile plaque, thought only to occur in older people. The disease was named after him, with neurofibrillary tangles, the earlier age of onset, and the presence of certain signs (like aphasia), as the differentiating characteristics.

For almost 50 years following Alzheimer's presentation, AD was consigned to a minor role in psychiatry and neurology where it was deemed to be extremely rare and limited to the young (Hodges, 2006: 2813). Senile dementia, however, was thought to be induced by ageing from psychological and/or environmental factors, or from atherosclerotic changes in the brain (Hodges, 2006: 2813). In the 1960s, interest in AD was reactivated by the advent of new technologies that made the brain more visible. This was when quantitative neuropathology quietly unified young onset and more common "elderly dementia" (Hodges, 2006: 2813). In the 1970s, biomedical interest in Alzheimer's reactivated through a focus on biochemical techniques and the emergence of the cholinergic hypothesis (Hodges, 2006: 2813).[30]

The 1970s was an important time in the genealogy I am tracing here because it was when AD became a term applied to dementia as a whole and not just to the pathology associated with an early onset form of dementia. It happened, as the result of several pragmatic decisions made in the attempt to attract funding for research in neuroscience, following the conspicuous success of lobbying for heart disease and cancer (Fox, 1989 cited in Kitwood, 1997: 22). According to seminal dementia theorist Tom Kitwood, this shift started in the USA, and eventually spread worldwide. As Kitwood states: "[t]his renaming proved extremely popular *all over the world*" (Kitwood, 1997: 22; my italics). In other words, with no additional data needed, senility was translated into AD (Kitwood, 1997: 22).

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[30] Important links between the cholinergic system and cognitive dysfunction were found. The cholinergic system has two main branches: a forebrain system in the so-called basal forebrain that projects to the neocortex and another branch projecting to the hippocampus. The cholinergic cells are involved in particular in vigilance arousal; in enhancing signal-to-noise ratios so that targets can be detected with great fidelity; and in contributing to memory-encoding processes and working-memory. This research paved the way for the development of drugs to treat symptoms: anticholinesterase inhibitors were and still are the mainstay of AD treatment at present (Hodges, 2006: 2813).

From the 1980s onwards, AD increasingly appeared as a major 'disease' entity in many countries around the world. A disease is classically understood to present distinct pathological features in all cases where the symptoms of the disease appear and none in the cases where they do not (Kitwood, 1997: 25). Yet all the common forms of neuropathology that are associated with the main dementias are also found in the brains of people without cognitive "impairment" (Kitwood, 1997: 24-25), muddying the territory and prompting debates as to whether or not they are in fact diseases, in the classical sense. At the same time as AD began to appear as a major disease entity, the discourses surrounding it began (and have continued) to be framed in the language of 'crisis' (and/or its companion term 'epidemic').

Today senility has been re-made and is sustained through scientific, medical, fiscal and public initiatives tied up with state- and corporate-funded pharmaceutical, epidemiological and genomic enterprises, as well as modes of therapeutic and non-therapeutic practice. Dementia is managed, within the growth of a "successful ageing enterprise",[31] as a normative apparatus, not as "an adjudication of values, but as the increasing prevalence of an insidious disease" (Cohen, 2006: 6-7). In other words, in this unique moment of history, the "rewriting of old age as a medical problem" (Gullette, 2004: 179) has been accomplished, apprehending senility in a (nearly) all-consuming biomedical gaze and ignoring the many other ways in which senility could be viewed, as well as disregarding the ethical and political opportunities offered by the 'crisis'.

Socio-political and economic contexts: the 'right kind' of dementia story

Uncovering the economic and political substructures of the discourse of the dementia 'crisis' is important for understanding how stories about dementia and those who live with it perform in public, private and theatrical domains. The 'right kind' of dementia story, which as I have already outlined is told in a variety of modes, one of which is that of a forthcoming crisis, works to alarm and panic the

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[31] The 1970s saw the emergence of the category of the 'young old', an ageing public now independent from the labour force and the support of their children, and thus able to avoid the stigma of physical and economic frailty. This change has been chronicled the "successful ageing enterprise", buoyed by narratives, and market and welfare reforms (Cohen, 2006: 6-7).

public, sell newspapers and garner money for research. However it does not help to alter the status of those living with a diagnosis of the disease, nor does it aid in shifting the focus towards the ethical responsibilities we as care partners (or as spectators) have in this so-called 'crisis'. In rousing public fears over a reputed social problem, media coverage and public relations campaigns also assist in constructing that problem.

A crisis has been defined as a critical moment necessitating action (OED Online, 2014/2015). The discourses surrounding it have been theorised as giving order to the world by "marking off limits, assigning positions and policing boundaries" (Nyers, 2006: 7 cited in Jeffers, 2012: 29-30). To fabricate a discourse of crisis, its oppositional relationship with normality must be advocated (Jeffers, 2012: 30). However the two states are not in proportion but organised by distinct power relationships so that the crisis becomes "that which is aberrant, unusual, not normal" (Nyers, 2006: 8 cited in Jeffers, 2012: 30).

Crisis is sustained by moral panic. First proposed by Stanley Cohen in 1978 in reference to what was perceived as a mugging crisis from 1972 to 1973 in Britain, the notion of moral panic has been roundly criticised for its totalising view of the damage done by the media in the present day and age when social media and citizen journalism prevail. However, I would argue its use is appropriate in reference to the dementia crisis. In a comprehensive work Hall et al. (1978: 16)[32] define moral panic as legitimated responses to a person, groups of persons or series of events not proportionate to the actual danger. It occurs when specialists like politicians and judges all see the danger in identical terms, talking 'with one voice' of rates, diagnoses, prognoses and solutions. It can be assured when the media "stress 'sudden and dramatic' increases (in numbers involved or events) and 'novelty', above and beyond that which a sober, realistic appraisal could sustain" (Hall et al., 1978: 16).

Writing on the global refugee crisis, Alison Jeffers proposes that moral panic is intensified through the semantic stratagem of the metonymic chain where

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[32] In *Policing the Crisis: Mugging, the State, and Law and Order*, Stuart Hall, Chas Critcher, Tony Jefferson, John Clarke and Brian Roberts offer a critical examination of a nationwide moral panic over mugging that befell Britain in 1972–1973.

metaphors deliver, very persuasively, cognitive scaffolds for standpoints on social issues (Charteris-Black, 2006: 565 cited in Jeffers, 2012: 28). Metaphors, like any sign can become 'sticky', argues cultural studies scholar Sarah Ahmed (2004: 91), which means that, through repetition, their history of articulation allows them to accrue meaning over time. According to Ahmed, there is also a "sticky relationship between signs and bodies" operating in the determination of the relations between signs, where language works not just as an instrument (rhetoric, style or part of speech) but as a form of power (2004: 191). In this territory, emotions align some bodies with others as well as stick different figures together.

Recent research by health sciences academic Megan-Jane Johnstone (2013) demonstrates how the 'sticky' metaphors attached to AD and dementia function, playing a crucial role in the continuous stigmatisation of AD. Focusing on data sampled and collected from various sources,[33] Johnstone identifies five main metaphors: the Alzheimer, the epidemic, the military, the predatory thief and the euthanasia metaphors, all used pervasively and inter-relatedly. Johnstone argues that the term AD itself is a powerful metaphor for losing one's mind and ultimately one's personal control, intimately connected to culturally constructed notions of personhood and eligibility for moral membership of humanity (2013: 382). For Johnstone, the epidemic metaphor (and other associated terms like 'plague' and 'afflicted') shows that AD is perceived as "intractable and capricious" (2013: 382), as for example AIDs once was and likely still is in certain quarters. She also argues that AD is "strongly *felt* to be contagious, literally and morally … because of its perceived causal link to the unbearable and 'sinful' destruction of the human moral agent" (Johnstone, 2013: 382; italics in the original).

According to Johnstone, the fear of contagion is reinforced by the pervasive and mutually enforcing use of two of the other key metaphors cited above: the military metaphor (invades, attacks, kills, enemy, fight against, alien invader) and the predatory thief metaphor (prowls, sneaks, creeps about, consumes, sucks, destroys). The military metaphor and its associated frames, "reflect and evoke

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[33] Sources included professional and academic literature databases, media databases (for news publications, television, radio, documentary and film), public opinion polling databases, legal databases and the homepages of select partisan groups, notably, AD/dementia associations, palliative care advocacy organisations, right-to-die (pro-euthanasia) and right-to-life (anti-euthanasia) activist groups.

people's deeply repressed anxieties about their own helplessness … mortality … and their own lack of control" (Johnstone, 2013: 383-384).[34] Other researchers in both dementia and disability studies have located the zombie metaphor, that is, variations on 'the living dead' (Behuniak, 2011) and the 'gothic' dimension to dementia (Matthews, 2014). The problem is of course that these metaphors refer to the people living with the diagnosis as much as to the disease itself.

In sum, public discourses about dementia, as they currently stand, are mostly consumed by the influential biomedical insistence on either the finding of cures for, or the prevention of, a treacherous group of diseases understood in the public domain, and also in some parts of the academy, to strip people of their personhood. In concert with these conceptualisations, powerful metaphors, which 'stick', determine people living with a dementia diagnosis to be the 'living dead'. 'We' are threatened the media tells 'us' with a pandemic of ever-increasing numbers of 'them': 'elderly' people with the potential of "bringing the global economy to its knees" (Lock, 2013: 1).[35]

Some room must be created in these discussions and debates, and amidst the media hype, for a consideration of values, ethics and a different kind of politics. The debates need to be turned towards an ethical re-evaluation of the relationship between the 'them' of dementia world and 'us', whose fear, anxiety and loathing about the coming of our own old age, possible dementia and inevitable death, partly funds a dismissal of people living with a dementia diagnosis as non-persons in need of behavioural management, drug therapy, incarceration and sidelining from participation in life. Australian dementia activist Kate Swaffer, diagnosed with early onset dementia, dubs this "prescribed disengagement" which in her words is:

> being told to go home, give up work, in my case, give up study, and put all the planning in place for their demise such as their wills. Their families and partners are also told they will have to give up work soon to

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[34] The military metaphor has been extensively used in medicine since the late 1800s, after bacteria were identified as being envoys of disease that patients had to fight because they attacked the body. Johnstone notes that the variation on this theme in AD comprises two associated frames: "the *enemy frame* and the *alien invader* frame "(2013: 383; italics in the original).

[35] Margaret Lock notes that the use of the term 'epidemic' has a long history from the time of Homer, but that its meaning has changed over time. It was only in the nineteenth century, when epidemiology was instigated, that its use became restricted to infection and its spread. But by the mid twentieth century, contagion was no longer its defining feature; rather, numerical data and statistical information became the benchmark for describing an epidemic in medicine and in the media (Lock, 2013: 1).

become full time 'carers'. Considering residential care facilities is also suggested (2014).

One of the key projects of this thesis is to posit that theatre and performance can be spaces where conceptualisations of normalcy and personhood can be unveiled to reveal the workings of social, political or medical thought about disability and dementia, and where alternative understandings of personhood can be offered. Having uncovered the socio-economic contexts in which the 'right kind' of dementia story is sustained, and their genealogies, in the next section of this chapter, I provide a gestalt of the disciplinary locations from which this thesis draws its ideas, followed by a sketch of its structure, a brief summary of its methodologies and then an outline of its chapters.

Theoretical contexts and disciplinary locations

The fundamental proclivity of this thesis is to read dementia, age and disability studies against theatre and performance studies and vice versa, which means that the case studies analysed here are placed in relation to ideas drawn from all these literatures, where pertinent, including reminiscence, the care home and warehousing. An introduction to each field and its concerns, as well as their differences and commonalities, now follows.

Dementia studies can be delineated into three main strands: firstly, medical and biomedical approaches; secondly, the 'personhood' approach, which appeared as a challenge to the biomedical episteme from the late 1980s; and thirdly, embodiment. Firstly, existing research into, and treatment of, AD (and other dementias) is dominated by biomedicine and medicine. The terms are often used interchangeably to refer to conventional medicine. Biomedicine is the application of the principles of the natural sciences, especially biology, physiology and biochemistry, to clinical medicine or research (MacIntosh, 1999; OED Online, 2014/2015). Medicine is "the science or practice of the diagnosis, treatment, and prevention of disease" (OED Online, 2014/2015).

While acknowledging that those working in these terrains warrant some respect in, for example, their tireless pursuit either to cure or prevent dementia,[36] they are "situated within a discourse of loss" (Beard, 2004: 417), prioritising drug treatments or molecular testing over attention to the social and ethical complexities that dementia also necessitates. Together they advance the separation of the physical, mental and cultural dimensions of illness and ageing, reducing the ageing body (and many other bodies) to a potential diagnosis, while the sociocultural, emotional and phenomenological aspects of illness and ageing for individuals and their families are quite often ignored (Beard, 2004: 416).[37] Factors like race, class, gender, sexual and religious orientation, disability, family of origin and cohort effects, will all contribute to differences in the experiences of both ageing and dementia, but these factors are beyond what medicine and biomedicine are generally structured to offer patients. (These factors are considered where possible and where relevant in this thesis, but it is beyond its scope to deal with them in detail.)

I am not arguing here for the de-medicalisation of dementia. There are often helpful and therapeutic outcomes to diagnoses, and medical definitions and categorisations also have their uses. People with dementia and their care partners require access to expert medical care, support services and income. The administration of these services rests, to a certain extent, on diagnostic definitions and categories. Without definitive medical assessment and certification, persons who require support, because of their diagnosis, as well as their care partners, would not have their needs met by institutionalised services.

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[36] In her recent book *The Alzheimer's Conundrum* (2013), Margaret Lock writes that despite repeated efforts to find a cure for AD, none has been found. Only four drugs are available at present that attenuate symptoms, not in all people, usually for only a few months, and often with side effects. Given the poor situation in terms of cures, Lock notes that researchers have now turned to finding ways to prevent the 'disease', facilitated by the development of recent biomedical technologies designed to detect molecular changes regarded as early signs of AD up to 20 years before the onset of the final stages of AD (for example: changes in protein levels in cerebrospinal fluid; the presence of insoluble amyloid plaque in the brain; and a genetic variant associated with increased risk for late onset AD). She has concerns about the intense medical surveillance that many people may be required to undergo based on the kind of individual biomarker testing that the move to prevention and away from cures may instigate. These biomarkers are inscriptions of changes concealed in the body assumed to signify future changes, but about which there is little certainty. In fact, as Lock argues, these preventive measures could very likely create intense anxiety in patients and will also likely uncover further uncertainties in the research world, as there is no surety of high rates of conversion from the biomarkers to AD or other dementias (Lock, 2013: 1-9).

[37] Illness is here used to refer to an individual's experience of 'disease' (pathology), or of poor health, although ''disease'' and 'illness' are words commonly used interchangeably (Dokumaci, 2013: 107).

Furthermore, to dismiss all biomedical and medical interventions and practitioners as 'bad', or to put them in a facile kind of opposition to the 'good' practices emanating from the newer paradigms in the field of dementia care and studies, like personhood and embodiment, is not helpful. In fact, many of the tenets of these latter paradigms have been interwoven into current medical care practices in particular, necessitating a much more nuanced criticism of biomedicine and medicine over a reductionist one (Leibing, 2006: 242).

Yet, as necessary as diagnoses, medical definitions and categorisations might be, they offer little insight into the lived experience of dementia, the creative possibilities still inherent in the people who live with it, and the depth and character of the relational interactions possible between people living with a diagnosis of dementia and their care partners. Rather, medicine and biomedicine provide a very specific framing of what dementia is, an incontestable and hegemonic framing in which both its limits as well as the politics of its knowledge construction are hidden (Hickey-Moody, 2009).

The second main approach in dementia studies is 'personhood'. This approach opposes the mainly negative ideas about the person diagnosed with dementia that have tended to dominate studies in biomedicine (Leibing, 2006: 254), gathering numerous new practices under its mantle. A person-centred focus in dementia care was initiated principally through the work of social psychologist Tom Kitwood (1997) and is slowly and steadily becoming a seminal paradigm in much dementia care, emanating from a reaction to the single-minded focus on cognition and neurological changes in the brain that had dominated the dementia industry till then. In this paradigm, personhood is conceptualised from the standpoint of interactionist social theory, the belief that selfhood is socially acquired and sustained (Kontos, 2012: 330).

As important as social interconnectedness is in providing a critique of the dominant biomedical paradigm, it ignores the importance of the body as a source of agency and the way in which people living with a diagnosis of dementia may convey their humanity through gestures, body habits and non-verbal body language. The personhood turn is also committed to memory as one of the carriers of individuality through narrative excursions into the past, which I think can foster a static view of

older adults living with a dementia diagnosis, rather than seeing how their lives are still continuing in the present.

The third approach gaining momentum in the dementia literature at present is that of 'embodiment': here scholarship captures "the social construction of surveillance, cultural priorities, and discursive conventions [and] the potentialities of the body for creativity and self-expression" (Martin, Kontos and Ward, 2013: 283). Live theatre and performance is one of the cousins of this turn, perhaps more so than other art forms, given that the primary medium of theatrical performance is the human body, which is always of a specific age and physical condition. This thesis holds that the 'gaze' of theatre and performance, as an arena of embodiment, could offer new ways of understanding older adults living with a dementia diagnosis to counter the double 'gazes' of biomedicine and of personhood (Cohen, 2006) which tend to dominate in dementia studies and care.[38]

The next disciplinary area I will introduce is contemporary age studies[39], which, on the whole, sees ageing as constructed not just biologically and chronologically, but also socially (Basting, 1998). Four main approaches to the study of age have been recently identified: cultural age; age as narrative; the performativity of age; and the materiality of age (Swinnen and Port, 2012: 12).[40] In part encouraged by leading

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[38] As theatre theorist Martin Welton (2012: 55), following Constance Classen (1998), argues "the many sins of (post)modern culture" have been attributed to this sense (such as the patriarchal gaze and the scientific gaze) to the neglect of the other senses. And yet, according to Welton, the alliance between vision and reason in Western humanities and social sciences as well as in medicine which this trope captures has been well forged, even if its use has ignored the findings of ecological psychology (J.J. Gibson, 1979) and anthropology (Tim Ingold, 2000) that the apparently discrete senses are implicated in each other and even if its use "sells short the affective powers of seeing itself" (Welton, 2012: 162).

[39] Age Studies is interdisciplinary and collaborative, drawing on research efforts from both the humanities and the social sciences, despite their very different research approaches. This is to be expected given that ageing is a phenomenon that affects so many areas of life. However, some scholars are surprised at how long it has taken for interest in the field to start to burgeon, as it is a relatively new area of inquiry. These same academics have been arguing about the importance of its presence in the academy for decades where it should take "its rightful place with other intersectional classifications, such as gender, race, class, and ability" (Lipscomb and Marshall, 2010: 4).

[40] Cultural age perceives age both as biology and as an accretion of all the various meanings assigned to age groupings across different cultures and historical periods. It is particularly interested in how knowledge about old age is constructed in gerontology and its sub-disciplines. It also directs attention to age as intersectional with other identity indicators, such as disability, gender, ethnicity, race, sexuality, class, and to the role of power in the co-construction of meaning. Age as a narrative refers to the way age identities are composed in and through narratives, defined through time and assigned between our personal circumstances and the expectations of the master narratives determining our lives. The materiality of age emphasises embodiment and the physical changes that undeniably come with age. It investigates the disciplining of bodies, body images,

age studies scholar Margaret Morganroth Gullette's call, "[a]bout age as a performance, we need to start the arguments" (2004: 159), the main approach I take in this thesis is that of age as a performative, in tandem with certain other scholars who have theorised in this direction. (I also draw on some of the other approaches, including the materiality of age.) The notion of performativity defines age "not only as a state of being but through acts of doing" (Swinnen and Port, 2012: 12). In general this approach enlists the theories of Judith Butler in *Gender Trouble* (1990) and *Bodies that Matter* (1993) where identity is an effect of "cultural apparatus[es]" (1990:199) and not nature. In age and performance scholarship, various academic iterations of Butler's theories of performativity have been worked with, expanded upon and, in some cases, challenged, under such monikers as: "age-effects" (Moore, 2014); "temporal depth" (Basting, 1998); "significant form" (Cristofici, 1999) and "absence" (Woodward, 1991).[41]

Dementia is also disabling. Unlike age studies, disability studies is a well-established academic discipline, fraught with complexities and arguments about various issues like disability definitions, the role of impairment and the body, and the origins of disability. There are two main models: the medical model, which defines disability as biological impairment (Depoy, Gilson and Cramer, 2003: 177) and the social model, in which disability is seen as a consequence of social oppression (Hughes and Paterson, 1997). Most contemporary disability studies

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disability management, (post)phenomenological approaches to bodily ageing and the economic conditions of ageing and its material effects (Swinnen and Port, 2012: 12).

[41] "Normative age-effects" is a term used by Bridie Moore (2014: 2), following Judith Butler, to underscore that age is produced as an effect generated by "cultural apparatus" (Butler, 1990: 199) through media images, performances of age on stage and so forth. "Temporal depth" is a model of age that embraces change across the life span (Basting, 1998:22; italics in the original). For Basting, the aging body on stage is valuable exactly because it can represent the spread of difference and variety of age across time (1998: 141). Cristofici's (1999) "significant form" is a term moved over from Cristofici's analysis of Jeff Wall's photography to performance by Bridie Moore (2014): it helps assess whether a specific representation of age might admit the possibility of agency for older subjects. Kathleeen Woodward's term "absence" is a reflection on the rejected and therefore missing aging body (1991: 53-71). Woodward suggests that at the end stage of life and comparable to Lacan's mirror stage of infancy but in reversal, the older person rejects their mirror image as not a true representation of self. This rejection brings on a psychic crisis (a dislocation of the imaginary). She sees the mirror stage of old age as "inherently triangular, involving the gaze of others as well as the two images of oneself" (Woodward, 1991: 69) (that is, the one looking in the mirror and the one looking back).

scholars (see Davis, 1995, 2002, 2013; Siebers, 2006, 2008; McCruer, 2006)[42] recognise the category of disability to be intensely problematic and unstable, for many reasons, one of which is that it swells and contracts to include so-called 'normal' people as well (Davis, 1995: xv): all people chance stepping on and off the disability continuum, especially as they get sick or age, or are diagnosed with diseases like dementia.

Nonetheless, within disability studies, there are debates as to whether or not diseases are disabilities. For example, critical disability theorist[43] Lucy Burke (2008b: i) argues that cognitive "impairment" is an appropriate term to describe a condition like dementia that progressively impacts language, memory, cognition and behaviour, where it has been seen as inappropriate for describing autism or schizophrenia (because of the wide range of personal and political identifications embedded in these conditions). Burke argues that there is a political and ethical obligation to make apparent the inadequacy of the term 'impairment' in the cases of autism or schizophrenia in particular, but that it can be justified for dementia.

But I would argue that the term 'disability' needs to be extended to dementia as well as seeing it as an 'impairment'. Social, ethical and political realities are as much imbricated in the co-construction of dementia as in these other conditions. The various diseases of dementia are cognitively disabling, with a raft of political and ethical problems marking them as distinctively different from the physical disabilities tending to dominate disability research. I hold that, although there is an undeniable materiality to bodies, any 'impairment' cannot only be framed somatically.

As with age studies scholars, some post-structuralist disability scholars have also drawn on Judith Butler's theories of performativity to talk about the discursive construction of disability identity. Both Petra Kuppers (2003, 2011) and Robert McCruer (2006) argue, following Butler that, as with gender, cultural scripts about disability can and should be resisted and disrupted along with the discursive practices that produce both the disabled and the able body. As old age may be experienced as disabling by some, and as dementia is both a cognitive impairment

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[42] Mike Oliver and Len Barton would be exceptions here, arguing that the current focus on postmodernism, representation and embodiment in disability studies is hard to justify in terms of their "immediate relevance to the struggles of disabled people to lead a decent life" (2002: 8).
[43] Critical disability theory critiques ableist assumptions through the lens of neo-Marxism and the Frankfurt School.

and a cognitive disability, representations of the older adult living with a diagnosis of dementia must be theorised on a spectrum stretching between the disciplinary locations of age and those of disability studies.

However, the relationship between the two holds many tensions. Age studies scholarship tends to undermine assumptions that ageing disables; it challenges commonly held generalisations that all old people are "warm but incompetent" (Basting, 2009a: 26).[44] On the other hand, some disability scholarship critiques assumptions that the able, fit and 'normal' body is always free from disability, using old age as the point towards which all able bodies are heading, a kind of 'disabling normalcy'. Feminist disability scholar Susan Wendell maintains that unless we die early "we are all disabled eventually" (1996: 18). In this thesis, I engage disability studies with age studies to show how the abilities of people diagnosed with dementia are greater than imagined while at the same time acknowledging the reality of their limits.

In summary, in this thesis I look to certain disability theorists to understand how the notion of 'normalcy' has been constructed and its intrinsic relationship to what is not normal, that is disability; I also work with research in disability and performance studies.[45] There is some recourse to theories of narrativity including the work of Arthur Frank (2010) and Paul John Eakin (2008), as well as that of the narrative philosopher Galen Strawson (2004). Selected input also comes from medical anthropology (Leibing and Cohen, 2006; Lock, 2013). Other philosophical material is also drawn on at various stages: Jacques Rancière (2004) features notably. Rancière's theories are invaluable to this thesis because they move beyond a Foucauldian consideration of the workings of power in the production and control of *subjects* through language and pay attention to the pre-discursive

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[44] Some social gerontologists have recognised different stages to old age, determining categories like the "fit elderly" and the "frail elderly" (Woodhouse et al., 1988: 505 cited in Mangan, 2013: 26-27). The picture is further complicated by the fact that definitions of what constitutes old age are determined by historical and cultural relativism (Mangan, 2012: 23).

[45] In general, scholarship on disability and performance is in a nascent state. Leading scholars in the terrain include Petra Kuppers (2003, 2011), Carrie Sandahl (2003, 2004, 2010) and Bree Hadley (2014). Some key issues of concern emerging from scholarship at present include: representing disability in novel ways to challenge current orthodoxies; the uneasy relationship between disability, disability politics and the dramatic arts; the integration and inclusion of disabled people in drama and issues to do with the subversion of assumptions about disability in drama pieces; the role of non-disabled allies and professionals; the 'performativity' of disability; and the concept of 'crip' aesthetics and alternative dramaturgies as a challenge to able-bodied aesthetics and elite drama (Roulstone, 2010: 753).

conditions by which those subjects appear, that is how these subjects are recognised and understood as (political) *subjects* in the first place. People living with a diagnosis of dementia are not construed as subjects, and rarely appear on public stages underscoring a strong connection between political distributions of visibility and aesthetic practices, part of Rancière's theoretical project in particular.

But the primary disciplinary location of my study is in 'theatre *and* performance studies'. I conflate the two disciplines, as they are "merging and intermingling in various ways" (Balme, 2008: 12), which I hold makes it increasingly difficult to separate theorists into particular camps. But despite the increasing affiliations between the two disciplines, there are still disciplinary differentiations, which can partly be tracked historically.[46]

Today theatre studies has many fields, a strong focus on live performance and a central focus on the study of texts (Balme, 2008: 11). It has been defined as a "site at which cultural problems, performed by cultural actors, are studied and investigated through critical theatre production[s]" (Dolan, 1993: 418). Work within performance studies[47] has inclined towards one of the two sectors articulated by Richard Schechner as either the "is" or the "as" of performance (2013: 38). The former centres on that which is historically, socially, culturally and traditionally accepted to be performance; the latter refers to the way in which events or practices can be seen to be performances, including gender, sexuality and ethnicity, amongst many others. In this way "performance studies grants itself a

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[46] The older discipline, theatre studies, in the Anglo-American academy in particular, was based on a positivistic approach to theatre history which was eventually challenged by the many profound changes in artistic practice and the impact of the 'theory explosion' of post-structuralism, psychoanalysis and phenomenology. The younger discipline, performance studies, emerged in the US from the 1960s as an interdisciplinary and social science based field which parted from the aesthetic and historical paradigms that had dominated theatre studies, seeing dramatic theatre as just one possible manifestation of performance (Balme, 2008: 11-12) and linking theatre performances to other kinds of cultural performances (like rituals, dance and sports). With the prodigious growth of performance studies departments from the 1980s, many theatre departments began to incorporate performance in their nomenclature or were wholly named as performance studies units (Balme, 2008: 11).

[47] As a coalescence of theatre studies, anthropology and sociology, performance studies is frequently referred to as an interdiscipline rather than as a discipline. Other descriptors have also been applied. It has also been called a "postdiscipline" by Joseph Roach (1995: 46) who was also noted to have referred to it as "antidisciplinary" at a conference in 1994 (quoted in Carlson, 2004: 206), indicating its interest in contesting and challenging the continuity, tradition, coherence and stability that marked prior, more traditional studies in theatre and anthropology, and the worlds from which they emerged.

wider range of 'objects' or case studies than theatre studies might" (Wake, 2010: 26).[48] In essence, my examination of both reality and applied theatre and performance in this thesis sits under the broad moniker of theatre *and* performance.

Structure

At the heart of this thesis are four main case studies of verbatim and autobiographical theatre productions and practices, supplemented by an examination of reminiscence therapies (RTs) and an investigation into two narrative space interventions.[49] Two of my case studies have been chosen from the Australian experimental 'art' theatre sector as mentioned earlier (*MBDJ* and *Sundowner):* neither yet analysed in the literature. *MBDJ* is a devised theatre piece located in a nursing home, staging many vignettes of its inhabitants and staff. *Sundowner* is a piece of dance theatre presenting a day in the life of a woman living with younger onset dementia. The other two, Time*Slips* and *To Whom I May Concern* (*TWIMC®),* are American applied theatre therapies which have received some attention, more often in social science literatures than in those of theatre and performance studies, and in both bodies of literature, mostly from the writings of Anne Basting (2001, 2003, 2006, 2009a). Time*Slips* is a method of improvisational storytelling. *TWIMC®* is an interactive theatre project where stories of living with a dementia diagnosis are performed by early diagnosed people to an audience of peers, friends, care partners, and professionals.

In essence, my reason for the choice of these four very different case studies is their verbatim input (of the words and stories of people living with a dementia diagnosis who may either tell their own stories or have others tell them). My focus on verbatim input facilitates a productive investigation into the tensions inherent in the coupling of a theatrical technique, relying for its textual foundation on the

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[48] Diana Taylor has described this difference as between that of probing performance as an object or ontology and deploying it as a method or epistemology (2003: 2-3).

[49] Other related theatre productions and practices are also acknowledged in the thesis (inclusive of theatres with and about the cognitively disabled) as well as modalities used in dementia facilities, like humour and music. Reference to mediatised performances is a feature of this study too, given that the barriers between the live and the mediatised are less clear than they once were (Auslander, 1999). The ubiquitous presence in our culture of YouTube and the Internet is reflected in the fact that *TWIMC®* is now operating its plays on the Internet and Time*Slips* is being practised in Australia because training for facilitators is now offered online.

words and stories of 'real' people, with people whose loss of narrative capacity and problems with language use puts their claim to 'real' (read 'normal') selfhood in jeopardy. This apparent paradox has the potential to facilitate a profitable analysis both of professional and applied verbatim and autobiographical theatre and performance interventions in sites of traumatic rupture . I define a traumatic rupture as one in which the person is wrenched out of the quotidian by a breach in the processes of cognition: accidents and diagnoses could be among the triggers for this rupture (Caruth, 1996). This paradox could also prompt a re-thinking towards alternative modalities, where the storytelling foundation on which the verbatim and autobiographical genres rely could be re-evaluated. For example, storytelling could be seen as a domain of perception in which senses rather than cognition lead the way, following neuroscientist Antonio Damasio's (2012) ideas about pre- or non-verbal neural structures; [50] or the uses of the story could be evaluated in terms of degrees of cultural resonance, drawing on applied theatre commentator James Thompson's (2009) ideas.

Given the very specific focus of this thesis, finding products to use as case studies was not easy, which is one of the reasons why the ones I have chosen may at first appear incongruent: two 'art' theatre pieces sharing a thesis with several applied theatre pieces. It is important to acknowledge that theatre productions and applied theatre and performance practices do have specific charters, along with separate literatures and histories which map them, and that these differences should be taken into account. For this reason, I have divided the thesis into two parts: part one is a foundational chapter to anchor the two chapters following, which are focused on verbatim 'art' theatre case studies; and part two is an applied theatre literature review, with two chapters following which are focused on applied theatre case studies. That is, both parts one and two include more detailed introductions and literature reviews, respectively, to concentrate on particular areas of the literature and of practice.

However, despite the importance of this division, I contend that when the seemingly 'incongruent' practices and products of select applied theatre

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[50] Damasio contends, "language … is a translation of something else, a conversation from non-linguistic images which stand for entities, events, relationships, inferences … symbolizing in words and sentences what exists first in a non-verbal form" (2000: 107-108).

interventions, made in contexts where the focus is health and well-being and the process is more important than the product, and which the general public may not see, are situated side by side with professionally devised 'art' theatre products for public stages, what emerges is their commonalities and the way they 'speak' to each other. For example, although innovation and experimentation may be more to the fore with 'art' pieces, where dramaturgical, aesthetic and reception issues are likely to surface, verbatim theatre may also intend to educate, inform and change political and ethical landscapes as well as the views of its spectators, and may also be less interested in aesthetics, or choose a stripped back aesthetic consonant with some theatres of social change. For instance, verbatim playwright Robin Soans contends that the essence of verbatim theatre "is a group of actors sitting on chairs, or cardboard boxes or a sofa, talking to the audience, simply telling stories" (2008: 21). Furthermore, crossovers exist between the concerns of the reality and applied theatre and performance literatures, given that many reality theatre and applied theatre practices are not always discrete. For example, an applied theatre intervention may also use reality theatre techniques, like verbatim or documentary materials, be devised in a community setting and be principally constructed from the autobiographical stories of its participants (as is *TWIMC®*).

In fact, certain applied theatre products may be framed as art pieces with a strong aesthetic focus, even if applied theatre has conventionally focused on social efficacy over aesthetics (Prentki, 1998; Thompson, 2009). Richard Schechner maintains that traditionally performances have been seen to alternate between the supposed extremes of entertainment and efficacy (Schechner, 1974, 1988: 129-163). But in fact, as Schechner argues, rather than being opposites, entertainment and efficacy interweave with each other (1988: 156). All performances have aspects of entertainment *and* efficacy, contingent on their evaluation. That is, while applied theatre may usually focus on the efficacy of its work, this does not mean that these performances do not also aim to be, and *may* be, entertaining.[51]

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[51] Schechner gives as an example a Broadway show: at first glance it looks like pure entertainment, but if the whole event is analysed (that is, from the ticket purchase, through to getting ready, flaunting dress choices in the foyer, meeting others, watching silently and clapping at the finish), then its efficacious social function becomes apparent (Schechner, 1974: 467-471).

Methodology

Having set out my reasons for structuring this thesis into two main parts, I will now examine the methodological underpinnings of this division. In part one of this thesis, I deploy 'performance analysis' (Pavis, 1985, 2003) as the principal approach for examining two 'art theatre' case studies: *MBDJ* (chapter 2) and *Sundowner* (chapter 3)*.* According to renowned theatre studies scholar Christopher Balme, performance analysis as a methodology draws on two main sources: (1) notation undertaken during a visit to live performances; and (2) video recordings of the performance (1985: 136). Other material, termed "supplementary documents" by theatre theorist and semiotician Patrice Pavis (2003:40), may also be used including theatre reviews, photographs, programs and other outreach materials like education packs and web sites pertaining both to the shows and the companies that produce them.

'Performance analysis' is a recognised methodology for examining 'art theatre' performances. Primary research, for example interviews, is not required in this approach. Moreover, *not* using interviews with the theatre practitioners in this thesis was a deliberate decision on my part. Although interviews can generate productive data, they are also subject to limitations, as theatre studies scholars Alison Burke and Paul Innes (2007) point out. One drawback may be the investment some theatre practitioners could have in 'promoting' their production with the entailed risk this has for impinging on the reliability of information generated. Another drawback is that if the interview occurs some time after the practitioner's involvement with the production, memory is likely to be compromised. For example, a theatre practitioner might have forgotten his/her experiences and aims in the production. Details might be distorted and the past interpreted through the present. Additionally, the attitude of the practitioner, his/her responses to the interview process, his/her experiences on the day of the interview, and the relationship between the researcher and the practitioner can all lead to a partisan presentation of events (Burke and Innes, 2007:n.p.). Burke and Innes summarise their concerns about the academic interview by stating that it is:

> only one mode of inquiry, which is no more authoritative than other modes. Simply, the comparison of different sources, rather than the privileging of

seemingly 'straight from the horse's mouth' data, is necessary for a balanced account (2007:n.p.).

In deploying performance analysis as a research methodology for chapters two and three in part one of this thesis, I have principally relied on the analysis and comparison of a *range of sources* rather than relying on interviews and similar primary materials. The sources I have drawn on include: publically available videos and scripts of the two shows; my direct experience of the shows; detailed comparative readings and critical responses to these shows; analysis of websites and blogs, photographs, programs and education packs; publicity such as reviews and articles on the web; print documents released by the companies; and any funding connections of significance or controversies in regards to the content of the shows or their sponsorship, including investigative reports by journalists.

In part two of this thesis, my focus is on applied performance practices, the mechanisms of such practices and the effects they have on people living with a dementia diagnosis. At present, a diversity of applied theatre research approaches exists including the 'reflective practitioner', critical ethnography and feminism, performance ethnography, narratology, action research, experimental research, arts-based research and ethnodrama (see Ackroyd, 2006; Ackroyd and O'Toole 2010; and O'Toole 2006 all cited in Rasmussen, 2014: 21- 22). Post-structuralist methodologies and case studies may also be used along with 'performance analysis' (Ackroyd, 2006 cited in Rasmussen, 2014: 21- 22; Balme, 2008:191). Current debates in the literature about adequate research methodologies have centred on whether or not performance analysis as used in more traditional aesthetic theatre endeavours is appropriate for the field or whether more 'empirical' data needs to be collected (Balme, 2008:191). The pressure for the latter is related to the increasing integration of applied theatre into institutions where the perceived need to monitor practices through precision and transparency in research approaches has also increased (Nicholson, 2005:3 cited in Balme, 2008:191). In an era where applied theatre interventions are progressively being measured by their ability to impact the task-focused culture of many institutions, a trend which worries me and to which I object given that it is human beings who are at the receiving end of these efficiencies, I have made a deliberate decision not to rely on empirical data in this thesis.

Therefore, in the second part of this thesis, my methodological approach of choice is that of case studies. As well, I mix in elements of 'performance analysis' along with recourse to (post-structuralist) discourse analysis due to the sustained interest this thesis has in how discourses shape reality. Once again I do not rely on primary research. This is mainly because I am not an applied theatre practitioner who can track the work in situ. Many of the methodologies listed above would be pertinent if I was. However, given my interest in the discourses circulating about dementia in in the mass media and on the internet, I do think that interviews of practitioners in the field of dementia care conducted by journalists have value in my analysis. However inadequately the journalists represent the practices and interventions of care homes, the discourses produced by these media accounts form part of the social context of the performances. In this regard it is entirely appropriate that my research takes into account comments made by facility managers recorded on videos and available on YouTube or journalists' interviews with the managers of these facilities or relevant others, to assess the effects of these practices (this type of research is used, for example, in chapter 5).

In both parts of the thesis, I interrogate the role the internet plays in the creation and/or circulation of the productions or interventions, as well as what and how any associated websites contribute to circulating hegemonic public discourses about dementia. *TWIMC®* and Time*Slips* both have websites: with Time*Slips* stories are collected there. I also examine the KAGE company website in part one of the thesis (chapter 3) with attention to what it tells me about the ideological foundations of the company that produced *Sundowner*. Doing this helps me to interrogate at the widest possible level how these case studies, and the companies who created them, function either to inadvertently reproduce and maintain hegemonic discourses and representations about people living with a diagnosis of dementia, or to fracture these discourses. Given the material force of discourses in forming and reforming the normal, the natural and the true, this thesis is primarily concerned with excavating the values and politics underlying these discourses in twenty-first century Western cultures, both to make them visible and to disturb their facile endorsement.

Additionally, following Carol Martin (2013:4), in order "[t]o consider the ways in which theatre of the real enacts social and personal realities by recycling reality for

the stage, I sometimes theorize audience reception-occasionally including my own". A brief foray into audience response is undertaken in chapter two using the anecdotal comments of the audience members who surrounded me when I saw *MBDJ*, along with an acknowledgement of my own discomfort as an audience member. I do this, not to enter a debate about audience reception, but for two other main reasons. Firstly it helps me to argue that there can be no direct causal relationship between representation and the re-storying of ageing and dementia on stages. In other words, disruption to normal ways of seeing through the postdramatic will not automatically produce a political effect on audiences. Secondly, I use it to springboard a discussion into disability and performance issues and theories.

In sum then, in both parts one and two of this thesis I track three main strands of 'material' and case studies: (1) theatrical performances on stage and online, either by older adults with dementia in applied theatre (*TWIMC®*) or by professional performers about older adults living with a diagnosis of dementia (*MBDJ* and *Sundowner*); (2) narratives produced from Time*Slips*, RTs and institutional spaces; and (3) public discourses about dementia and its peoples.

Chapter outlines

This thesis is situated at the intersection of theatre and performance studies with reticulation to disability, dementia and age studies. Individual chapters sit at various points on this network, depending on which particular problem the chapter is trailing. In this chapter and in the conclusion I ask: How might theatre and performance studies shift or add to both popular and theoretical conceptions of dementia and people diagnosed with dementia? Across all the other chapters, in some to a greater extent than in others, I reverse this question to ask: How might dementia shift or add to questions, debates and issues in theatre and performance studies? Key questions asked across all the case study chapters are: To what extent is the 'right kind' of dementia story being told or not? If so, why? And how is this accomplished?

Chapter 1 is foundational to the whole thesis, as well as dealing with key areas of concern to part one of the thesis: professional reality theatre. In this chapter, I begin

an investigation into the connection between stories, words, identity and the materialisation of 'reality' as 'normalcy'. I also investigate reality theatre, unpacking its links to reality and representation in order to expose foundational issues to do with the 'real' in reference to people who are usually marginalised from conceptions of the accepted 'real'. I also propose how dementia might shift debates and issues in relation to the ontological, relational and performative properties of verbatim theatre products and processes, galvanising certain debates in the literature through the dementia 'filter'.

In Chapters 2 and 3, I examine two very different experimental theatre productions as optics through which ethical, political and aesthetic problems to do with dementia and age representation can be exposed. In particular, I test how novel the representation of dementia and ageing is in these pieces, and how far they challenge and subvert current orthodoxies. That is, I consider to what extent they tell the 'right kind' of dementia story. These chapters, especially Chapter 3, pay specific attention to the people *behind* the stories being performed, as well as to their frames of reception.

In Chapter 4, I review extant concerns in the applied theatre literature and map these to conceptions of the narrative self, to underscore the problematic link between certain conceptions of narrative and identity. In Chapter 5, I compare two storytelling interventions used in aged care facilities: the popular RT, and the less well-known Time*Slips*. I critique chronological life story narrative when conceived as a universal ethical and political act of healing for people with senile dementia, or as an unfailing practice of late life therapy, by extending James Thompson's (2009) challenges to narrative hegemony in applied theatre contexts. In contrast, I argue that Time*Slips* works innovatively because it uses the present moment and not the past, extricating storytelling from reminiscence but still accepting and working with long-term memories in a creative way. I also look at what I term 'narrative spaces': alternative ways of reconfiguring performance in care homes which take seriously the opportunities offered by the location itself in transforming the lives of people living in care homes.

In Chapter 6, I probe one specific autobiographical performance modality by people with dementia, *TWIMC®,* both a play and a therapy, operating both virtually

and as a live theatre piece. This modality galvanises a welter of issues in the scholarship reframing well-worn issues in the autobiographical literature as complex and fresh, especially the construction of the self and its relationship to narrative, identity and representation. The public performance of autobiography has not been widely taken up by older adults living with a dementia diagnosis. I argue that the absence of these adults from public life narrative performances is undoubtedly connected to and limited by generalised discursive understandings of dementia. It is also affected by discourses about their *capacities*, which both create and control the situations, perceptions and worlds in which these people can perform their narratives and their audiences listen to them. I make the point that whether or not people living with a diagnosis can partake in an autobiographical representational system may be as much to do with the constraints of these understandings as with the 'reality' of their diseases. It will also be connected to the impact of the countless iterations of the 'right kind' of dementia story sifted through the media and other discourse systems. (In making these points, I am not claiming that individuals diagnosed with dementia will, all of a sudden, clamour to create their stories for public consumption, or indeed even be able to. Nor am I claiming that there is something intrinsically liberating about dementia.) My concluding chapter not only summarises the arguments of the thesis but also rehearses a theory of dementia as performance.

In sum, this thesis aims to bring the fields of theatre, performance, age, dementia and disability studies into a productive conversation to make it a little more difficult for thinking and doing as we have habitually thought and done in regards to dementia and the people who live with it.

Part One

Chapter 1

Reality Effects: Mapping Issues in Reality Theatre

As was made clear in the introductory chapter, the overarching aim of this thesis is to locate and explore the ways theatre and performance (in particular, verbatim and autobiographical) can best respond to and represent people living with a dementia diagnosis (senile dementia in the main): an aim not without problems. At the broadest end of this intention, cultural entities such as theatre shows risk drawing on and repeating the very cultural materials, like stereotypes, metaphors and other elements present in the 'right kind' of dementia stories, likely to perpetuate negative ideas about people living with a dementia diagnosis. When it comes to the more specific staged 'reality' of reality theatre representations, like professional verbatim theatre productions, these 'right kinds' of stories about dementia will undoubtedly play a part in creating their "reality effects" (Schneider, 1997: 22) on stage, which in turn will feed back into how the 'reality' of dementia is materialised in the world. For theatre theorist Rebecca Schneider, "reality effects" refers to the staging of reality in the theatre where even though 'the real' may always be "performative, or constructed, that construction and its re-construction and its re-reconstruction exist in a battlefield ghosted by that construction's historical effectivity— its reality effects" (1997: 22). In other words, "[s]taging reality effects in the theatre involves entering an already charged sphere of contested representations" (Evans, 2008: 4). Whatever the reality being framed on stage, it will involve citation of a reality always already mediated, which is not to say that a real outside of language and performance does not exist (Evans, 2008: 3).

Given the circularity of these seemingly sealed feedback loops, is it even possible for theatrical representations to avoid replaying the 'right kind' of dementia stories? If so, how? And does working in a reality theatre genre like verbatim add to these quandaries or provide an answer to them? These thorny questions, for which no easy answers are to be found, form the cynosure of this chapter. In attempting to navigate these questions, along with thinking about how dementia might catalyse

issues in reality theatre and performance studies, this chapter presses in three main yet intersecting directions which subsequently lay the foundations for, and inform, the concerns charted in the two case study chapters following this one.

The first direction this chapter takes is to begin an investigation into the connection between words, stories, identity and the materialisation of 'reality' in "reality theatre" (Garde, Mumford and Wake, 2010) or "theatre of the real" (Martin, 2013), with a particular interest in words. As part of this tack, and although I frequently draw on both the above terms ('reality theatre' and 'theatre of the real') to explore issues to do with representing the real, I also run with the term 'verbatim' throughout this chapter. I deliberately deploy the term 'verbatim', whose denotation is 'word for word; in the exact words' (OED online: 2014/2015), despite my knowledge that there has been scholarly concern about it. I am aware that in theatre scholarship, arguments have been made that, embedded in the word 'verbatim' are problematic connotations about the possibility of unmediated truths in regards to theatre productions. Theatre scholar Janelle Reinelt argues that the term 'verbatim' promises "what you will hear spoken are the *authentic and unaltered words* of various real-life agents" (2009: 13; my italics) which is, of course, impossible, as the final verbatim theatre production will necessarily present an edited version of the source material, interpreted by actors and directors (in the main). However, and arguably, there is also a similar problem for the word 'reality' in which problematic connotations about authenticity and actuality are also embedded, matters which this chapter also addresses.

My insistence on the term 'verbatim' underpins a particular interest that this chapter has in words. Apart from the fact that my choice of and interest in researching all the case studies that follow this chapter began with their deployment of the *words* of people living with a dementia diagnosis as foundational to their scripting, using the term 'verbatim' enables me to explore two apparently contradictory propositions connected to words. These are that words both do and don't matter when it comes to representations of the reality of dementia on stage (in light of the fact that words are one of the challenges faced in the progress of many of the dementias). However, in arguing partly for the worth of verbatim ontology in regards to these representations, I am not suggesting that

theatre-makers should deliver meticulous and exact word for word productions in pursuit of a notion of the real which cannot exist within theatrical parameters.

The second direction this chapter tracks is how dementia might shift or add to debates in the reality theatre scholarship, an idea threaded throughout this chapter's various sections, but which is also specifically addressed in one section dubbed 'what dementia offers verbatim theatre'. Lastly, the third direction this chapter tracks is my contention that any pursuit of the accepted real risks reinforcing the arrangements of a 'real' world in need of change if people living with a diagnosis of dementia are to be seen and heard, in the best tradition of politically inflected reality theatre. That is, for radical change to ensue from reality theatre projects about dementia, there is first and foremost a critical requirement for theatre practitioners to rethink the frames of reference that establish such a real world and which are embedded in stories and discourse.

As AD mostly affects older adults, rethinking these frames of reference entails analysing assumptions underpinning attitudes towards ageing, that is, their "normative age-effects", as age studies researcher Bridie Moore (2014: 2) calls them. Rethinking these frames also entails unpacking the many ways people living with a diagnosis of dementia have been discursively represented, along with all the biases and assumptions accompanying these representations, what I term their 'normative age-and-dementia-effects', following Moore (2014: 2). It is also most specifically and primarily a memory disease: cultural attitudes towards memory need probing.[52] And finally, as dementia assaults popular and philosophical conceptions about the self, these also need to be taken into account.

I begin this chapter by outlining a history of the staging of real life voices in the theatre, to demonstrate that hearing different voices, hand in hand with seeing lives different from conceptions of the accepted real (that is an ahistorical universal white man), became seminal to movements for social and political change, both on and off stage from the late eighteenth century through to the present day: a fact which still holds sway in current reality theatre endeavours. However, when it comes to contemporary reality theatre representations of dementia, this impetus for

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[52] Although memory is somewhat addressed in Chapter 2 and in Chapter 7, its domain is too large and unwieldy for me to do it justice in this thesis.

showing the 'real' world (that is, to prompt action to change it) should not be accepted without prudence: the risks of on stage visibility and/or audibility need to be counterbalanced by concerns about how this type of representation might in fact only reinforce stereotypes about dementia and its peoples as their stories and lives do not always fit accepted versions of the 'real'. In fact, the reality of dementia may best be represented in forms that do not hinge on the literal, but rather the symbolic. These ideas are explored in more detail later on in this chapter.

Staging real life voices

The Western interest in staging reality goes back at least to the Greeks, but an interest in everyday voice and idiom started to emerge in the 'Sturm and Drang' (or 'Storm and Stress') drama of late eighteenth-century German theatre, from the 1760s to the 1780s (Garde, Mumford and Wake, 2010: 9-10). In this period, playwrights began to use idiomatic prose littered with colloquialisms and swear words, challenging the neo-classical insistence on presenting universal truth through stilted prose and poetic verse and attempting to address the reality of human diversity.[53]

The first play to resemble a documentary drama was arguably Georg Buchner's 1835 *Danton's Death* (1993), a type of history play dealing with the social disorder ensuing from the French Revolution. *Danton's Death* utilises verbatim or paraphrased quotes from historical texts based on primary sources. Buchner's next two plays *Lenz,* written in *1835*, and the uncompleted *Woyzeck* of 1837 (both in Buchner, 1993), were based on documentation and the lives of those marginalised by class and mental health.[54] Buchner's use of documentation, his interest in the representation of the marginalised, and his talent for observation, were developed by the later nineteenth-century European 'naturalist' playwrights,

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[53] Johann Christoph Friedrich von Schiller, Johann Wolfgang von Goethe and Jakob Michael Reinhold Lenz were among these playwrights.

[54] *Lenz* (1835) is a study of schizophrenia based on a Minister's journal notes. *Woyzeck* (1837) is a working-class tragedy based on documentation about three nineteenth-century murders and medical reports on the mental health of Johann Woyzeck, an actual person (Garde, Mumford and Wake: 2010: 10).

chiefly Emile Zola, Henrik Ibsen and Anton Chekov, who gave voice to modern issues, including alcoholism and syphilis, in a writing style highlighting the quirks and oddities of their characters' speech (Garde, Mumford and Wake, 2010:10).

According to theatre commentator James Frieze, despite this important interest in the everyday, these 'naturalist' plays "echo the triadic process of medical diagnosis" (2011:149), also gaining power at the time, which is first, to read the subject's symptoms, then to pronounce the subject's condition and after that, to prescribe treatment. Frieze argues that this process is echoed structurally and rhetorically in the well-made naturalist play of the later nineteenth-century where the first act scratches away at the surface of a brewing conflict; the second identifies the breakdown in the social body; and the third, the denouement, purges the effects of the breakdown. As Frieze sees it, in this way the 'naturalistic' play, along with medicine, cemented the idea that 'truth' (including the paradoxical rationalisation of the body's materiality) could be found and shown by the purported objectivity of the 'expert', whether clinician, writer or spectator.

As a related digression, this idea about truth has not only undergirded the development of *naturalist* scripts into the twentieth century but has also influenced certain types of reality theatre emerging from the beginning of the twentieth century up to the present. One recent example is tribunal theatre's commitment to exposing 'the truth' in the new 'public sphere' of theatre: a sphere replacing mainstream media platforms compromised by corporate interference. Tribunal theatre relies specifically on using documents located in public archives, a process underpinning the idea that truth can firstly be *located*; secondly, that it can be *identified* by expert truth seekers such as investigative journalists turned playwrights; and thirdly, that it can be *presented* to audiences without bias or interference (Tribunal theatre relies is to be discussed in more detail later on in this chapter). Interestingly however, when verbatim theatre burst onto theatrical stages in the latter half of the twentieth century (also to be discussed in more detail later in this chapter), its main purpose was to air the subjective voice and experiences of the 'everyman/woman'. This type of verbatim theatre directly challenged the authority and objectivity of 'experts' writing dramatic scripts on everyday life. Moreover, the previous surety of the 'expert' spectator mentioned above is being

challenged today in certain iterations of verbatim theatre. In some instances, the use of a postdramatic aesthetic can muddle and confuse the certainty of this 'expert' viewer.

Turning back now to the 1920s: this was when Erwin Piscator exploited the newer technologies emerging at the time (like the slide projector and film) to create a particular brand of political theatre in which recordings and slides and film were used to address topical issues.[55] According to Carol Martin, Piscator used this new technology to make a socially engaged theatre initiating "theatre of the real", as we now know it (2013: 16). From its inception then, documentary theatre was enmeshed with "politics, technology and an oppositional or questioning attitude towards mainstream media" (Garde, Mumford and Wake, 2010: 11).

Both before and after the Great Depression of 1929, the documentary form burgeoned all over the world,[56] yet it was silenced by the strengthening of totalitarianism across both Europe and the United States of America (USA) in the years preceding the Second World War. However, in the period from the late 1930s until the early 1960s, it re-emerged concurrently with episodes of social unrest marked by student demonstrations, civil rights movements and anti-Vietnam war protests. This "second wave of documentary theatre" (Garde, Mumford and Wake, 2010: 12) was first centred in West Germany where contemporary plays interrogated past traumatic events connected to the Holocaust.[57] As Janelle Reinelt points out, this "valorization and desire for 'facts,' for the materiality of

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[55] An example is *In Spite of Everything!* (*Trotz alledem!*) (1925), co-produced with Felix Gasbarra, a political revue of a 10-year history of the German Communist Party. This production marked the emergence of "a new form of theatre composed entirely of visual and verbal documents" (Favorini, xviii cited in Garde, Mumford and Wake, 2010: 11), including montages of projected newsreel footage, recorded speeches, news-extracts, photographs and film sequences from the First World War.

[56] As Garde, Mumford and Wake (2010) report, in the Union of Socialist Soviet Republics (USSR), the Blue Blouse troupe presented Living Newspapers commissioned by the Department of Agitation and Propaganda (Agitprop) to present 'facts' and information about the Russian Revolution to a vast number of mostly illiterate people. Starting from actors just reading the newspapers, these shows became livelier over the years with the use of slides, songs and snippets of film. In the Depression era, from 1929, the form spread both to the United Kingdom (UK) and to the USA. In the USA, the form manifested in the Federal Theatre Project's Living Newspapers, which were socially engaged plays based on newspaper reports; in the UK, the Unity Theatre took up the form. Both presented challenges to totalitarian regimes and told stories about the capitalist victims of the Depression.

[57] Two of these were Rolf Hochnuth's *The Representative* (1962) and Peter Weiss' *The Investigation* (1965), both written nearly 20 years after the end of World War Two. Of interest here is that Piscator directed both of these productions as well as Heinar Kipphardt's *In the Matter of J. Robert Oppenheimer* (1964) (Cantrell, 2015).

events, for a brute display of evidence" was most likely "a reaction against the fear of total fiction" in the face of Holocaust deniers and their scepticism of historical archives (2006: 82). In this case, Reinelt argues "there is not much to do besides point to the bodies of evidence and demand they not be discounted" (2006: 82).

Theatre of the real emerged in America from the 1960s, and, according to Carol Martin, can be categorised into two main strands: one, based on the take up of the Growtowskian valorisation of the body and presence on stage; the other, in which playwrights turned to the word to represent 'the voiceless'. Martin writes that "[s]ome theatre of the real is connected, at least ideologically, to the historical avant-garde, while other takes the form of orthodox contemporary realism" (2015: 136). In the USA, the first type of theatre is exemplified in the work of the Performance Group, which relies on the body, and the latter in the theatre of Emily Mann and Anna Deavere Smith, which relies on the word. Verbatim theatre relies on the word as its name suggests.

Verbatim theatre emerged in "the second half of the twentieth century, and remains very much alive, evolving and contemporary today" (Brown, 2010: Preface). Derek Paget principally exploited the term 'verbatim' during his extensive research into the work of those early contemporary practitioners of the form operating in the 1960s in regional Britain, amongst whom were John Cheeseman, Chris Honer, Rony Robinson, David Thacker and Ron Rose.[58] This form of theatre was advanced to give a public voice to specific regional communities in the United Kingdom (UK) suffering traumatic events, like the closure of factories, which were their livelihood and lifeblood (Anderson and Wilkinson, 2007: 157). Providing an arena for the silent or marginalised, these theatre-makers were committed to 'authenticity', transcribing and feeding back to their source communities, through performance, with some exactitude and respect, life stories and oral history remembrances garnered from taped interviews (Paget, 1987). Out of these early productions, the fundamental architecture of verbatim theatre was established: the alignment of the old art of storytelling with newer technologies like taping, in order to make a performance script out of the words of the original storytellers (Brown, 2010).

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[58] The work of these practitioners was in the lineage of the British radio ballads of the 1950s, which culminated in Joan Littlewood's *Oh What a Lovely War* (1963); as well, they were clearly indebted to the British documentary films of the 1930s and 1940s and the European plays of Berthold Brecht and Erwin Piscator (Paget, 1987: 318-319).

In general, over the last 20 years or more, there has been a "remarkable mobilisation and proliferation of documentary forms across Western theatre cultures" (Forsyth and Megson, 2009: 1). Numerous productions have showcased stories of trauma, displacement and exile, all hallmarks of the wars, diasporas, holocausts, terrorist attacks and human rights violations these last two to three decades have delivered. This trend can be termed 'the revival of the real'.

The revival of the real: verbatim theatre and the 'lie of the literal'

According to Janelle Reinelt (2006), the revival of the real can be attributed to two seemingly opposite reasons. The first is the fundamental angst of an epoch that is "specifically and technically theatrical and performative" (Reinelt, 2006: 71). The second is an insistence on facticity in the face of and in reaction to this angst. For Reinelt, this is a reaction to the 'society of the spectacle', first defined by Guy Debord as a "mode of social relations mediated by images" (1994: 12) and controlled by the all-pervasive commodity to the extent that the world as we see it is the world of the commodity (Debord, 1994: 29). Reinelt argues that verbatim and documentary theatre forms have achieved popularity because in a world of simulation where everything is seen to be *"only a copy of a copy and nothing is for sure, public rehearsal of 'facts' becomes one way of holding onto the very notion of facts"* (2006: 81).

Certain practitioners of documentary and verbatim theatres *do* feel there is an urgent need in the contemporary economy of the spectacle for the real; yet this very need appears to drive them towards what David Hare refers to, incorrectly, as "red-blooded realism" (Bottoms, 2006: 56 cited in Evans, 2008: 4). His reference is incorrect because it refers to the use of verbatim materials in fashioning scripts rather than the realistic simulations associated with the modern drama, such as everyday settings, conversational speech and truthful acting styles.[59] Much

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[59] Theatrical realism first developed in the 1870s with a set of dramatic conventions targeting a greater fidelity to 'real' life in both text and performance. It centred on the ordinary speech, behaviour and settings of the middle classes. It was a theatre interested in the actual problems of people's lives and was established in reaction to the artificial comedies and melodramas which were the mainstay of most of the nineteenth century stages of Europe (Kernodle and Kernodle, 1978:126-130).

verbatim work has leaned towards a faithfully mimetic representation of the real or insisted on being faithful to the words of the storyteller in order to uncover the truth, rather than towards the problematising of "illusory reality" (Lehmann, 2006: 17) and despite the fact that verbatim theatre can and has worked imaginatively and not just factually.

Plays from the 'British school' [60] of verbatim playwrights are good examples of this leaning towards 'red-blooded realism'. Many of these playwrights are journalists or journalists who collaborate with theatre artists. Some examples are Katherine Viner, deputy editor of the *Guardian* who collaborated with Alan Rickman on the script for *My Name is Rachel Corrie*, and Victoria Britain, who co-wrote *Guantanamo* with Gillian Slovo (Frieze, 2011:153-154). Playwright and security affairs editor for the *Guardian* newspaper Richard Norton-Taylor pioneered a related form of verbatim theatre known as 'Tribunal Theatre' at The Tricycle Theatre in London. Tribunal plays are verbatim plays that use official transcripts of legal proceedings as their lone foundation (Reinelt, 2009:13). Norton-Taylor has mined documents from many public inquiries for his plays, including state inquiries into arms to Iraq (*Half the Picture,* 1994) and the Nuremberg war crimes tribunal (*Nuremberg*, 1996). He is unequivocal about the purpose of his projects: "exposing the truth has been the goal of each of our tribunal plays" (Norton-Taylor, 2008: 106). As admirable as these aims are, and also as possibly effective in some ways, in seeing themselves as the guardians of 'truth' in the public sphere, these playwrights may dismiss their bias in the creation of their work and use "categorical thinking" to justify "prejudices and excesses" (Frieze, 2011:154). They may also overlook the impossibility of locating and exposing the 'one' truth in the fictive domain of the theatre. On top of these issues, there are two other main risks with this type of verbatim theatre.

The first risk is that verbatim plays "faithful to the integrity of the storyteller" (Salverson, 1996: 183), or the archive in the case of the tribunal form, and which follow the stricture "not to interfere with the words" (Salverson, 1996: 183), expose

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[60] In using the phrase the 'British school', I do not mean to infer that all British verbatim theatre follows in this line. I use it to refer to those playwrights who talk about their practices in the book *Verbatim Verbatim* (2008) edited by Will Hammond and Dan Steward: Richard Norton-Taylor, Robin Soans, David Hare, Nicholas Kent and Alecky Blythe, among others. Their ideas about the value of verbatim as a technology of truth share many similarities.

what Julie Salverson has coined the "lie of the literal" (1996: 183). Salverson writes about storytelling in applied theatre sites specifically, but her ideas also have resonance in regards to professional verbatim theatre-making with people's stories. For Salverson, the 'lie of the literal' is one of the dangers in the transmission of stories, especially stories that move from the mouths of vulnerable people to theatre-makers and then on to audiences. It often involves "an overemphasis upon a single, authentic story [and] does not allow for sufficient complexity, nuance, and multiple points of entry" (Salverson, 1996: 184).

Moreover, as Salverson (1996) also argues, these types of verbatim plays tend to focus on certain types of stories from certain types of people, often those perceived to be 'victims' or 'sufferers' of trauma. Yet, as Salverson (1996) goes on to argue, in creating theatres based on 'real-life' stories of trauma or oppression, faithfully mimetic theatrical representations may end up re-inscribing and reinforcing the very pain and exclusion that the theatre-makers were seeking to change in the first place. By painting reductive images of victims in some variation of documentary realism, the aesthetics and the ethics of the theatre piece could be sacrificed for the privileging of injury. Salverson terms this "an aesthetic of injury" (2001: 122).

The second risk with these types of reality theatres is that audience members, too, may get 'hooked on' going to see these theatre pieces as a way to salve their consciences in regards to the issues on display. Salverson coined the term the "erotics of suffering" (2001: 123) to encapsulate this phenomenon. The 'erotics of suffering' may leave theatre-goers satisfied through the experience of empathic responses to suffering, but may not move them into the much more uncomfortable space that will, in fact, affect change.

Maryrose Casey (2009), writing on Australian Indigenous theatre, argues a connected point. Casey articulates the "epistemic violence" wrought on Indigenous cultures through Euro-Australian theatre-goers' desire to witness "testimonies of oppression" (2009: 136). This witnessing of oppression testimonies, Casey argues, is a way audiences expect to be offered back their own world view: that of the suffering wrought on Indigenous people (the oppressed) by the non-Indigenous (the oppressors). This view does not allow the Indigenous to be painted in any other light than that of victims. In turn, theatre-makers, Indigenous and non-

Indigenous, sometimes unknowingly, make theatre that fits this worldview. Non–Indigenous audiences come to the theatre to "recuperate virtue" (Casey, 2009: 136) as believers in a reconciliation process in which they admit to being the oppressors, but in fact, this recuperation perpetuates a kind of "epistemic violence" (Casey, 2009: 136). This is because no other view, especially that of an Indigenous world constructed of other more positive realities, can be tolerated.

The main trouble with verbatim theatres that emanate from these types of ideological platforms is that they lock down what verbatim theatre can be and can do, restricting its scope rather than opening it up. In the next section of this chapter, I turn to debates over the term and its usefulness. I critique definitions of verbatim theatre offered by theorists of the 'British school', which well show this tendency for restricting the form to scripts enacted on the stage through dramatic presentations and which tend to ignore the many emerging contributions of the postdramatic to the verbatim form. I then explore how verbatim can shine when its theatricality is afforded as much room as its source material, hand in hand with problematic notions of truth, authenticity and testimony. This then allows me to turn towards an examination of how words both do and don't matter in presenting the reality of dementia on stage.

Defining verbatim theatre and locating its cultural work

Debates over the term 'verbatim theatre', and its meaning, have been widespread in the scholarship up to the present despite, or perhaps because of, the pleas of *Get Real* editors Alison Forysth and Chris Megson to put aside definitional debates in favour of critical approaches that probe the utility and viability of the various terms circulating under this category of theatre and others that cite reality (Forsyth and Megson, 2009: 2). As I have already stated, I draw largely on Carol Martin's idea that it is time for scholarship to focus on the performances and issues associated with them rather than the playwrights and their plays, and the specificities of various practices.

In the introduction to their book entitled *Verbatim, Verbatim,* which has a compilation of essays and interviews with six leading British practitioners, editors

Will Hammond and Dan Steward posit that verbatim is a "technique" rather than a "form" of theatre (2008: 9). By this they mean that it refers to "the origins of the text spoken in the play" and is "a means rather than an end" (Hammond and Steward, 2008: 9). They write that it is:

> [t]he words of real people … *recorded or transcribed by a dramatist during an interview or research process, or … appropriated from existing records* … [that] are then edited, arranged or recontextualised to form a *dramatic presentation*, in which *actors* take on the *characters* of the real individuals whose words are being used (Hammond and Steward, 2008: 9; my italics).

There are three main criticisms I want to make about this definition. The first is the reference to actors and to characters. In this vein, writing on verbatim theatre in South Africa from the 1970s to the present, theatre studies scholar Yvette Hutchison's question seems prescient: "[I]s it actual words, transcribed and performed by actors, or can it be stories performed by and about the protagonists themselves?" (2009: 211). Like Hutchison, I think that verbatim is a theatre where, although the words and stories used should have importantly emanated, in part at least, from 'real' mouths and lives, they may also be performed by those people, and not just actors. In practice, this is happening frequently: the German company Rimini Protocol has the actual people, not actors, perform their own stories on stage. Their *Radio Muezzin* (which I saw at the Sydney Festival in early 2012) has four muezzins from mosques in Cairo recount their ceremonial practices through telling their distinct stories. These are "'the experts of the everyday' (people who are specialists in a particular field of life)" (Garde and Mumford, 2013: 149). Writing mainly in reference to performance art, art historian Claire Bishop (2012: 219) uses the term "delegated performance" to account for this practice of professionals hiring non-professionals to do work on their behalf (for example, performance artist Marina Abramović).

The second problem I have with Hammond and Steward's definition of verbatim is the reference to a 'dramatic presentation'. Martin's 'big picture' view of the theatre of the real underscores how scholars have overlooked contemporary innovations in the *performance* of verbatim source words and stories, including its postdramatic innovations, compared to their focus on the archival sources to the plays, assembled by playwrights and performed by actors. In part, this points to a

bias in terms of written drama and traditional playwriting, ignoring the many emerging contributions of postdramatic reality theatres, along with all their challenges.

The third criticism I wish to make about Hammond and Steward's definition is the insistence on the way in which the words and stories of the subjects are gathered: that is, their *'record[ing] or transcrib[ing]'* most often by audio and/or video-tape. Particular contemporary verbatim practitioners may in fact be scribbling these stories in notes or recollecting them, even if in faulty memories. This latter practice is the technique used by Theatre Kantanka in *MBDJ*. Another example is that of verbatim theatre-maker Laurie Lathem who worked with a group of young drama students interviewing older people in a senior citizens' centre, without tape recorders, supposedly the hallmark of the verbatim technique. Lathem did this because she wanted the students to listen closely and also because she did not want it to be "verbatim — in any strict sense of the word" (2005: 76-77). Lathem wanted the young interviewers to create their own dramas on the basis of "what would make for a good play" (2005: 76-77) rather than proposing an 'authentic' retelling (Heddon, 2008: 139).

I would argue that these so-called 'exceptions' to the verbatim form are recurring more and more frequently in practice, showing that verbatim shapes and is shaped by "contemporary cultural discourses about the real on stage and off" (Martin, 2010:1), including innovative forms of writing as well as the postdramatic (Taylor, 2013: 379). The issue then appears to be whether or not these 'exceptions' will render their membership in the verbatim family null and void, and therefore that they should be housed under a different rubric; or whether the form itself has been rendered hollow by these exceptions; or whether they should be accepted, thus widening the possibilities of the verbatim form to reflect the creative ways practitioners are actually using, challenging and reforming it in contemporary practice. I would opt for the last alternative.

Along with theatre and performance scholars like Yvette Hutchison (2009), Ulrike Garde and Meg Mumford (2013), as well as applied theatre scholar Amanda Stuart Fisher (2011), I assert verbatim theatre as a space for the realisation of creativity, imagination and poetry. When the form is allowed some latitude, it opens up

horizons on what it can be, rather than narrowing them, permitting a variety of theatrical products to be produced under its rubric and allowing non-literal renderings of source material, along with problematic notions of truth and authenticity. Sydney-based educational theatre scholars Michael Anderson and Linden Wilkinson maintain that verbatim "has now become a portmanteau term, incorporating a stylistically rich and varied product that owes its origins to spoken text but does not always perform these words literally as they are spoken" (2007: 154). This is a good definition which captures the many ways verbatim material can be gathered and performed while still relying on its ontology: the spoken word and the story. This definition refuses to limit verbatim dramaturgy to what Janelle Reinelt has termed "simple facticity … the corroboration that something happened, that events took place" (2009: 10). Verbatim theatre can be allowed to be a stylistically prolific product, created in such a way that its 'makeup' as theatre can be more readily afforded over its association with its source material.

An example of how it is being used in this way is *Romeo and Juliet* a (headphone) verbatim work from New York based Nature Theater of Oklahoma (Theater of Chance), which, as the brainchild of Pavol Liska and Kelly Copper, has worked verbatim since its inception.[61] I saw *Romeo and Juliet* at The Kitchen in the West Village, New York, December 2009, with Anne Gridley as Juliet and Robert M. Johanson as Romeo. In the middle of the stage was a box where the person who doubled as the chicken act between the performers' monologues (Elisabeth Conner) prompted the gestural and verbal choreography of the piece, according to chance.

Romeo and Juliet emerged from a desire to stage an unconventional take on the Shakespearean classic and to do so, Liska and Copper rang up friends and relatives to ask them what they remembered about the tale. They recorded people's responses and created a work in which the words of people interviewed

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[61] Headphone-verbatim faithfully reproduces the speech patterns of its sources. Using headphones, actors listen to and deliver as closely as possible the words and vocal inflections of a pre-written and carefully edited script recorded from interviews (including pauses and stutters). The form was first introduced in Britain by Mark Wing-Davey at a workshop at the London Actors Centre, at which both British theatre-maker Alecky Blythe and Australian Carolyn Oades were participants (Brown, 2010: 84). Blythe went on to found the company Recorded Delivery; Oades to work with Sydney-based Urban Theatre Projects. Blythe has expressed the strains of the commitment to "remaining faithful to the interview and creating a dramatic narrative" (2008: 95), concerns which most of the British verbatim practitioners in the book *Verbatim, Verbatim* also repeatedly express.

about their recollections of the story of *Romeo and Juliet* are the base material for the performance. The text remains faithful to its conversational origins, not only in terms of the words but in terms of paralinguistic expressions like coughs, sighs, word stress, timbre, volume, and rhythm, as well as pauses, repetitions, mistakes. This means that the story of *Romeo and Juliet* is not told as a linear narrative but, rather, impressionistically and according to the memories of the interviewees. Thus the show works with notions of truth, accuracy and memory in storytelling as well as the role and importance of Shakespearean text to people today. The production ironically contrasts modern conversational idiom and pop cultural references with the melodramatic gestural delivery of its actors. Melodrama is a type of theatre that became popular in Britain and other parts of Europe in the nineteenth century, and arguably still lives on in the conventions of television soap operas. Melodrama codified thoughts and emotions "in the form of significant postures, gestures and vocal intonations" (Hurley, 2010:43).[62] Examples of this type of delivery in the production include Johanson's placing of one hand on his hip with the other hand out and his placing of the feet in modified fourth position, a typical gesture associated with the nineteenth century hero; and Gridley's consistent use of a left hand and arm flourish, almost as if she were carrying a tray of food through a restaurant, no doubt an ironic comment on Johanson's more traditional gestural delivery.[63]

There are two important points of interest about *Romeo and Juliet* for this discussion. The first is that unlike so many verbatim theatre pieces, especially those from the 'British school' I mentioned earlier, its 'politics' are not obvious. By this I mean that it is concerned with unveiling the mechanisms of the oral story or anecdote, rather than telling a 'true' story from a marginalised or abject source. In this way *Romeo and Juliet* not only exposes the 'lie of the literal', but in making certain aesthetic choices that disrupt the accepted structures of storytelling in a verbatim piece, it makes a political point: that all memories are not dependable, not just the memories of those living with a diagnosis of dementia. This choice also

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[62] English actor and director Henry Siddons, along with Johann Jacob Engel, documented many of these nineteenth century gestures in *Practical Illustrations of Rhetorical Gestures and Action* (1822).

[63] Both also deploy what *The New Yorker* theatre reviewer Hilton Als terms "the round tones of a classically trained *act*-or" (2015: n.p; italics in the original).

adds weight to Hans-Thies Lehmann's (2006) theorisations that all aesthetic choices are political.

The second point of interest about *Romeo and Juliet* is that on one level, it is committed to the faithful reproduction of the words and speech patterns of its sources; on another level, it disrupts notions of fidelity to the source by having the actors deliver lines prompted through their headphones, by chance. In this way *Romeo and Juliet* juxtaposes fidelity to a source with a critical exposition of its theatrical artistry. *Romeo and Juliet* also underscores, as does much headphone verbatim in particular, that words and speech patterns are produced in and through the actor's body on stage, mediated by technology; they do not just owe allegiance to an authentic source. In *Romeo and Juliet,* Gridley and Johanson work through their bodies to listen, and then to create the speech patterns of the original speakers through the medium of audio technology.

But *Romeo and Juliet* also emphasises that the power of (some types of) verbatim theatre does also lie, at least in part, in the words and speech patterns of those interviewed. Australian verbatim scholar Paul Brown (2010) refers to these as "voiceprints". He explains that "voiceprints are like fingerprints in the sense that they are utterly unique and almost impossible to reproduce", allowing audiences to hear particular speaking patterns and rhythms and to follow an individual's thinking (Brown, 2010: 3).

Recognising that each person has an idiosyncratic personal dialect, linguists long ago coined the term 'idiolect', which denotes distinctive choices in each person's vocabulary, pronunciation, collocation and semantics, built up over many years and differing from those of other people (Halliday et al., 1964; Abercrombie, 1969 cited in Coulthard, 2004: 432). According to linguist and blogger Gretchen McCulloch:

> Your sense of English as a whole is really an abstract combination of all of the idiolects that you've experienced over the course of your life, especially at a young and formative age. The conversations you've had, the books you've read, the television you've watched: all of these give you a sense of what exists out there as possible variants on the English language. The elements that you hear more commonly, or the features that you prefer for whatever reason, are the ones you latch onto as prototypical (2014).

The notion of an idiolect has been used to determine authorship in forensic linguistics and termed "linguistic fingerprinting" (Coulthard, 2004: 432). However,

the idea of it being like a signature for the purposes of, for example, identification and prosecution in court cases, has been much harder to implement, given issues about the quantity and type of data needed to characterise an idiolect (Coulthard, 2004: 432).

I hold that in verbatim theatre, both words (vocabulary) and speech patterns (pronunciation, collocation and semantics) may create an important *trace* link to the people behind the performed stage story told by actors on stage, which could reveal important biographical and geographical elements about these people, among many other factors. In this dispensation, words and speech patterns fashion a *link* to people who may not be able to represent themselves in person because of their cognitive disabilities and become of seminal importance. Audiences might come to the theatre to get "*a sense of* direct contact with living people and truthful representations of their lives and social contexts" (Garde and Mumford, 2013:148; italics in the original), what Garde and Mumford term their "authenticity effects", as strategically created or dismantled by reality theatre practitioners.[64]

Words and dementia: do they matter?

The issue of words and dementia is vexed, without even considering their stage effects. People living with a diagnosis of dementia lose words or struggle to speak them and yet words, as opposed to even fully formed sentences or phrases, or even sounds, are sometimes the only way they can communicate, along with a vast repertoire of non-verbal language. Of course, words on their own do not 'do' much. They are arbitrary sounds and symbols given symbolic meanings dependent on the socio-cultural environments in which they are used and understood. In 1916, the linguist Ferdinand de Saussure (1983) proposed the arbitrary nature of the symbol dependent for its clarity on the language system (langue) in which it is embedded. But he also argued that these symbols exist in

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[64] Drawing on Janelle Reinelt's (2009: 9) arguments in 'The Promise of Documentary', Garde and Mumford argue that: "Reality theatre relies on and/or plays with the assumption that 'knowledge is available through sense perception and cognition linked to objects/documents' and that such aspects of a performance can put people in contact with the 'reality they are trying to experience or understand'"(2013: 149).

inter-relationship, which he classified into two dimensions: the syntagmatic (a horizontal sequential arrangement) and the paradigmatic (a vertical associative dimension created by memory, custom, and culture). Roman Jakobson (1956) refined this early theory by arguing that the paradigmatic involves selection among possible alternatives, for example: tree, shrub, bush. The syntagmatic, on the other hand, involves a process of combination, for example: 'the cat sat on the mat', but not 'the sat cat on mat the'.

The words of people living with a diagnosis of dementia are seldom heard in public, most likely because of factors to do with the syntagmatic and the paradigmatic meanings of their language use. If both the syntagmatic and the paradigmatic meanings assigned are out of joint with each other, as well as the language users of the particular language group being considered, as they may well be when they issue from the mouths of people living with a diagnosis of dementia, words may not provide surety but in fact cause confusion. At a syntagmatic level their sentences might be a-syntactic and/or their stories irrational (especially if they are from people in the more advanced stages of dementia), or as memory stories, highly creatively infused as opposed to literal renditions of family histories, and will most likely be, as a result, dismissed. In this sense, words do count, not only given how dementia often operates to test, restrict and sometimes annihilate verbal language capacities, but for the fact that this often means people living with a diagnosis of dementia are not often asked, or are regarded as unable, to communicate in larger linguistic word bodies (like sentences or stories).

Linguistic limits are no doubt also one of the reasons for the dearth of theatre made from the verbatim input of people living with a diagnosis of dementia. Along with these limits, and no doubt also because of them, the selves who exhibit these difficulties are commonly relegated to biosocial death. In referring to a biosocial death, I am relying on social gerontologist Annette Leibing's (2006: 248) definition as one in which a person's capacity to partake in society diminishes to the point of not being considered a person. She argues that social death happens as a result of biology, but that biology cannot be considered apart from the social body. Therefore, to have the words of people living with a dementia diagnosis present and performing in a public theatre or performance space is, in one respect, an

ethical and political triumph; in another, their appearance may in fact reinforce ideas about 'the living dead' discursively prominent in socio-cultural understandings.

However, at the same time, I concede that words also don't matter, or matter that much in any performance. There are five main reasons for this assertion. The first reason is that, when linguistic powers well recede, as they undoubtedly will for people in the later stages of dementia, verbal links will likely become fatuous, necessitating other ways for theatre makers to conceive the shape of stories which are then gathered from people living with dementia diagnoses (such as non-verbal language, body movements, gestures and so on).

The second reason is to do with the ontology of performance; that is, performance is always much more than just the text (it is among many other factors bodies, non-verbal language, gestures, lighting and so on). The significance of any words will be moderated by the fact that theatre-makers take the words as their base material and then translate and interpret them into an aesthetic entity, including the "extratextual and subtextual languages" of the body — "glances, gestures, body language, the felt experience of space and the proximity of bodies" (Martin, 2006: 11). Bodies on stage are as responsible for creating stimulating theatre as are words. In theatrical spaces, there is the manifest "meatiness" of bodies (Gullette, 2004: 163) which can be seen from all angles, not just as the camera dictates, and which may compete with words to tell 'truths', invalidate these 'truths', a combination of both, and more. What we also have on stage when actors are playing 'real' others are what Margaret Morganroth Gullette calls their "default bodies" (2004: 162). Gullette uses this phrase in reference to the diverse age effects from all stages of the life course on bodies (intersected by race, gender and disability). These effects are always at work, particularly on the real bodies of the actors on stage, and not just on the bodies of the characters they are playing based on real people.

Thirdly, in performance, words are doomed to ephemerality and in this regard, to ontological failure, wiped out from certainty except in the memories of those audience members hearing them (or unless a script is available and purchased); but given that human memories are notoriously unstable and creative, they will

likely also lose the certainty of their textuality in these memories. The ontology of verbatim words will also lose some or all of their force in the relational and epistemological meanings generated between audiences and performers. However, the lines between categorically opposed domains always and inevitably overlap. But theatre has the potential to provide a temporal, located and embodied space where the effects of this blurring of boundaries between ontology, epistemology and relationality can be understood and witnessed. It is at this macro level, at the level of the kind of story told and of the face-to-face encounters specific to theatre, that social and ethical meanings are forged, and where political master narratives may be re-inscribed or challenged.

The fourth reason is that in any verbatim theatrical representation, it will not just be the words or scripts but how they are used, by whom and for what purposes. This could include, for instance, whether the final productions are exact transcriptions or imaginatively reconstructed versions of the source data, to what extent devising played a role, the degree to which the subjects were involved in decision-making processes like the drafting of play scripts, and whether or not the productions tout the 'right kind' of story. The fifth reason is that it is in the accommodation between frame and contents that meaning is always composed for (and by) an audience; and formal elements are critical in determining these meanings, notwithstanding "the tendency of the contemporary verbatim theatre to downplay its own artifice" (Bottoms and Martin, 2006 cited in Evans, 2008: 3). It is because of the fourth and fifth reasons that, in my examination of the two case studies following this chapter, I track the impact of the people and institutions behind the words and stories presented on stage (that is, the actor-devisers, the producers, the funding bodies) and do not just take into account the people who told the stories in the first place, or their words. Differences in these factors contributed to two very different verbatim productions that worked to very different ends.

Having probed the connection between words, stories and the materialisation of 'reality' in reality theatre, with a particular interest in how words both do and don't matter in verbatim theatre, I will now put verbatim theatre through the dementia 'filter' to see how it disrupts and reconfigures certain ideas about the scope and latitude of this type of theatre.

What dementia offers verbatim theatre

Dementia will pose a problem to theatre forms like verbatim, conceived solely as, and thereby limited to, the re-performance of real life stories and the pursuit of 'truth', if 'truth' is construed as a literal correspondence to the facts, or to the revelation of a single, unified, coherent and authentic self at the core of every human life story (Stuart Fisher, 2011). This is because dementia points to the nature of the 'truth' of any story, whether from someone with dementia or not. It is impossible for anyone to tell a logical, unchanging truth of their lives, which then can be represented on stage in a direct, less-mediated fashion. Theatre which attempts to do this is based firstly, on a false notion of fidelity to one 'original' or 'authentic' narrative self; and secondly, it does not take into account the numerous acts of collaborative construction, interpretation, translation and reception, at many layers of removal from the source, not only in theatrical representations but prior, in the very act of constructing, presenting and re-telling these stories to a listener in different places, times and to different people, in the framework of a complex web of recollection and forgetting. Put simply, our stories depend on others and will be altered by their repetitions and rehearsals, performance and re-performance over time depending on circumstances and context. The loss of memory which is a common part of the progress of dementia underlines the slippery nature of memory in general, and the many creative endeavours undertaken by us all in the act of telling 'our' stories to others, as well as the ways in which others help us to create who we are.

I suggest that the 'truth' of dementia (especially as a traumatic rupture) may lie in overlooking memory and notions of truth and, instead, in looking to the symbolic, not the literal. The theatrical has long been seen as the failure of the authentic (Barrish, 1981), and in some verbatim theatre pieces this has inclined theatre-makers towards a style of theatre that eschews all traces of being staged. A better way to uncover the 'truth' of dementia may in fact be to celebrate the theatricality of the theatre event. I propose that dementia (and the theatre that could emerge from it) provides a provocation to many widely held beliefs in our present day Western culture, especially certain foundational beliefs about testimony, and notions of authentic voice and agency.

Certain contemporary verbatim theatre tends to uncritically valorise the ethico-political importance of marginalised and vulnerable people and communities telling their 'true' stories in order to heal, or having these stories heard on public stages through the medium of a professional or community theatre production. Dementia offers verbatim theatre-makers opportunities for ethical reflection on the nature of truth and the value of the story itself, as well as the complex relations between the self and others, and the self and society. The status of the story (based on trauma theory and psychoanalysis) has been unchallenged in many verbatim theatre projects with vulnerable people and communities, where the notion tends to dominate that telling (the truth) always helps; in fact, in the case of dementia, the pressure to tell the truth may only exacerbate the stigma and marginalisation that some people living with a diagnosis could feel in the face of the loss of memory or language. Importantly, verbatim theatre must be allowed scope to work in ways other than being faithful to the words of the storyteller. It can be used, for example, to bring to the stage those experiences and testimonies irreducible to facts: whether the disordered and/or fabricated stories of those with dementia; or indeed, for any traumatic event, arguably not transparent, knowable or even communicable.[65]

Having discussed the illusions of truth which dementia highlights in verbatim theatre in particular, I will now expand my focus to turn to an exploration of the complexities of representing 'the real' which risk sustaining the problematic provisions of this 'real' world, especially for those seen as 'not real' or even 'people', as is common for older adults living with a dementia diagnosis. According to theatre theorist Elin Diamond, drawing on Brechtian theory, theatrical realism "depends on, insists on a stability of reference, an objective world that is the

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[65] There are correspondences between dementia testimonies and trauma testimonies. Cathy Caruth, following Freud, defines trauma as "that which resists simple comprehension" (1996: 6) and argues that it is best apprehended as an unqualified break in consciousness of being in the world; "a wound inflicted not on the body but on the mind … a breach in the process of cognition" (1996, 3-4 cited in Stuart Fisher, 2011:114). Research into the experience of living with dementia describes how individuals experience frequent traumatic ruptures in the fabric of their lives, usually to do with memory loss. It is quite common for people with dementia to endure bewildering absences in everyday life "threatening the continuity and familiarity of assumptions that enable us all to live day-by-day" (Mitchell et al, 2011:23). One moment the person could be having breakfast and the next he or she could be down at the shops with four to five hours having passed and no idea of how they got there. The 'reality' of AD, in itself and as a lived trauma, is that it may not be able to be 'told' by those who have it, depending on the stage of the disease of course; or at least it may not be able to be told in a linear, logical and continuous narrative mode.

source and guarantor of knowledge" (1989: 61). For this reason, Diamond argues that realism "surreptitiously reinforces (even if it argues with) the arrangements of that world" (1989: 61) leading to an unquestioned acceptance of "the constructed and propositional frames of reference that structure such a world" (Evans. 2008:7). This acceptance arguably also applies to any reality theatre production insisting on truth and the pursuit of the real. For change to the 'right kind' of dementia stories the frames of reference that constitute such a real world and which are embedded in stories and discourse need to be put under the microscope.

Constructing 'real' worlds

When reality theatre is created, it will be directed by underlying conceptual frames of reference about the 'real' world. One of these seminal frames is the modern myth of the possibility of seeing things as they 'really' are (Crary, 1999 cited in Bleeker, 2011: 27), even though they are always presented from within a certain 'vision'. Seeing and knowing are closely linked, as performance studies scholar Dwight Conquergood (2002) contends, writing in reference to dominant ways in which the academy conceptualises research. As Conquergood points out, dominant epistemologies which link knowing with seeing (usually from a superior distance) are not attuned to "meanings which are masked, camouflaged, indirect, embedded or hidden in context" (Conquergood, 2002: 146), nor do they easily accommodate meanings which are "local, regional, vernacular, naïve" (Conquergood, 2002: 146). Consequently, Conquergood maintains that communities and people marginalised by virtue of their race and culture have had their lives misinterpreted by white "scriptocentric" ethnographers (de Certeau, 1984: 161 cited in Conquergood, 2002: 147) and their particular ways of knowing disregarded. Through what Conquergood terms "the visual/verbal bias of Western regimes of knowledge", meanings that are expressed by people in what are seen as "nonserious ways of knowing", that is, through the cadence and timbre of their utterances, or their silences, or their body language, will probably ignored, subjugated, or not recognised (2002: 146).

Conquergood's ideas can be applied to the ways people living with a dementia diagnosis, particularly late stage dementia, make meaning in the world and to the

ways meanings are made about them. Conquergood's 'visual/verbal bias' dominates not only throughout the academy, but through Western systems of knowledge and meaning making, affecting the ways people diagnosed with dementia are seen and understood by other people, even verbatim theatre-makers. These practitioners might think they are 'seeing' people living with a dementia diagnosis as they 'really' are, but they may only be seeing them within and through a particular knowledge system that has become naturalised and taken for granted. The 'visual/verbal bias' would therefore have an impact on whether or not people living with a dementia diagnosis would be considered as worthy subjects for a verbatim interview, especially in the light of their non-normative communication styles.

How the subject has been constructed within these knowledge and meaning-making systems is therefore of significance. The dominant paradigm in Western modernity, despite incursions by ideas about the postmodern subject is "the liberal-humanist subject who is assumed to be unproblematically oriented in time, place and person" (Kelly, 2012: 44). This 'I' is a legacy of the Enlightenment turn in philosophy and, in particular, Descartes' separation of the mind and the brain. This 'I' irons out different subject positions and posits instead a singular, normate self; by doing this, it also irons out all the wrinkles of those subjectivities that sit in opposition to this hegemonic subject. There is no place in this picture for the disoriented, the inchoate, the confused, the non-rational. Those who do not fit the paradigm risk being deemed, and often are deemed, either not to be human or not to be persons, that is not 'real'.

Perhaps for these reasons, little theatre of the real has emerged from people living in Alzheimer's worlds, despite recent innovations in the verbatim genre which present a "creative interplay between fact and fiction" (Garde and Mumford, 2013: 148), and also despite the fact that dementia 'worlds' are the perfect examples of 'real' worlds which merge fact and fiction, mirroring what happens in reality theatre. I think that this dearth of theatre is, in part at least, because of a fundamental linkage between ideas about reality and cognitive function. In other words, at base, people living with a diagnosis of dementia are not seen as 'real' or even as 'people', because of their cognitive impairments.

As evidence, I point to the recent definition of reality given by verbatim theatre scholars Ulrike Garde and Meg Mumford in writing on postdramatic reality theatre: "[w]hen using the term 'reality' we draw on the pragmatic approach adopted by Pam Morris and define it as that which, in intersubjective communication, is agreed to exist" (2013: 149). The fact that these scholars did not make assumptions that the word is commonly understood is to be commended. However, because their definition includes an agreement between subjects, the absence of any reference to non-normative communication is highlighted. The choice of the descriptor 'intersubjective' for the type of communication points to an assumption that those agreed to be subjects are communicating with each other. Due to their cognitive impairments, people living with a dementia diagnosis at certain stages will not be seen as subjects (Hardcastle, 2008; Singer, 1996, 2009; McMahan, 1996, 2003, 2008). Neither are they, at stages of the progress of dementia, likely to be able to make and seal explicit agreements. As what Conquergood terms "subordinate people", they "do not have the privilege of explicitness … the presumptive norm of clear and direct communication, free and open debate on a level playing field that the privileged classes take for granted" (2002: 146).

Representation and reality

As well as the issues discussed above when considering the real, there is also the extremely complex relationship between representation and reality, with both predicated on semiosis, if to different extents. The word 'reality' suggests some kind of authentic and truthful originary source. Its denotations include: "[t]he quality or state of being real; [t]he quality of being real or having an actual existence; [c]orrespondence to fact; truth; [s]omething that is real; a real fact or state of things; (also) the real nature of something; [r]esemblance to what is real or to an original" (OED Online 2014/2015). In this chain of definitions, the ironies abound. The signifiers used to express the meaning of the signified, 'reality', are mostly trapped in a tautological treadmill (the signifier 'real' used to explain what reality is). Finally, with the last commentary, 'resemblance to an original', reality is linked to a representation, or resemblance, of an original. No leverage can be established to work out exactly what reality really is in this semiotic landscape. There are

indeed correspondences between 'reality' and its representation, as the last commentary reveals. And, as I have already noted, how things supposedly are in the 'real' world are very much connected with how they have been presented and represented, over and over again, in different locales and to different people, and in turn how they are perceived.

In the theatre, the already complex relationship between representation and reality will be heightened for various reasons, amongst which is the theatre's own paradoxical ontology. Real bodies and objects share doubled space with an audience, summoning both absent and fictional presences. In this space, both past and present (presence) oscillate together in embodied appearance: at once virtual (signaling towards imagined elsewheres) and material (using real bodies, objects and places), and theatrical, with "all the tacky fakery and tinfoil that attaches so embarrassingly to the term" (Evans, 2008: 2).

This complexity will be even further amplified in the case of theatre of the real productions, because actors who are 'real' people will be playing at being real people, who could also be known in the real world and even be known personally to the audiences watching the production. To make matters more labyrinthine, sometimes the actor playing the real person will be the self-same person (for example, in autobiographical theatre) and could be sharing the stage with others who are not playing themselves. An example of this complexity is the original Tectonic Theater Project production of *The Laramie Project*. Actors played themselves in their role as researchers to audiences comprised of the 'real' people who had become characters in the play, whom the actors also portrayed (Tigner, 2002; Dolan, 2005).

Matters become even further complicated when dementia is introduced into the mix because, as people living with a diagnosis of dementia are usually not seen as 'real' people, they may not be seen as fit subjects for interview or research; secondly, if stories *are* collected from them by theatre-makers, these stories may be found wanting in terms of logic and coherence, which will likely negate their 'truth' value; and thirdly, for reasons already mentioned, actors living with a diagnosis of dementia are less likely to perform their own stories on stage or pretend to be other 'real' (read non-cognitively disabled) people on stage in reality theatre productions.

These three instances underscore the relationship between words and the materialisation of reality as 'normalcy' in performance. It would take tremendous courage for the deeply forgetful to stand on stage and try to *remember* the words and actions necessary to perform their own stories, let alone those of other persons. Forgetting in public would likely be shameful for them and could further promote the notion (to audiences) that people with dementia are not 'real' or even 'people' because they can't feign the idea of the real as it is usually staged (wherein real people (actors) pretend to be other real people and spout their words as proof).

To sum up, staging reality in the theatre is not only complex but is replete with challenges, especially when dementia is taken into account. Staging the 'reality' of dementia will inevitably involve the use of representative systems already part of cultural performances and texts, "especially the text of the actor's body" (Gullette, 2004: 163) which, for example, usually facilitate the ideological devaluation of aged bodies living with a dementia diagnosis. It likely means resorting to or being influenced by the 'right kinds' of dementia stories, so deeply embedded not only in representational circuits but in personal and social psyches.

As I move into the final section of this chapter, I want to underscore that the idea of the 'real' in theatre of the real, though broadened over the years to include different classes, genders, religions, races and even disabilities, cognitive as well as physical, has not favoured the stories and words of people living with a diagnosis of dementia. In a 'Catch 22' situation, scholarship in this area is thin. In general though, scholarly interest in staging reality is enjoying a revival.[66]

Staging reality: scholarly interest

In 2006, in the fall edition of *TDR: The Drama Review*, a collection of essays on documentary theatre edited by Carol Martin reanimated dialogue in a timely manner. Since the 2006 edition of *TDR*, three new volumes on reality theatre have been published. The first is *Get Real: Documentary Theatre Past and Present*,

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[66] In the late 1960s and early 1970s, when verbatim and documentary theatre were enjoying revivals in Britain and in Germany respectively, scholarship was also flourishing (see Weiss, 1968, 1971; Cheeseman, 1970; Isaac, 1971 and Elvgren, 1974). Despite some input in the 1980s (see Filewood, 1987; Paget, 1987), and in the 1990s (see Paget, 1990, Favorini, 1995 and Dawson, 1999), in these decades, scholarship on documentary and verbatim theatre essentially abated.

edited by UK-based theatre studies scholars Alison Forsyth and Chris Megson, which claims to be "the first book length study of contemporary documentary performance" (Forsyth and Megson, 2009: 1). The other two are offerings from Carol Martin: *Dramaturgy of the Real on the World Stage* (2010),[67] and *Theatre of the Real: Studies in International Performance* (2013).[68] Articles and books have also been published on the various manifestations of reality theatre in Australia (Anderson and Wilkinson, 2007; Hazou, 2009; Brown, 2010; Wake, 2010, 2013), as well as in the USA (Richards, 1993; Salz, 1996; Tigner, 2002; Claycomb, 2003; Dolan, 2005; Bottoms, 2006), and in Europe (see for example Hammond and Steward, 2008). Of all these offerings, three main texts have proved of particular value for this thesis. These are Carol Martin's *Theatre of the Real* (2013), and two chapters in *Postdramatic Theatre and the Political* (Jürs-Munby, Carroll and Giles, 2013): one by Theron Schmidt, the other by Ulrike Garde and Meg Mumford.

Carol Martin's most recent book, *Theatre of the Real* (2013), has been valuable for my research mostly because of her insistence on the 'big picture' of the field along with its recent radical changes. The field now encompasses a wide and varied range of practices, forms and methods as well as perspectives, subjects and methodologies. For Martin, there is an "emerging consensus" that it includes:

> documentary theatre, verbatim theatre, reality-based theatre, theatre-of-fact, theatre of witness, tribunal theatre, nonfiction theatre, restored village performances, war and battle reenactments and autobiographical theatre. All of these types of theatre claim a relationship to reality, a relationship that has generated both textual and performance innovations. The array of terms indicates a range of methods of theatrical creation that are not always discrete, but may overlap and cross-fertilize. These methods include, but are not limited to: theatre created from the verbatim use of transcripts, facts, trials, autobiography and interviews; theatre created from reenacting the experiences of witnesses, portraying historic events, and reconstructing real

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[67] All the essays in this collection furnish culturally specific ways of thinking about terms like 'verbatim', 'documentary' and 'truth', broadening scholarship on documentary performance as well as paying attention to the "blurred space" between reality and fiction (Martin, 2010: 262). There is also an assemblage of seven scripts from the Netherlands, Lebanon, Poland, Argentina as well as the USA. Martin also includes prefatory essays from scholars and practitioners that frame these texts within specific political and theatrical contexts.

[68] In all three, Carol Martin figures prominently as a contributing author (*Get Real*), an editor (*Dramaturgy of the Real on the World Stage*) and a sole author (*Theatre of the Real*). Furthermore, her edited issue of *TDR* (2006) is the foundation upon which both *Get Real* and *Dramaturgy of the Real on the World Stage* are built. In the case of *Get Real*, editors Alison Forsyth and Chris Megson state at the beginning that Martin's "collection of articles mapped the conceptual parameters of a burgeoning field of theatre practice ... and we are indebted to the scholarship in her collection" (2009: 1-2).

places; theatre created from the Internet including YouTube and Facebook; and any combination of these. In this kind of theatre there is an obsession with forming and reframing what has already happened (2013: 5).

Martin's judgment that theatre of the real is as much about blurring the boundaries between the real and the imaginary as well as "between the stage and the 'real' world" (Martin, 2013: 4) is significant for the arguments I present in this thesis about the way dementia can inform verbatim dramaturgies. Martin also argues that verbatim and documentary playwriting have been well covered in the scholarship, whereas less well attended have been the effects of revised approaches to staging, acting and directing on contemporary theatre of the real, a gap her book attempts to fill.

Another book of worth to my thesis has been *Postdramatic Theatre and the Political* (2013), edited by Karen Jürs-Munby, Jerome Carroll and Steve Giles. In it, two chapters trace the relationship between theatre of the real and the postdramatic: Ulrike Garde and Meg Mumford's 'Postdramatic reality theatre and productive insecurity: destabilising encounters with the unfamiliar in theatre from Sydney and Berlin' and Theron Schmidt's 'Acting disabled: Back to Back Theatre and the politics of appearance'. Both have stimulated ideas about whether or not the 'right kind' of dementia stories can be disrupted through deploying the postdramatic aesthetic as a resistant strategy to 'normative age-and-dementia -effects'.

Theron Schmidt (2013) writes about the Australian company Back to Back theatre, a company of theatre artists with perceived intellectual disabilities. Schmidt makes his arguments by taking up German theatre theorist Hans-Thies Lehmann's ideas about a postdramatic "politics of perception" (2006: 184), as well as Jacques Rancière's (2004) theorisations about perception, both of which I will now briefly outline. But first I will give a brief definition of postdramatic theatre.

German theatre theorist Hans-Thies Lehmann coined the term 'postdramatic theatre' in his 2006 book of the same name to refer to theatre that fundamentally challenges the basic tenets of dramatic theatre: that is, goal oriented theatre dependent on narrative, plot, action and character and usually derived from a written text. In contrast, postdramatic theatre deploys multiple frames and shuns the conventional devices of narrative, plot, action and character. This in turn often entails more effort on the part of the spectator as confusion can ensue without the

presence of these familiar theatrical devices. The essential opposition of the dramatic and the postdramatic has been encapsulated by Lehmann as "appearance instead of plot action, performance instead of representation" (2006:58).

According to Lehmann, when the dramatic impulse to present enclosed and bounded worlds of plot, action and character is eliminated, theatre's fundamental machinery will be revealed, enabling a "politics of perception" (2006:184). For Lehmann, theatre at base is an assemblage of appearances and sensations, and their interlocking frames of sense perception. Lehmann argues that perception cannot be removed from the world of media in which we all live, where the connection between the receiving and sending of signs has been dismantled. Nor can it be removed from the commodification of life and human relations as described by Guy Debord. According to Lehmann, the theatre is "…an art of the social par excellence" (2006:183). In it, there is a "…*mutual implication of actors and spectators in the theatrical production of images"* which can be moved centre stage and "…make visible the broken thread between personal experience and perception" (Lehmann, 2006: 186; italics in the original). Lehmann goes on to argue that "[s]uch an experience would be not only aesthetic but therein at the same time ethico-political" (2006: 186). The politics of perception is therefore also an "ethics of responsibility (or response-ability)" in the face of "Baudrillard's diagnosis that we are dealing only with circulating simulacra" (Lehmann, 2006: 185-186).

A seminal idea of Rancière's is "the distribution of the sensible": this is the "…system of self-evident facts of sense perception that simultaneously discloses the existence of something in common and the delimitations that define the respective parts and positions within it" (2004:12). It reveals who can have a share in what is common to the community. Both aesthetics and politics have in common, according to Rancière, the marking out of what can be visible and what invisible, what audible and what inaudible. Appearance is part of the 'distribution of the sensible' (2004) and the essence of politics consists of "interrupting the distribution of the sensible by supplementing it with those who have no part in the perceptual coordinates of the community, thereby modifying the very aesthetic-political field of possibility" (2004:12).

Schmidt (2013) draws on both Rancière's and Lehmann's ideas about perception to argue that Back to Back's work has the potential to revamp the disability landscape which, as Lennard Davis argues "exists in the realm of the senses" (1995:13), not by resisting disability, but by staging the idea that disability is indeed a matter of appearance. Schmidt argues that in this way Back to Back's work is political, not because it is resistant to spectacle, but because it is fashioned as spectacle (2013: 195), staging dynamics from the world outside the theatre, in what disability and performance scholar Bree Hadley, following Rosemarie Garland Thomson (2009), terms "the starer-staree relation" (2014: 12).

In her investigation of people staring at disabled people, Garland Thomson refers to the gaze "defined as an oppressive act of disciplinary looking that subordinates its victims" (2009: 6). According to Garland Thomson, the staring encounter enlists "starees into a story of the starer's making" via the gaze (2009: 8). For example, the dementia story of tragedy is part of materialising the 'reality' of dementia as a tragedy. But as a "live" and "performative" encounter (Hadley, 2014: 64) the gaze also has the potential to problematise the governing cultural judgements it endorses and it also has consequences for telling us about how we "look *at*" and "look *to* each other" (Garland Thomson, 2009: 3, 4 and 6; italics in the original) with both theatrical and ethical undertones.

Schmidt's (2013) ideas might be useful in re-strategising the theatrical 'real' in terms of performances by people living with a dementia diagnosis. Based on his ideas about spectacle, one solution to the challenge of the representation of the reality of dementia could be theatricalisation not literalism (Silverman, 1996: 103 cited in Bleeker, 2011: 115) and a move away from a reliance on words to the reality of bodies in the theatrical space. For example, bodies which look non-ideal (in current representational circuits) might be presented in the shape of the "ideality" (Bleeker, 2011: 115) they lack, simultaneously helping audiences to understand that ideality "'as a garment rather than the body itself'" (Silverman, 1996: 103 cited in Bleeker, 2011: 115). This means that as spectators we can be guided to understand the appearance of bodies as the effect of signs (read, interpreted and viewed) as much as biology. We may ask: "What is actually there

to be seen and where do [our] own projections, desires, and denials begin?"
(Bleeker, 2011: 115). This might then give spectators a chance to make "the
ethical … operative" (Silverman, 1996:173 cited in Bleeker, 2011: 115).

However, there are two main issues with these ideas being applied to
performances involving people living with a dementia diagnosis. One is that
Schmidt's ideas can only be applied to people who perform their own work on stage
and not to actors without disabilities who may stand in for them. Verbatim theatre
commonly uses actors to tell other people's stories, although this is changing.
When actors stand in for people with disabilities, this is termed 'cripping up' which,
in disability advocacy circles, means having non-disabled actors play disabled
parts. In these circles 'cripping up' has been equated to 'blacking up' which is when
white actors play people of colour, and which would likely not be tolerated in this
day and age in the way 'cripping up' is.[69] When a production crips up, even if the
production openly problematises and foregrounds this representation, what
becomes apparent is the absence of the disabled body the able-bodied actor is
representing, with all the issues of power and voice that this engenders. However,
when it comes to actors living with a dementia diagnosis, cripping up is complicated
by the way in which, at some stages in the progression of dementia, other people
will likely have to perform verbatim stories for these actors.

Another problem with using Schmidt's (2013) ideas about staging disability as a
spectacle is that Back to Back seem to rely on distinctive physical markers to
create that spectacle, such as the facial characteristics of someone with Down's.
But dementia may not activate the 'the starer-staree relation' as do certain other
disabilities, although this is also dependent on its particular etiology (whether AD
or Korsakov's for example) and the particular physical manifestations of dementia
involved (for example, towards the final stages of AD, people may have difficulties
with spatio-temporal adjustments and tip to one side as they walk). But the most

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[69] The opposite to 'cripping up' is authentic casting. The authentic casting movement has been
taken up as an advocacy issue by Arts Access Australia (AAA) in its distribution of an advice sheet
titled 'Authentic Casting: Bringing People with Disability to our Stages and Screens.' The AAA
sheet states quite categorically "Never cast people without disability to play roles where the
character is a person with disability." At 'The Other Film Festival' in Melbourne in October 2012,
Christine Bruno, an American actor and activist with a physical disability led a forum on authentic
casting. She made the statement that "a non-disabled actor playing a disabled character is
tantamount to blackface" (author's personal notes).

important point I want to make here is that for actors with cognitive disabilities who stage 'spectacular appearances', it is likely that their memories are (somewhat) intact. For performers living with a dementia diagnosis, particularly because of the symbiotic link in Western culture between memory, cognition and personhood, the risk of the exposure of fallible memories and the concomitant fear of being seen as non-persons could be too great. For this reason, other solutions need to be found.

Garde and Mumford's (2013) chapter 'Postdramatic reality theatre and productive insecurity' is important to my project because it presents the important idea of "A-effects",[70] shorthand for "authenticity effects", which Garde and Mumford define as "strategies for creating (and in some cases then unseating) *a sense of* direct contact with living people and truthful representations of their lives and social contexts" often for ethico-political reasons (2013: 148-149; italics in the original). For Garde and Mumford, following Reinelt (2009:9), these are strategies that either depend on or manipulate mainstream realist assumptions that "knowledge is available through sense perception and cognition linked to objects/documents" putting spectators in contact with "the reality they are trying to experience or understand". Examples of these strategies include: the use of 'actual' people rather than professional actors for example, Rimini Protokol's "'experts of the everyday' (people who are specialists in a particular field of life)"; the deployment of characters and texts taken directly from legal transcripts, for example, Version 1.0's *CMI (A Certain Maritime Incident);* and "the use of advance signs that highlight the production's close connection to social reality" such as the program notes from *CMI* where the reader is assured that "the transcripts are quoted verbatim" (Garde and Mumford, 2013:149, 152-153). In postdramatic theatre, Garde and Mumford argue that there is the potential for the "*volatile* and *constructed* nature of the authentic … [to] unfix stable and possibly oppressive perceptions of strangers and the unfamiliar" which, as I argued in the introduction, people diagnosed with dementia often become to others (2013: 149; italics in the original). Discussing to what extent these destabilisations can help or hinder the re-storying of those who live with a dementia diagnosis is a concern of the next chapter.

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[70] Garde and Mumford caution that these effects should not be confused with V-effects, shorthand for Brecht's Verfremdungseffekte or "defamiliarisation effects" (2013: 149).

In their two respective chapters in *Postdramatic Theatre and the Political* (Jürs-Munby, Carroll and Giles, 2013), Schmidt and Mumford and Garde agree that the postdramatic may transform the ethico-political attitudes of audience members towards marginalised groups. This may be true and could be one of the ways "productive looking" could be facilitated, "turning confusing experiences on the post-dramatic stage into a political act" (Bleeker, 2011: 115). However, I think that a postdramatic production may also risk alienating certain spectators by either an unfamiliar treatment of the subject matter (like comedy as opposed to tragedy), or an unexpected aesthetics, which could be foreign to them. Given the ubiquitous presence of the dramatic, especially in much mainstream drama, certain audience members might not be conversant with postdramatic theatrical styles where a narrative storyline or coherent psychological characters may be missing. Instead of cracking open habitual perceptions about a subject, which has been claimed to have political ramifications as I have already noted, aesthetic difference could work contrary to this, reinforcing habitual ways of seeing the subject.

In summary, this chapter has laid the foundations for the two chapters to follow arguing that any reality being framed on stage will inevitably cite the frames of reference underpinning and bolstering this reality, which is a reality always already mediated, making it almost impossible to avoid replaying the 'right kind' of dementia story. These stories include discourses about the ageing and about those living with dementia diagnoses, which summon 'normative age-and-dementia-effects'. However, this chapter has also investigated possible ways in which these replications of reality can be disrupted on stage, especially when the postdramatic is considered.

The other important project of this chapter, given that the genesis of this thesis came from an interest in words, has been to begin an examination into the connection between words, stories, identity and the materialisation of reality in reality theatre. For this reason the chapter took a particular interest in the verbatim form, looking into the history of the inclusion of the words and voices of marginalised people on the stage, which importantly challenged regnant ideas on pre-nineteenth-century stages that the only fit subjects worth presenting were those who spoke universal truths in wooden prose and uplifting verse. The inclusion of everyday words and speech patterns, especially in the arrival of the

verbatim form, helped to make a link to marginalised worlds, lives and stories, shifting ideas about what was valuable on the stage and who was fit to be a speaking subject on it. Because of the importance of this history and also because of the challenges words throw to dementia, this chapter has argued that words do matter when it comes to representations of the reality of dementia on stage. It has argued that words (vocabulary) and speech patterns (pronunciation, collocation and semantics) may fashion a *trace* link connecting audiences to the people behind the performed stage story told by actors on stage, who may not be able to represent themselves in person because of their cognitive disabilities. But the chapter has also listed many reasons as to why words can never be the only factor of importance in the creation of reality theatre. This chapter also took an interest in what dementia can offer verbatim theatre and its scholarship, as dementia draws attention to the nature of the 'truth' of any story, whether from someone with dementia or not. No one can tell an unchanging and true life story which can then be represented on stage in a direct and unmediated fashion.

To close, I maintain that verbatim plays based on the words and stories of people diagnosed with dementia make extremely good 'objects' through which to examine the role played by stories and words in the materialisation of 'reality' as 'normalcy'. They also provide an important lens through which to rethink the frames of reference that constitute such a 'real' world, which then feedback into representational circuits. In the next chapter, one such play, *MBDJ*, will be catechised with a particular interest in the extent to which it unsettles 'normative age-and-dementia-effects' (that is, culture-shaped effects) and the consequences of this for its audiences. That is, the next chapter asks: To what extent does *MBDJ* disrupt the telling of the 'right kind' of ageing and dementia story?

Chapter 2
***Missing the Bus to David Jones*, Theatre Kantanka**

In the 2011 program notes for Theatre Kantanka's[71] production of *MBDJ*,[72] the director Carlos Gomes,[73] credits his experiences of living with his grandfather Guillerme, diagnosed with senile dementia, both as one of his boyhood joys and as one of the driving inspirations behind the production, along with an abiding interest in telling "untold stories" (Theatre Kantanka, 2013). According to Gomes, *MBDJ* is "[a] process that has involved years of listening to stories, reflecting upon my own story, observing and visiting the elderly in a variety of settings" (Seymour Centre and Performing Lines, 2011). In the program notes, he also acknowledges that "[m]ost of the verbal text in the work is from those people we met in facilities we visited" (Seymour Centre and Performing Lines, 2011). Adapted by Gomes and his actor-devisers from stories and words garnered from people living and working in various aged care facilities in Sydney, *MBDJ* is an imaginatively devised postdramatic recreation of the dealings of a group of older adults with diminishing mental and physical capacities who live in a nursing home (somewhere in Australia).[74] It is the primary focus of this chapter for several reasons.

Firstly, it is a significant work in terms of the overall charter of this thesis, as it is built from the stories and words of people living with a diagnosis of dementia. For this reason it provides a lens through which to analyse the link between stories, words and the materialisation of the 'real' in verbatim theatre. Secondly, through its

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[71] Theatre Kantanka is a project-based arts company specialising in the development of small to medium-scale site-specific performances in non-traditional locations like gaols, gardens and car parks (Theatre Kantanka, 2013). Established in Sydney in 1995 by Michael Cohen, Carlos Gomes and Chris Murphy, it now operates with a staple of creative personnel whose input is augmented when needed by the collaboration of visiting artists. It is not a mainstream theatre company like Sydney Theatre Company but it does employ artists with a high level of skill and artistry (Theatre Kantanka, 2013).

[72] David Jones is an Australian department store chain with a slightly conservative and/or moneyed image.

[73] Brazilian born Gomes has worked with numerous companies in Australia whose works cross the boundaries from text-based to physical theatre: companies like Legs on the Wall and Urban Theatre Project. He is now the Artistic Director of Theatre Kantanka and is accredited with the original concept behind *MBDJ* (Seymour Centre and Performing Lines, 2011).

[74] *MBDJ* premiered at Campbelltown Arts Centre in 2009 after residencies supported by the Campbelltown Arts Centre and Performance Space. It also had a short showing at the Performance Space in October 2009. The show was filmed on one of these dates. There was a later production at the Seymour Centre in early 2011 from Tuesday 29th March to Saturday 2nd April. Further references in the chapter will be to this latter production, which I saw on Saturday 2nd April 2011 and/or to the DVD of the show kindly sent to me by Carlos Gomes. I will differentiate references through the use of 'DVD'.

evocation of the "closed fictive cosmos" (Lehmann, 2006: 99) of a nursing home, Kantanka dissects the politics of the care home and its links to profit,[75] as well as the run-on effects this could have for those people living and working in these homes, which have largely not been explored in dementia-themed theatre, in Australia at least.[76] Thirdly, in this production, representations of those living with a diagnosis of dementia intersect with representations of ageing, making it an ideal vehicle for investigating this nexus, and demanding a closer recourse to age studies literature than I adopt in any other chapters.

In essence, this chapter addresses my major research question regarding how theatrical performances can best act to represent and/or respond to the figure of the older adult with dementia. In particular the chapter tackles the subsidiary but related research questions posed in the introduction concerning the extent to which, as well as how and for what reasons, the production unsettles the 'right kind' of dementia story. The chapter does this by exploring the contributions made by a devised physical and visual verbatim theatre piece in the postdramatic mode towards the disruption of 'normative age-and-dementia-effects' (after Moore, 2014). The chapter is also interested to consider the extent to which this production's postdramatic aesthetic helps or hinders the political and ethical work of re-imagining other possible stories about older adults living with a dementia diagnosis. Additionally, it investigates the consequences of this re-storying of dementia and age for its audiences (given that 'reality' is mediated by the predispositions, attitudes and values of those who experience it, whether in the theatre or out). The chapter also looks to the role words play in this re-storying, relating to the critical interest this thesis has in drilling down to the relationship between stories, words, identity and dementia in theatre and performance

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[75] In Australia, as at 2014, there were 1,000 aged care organisations operating 2,700 facilities with 180,000 placements (Chomik and MacLennan, 2014). Nursing homes and aged care facilities are usually operated either by not for profits or by profit-making corporations (Baldwin, Kelly and Sharp, 2014). Eighty four per cent of these facilities report positive earnings. Due to changes to fees and subsidies issuing from government and socio-economic shifts (inclusive of perceptions of whether or not these facilities will make a good investment), there has been an investment trend towards the large for-profit high-care facilities over smaller not for profits (Chomik and MacLennan, 2014).

[76] Focusing mostly on stage and screen drama in the UK, drama studies scholar Michael Mangan argues that "the care home… has become a frequently used dramatic setting: even a sub-genre in its own right, with its own conventions, repeatable stock characters and recyclable tropes and plotlines" (2013: 199). However, I would argue that, although it might serve as a trope for oppression, the political contexts of the care home are largely left unexplored in many of these dramas. The nasty characters ruling over and abusing older adults in these homes are doing it because of flaws in their personalities; the larger political contexts of the free market have been neglected.

productions and practices. Building on the foundations laid down in the previous chapter, this chapter also touches on if, how, why and to what effect the production uses, or dispenses with, "authenticity effects" or in shorthand, "A-effects" (Garde and Mumford, 2013: 148-149).

In this chapter, through a close analysis of the minutiae of some of its performing moments (in particular its opening and closing scenes), I argue that *MBDJ* offers a carnivalesque panoply of ageing and dementia, displacing many of their accepted enactments. *MBDJ* also does particularly well in presenting a political critique of nursing homes, investigating the politics of caring and the warehousing of elders, and correlating age and dementia with neo-liberal profitmaking. In doing this, *MBDJ* contributes to framing both the materiality as well as the performativity of age (in age studies terms) showing how theatre can question implicit cultural norms parading as biological imperatives. However, given theatre's complexity, whether or not and to what extent audiences are able to negotiate these meanings remains questionable, undermining any certainty in a direct correlation between theatrical innovations and the re-storying of ageing and dementia in theatre and performance. The chapter begins with an overview of the production, focusing on its staging and its opening scenes, followed by an analysis of warehousing issues, and then an examination of its 'A-effects', of any resistant strategies to the 'right kind' of dementia story, as well as of its closing scene. It finishes by pondering on some of the disapproving responses I overheard at the performance of *MBDJ* I attended, in tandem with an acknowledgement of the partial discomfort I felt due to disability representation issues: highly complex issues which this production brought to the fore for me.

***Missing the Bus to David Jones*, the production**

MBDJ blends text, image, new media, sound and performance in a series of highly physical, disjunct vignettes mostly centring on the activities room of a nursing home.[77] I will begin this analysis with a description of the set design (or mise-en-scène), which, on the whole, connects the space utilised with the fictional world of

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[77] The multi-media work is by Joanne Saad and Fadia Aboud, the lighting design by Sydney Bouhaniche and the soundscape by Nick Wishart (Seymour Centre and Performing Lines, 2011).

the production rather than uncoupling it (Pavis, 2003: 37-40). This is a move more in line with mainstream aesthetics than postdramatic, pointing to what drama scholar Elinor Fuchs, in writing about Elevator Repair Service's *Gatz,* has called a "layered …cosmos of the imagination", typical of what persists of the "story" or the "affective life" in postdramatic aesthetics (2011: 66-68 cited in Jürs-Munby, Carroll and Giles, 2013: 25). Apposite to life in many care homes, green linoleum is used to cover the stage (in care homes, linoleum makes it easier to wipe up the soils of age than carpet). Several different size 'screens' upstage are set into a wall running all the way across the back of the stage (*MBDJ*, DVD). One of the 'screens' upstage left is in fact two swinging doors, very similar to those commonly found in nursing homes and hospitals. Onto these doors, various images of life in a facility are projected. The opening images are of the bare legs of an older woman in scuffs walking very slowly towards some stairs in the background. These doors allow access to the activity room from other parts of the fictive facility. Entrances and exits are mostly made from these doors, although there is the occasional imaginative use of the window, which is the middle 'screen'. From this window, characters speak to the audience or to other characters, by this means allowing the audience to see what is happening behind the window, in the illusory 'corridors' of the nursing home. There is also a 'screen' upstage right. This is a television, which is always on, another appropriate design choice given that it is one of the staples of life in a nursing home, and in front of which elders are often left to sit and stare. Finally, the whole wall in which the doors and the window are positioned functions as a screen across which images are sometimes shown during the course of the show. There are several chairs and a table downstage left and some armchairs upstage right, as well as lamps.

Although the production I saw took place in a traditional theatre space with a proscenium stage (Downstairs, Seymour Centre, Sydney), it was a stage minus curtains. As the audience enters the theatre, an important non-speaking scene is underway, one that blurs the boundaries between the start and finish of the 'show', and also perhaps onstage and offstage worlds, which the raising of a curtain would delineate. Furthermore, and crucially, the scene itself and the actors playing it, reveal common stereotypes about, as well as contesting, the cultural, material and political ramifications of care staffing. On stage is a hospital trolley, covered by the

seemingly ubiquitous colourful crocheted blanket (often found in a care home), under which lies a sleeping body whose mouth is open in the recognisable posture of the last stages of dying, struggling to breathe (*MBDJ*, DVD). It is hard to determine the gender of the body although the skin is fair. Through the middle window, a nurse or care assistant is watching and tending to the body, gently stroking its forehead as a mother would a child. Valerie Berry, who is Filipino, plays the nurse.

As I see it, the choice of Berry to be the first carer seen is salient, functioning as a comment on the cultural and material conditions of ageing, both in Australia and around the Western world. Care homes are often staffed by migrants, working in various roles, as formal qualifications or training in nursing are not required for the majority of jobs in these homes.[78] In some cases, these migrants may have formal qualifications in their own countries of origin but cannot get official recognition of previous training, occasioning them to take whatever job they can get, often with poor pay. Moreover, Berry is female, another choice that I take to deliberately reflect the intersection between the female gender, care-giving roles and low pay, which is still the reality for female workers on the whole.[79] Furthermore, low pay maximises company profit: if banks or large corporations run these homes, then the needs of their shareholders could outweigh ethical compunctions in terms of client care.[80]

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[78] Baldwin, Kelly and Sharp's 2014 Aged and Community Services white paper on the aged care industry in Australia shows that 35 per cent of this workforce was born outside Australia and that 28 per cent of all Australian 'citizen' workers in aged care were not born here. Between 2003 and 2007, overseas-born residential aged care employees increased from 25 per cent to 33 per cent of the workforce (Martin and King, 2008 cited in Baldwin, Kelly and Sharp, 2014:13), but between 2007 and 2012 only a marginal percentage increase in workers born overseas was noted (King, Mavromaras et al., 2013 cited in Baldwin, Kelly and Sharp, 2014:13). Of these workers, there was a small increase in the percentage of employees from South East Asia, China and India, and a slight decrease in the percentage of staff from the UK, Ireland and South Africa. Of particular interest is that only 4.3 per cent of the migrant worker population in community aged care are registered nurses or RNs: RNs are only 8 per cent of the total community care workforce whereas 87 per cent are migrants (82 per cent of the overall community aged care workforce).

[79] According to the 2014 CEPAR report on aged care in Australia (CEPAR is the ARC Centre of Excellence in Population Ageing Research, deploying researchers from the Australian government as well as the universities of Sydney, New South Wales and the Australian National University), there has been a growth in lower skilled workers in place of nurses in the aged care sector. Although there are generally high rates of satisfaction with work, this does not extend to pay, which averages $600–650 per week, for personal and community care workers (Chomik and MacLennan, 2014).

[80] The CEPAR report also notes that the aged care industry is dominated by not for profits (58 per cent in residential and 81 per cent in home care), although for-profit provision has grown in importance recently. It also states that positive earnings are higher among for-profit, high-care, city-

However, in these early 'scenes', both Berry and her replacement are gentle and caring: Caucasian Kym Vercoe takes over when Berry leaves the stage, just before the show starts. These casting selections challenge the assumption of any direct correspondence between low pay and patient mistreatment. A quota of highly dedicated staff works in many of these institutions. Both through these initial role choices and the two performers' caring actions, *MBDJ* challenges common stereotypes while also exposing the cultural, material and political ramifications of care staffing connecting hidden frail white elders and "the female-gendered caregivers from diverse backgrounds who operate in globalized chains of care, in the public sphere and representational circuits alike" (Swinnen and Port, 2012: 14). As Kathleen Woodward argues in her article 'A public secret: assisted living, caregivers, globalization', in reference to American contexts, if older adults living with a dementia diagnosis are non-citizens:

> their caregivers, many of whom have crossed national borders in order to find work, are in many cases literally not citizens of the nation-states where they offer care, and there is no social contract to speak of worthy of the name (2012: 20).

Woodward sees it as vital that age studies investigate the politics of caring, which incorporates both the infirm elderly and their caregivers.[81] For Woodward, both are "virtually invisible in representational circuits (film, the novel, photography, television, the web, newspapers)" (2012: 17). She goes on to ask: "How can we bring what is a scandalous public secret of everyday life into visibility as care of the elderly increasingly becomes a matter of the global market in our neoliberal economies?" (Woodward, 2012: 17).

I suggest that one of the many strengths of *MBDJ* is the way in which it does bring these 'public secrets' to the stage. However, visibility does not necessarily bring about change in terms of political power (Phelan, 1993: 10), and, in addition, the non-mainstream, postdramatic aesthetics of this piece could have worked against the reception of this politics by some *MBDJ* audience members, seniors in the case of the performance I attended. For now, I will turn to an analysis of the opening 'scene' of this production as a way of showing how the company

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based, single-service providers.
[81] Interestingly, research shows that the vast majority of workers in Australian aged care industries are not only female but older females (Baldwin, Kelly and Sharp, 2014).

correlates age, dementia and the neo-liberal care home in what age studies scholars would term a 'material' framing of age. This scene also makes clear that age, and by association dementia, must be understood not just in biological terms but also in cultural (Gullette, 2004). That is, it highlights their performativity or mutability, both on and off stage (Basting, 1998).

The coming of age

Just before one of the initial talking 'scenes' of the play, all the actors come on stage in their care assistant uniforms: flat shoes, trousers and white shirts. To very discordant music, they set down their costumes, Zimmer frames and other props in piles in front of them, before undressing down to their underpants and/or bras and standing in a row in a neutral stance mid-stage. This initial strip is a meta-theatrical technique drawing attention to the fictional nature of the theatre by deliberately breaching any illusions that what we are to see is real (Ridout, 2006: 88), and by exposing the stage as a place of representation (Power, 2008: 118). It also sets the pace for a show in which transformations between characters happen swiftly. One moment an actor (Kym Vercoe) is a diversional therapist, clear voiced and strong of body; the next, a resident, whose Parkinson's disease makes her hands shake relentlessly.

As the initial voiceover begins (spoken by Lina Kastoumis), the actors start to put on their character costumes. Six company members (Valerie Berry, Michael Denkha or Arky Michael in the DVD, Rosie Lalevich, Phillip Mills, Katia Molino and Kym Vercoe) play all the characters: the nursing home staff, the residents, and their relatives. The text of the voiceover is verbatim from French existentialist philosopher Simone de Beauvoir's *The Coming of Age* (1996), first published in 1970, well used as a verbal parallel to the physical manifestations of ageing that are performed as the actors change into 'old' people in front of our eyes. Part of de Beauvoir's summary of the biomedical research on the manifestations of ageing at the time she wrote the book starts the (female) voiceover about the bodily changes which occur with ageing:

> Between forty-five and eighty-five men's chest measurements *diminish* by ten centimetres and women's by fifteen. The shoulders become *less* wide, the pelvis broader: the thorax tends to assume a *sagittal* shape, particularly in the case of women. Muscular *atrophy* and the sclerosis of the joints *cause difficulties* in working and movement. The skeleton *suffers from* osteoporosis: the dense part of the bone becomes spongy and *fragile*, and this is why a fracture of the head of the femur, which supports the body's weight, is a common accident (1996: 26; my italics).

This voiceover at first seems to reinforce the association of old age with decline and deficit. Words and phrases such as 'diminish', 'cause difficulties' and 'suffers from' ally age with the loss of physical capabilities. But after this initial biomedical substratum, the expected tack of the voiceover changes, directing the variations that do occur in ageing towards the reality that all life is a process of change, not just the latter part:

> Old age is not a mere statistical fact; it is the prolongation and the last stage of a certain process. What does this process consist of? In other words, what does growing old mean? The notion is bound up with that of change. Yet the life of the foetus, of the new-born baby and of the child is one of continuous change. Must we therefore say, as some have said, that our life is a gradual death? Certainly not. A paradox of this kind disregards the basic truth of life — life is an unstable system in which balance is continually lost and continually recovered: it is inertia that is synonymous with death (de Beauvoir, 1996: 11).

In the initial voiceover, de Beauvoir's association of age with a loss of physical capabilities accentuates the way this loss undermines the ability of the ageing to partake as actors in a capitalist socio-economic framework ('cause difficulties in working'). They may then be devalued as a result: viewed as debits rather than credits because they cannot work or contribute to the economy (and, as was shown in the introduction, attitudes to the aged began to change with the onset of industrialisation in nineteenth century western societies). But de Beauvoir is better known for her contributions to feminist thinking than for her Marxism, arguably most well-known for *The Second Sex*, first published in 1949, in which she made the now famous assertion that, "One is not born, but rather becomes, woman" (2011: 283).

Judith Butler claims that in saying this de Beauvoir is affirming that gender is not a stable location from which various acts ensue, but an identity constructed through "a *stylized repetition of acts"* such as "bodily gestures, movements, and

enactments of various kinds [that] constitute the illusion of an abiding gendered self" (1988: 519-520; italics in the original). When gender identity is seen as a type of repetition of acts through time, and not a continuous uniform entity, then for Butler, "the possibilities of gender transformation are to be found in the arbitrary relation between such acts, in the possibility of a different sort of repeating, in the breaking or subversive repetition of that style" (1988: 519-520).

The choice of de Beauvoir's text to open the show, along with the meta-theatrical instability shown in the initial divesting of garments, point *MBDJ's* audiences towards an understanding that age may be a biological function, but that the *meanings* associated with these biological aspects are constructed. As Judith Butler quips in regards to gender, one does not wake each morning and choose a different gender from the wardrobe and then put it back in its place at night (1993: ix). But "the matter of bodies will be indissociable from the regulatory norms that govern their materialization and the signification of those material effects" (1993: xii), variable off stage and on. *MBDJ's* opening 'scene' unveils the potential of the theatre to question embedded cultural norms camouflaged as biological essentials: for aged bodies as well as for those with dementia.

Once the opening voiceover has finished, a spotlight comes up on Rosie Lalevich who straightens up out of her crumpled bodily posture, with nightie caught up in underpants, to declaim:

> This facility is purpose built and has been recently renovated. It offers the luxury of a five star hotel plus services that rival any comfortable home. Our residents love the freedom and the peace of mind provided by this secured unit.

Kym Vercoe abandons the support of her Zimmer frame to proudly trumpet:

> All our meals are cooked in our sparkling professional kitchen. Fresh hygienic ingredients prepared on non-scratch surfaces provide nutrition and satisfaction.

From these opening remarks, we know we are in advertising territory: the actors could be reading verbatim from a brochure designed to encourage shareholder investment or to help family members and care partners in their choice of a facility. It goes on. Valerie Berry waxes lyrical about the bathroom; Arky Michael about the 'Xanadu' gardens and Katia Molino about the 'Shangri-La' living room:

> The Shangri-La living room is a carnival of entertainment and activity. It contains the media centre: state of the art, streamlined and high functioning. This is a vital social space where our residents can extend themselves and network.

Although this audience member easily interpreted both Rosie and Kym's comments as tongue-in-cheek and full of irony, especially when thinking back to my own mother's reaction to the secured unit she found herself in, it is not really until the exotic naming of the gardens and the living room, which is where all the 'scenes' of the play are set, that I could be confident of sardonic intent. Advertising makes links between unlikely items (think of cars and half-naked women); this proclivity is reflected in the use of the names 'Xanadu' and 'Shangri-La'. In 1933, James Hilton's *Lost Horizon* was published. In it he describes a fictional place named Shangri-La: a magic, agreeable dell, surrounded by the Tibetan Mountains and ruled by monks. In the novel, the people of Shangri-La live for years, only ageing very slowly. In popular culture today, the name now connotes an earthly paradise, in which people, isolated from the world, are forever young and happy. It also conjures up the exoticism of the East, as does the name Xanadu, which was the summer capital of Kubla Khan's dynasty in China and was used by Samuel Taylor Coleridge in his great poem, *Kubla Khan*, written after he awoke from an opium-infused dream. Through the use of these exuberant and inflated metaphors, Kantanka presents us with the idea of the aged with senile dementia as 'Other', removed far out of sight in enclosed institutions, as far out of sight as were the exotic Orientals to nineteenth- and early twentieth-century poetic sensibilities. Of interest is that some of these exotic 'Others' may have ended up as one of P.T. Barnum's 'freaks' at a carnival show. In this way the metaphors chosen link the concerns of the aged to disability histories.[82]

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[82] According to Rosemarie Garland Thomson, many of the 'freaks' in these shows were people with an appearance atypical to that of the ideal Euro-American body. 'Freaks' were not necessarily disabled but were sometimes from those countries affected by colonisation, such as Africa and Mexico (like the Hottentot woman or Julia Pastrana, the bearded lady, a hirsute Mexican-Indian woman). For Garland Thomson, showing these different bodies gave the masses an opportunity to formulate 'the self' in terms of what it was not. These bodies also operated as subdued and often colonised tokens for all that was inexplicable and unpredictable in nineteenth-century American society in particular, in order to "efface suspicions that the world might indeed be intractable, chaotic and opaque" and not predictable, orderly and safe (Garland Thomson, 1997: 59-66).

However, despite the ludicrous connections between the home and these faraway destinations, the descriptions do somewhat reference what the audience witnesses. For example, the living room/activities room does become more like a carnival site as the play advances: there is a scene where balloons are bounced around the room and a slapstick birthday party scene where faces are smeared with shaving cream (see figure 1).[83]

Figure 1: Katia Molino and Phillip Mills in a scene from Theatre Kantanka's *Missing the Bus to David Jones*. Photo by Heidrun Löhr used with permission from Carlos Gomes.

But, on the whole, these words do excel in their absurdity, as they are more appropriate to the corporate world, and out of context in regards to the living room of a nursing home. In this way *MBDJ* exposes the way advertising goes to any lengths to connect a product to the reigning zeitgeist of the times, in this case, managerial or public relations speak.[84]

But the comedy also arises from the jargon applied to a group of people for whom (spectators may think) opportunities are over, whose life is nearing its end and who are locked in a secure ward away from normal life. Arguably these are common ideas about these homes, what happens in them and the capacities of their residents. In this way, the comedy most likely issues both from a recognition that capitalism will go to any extremes to sell its products, and from an understanding that spectators are laughing in some kind of uncomfortable agreement with age stereotypes (Basting, 1998, 2009a).

These 'advertorials' provide a fitting segue into the next comment made by Rosie Lalevich about the way nursing homes are capitalist enterprises in a strongly

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[83] In addition, the three screens of the set suggest a media centre making some sense of the words in the last absurd phrase ('vital', 'social' and 'network'), an apt reference to the way all of us are digitally connected in the global world through various media technologies.
[84] These words are what Australian writer Don Watson calls 'weasel words' in his book *Watson's Dictionary of Weasel Words* (2005), building on the phrase first coined by American president Theodore Roosevelt.

competitive field. This comment also objectifies older adults as bodies to which actions are done rather than bodies which are their own agents (as is demonstrated in the words I have italicised below):

> Each member of our community *is hydrated and moisturised* to a strict timetable because they are worth it. This level of care is seldom found amongst our competitors.

Valerie Berry finishes with:

> This is a place where everyone is welcome. We care for our residents and we care for our shareholders.

In fact, all the above-cited proclamations are displays of rampant capitalism, but it is these two last references in particular, to 'competitors' and 'shareholders', which place the world of the home within the wider landscape of neoliberal capitalism and the workings of the free market.[85]

To punctuate the ending of these hyperbolic opening speeches, one of the characters that Katia Molino plays, a woman with some kind of dementia (most likely), tells the lampshade to "Shut the f…k up", a very funny way to end these opening scenes. A care assistant responds with "settle down". After that, a male patient (Arky Michael, *MBDJ*, DVD) repeatedly chants a mantra about going swimming: repetition is common for people living with a dementia diagnosis. These opening tallies provide two very clear references to dementia, early cementing the relationship between age and dementia in this piece, and undermining the smooth advertorial speak of the preceding declarations with the 'reality' of the nursing home.

As I understand, these opening scenes also show an insistence by Kantanka on the broader political frames of dementia and ageing. In the age studies literature this kind of framing is referred to as "the materiality of age … [that is the] [a]ttention to the economic conditions of aging and its material effects" (Swinnen and Port, 2012: 12). Important political reasons drive the setting of *MBDJ* in an institution,

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[85] Neoliberalism is "a theory of political economic practices that proposes that human well-being can best be advanced by liberating individual entrepreneurial freedoms and skills within an institutional framework characterised by strong private property rights, free markets, and free trade … [I]f markets do not exist (in areas such as land, water, education, health care…) then they must be created, by state action if necessary" (Harvey ,2007: 2). It is a pervasive global ideology referring to the privileged position governments have given to markets in determining global economic, political and social policies. It has also been incorporated into "the common-sense way many of us interpret, live in, and understand the world" (Harvey, 2007: 3). There has been an emphatic turn since the 1970s to neoliberalism.

apparent in the opening scenes, but also threaded throughout the production. Although it treats the topic of care workers without resorting to stereotypes, and shows how people adapt to change and make new 'homes', Kantanka is critical of certain aspects of institutionalisation, or what Tom Kitwood (1997:45) terms "warehousing". This is one of at least four depersonalising traditions which Kitwood sees as the outcome of a preceding history of care practice in general, whether in institutions or in the community. The others are "bestialization, the attribution of moral deficit, …and the unnecessary use of a medical model" (Kitwood, 1997: 45), many of which are not discrete but overlap, systemically. It is to institutionalised care practice and its genealogy, that this chapter now turns, followed by an investigation into the way the production deals with institutionalisation.

Warehousing

Warehouses were, and still are, used by businesses to store large amounts of goods for sale on the market. Kitwood deliberately uses the affiliated term "warehousing" in regards to the care home to underscore its genealogy, and in this way to link it to the rise of industry, and also to make an important connection between capitalism and morality. As Kitwood reports, modern societies as we now understand them emerged through the seventeenth century, when many European nation states started to press their economic interests through the globe (1997: 42). Property, trade and empire were its hallmarks, and confusion and turmoil had to be curbed in order for the effective functioning of the economy (Kitwood, 1997: 42). Therefore, during this period, many institutions of confinement were built: "the misfits of society — beggars, tramps, criminals, dissidents, the mad, the disabled and the fragrantly *immoral* — were taken off the streets" (Foucault, 1967 cited in Kitwood, 1997:42; my italics). Some were forced into menial labour; some were locked away and treated like animals; the violent ones were kept in chains (Kitwood, 1997: 42).

At the same time,[86] workhouses began to open, and by the 1770s, the number of parish workhouses in England and Wales had soared to around 2,000. During the early nineteenth century, as a result of certain conditions[87] and the Jeremy Bentham-inspired Poor Law Amendment Act in 1834, more than 600 edifices were built. (Bentham is arguably better known today for his notion of the Panopticon, designed to facilitate the operation of institutional power in prisons through a denial of privacy. It was designed so that every action of every convict could be seen).[88] As drama scholar Michael Mangan argues, the central ideology of this Act was moral: to distinguish between "the 'deserving' and the 'undeserving' poor" (2013:207). The Act stipulated that poor relief was to be dependent on admittance to and residence in a workhouse which, as Mangan notes, created the 'deserving' poor as a group to be managed and controlled institutionally rather than individually. Moreover, in an economy where there was no old age pension (it was introduced in 1928 in England), the elderly made up a large percentage of these workhouses. The workhouse also acted as both infirmary and hospital. In effect therefore, workhouses became storage holders for elderly bodies, 'warehousing' them in a dehumanising environment: of concern towards the end of the nineteenth century because of "widespread inefficiency, ignorance and inadequate staffing" (Mangan, 2013: 208). Care homes are therefore, to an extent, a direct descendant of the Victorian workhouse, various kinds of which have existed since Elizabethan times (Mangan, 2013: 207), although in the late middle ages and through the fourteenth, fifteenth and sixteenth centuries, the more vulnerable of society were mostly dependent on individual acts of charity and religious organisations, (see Hodgeman, 2014).

In Australia, at the beginning of the nineteenth century, there was no social security system, mirroring that of England, so either families took the bulk of the

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[86] Prior to this, state-provided poor relief was set in motion through the 1601 Poor Relief Act. Rates collected in parishes were spent on the 'deserving' poor (the sick, the oldest and infirm) in the form of bread, clothing, fuel or money (Hodgeman, 2014).

[87] Examples include the return of unemployed or injured servicemen from the Napoleonic Wars and the new Corn Laws that restricted grain imports and pushed up the cost of bread (Hodgeman, 2014).

[88] Using the Panopticon as an illustration of "discipline", a specific historical form of power taken up by the state in the seventeenth century, Michel Foucault wrote on the workings of institutionalised power; first of all, with professional soldiering and then spreading widely across society via the panoptic prison, the division of labour in the factory and universal education (in *The Birth of the Clinic* (1975), first published in 1963; and *Discipline and Punish: The Birth of the Prison* (1991), first published in 1977). For Foucault, the purpose of discipline is to produce "docile bodies" (1991: 135).

responsibility for the sick, the elderly, the disabled and the 'demented' (Goggin and Newell, 2005:124) or charitable relief was provided to needy persons by voluntary organisations, in some cases with the assistance of government grants. The main areas of need which attracted charitable assistance were the 'sick poor', neglected children, old people who were destitute, and women who had been deserted or who had 'fallen' pregnant. Those unable to care for themselves were placed in institutions, although they tended to be segregated into "people with impairments, 'lunatics' and convicts" (Cocks and Stehlik, 1966: 11 cited in Goggin and Newell, 2005:124). Many hundreds of people with disabilities were also incarcerated in institutions like mental hospitals, nursing homes or hostels for the visually impaired in Australia and all over the world, separated from the community often for their entire lives. The advent of the twentieth century saw major changes for people with disabilities in Australia and all over the world, including the rise of independent living facilities (Goggin and Newell, 2005).

MBDJ is a production that puts the stories and words of people living with a diagnosis of dementia to good use in examining the politics of the care home and by proxy, issues of warehousing, thereby troubling the 'right kind' of dementia story. Several scenes in *MBDJ* offer critical glimpses into institutional life. In one scene, an exercise therapist (Kym Vercoe), with maracas in hand and loud music pumping, makes her patients move their limbs to very loud music. The first 'patient' she works on is a jumper (sweater) draped over a chair; the second, a pair of trousers. As Vercoe works the arms of the jumper up and down, she makes it shake in a manner reminiscent of Parkinson's disease. The whole time, this movement is accompanied by her patronising banter: "Ok everyone — wake up — good morning — let's go — arms lift — lift — Come on — one — beautiful — and 2 — push — nice job." An enthusiastic torturer let loose on the residents without constraint, she has her job to do and she will do it regardless. Another scene has two female staff members talking to each other about sex while bathing a man (rather distractedly). "I f…ed an albino last night," says one to the other, carrying on a conversation without including him. They presume he can't hear them because he has dementia. There is a similar scene with a cleaner (Michael Denkha/Arky Michael, *MBDJ,* DVD). Disinhibited by thinking that these 'old people' won't understand anything and taking out his frustrations with his life and his lot in

a kind of verbal abuse, he expresses his own troubles saying to them: "Just go! Time's up! Give us a break!"

All these scenes may be read as indications that abusive behaviour is one of the key worries many families have when they leave their loved ones in such institutions, often prompting feelings of guilt as a result. Care homes may be feared, along with ageing, because we dread that they could expose us, or our loved ones, at the worst to abusive behaviour, and at the best, to control of basic personal freedoms (such as the time we sleep, wake up, eat or take a shower). Drama scholar Michael Mangan (2013: 209) argues that the care home has become a trope for the institutional oppression of both older adults and those with dementia, a trope that is well run in the press and on mainstream stages in Britain. The trope is funded by images of unfeeling entrepreneurs, the breach of basic human rights and physical abuse that in most cases sells newspapers rather than reports the full story. He also contends that it may create the very thing it describes. What the media forgets to tell us, he argues is:

> the excellent quality of care that exists in so many facilities, and all the good work that is being done in nursing homes to provide the residents with a better quality of life (Mangan, 2013: 212).

But Mangan then acknowledges that the UK Care Quality Commission reports done on these homes have, to date, mostly been critical.

There are no doubt many homes, and staff in these homes, doing the best they can (as *MBDJ* also shows); however, care homes are still institutions and open to the problems besetting "total institutions", as Erving Goffman (1961: xiii) terms them. For Goffman, total institutions (the prison, the mid-twentieth century mental institution and the concentration camp) are those enclosed and formally administered places where a large number of "like-situated" individuals are placed together, away from majoritarian society for a long period of time (1961: xiii) and where they may be subjected to "abasements, degradations, humiliations, and profanations of self" (1961: 14). According to Goffman, "[t]he total institution is a social hybrid, part residential community, part formal organization" (1961: 12). All aspects of life are conducted in the same place and under the same single authority; large blocks of managed people are all treated much alike; activities are enforced; the inmates are excluded from knowledge of diagnosis or plan of

treatment (Goffman, 1961: 6-9). Goffman's work pre-dates that of Michel Foucault (1991) who in 1977 argued a similar point: that institutions carry power in an enduring way and each major institution has its 'regime of truth'.

I do read the descendants of workhouses and warehouses, care homes, as total institutions in Goffman's dispensation, despite concerns I have with any institution being described as wholly total or indeed wholly discursive, in Foucault's sense, as these readings seem rather deterministic, reducing the human beings residing in them to nonentities, incapable of resistance. Despite risks to their health, people will often challenge and refuse the strictures imposed on them in institutional contexts (Fox, 2002: 366). However, the problem when it comes to older adults diagnosed with dementia who live in these institutions is that their defiance may be expressed in non-verbal ways (such as wandering, crying and hitting) and interpreted by the workers as behavioural problems to be medicated or restrained (Boyle, 2014). In other words, their efforts to resist institutional impositions are often attributed to their diseased minds, and not seen as acts of agency. As a consequence, for some people diagnosed with dementia, being incarcerated in these institutions can catapult them into what Giorgio Agamben calls "bare life" (or *homo sacer*) lived as a "state of exception" (1998: 7), a borderline state where only the body counts and not the person.

For Agamben, some categories of the human are considered more "*zoē*" or animal than "*bios*", life as incorporated into and demarcated by the state (1998: 1). These bare forms might be termed "abject" by Julia Kristeva (1982: 99) or the "not yet subjects … who form the constitutive outside to the domain of the subject" by Judith Butler (1993: xiii). Agamben theorises the state as founded on the early exclusion of bare life, of which concentration camps or organ harvesting from comatose patients are modern examples. Following Lennard Davis (2013: 29), I link bare life to utilitarian philosopher Peter Singer's ideas of the barely human to open up Agamben's theorisations in relation to disability studies.

Singer (1996, 2009) is an animal rights activist who, along with Jeff McMahan (1996, 2003, 2008) argues that the line between animals and humans is not clear. But, if it is to be demarcated, being human can be seen as the capacity to decision-make, among a few other features. This means that certain kinds of

humans do not fit into the category of human. The severely cognitively disabled do not fit into Singer's category of the human; neither do those with severe dementia. A large part of the project of this thesis is arguing for including the abject into ideas of what is human as well as into the polis (or perhaps dispensing with the notion of the human altogether) which might then dissolve the ideological formations of what is constituted as human and included, and non-human and excluded.

In claiming that care homes can be interpreted as total institutions, I am not arguing that all institutions are bad, or that all older adults diagnosed with dementia do not like them, or that they cannot be of benefit to some older adults and their care partners. I am arguing that there are political and ethical sides to the confinement and treatment of older adults diagnosed with dementia in these institutions that are often overlooked. If, as Mangan points out, "like any kind of identity construction, [ageing] does not operate in a vacuum, but also as part of the complex web of beliefs, assumptions and power relations that make up the ideological formations of a culture" (2013: 5), then institutions will not be value free.

By setting *MBDJ* in an institution, Kantanka makes an important contribution to the contextual, material and political dimensions of age and dementia care studies, foregrounding the current trends towards an economy of care in which market forces have free reign. In a market economy, competition supposedly raises quality and keeps prices low. However, as Tom Kitwood notes, "[c]onditions such as these can never be fulfilled when there is a human service being delivered" (1997: 44).[89]

I will now turn briefly to examine, with more precision, the uses to which *MBDJ's* verbatim input has been directed, and to what effect, that is, its relationship with the 'true' words and stories collected from 'real' people in aged care facilities, as well as its use of A-effects, to investigate the importance or not of this relationship in the creation of the 'right kind' of dementia story.

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[89] One perturbing trend in Australian health care practice is the use of the word 'consumers' for those who used to be called 'clients' or 'patients', demonstrating the march of the free market into human services (author's personal notes: from the Schizophrenia Fellowship NSW conference, 2014).

A-effects

In using the stories and/or words of the marginalised, the oppressed or those affected by traumatic events, some reality theatre-makers wish to highlight social and political injustice and, in many instances, to tell the 'truth' of stories that are either not being told in the public sphere or are being told in ways that serve conservative socio-political ends rather than those of the traumatised themselves. These are the "untold stories" forming part of Theatre Kantanka's mission statement (Theatre Kantanka, 2013). To draw audiences and to underscore the authenticity and value of their work, theatre-makers are often not shy about advertising a connection to 'the real' through A-effects, which include "the use of advance signs that highlight their close connection to social reality" (Garde and Mumford, 2013: 152). One example of *MBDJ's* use of A-effects is Gomes' testimony in the program notes as to the origin of the verbal text (quoted in the introduction to this chapter), as well as the statement directly following this that "[t]heir words carry the richness of those realities to us, the observers" (Seymour Centre and Performing Lines, 2011). And yet Gomes does not advertise that the company did *not* rely on the traditional tools of verbatim theatre, such as tape recorders or writing conversations verbatim, but rather on their memories and reactions to what was observed.[90] Another example of the impact of the use of these 'advance signs' is from a theatre review. One critic wrote, "[t]he dialogue, taken directly from life, is the kind of stuff you can't make up. ("Your son is coming out of the wall!" a strident old dame repeatedly insists)" (Dent, 2013). However, the actor-devisers may in fact have made up these words. Both these examples show how *MBDJ* calls attention to its A-effects (through advertising its textual roots and documentary processes), but then overthrows this association by creating and then producing a highly theatrical response to these factual roots.

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[90] *MBDJ* was researched and developed over a two-year period of three phases of four weeks. There was a four-week research period that informed the piece (Translab); a four-week creative development to explore the potential for a live performance; and four weeks in production for the work's public presentation. Prior to the commencement of Translab, Gomes started to make contact with aged care facilities, to determine a number of sites that would be interested in hosting an artist for a period of time as part of the research process. Contact was made through a mixture of: cold-canvassing of professionals working in the industry (like people from the Department of Aged Care, Diversional Therapists, Directors of Nursing), and through personal contacts: a mother of one of the performers was living in a nursing home during that period (Gomes, 2015).

This double move can also be seen in their creation of characters who are an amalgamation of the many people the company met and in the fact that, although much of the dialogue was taken directly from observed conversations and situations, the artists also wrote material that ended up in the final piece, with what is real and what is not real, deliberately indistinguishable. Similarly, the video footage is a mixture of actual people (the woman playing the violin during the final scene was a resident of one of the facilities the company researched and the footage was donated by her family from their family archive), and set-ups (the man in the rain under the umbrella is one of the performers). The audience is not privy to this mixing of fact and fantasy. Determining what is real and what is not, they will likely have to refer to their understandings of the subject and other representations to detect reality. Because of this, the world created in *MBDJ* is "surreal, yet so real" (Gomes, 2015) both informed by visits to a variety of aged care facilities, and derived from all the places visited and the people met in a creative leveraging of the verbatim technique.

For this audience member, the 'reality' presented by *MBDJ* is very real because what AD taught me is that 'reality' for people living with a diagnosis is constructed in a type of liminal zone between fact and fiction: stories emerging from this locale also reflect this liminality. But this is not so different from how reality is constructed for so many of us. The semiotic turn has highlighted that reality, whether on or off the stage, is up to a point mediated by language and discourse (encompassing societal attitudes and values). Any theatrical destabilisations of norms will happen within the realm of representation, with any move beyond representation therefore entailing a deep engagement with representation itself.

In this section of the chapter I have examined how *MBDJ* created and traded on A-effects. Previous to that I assessed its important framing of the materiality of age and dementia as well as it politics. In the next few sections of this chapter, I will scrutinise how this piece of 'layered' postdramatic verbatim theatre disrupts and re-imagines 'normative age-and-dementia-effects' and the consequences of this for its audiences given that spectating is as much "an act of *self-implication*" (Jürs-Munby, Carroll and Giles, 2013: 24; italics in the original), that is, of individual attitudes and values, as a social undertaking. To do this, I focus on *MBDJ's* mixed

palette of tragedy and comedy as well as its postdramatic style, questioning the claims made for the political potential of this type of aesthetic (Jürs-Munby, Carroll and Giles, 2013) as a resistant strategy.

Resistant strategies

MBDJ paints senile dementia and other issues of aging with a mix of both tragedy and comedy. However, "a tragi-comic view of aging" is fairly consistent with Western mainstream theatre representations (Moore, 2014: 5). Therefore this mix cannot be seen in itself to be resistant or disruptive to 'normative age-and-dementia-effects'. Comedy is generally well used in *MBDJ* to expose both what is of value and not in institutional life. One sweet moment, and the iconic image of the show, is that of the 'David Jones' character (Katia Molino) who with regularity makes a trip to a bus stop, which in reality is just a seat in the facility (see figure 2).

Figure 2: Katia Molino waiting for the bus in Theatre Kantanka's *Missing the Bus to David Jones.* Photo by Heidrun Löhr used with permission from Carlos Gomes.

Every time she makes a move there, a jaunty little tune plays as she shuffles along walking frame in front to make it to the seat in time to catch the bus. She is well dressed in a black and white hounds-tooth jacket (with reference to the hounds-tooth David Jones logo) replete with hat and purse. She puts her white gloves on while sitting and waiting for a bus that does not come. When a kind-hearted nurse (Valerie Berry) informs the woman that she has missed the bus, working in the woman's reality rather than contradicting it, the woman's response is "Bugger". The nurse then suggests that they have a cup of tea and tells the woman to come earlier tomorrow in order not to miss the bus again. In both the fact that the facility (or the nurse?) has provided the bus seat as a space in which the woman's reality can be supported, and the fact that the nurse plays along with her, we are allowed to see some of the

positive changes wrought in dementia care: the creation of narrative spaces (the bus stop) and the diversional treatment encouraged by the nurse's suggestion to have a cup of tea.

There are also several 'tragic' scenes. In one, we see the fraught efforts of a son (Arky Michael in the *MBDJ,* DVD, and Michael Denkha in the play) to communicate with his dementia-ridden mother (Kym Vercoe). In another, a wife (Rosie Lalevich) visits her husband (Phillip Mills, *MBDJ,* DVD). "When are we going home?" he asks her, looking at the chocolates she has brought him without understanding what they are, possibly thinking that she is in fact his mother not his wife. Upset, she quickly leaves the living room. Neither of these scenes can be said to resist or trouble the way dementia is normally portrayed, which is not to say that either of these scenes is presenting instances of untruth. In fact these scenes are based on the 'reality' many audiences would be familiar with, either from their own experiences or those reported in the media. In tandem with the knowledge the audience has likely garnered from the program notes, or other sources, that the verbal text of the play is from the words and stories of people living and working in facilities, these scenes would imply the reality of the experience of dementia (from a long-suffering 'carer's' perspective).

But, in contrast, in a swift move from tragedy to comedy, from reality to fantasy, and from a more typical dramatic scene as catalogued above to one where the fictional cosmos Kantanka has created is ruptured, the scene between the mother and son ends by indicating, in my view, that those relating to people living in the later stages of dementia have an important role to play in the tenor of the relationship. It also indicates that care partners may in fact limit, rather than open up, possibilities in this relationship. It does this by moving beyond any constraints of character determined by holding to realistic character portrayals.

Towards the end of the scene, the son is talking to his mother about the dog having puppies and she is still not responding. He gets more and more annoyed by this, and keeps repeating the phrase, almost barking it at her. The scene ends with him actually barking at her like a dog. The son, adamant that his mother hears what he has to say, has literally become a dog through his insistence on his mother responding to him in what he would dearly love to be a 'normal'

conversation. Although his frustration is understandable, in this barking he is shown for a moment to be less than human, a reversal of the normal representation of the person with dementia as less than human (a kind of bestialisation, which is another one of Kitwood's (1997) four depersonalising traditions). Given that performance has multiple realities, there may be many other ways that this scene can be interpreted, but I think that at the very least we are privy to a troubling of the accepted script that care partners are normal humans, and by default, those with dementia are not. As the 'barking' is repetitive, I think there may also be an inference here that repetition is not the sole domain of the person with dementia, but is also shared by those carers who demand their loved ones be who they were, rather than who they are now: an idea that this thesis challenges.

As is consistent with a postdramatic ethos, the world created in *MBDJ*, although based on real words and stories, is peopled by characters like this son who moves from being a recognisable human to the embodiment of a metaphor. Characters largely without coherent psychological interiority also inhabit this cosmos, which paradoxically is congruous with a common view that people ageing with dementia are not psychologically intact. In this sense, the play honours the 'reality' of those living with a dementia diagnosis (when 'reality' is seen as created by perception as well as by biology) by connecting an imaginative world to a real world outside the theatre, enforcing Hans-Thies Lehmann's ideas that the postdramatic distance from reality (its 'aesthetic autonomy' in Adornian terms) within a situation that is somehow real, permits a "politics of perception" (2006: 185).

Additionally, *MBDJ* has no narrative development or storyline. Many small stories are told, not just one: stories from men and women, a range of classes (the cleaner, the migrant care workers) and ethnicities (for example, Arky Michael's Greek man and the Filipino nurse). Time is stretched not paced as, for example, a character takes a long time to walk from one part of the stage to another, referencing disability or 'crip' aesthetics. According to Petra Kuppers, disability aesthetics is the use of specific theatrical devices, like non-narrative storylines, slow-motion movements, voiceovers and other techniques that create a specific "disability" style of communicating in performance that allows the audience to see and feel the aesthetics of the piece differently (2003: 95-97). However, disability

aesthetics, should importantly be used by *disabled* performers. Furthermore, the movement of the whole piece is erratic rather than smooth, embodying the "postdramatic … demand for an open and fragmenting perception in place of a unifying and closed perception" which marks the traditions of the dramatic theatre (Lehmann, 2006: 82).

Although *MBDJ* has many of the hallmarks of the postdramatic, it is worthwhile considering the degree to which these conventions, also a familiar part of devising theatre strategies, are in themselves resistant or compliant to normative scripts of ageing and dementia. In devising theatre, the entire script usually emerges from the collaborative improvisations of a group and not prior to the work's creation (Heddon and Milling, 2006: 3). Theatre practitioners who use devising tend to see this approach as alternative and experimental, undermining and challenging mainstream dramaturgies and theatrical representations. But while *MBDJ* works in resistance to mainstream dramaturgies and representational circuits, it should not be automatically conflated with troubling the generation of 'normative age-and-dementia-effects'. This is partly because the mechanics of theatre are neither simple nor transparent, so that when conventional depictions of age and dementia are dislodged, especially through the use of a postdramatic aesthetic, and the 'right kind' of dementia story challenged, it cannot be assumed that audiences will either accept or understand the challenge. Certain scholars have argued, along with Lehmann (2006) that, the disruption to normal ways of seeing through the postdramatic will produce a political effect. However, I hold that there can be no direct causal relationship between representation and the re-storying of ageing and dementia: an in-depth exploration of the last scene of the play, and a snapshot of some of the audience responses I heard on the afternoon I saw the play, will help to shed some light on this issue.

Lust for life

In the final scene of *MBDJ*, all the actors gyrate to Iggy Pop's song 'Lust for Life', frantically waving their arms and legs around in a kind of riotously grotesque epileptic movement sequence (similar to how Iggy Pop himself performed the song on music video). The scene is most likely triumphant, particularly given that the

image projected on the back wall is of an older adult violinist joyously playing her instrument, but it could also be interpreted as one maliciously mocking the elderly disabled. In fact, its meaning may have been deliberately left as ambiguous, open rather than closed, in the best tradition of postdramatic theatre, so that the audience could interpret it as they saw fit. The goal of much postdramatic theatre is not comprehensibility but a "loosening of onstage phenomena from conceptual, referential, representational logics … in the preference for 'presentation' over 'representation'" (Jürs-Munby, Carroll and Giles, 2013: 11).

The matinee performance of *MBDJ* that I attended was advertised as part of 'Seniors Week': a limited season at a mainstream theatre as opposed to one of the first airings of this piece at a non-traditional performance site (Performance Space, Sydney). Pairs and groups of seniors surrounded me that afternoon. As the performance came to an end with the raucous tones of Iggy Pop, I was privy to various comments from a group of seniors in front of and beside me who did not seem to have enjoyed the production. Phrases like "lack of respect" and "not a laughing matter" were repeated several times, accompanied by headshaking and 'tut tutting'. In this finale, the cultural norms that present the oldest old and those living with a diagnosis of dementia mostly in terms of tragedy were not endorsed. However, the comedic and celebratory ending with disability colourings (epilepsy or dementia?) clearly disturbed many audience members, challenging certain ideas they might have about how old age and dementia should be represented.

As I have already noted, the scene is open to interpretation. Is this yet another comic exposé of the aged body? Or is it an ending where ageing is celebrated? Is the possibility of escape from the confinement of the nursing home, as well as from restrictive ideas about how people should behave when they are ageing, being suggested? These questions cannot be answered with certitude. Kantanka could give answers about their intent but even then there can be no certainty, as what audiences take from productions can never really be known, unless surveys are taken, but these also may not always be exact. But several issues emanate from this ending around the question of whether or not we can equate the troubling of 'normative age-and-dementia-effects' with a re-storying of dementia and ageing on public stages in terms of audience impact, depending on the audience demographic including many factors like age and theatre literacy.

What I overheard that afternoon shines light on the *attempts* that audience members make in post-show utterances to begin to unravel and clarify what it is they have experienced, in this instance, in relation to theatrical representations of dementia and ageing (Reason, 2010: 16). These utterances may either circumscribe perceptions of those worlds or help build new ones, if only in increments. In coming to the theatre, audiences can have their understandings of how the world is, either reinforced or challenged by theatre experiences, or a whole continuum between these two binaries. They may disagree with radical interpretations of that world if it conflicts with what they understand to be true; but they may also partly accept the overriding line of the production as determined by the director and others, if there is one, while at the same time negotiating their own meaning about it in ways tangential to the expected. Drawing on Alice Rayner's 1993 essay 'The audience: subjectivity, community and the ethics of listening', Helen Freshwater points out that one person may also experience manifold and contradictory reactions to a performance (2009: 6). This is all inflected by the surfeit of recent theatre, making active interpretation on the part of the spectator a vital part of the production, often requiring a type of co-creation or intervention in the piece. Blast Theory in the UK or the Wooster Group in New York provide good examples of this trend (Freshwater, 2009: 17).[91]

Nonetheless the impressions of ordinary audience members are valuable, especially if they sit in opposition to those of so-called more 'informed' theatre-goers, like academics or critics, because they enable a recalibration of what it is that theatre does and does not do well, specifically in relation to representations of older adults with dementia. Moreover, in the case of *MBDJ*, many of these 'uninformed' responses to the show which I heard differed markedly from those emanating from arguably more 'informed' points of view, like those of seasoned theatre critics, most of whom were incredibly enthusiastic about the production.[92]

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[91] Both Blast Theory and the Wooster Group create performances where audiences often interact with the materials or the performers. Blast Theory use interactive media and art creating performances to audiences live, across the internet and through digital broadcasting. The Wooster Group productions require that the spectator make choices once considered to be the province of the writer/performer (Savran, 1998: 55 cited in Freshwater, 2009: 17-18).

[92] I do not intend here to belittle the responses of people who may not be as informed as others when they see a theatre production relying on a physical and postdramatic aesthetic to tell a story. The declension is a way to tease out what lies behind oppositional responses to the treatment of ageing and dementia in public performances.

Theatre reviews

However positive they were about the production, many of the reviews mentioned the subject matter as 'uncheery', 'a living death' and that which is awaiting most of us, and which most of us do not want to face. It is the gloomy picture of 'what lies ahead'. This all, according to one critic, Kevin Jackson, would make it very "difficult to "sell" this show" (2013). In an otherwise enthusiastic review of *MBDJ*, former *Sydney Morning Herald* [93] theatre critic James Waites writes of the perceived difficulty of attracting audiences to this subject matter:

> This is a wonderfully put together examination/celebration/homage/lament to the lives of those among our elderly living out their last days in 'assisted care' in nursing homes. Yes, I know, I can feel you shrink. It's what the company does with this seemingly *uncheery topic* that makes the production so wonderful … It exposes a huge dirty secret — that we are all mortal. And increasingly so. If you have not already been drawn into the world of this play by visits to a family member — well that time cannot be postponed forever. This production not only gives you an insight into what lies ahead. It is at the same time a glorious celebration of life itself (Waites, 2013; my italics).

Another blogger, Lloyd Bradford Syke, in his online review for *Australian Stage* writes:

> One day, notwithstanding the vigour we might now possess, or assert, you and I might well lapse into a social stratum to which we've no particular aspiration. *The drooling class*. We are all born to die. But it's *a living death*, perhaps, we fear most (Syke, 2013; my italics).

Added to this, Kevin Jackson comments on his blog that:

> In seeing this work again, the gained perspective is in the subtle and sensitive care that the company have chosen to illustrate the world that, although at this time is 'someone else's reality', but, given the whirlygig of time, my possible future … I encourage you to take your family of all generations. It will awaken a subject not always publicly aired … rather delicately avoided or mocked. This beautiful production could open the doors to personal preparation and political action to ensure the final stages of life are respected, comfortable and normal (2013).

I concur with the majority of these reviewers that the subject matter is challenging. Old age may disable, and it is the one direction in which most (temporarily) able-bodied people are heading with surety. It may also be a reminder that disability is

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[93] The *Sydney Morning Herald* is a weekly newspaper owned by Fairfax media, published in Sydney but with distribution around the capital cities of Australia.

not just a state for some people, but for all of us if we live long enough. Age and dementia can serve as reminders, prompting the able-bodied toward the insight that:

> people with disabilities are not 'Other'. That they are really themselves at a later time. Unless we die suddenly, we are all disabled eventually. Most of us will live part of our lives with bodies that hurt, that move with difficulty or not at all, that deprive us of activities we once took for granted — bodies that make daily life a physical struggle (Wendell, 1996: 18).

Dementia, along with some of the cognitive and physical disabilities that ageing may bring, has the potential to close the gap in consciousness between the exclusionary locations of disability and those normalising loci of the abled bodied, because it is something that all of us will most likely have to face in the future, either for ourselves or our loved ones, if we live that long. But it can also move people in the other direction. Rosemarie Garland Thomson argues that the potential for disabilities (including those of ageing) to close the gap between the extremities of disability and ability can be reversed by fear. She maintains that disability is disturbing for many so-called able-bodied people because it suggests that "the cultural other lies dormant within the cultural self, threatening abrupt or gradual transformation from "man" to "invalid" " (Garland Thomson, 1997: 43).

In particular regards to dementia, and as I have previously argued, the cultural consciousness of much of the Western world is permeated with anxiety because of the loss of memory and cognition entailed, given that memory and identity have become symbiotic in Western thought. There is also the issue of the "myth of control", a myth based on the idea that it "is possible, by means of human actions, to have the bodies we want, and to avoid illness, disability and death" (Wendell, 1996: 9).

Senile dementia is not the type of subject matter towards which many theatre companies have rushed to create work; neither have audiences to see the work (although this is likely changing given the demographic changes in the numbers of the ageing and the implications this has socio-economically).[94] Its unpopularity may be because of contiguous cultural attitudes about it as a living death and the people who live with it, as the living dead (see critic Lloyd Bradford Sykes' words earlier).

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[94] Bridie Moore notes that in a selective survey of British theatre in the autumn/winter of 2011 to 2012, 22 of 25 productions were new works highlighting one aspect of ageing (including dementia). She attributes this to the impact of the ageing population on Western economies (Moore, 2014: 4).

Nor has there been much theatre produced critiquing the link between nursing homes and neoliberal capital, most likely because they are seen as a necessity about which there is also shame, worry and guilt. Shame when the demands of living with an ageing elder with dementia become too much and the family cannot cope; worry and guilt about leaving loved ones in places where they may be treated badly when the services are impacted by shareholder demands for profit.

When elders, and in particular those living with a diagnosis of dementia, are storied in different ways in public theatre stagings, audience responses will vary and most likely conflict. *MBDJ* may have been confrontational and unsettling for the senior audience members whose negative comments I overheard for too many reasons to put here, including the aesthetic style of the show. But it is the blog review from *Same Same's*[95] Matthew D'Silva that intrigues me the most, and I think provides a way to unpack these negative responses to the show. Matthew D'Silva, who does not appear to have the credentials of a seasoned theatre reviewer, expresses similar views of those of the audience members I heard:

> Eventually at some stage in our life we will have to deal with a loved one or be the person who is living in a nursing home. Seeing this portrayed on stage in a *non-compassionate way* was depressing and a little shocking.
>
> There is nothing appealing about *making a joke of someone who is incapacitated especially when they cannot stand up for themselves* — and this production seems to make light of people who are in a nursing home. This is confrontational theatre at its best …
>
> Director Carlos Gomes has directed and created a very confronting and difficult production and the hardship and realities of aged care living. This stage play has highs and lows and there are moments where the performers seem to be presenting charactertures [sic] of the patients. It is a clever but also a little crass in the way it presents the patients of the aged care home *as there seems to be little respect and more comedy* (D'Silva, 2013; my italics).

One of Matthew D'Silva's statements about *MBDJ* particularly intrigues me, as it uncannily calls into question issues around representation of vulnerable and marginalised bodies who rely on other bodies to tell their stories while at the same

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[95] *Same Same* is a lifestyle blog for the Gay and Lesbian community. The style of the review does not exhibit the reviewer's understanding of critical and historical issues in the theatre. Interestingly, snippets from this review were posted on the online Aged Care guide which would have had lots of hits from carers and other people affiliated with the aged care industry, who would also have been potential marketing fodder for this show (DPS News, 2013).

time calling up comedy as an inappropriate mode: "making a joke of someone who is incapacitated *especially when they cannot stand up for themselves*". I want to explore this latter idea in more detail, as it pinpoints particular problems to do with underlying assumptions about ability and the age normative scripts on which much theatre is based, and raises issues to do with ethico-political praxis in reality theatre. It is on the complex interrelationship between disability and representation issues that I conclude this chapter.

Figure 3: Katia Molino, Rosie Lalevich and Valerie Berry in a scene from Theatre Kantanka's *Missing the Bus to David Jones.* Photo by Heidrun Löhr used with permission from Carlos Gomes.

What is missing in *Missing the Bus to David Jones*?

What is present in *MBDJ* calls up what is absent. The six actors in *MBDJ* range from their 30s to their 50s, and play a wide range of roles. Their performances largely involve the somatic mimesis of frailty, clearly identified, including that of an old man with a Zimmer frame who spends 15 minutes getting across the stage (Phillip Mills), and that of the old woman with late stage Parkinson's, whose hand movements have been intricately and painstakingly observed and copied by the actor playing her (Kym Vercoe). At the beginning of the play the actors, a varying range of body types, strip down to their underclothes before assuming their attire and the various poses of old age that they will at different times embody in the production. This is a typical Brechtian gesture signalling the disjuncture between actor and role and acknowledging the body of the actor under the body of the character. *MBDJ* comes clean in its location as a vehicle of pretence.

So what then caused so much discomfort to Matthew D'Silva, the seniors around me and partly myself that afternoon? The probable "ontological queasiness", which theatre scholar Jonas Barrish (1981: 3) identified as an historical mistrust of theatre's deceptive nature felt by many people is, I contend, partly related to the problem of the absent body invoked in this initial theatrical gesture of disrobing.

Exposing theatrical counterfeit has long been proposed as a way that the complicity of the audience can be gained through techniques like direct address (Ridout, 2006). All performances give testimony to absences (Park- Fuller, 2000: 20); therefore of course what is present in *MBDJ* calls up what is absent. But in this instance, the unveiling of the pretence of the theatre through the uncovering of the bodies who will make the fiction very clearly invokes the absence of the ones being represented, and in so doing, not only bares the illusion of the theatre, but calls into question issues around the representation of vulnerable, marginalised and age-affected bodies who rely on others to tell their stories. When Butler proposes that any disruptions to the normative scripts of gender (through expressions, gestures, images, speech acts or performative moments) may help to build, even in increments, towards a displacement of conventional representations of gender which can then open up the possibility of agency, she is referring to modes of self-presentation (1990: 202–203). When actors do this for those they are representing, particular issues will be raised which could displace the effects of the displacement itself. The audience remarks I overheard and Matthew D' Silva's 'uninformed' judgement should not be dismissed offhand, but should be mined for the valuable insights they yield into the construction of disability representation.

When the company disrobes at the beginning of the show, this corporeal movement not only lays bare theatre as a location of make believe, but also serves to highlight the able and/or younger bodies making that movement, in turn calling up both the disabled and the older body. Revealing the able body becomes " "the very coinage" of an aesthetic exchange" (Power, 2008: 119) calling up what is absent. The absent body is the rejected body (whether because it is older or because it is infirm or because it has dementia).

Physical theatre commonly employs "youthful performers who are able to achieve extraordinary physical feats" (Moore, 2014: 8). In *MBDJ*, with Kym Vercoe's work in particular, we are witness to some extraordinary manipulations of the body. Her foreign-accented woman who has lived most of her life in a caravan in Budgewoi[96] moves diagonally across the stage with the help of her Zimmer frame, in a

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[96] Budgewoi is a suburb on the Central Coast of New South Wales, Australia, only 100 kilometres away from Sydney. It is surrounded by lakes and the Pacific Ocean, making it a popular holiday spot for people from Sydney. It has a lower socio- economic demographic.

horizontal position with elbows extending upward, reminiscent of a praying mantis. Following this, we see the same woman at an earlier time in her life dancing with her husband in a triumphant ride on the top of her frame. In this manipulation of the body we are also witnessing the manipulation of time, confounding any strictly chronometric notions (Barr, 2012 cited in Moore, 2014: 7). But in this instance, old age is put in relation to youth and will therefore be defined, to an extent, by what it lacks (Cristofovici, 1999: 269), once again reinforcing a narrative of decline (Gullette, 2004). Some of the other performers are slightly closer in age than Vercoe or Berry are to the aged subjects: Lalevich and Denkha, for example. But there is still a sizeable gap between their ages (early 50s) and that of many of the characters they play (70s and 80s).

Of course, the actors in this production also have to play younger characters, which is a justification for the casting; further, all stage representation is a form of pretence wherein actors pass for others of a different class, sexuality or gender and so on (Moore, 2014: 10). However, the unveiling of the able and much younger body underscores specific issues to do with disability representation unveiling the ideology of ability underlying this aesthetic endeavour. At its simplest "[t]he ideology of ability is the preference for able-bodiedness" (Siebers, 2008: 8); at its most extreme, it is those standards by which what it is to be human is determined, exclusionary standards affecting judgements about and definitions of human beings, including our aesthetic judgements and ethical systems, and denying that status to some people. These standards could also create fear of disability, describing it as what has been escaped in the past and what can be overcome in the future, or what is to be feared in the future in the case of ageing and dementia. Disability disturbs and challenges the ideology of ability, as well as offering a critical framework to critique it (Siebers, 2008).

This ideology of ability underlies many assumptions in mainstream and/or professional dramatic theatre practice by both producing and re-producing ideas about which bodies are allowed to stand in the spotlight and which not, especially as protagonists or heroes. Professional acting methods and techniques are an example. Disability and performance researcher Dave Calvert proposes that training towards "'Shakespearian clarity'" conceals the hegemonic values of ability (2009: 77) running theatre endeavours. Rehearsals for productions are expected

to start on time and to be attended; "performance paradigms of stamina and punctuality … shape the work" (Kuppers, 2011: 123). The end product is always a performance that can be repeated with assured regularity over the season. Many of these attributes cannot be met by people with disabilities; the attributes are assumptions mired in the ideology of ability.

I am not suggesting that people without disabilities should never play disabled characters despite the cries of 'cripping up' from some parts of the disability sector. These are complex issues to discuss and, as they are not the primary concern of this thesis, I will not discuss them further. I want however to state that any theatre projects which use disability stories must consider whether or not the aesthetic frameworks in which they are told are mired in an ideology of ability or not. Public theatre representing the bodies and the stories of the disabled and/ or ageing body needs to take seriously what its subject matter provokes. I argue that this involves a radical reframing and reconceptualising of many of the underpinnings, not only of traditional, but also of postdramatic and physical theatres. This radical reframing involves taking up and exploring the challenges that disability throws to theatre. Irish disabled playwright Kaite O'Reilly puts it well when she asks these important questions about what makes up disability dramaturgies: "Is it in the aesthetic, the narratives, the form, the bodies of the performers? I personally believe it is all of these" (2009: 32).

'It' also involves the complicity of those able-bodied audience members who may be challenged by the dethroning of conventions and traditions with which they are comfortable, like acting mastery skills. And yet, with *MBDJ*, my sense is that members of a purportedly traditional audience, although perhaps challenged in some of their views about older adults living with a diagnosis of dementia and other disabilities of ageing, and ideas about their incapacitation, may also have been intuitively aware that something was fundamentally not right in the theatre piece they saw, and with good reason. When disabled bodies are absent in representations about them, in this instance, older adults living with senile dementia and other disabilities of ageing, then disrobing will only reveal the usual cultural script of strength, power and perfect, or near-perfect, bodies. Dementia

reverses this script. The absence of these bodies in *MBDJ* speaks to general questions about disability, representation and the politics of the appearance or erasure of disability on any public stage (Rancière, 2004).

But the politics of appearance is also about the manner in which disability is framed in various representational and aesthetic systems, and in various communities and contexts. As Joe Kelleher maintains, the politics of appearance is:

> the very activities of showing and saying through which some are made visible who would otherwise have 'no business' being seen and others get to speak, who would not in 'normal' circumstances, count as speaking beings (Kelleher, 2009: 68).

In conclusion, in *MBDJ*, despite the issues just tracked, the vulnerable do get to 'speak' (if not show themselves) through the use of an imaginatively reworked verbatim technique which lovingly brings to the stage the words and stories of elders often invisible to the world once confined to the care home. *MBDJ* disrupts the 'right kind' of ageing and dementia story by refusing to tell a "tightly told traged[y]" (Basting, 2009:40) of dementia and by refusing to further sentimentalise this tragedy through restricting it to the tale of one person. Instead, *MBDJ* presents a carnivalesque enactment of the various ways in which the deeply forgetful oldest old (of various classes, genders and ethnicities) re-shape their lives in a new 'home'. It also disrupts the 'right kind' of story by revealing the material framing of ageing and dementia, moving beyond the well-worn trope of the oppressive nursing home where staff rule over and abuse older adults because of weaknesses in their personalities, instead engaging the broader political and material contexts of the care home without resorting to stereotypes. *MBDJ* also contributes to framing the performativity of age and dementia by questioning cultural norms posturing as biological facts. *MBDJ* also refuses the 'right kind' of story through its use of a postdramatic aesthetic. But to what extent this aesthetic changes the story of ageing and dementia in the minds of its audiences cannot be known with certainty. In the next chapter, I analyse another Australian verbatim theatre production, *Sundowner,* which tells the 'right kind' of dementia story, in contrast to *MBDJ*, which on the whole, does not.

Chapter 3

Sundowner, KAGE

At the heart of this chapter is *Sundowner*, a production from KAGE Dance Theatre Company (based in Victoria, Australia).[97] *Sundowner* [98] presents a day in the life of Peggy (Helen Morse) and her family (her daughter, son-in-law, son and grandson played by Michelle Heaven, Gerard van Dyck and Stuart Christie respectively; the child actor who plays Spike, the grandson, is not named in the program). There are also the Tivoli Lovelies, a tap-dance ensemble from Victoria composed of five older women who danced at a Melbourne venue known as The Tivoli when they were younger. In her late 50s or early to mid 60s, Peggy has early onset or younger onset dementia:

> The term younger onset dementia is usually used to describe any form of dementia diagnosed in people under the age of 65. Dementia has been diagnosed in people in their 50s, 40s and even in their 30s.Dementia in younger people is much less common than dementia occurring after the age of 65. For this reason it can be difficult and timely to diagnose, but the latest figures show that younger onset dementia affects approximately 16,000 Australians (Alzheimer's Australia, 2013).

Much of the real time of the production explores Peggy's world of dementia, with its jumble of reality and memory, and the effects of this on her daughter in particular. But its main focus is Sundowner Syndrome (as is apparent from its title), an increasingly well-known and well-documented part of living with dementia. Sundowner Syndrome can be summarised as a condition of restlessness and confusion known to afflict people living with a dementia diagnosis in the early

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[97] References to the production in this chapter are to the DVD of the show, which I purchased from KAGE. I also saw the show live in Brisbane, Australia, on Wednesday 17 April 2013 at the QUT Gardens Theatre, but it is not to this performance I refer in this chapter, except in the section titled 'Seeing Sundowner.'

[98] *Sundowner* premiered at the Castlemaine State Festival, Victoria, on 1st April 2011 finishing its run on 3rd April. On 27th February 2012 it ran for one night only at the Festival Centre Playhouse Adelaide, South Australia, as part of the Australian Performing Arts Market 2012. It then moved back to its home state of Victoria. From the 19th until 21st April 2012 it played at GPAC, the Geelong Performing Arts Centre, Geelong, Victoria. Then, from the 8th to the 1st May, it was at the Fairfax Studio, in the Arts Centre, Melbourne. In 2013, it toured many cities and towns of the eastern states including New South Wales (NSW). Sydney venues were Riverside Parramatta and Glen Street Theatre, Belrose; rural areas included Orange, Bathurst, Cessnock and Wagga Wagga. It also went to Western Australia and back to South Australia, as well as Tasmania and Queensland (KAGE, 2013b).

evening. It affects only 20 per cent of the diagnosed population. Medical science has no surety about its causes, and publicity for *Sundowner* made good use of this by theorising its "mysteries", as well as those of memory. In their online description of *Sundowner*, KAGE write that:

> Despite the explorations of poets, novelists, scientists and philosophers, the realm of memory remains a great *mystery*. And Sundowner's Syndrome remains an unanswered question. Why is it that just as the sun goes down, so many of those with Alzheimer's become particularly disorientated and confused? KAGE, in partnership with Alzheimer's Australia, invites you into this *mystery* (KAGE, 2013c; my italics).

In this chapter, I unpack the taken-for -granted patterns of image, text and affect structured into this specific representation of early onset dementia and gauge the appropriateness of this patterning. Key areas examined are the uses to which its verbatim input has been manipulated, and to what effect, including the dissonance between what I see as *Sundowner's* postdramatic appearance but solidly modernist dramatic aesthetic, as well as the ways in which a conventional 'storying' of dementia is repeated. In other words, following Christopher Balme (2008: 166), my analytic interests lie mainly in the ideological function of this production rather than in any structural analysis.

I argue that *Sundowner* does tell the 'right kind' of dementia story, an argument partly articulated through an examination of the ways in which *Sundowner* deliberately sets itself up as a tragedy, tells a private story about dementia which stands in for a universal story, proposes that love and family are the answers, relies on the trope of memory as the main carrier of identity for people living with a dementia diagnosis, and stereotypes age (and gender) across generations. My argument also rests on a comparison of the differences between *Sundowner* and *MBDJ*, as this comparison yields valuable insights into the ethico-political and socio-economic elements which may run an aesthetic endeavour like a theatre show whose subject matter is dementia and ageing. This comparison exposes who the people are behind *Sundowner*: in other words, who is served by, who is involved with and who is positioned by this performed narrative (or not), which is an important part of the charter of my thesis.

I begin this chapter with a brief overview of these ideas. This is followed by a short survey of dance theatre and its parameters, in order to contextualise what I regard

as the *minor* artistic vehicle through which this particular verbatim constructed story is partly told, that is dance, and to lay out what my approach will be, because the grammar of dance is not familiar to me. I then move onto an analysis of the production, which is followed by my argument that *Sundowner* is a modern drama in postdramatic clothes, as well as tracing what this implies. After that, I discuss the issues I have with the KAGE company manifesto in relation to dementia, and then I examine its problematic sponsorship. I finish by putting both *Sundowner* and *MBDJ* in conversation.

The people behind the story

My focus on exposing the people behind the story has been partly inspired by theatre scholar Nicholas Ridout's (2006) arguments about the importance of the wider social and political meanings of the modern theatre as determined through the spectator/actor interface.[99] Theatre scholar Alan Read's interest in "the slower, but harder politics of performance" (2007: 272) has also encouraged this tack. Taking Ridout's (2006) focus on audiences and actors further out to the economic and political machinations which affect how a theatre piece 'travels', or not, as the case may be, I argue that political and economic interests influence what particular stories are told to us on stage; they also affect what bodies are seen with regularity, as well as what particular voices, languages and gestures we are privy to (Kelleher, 2009: 42), all in large part creating the 'reality' of reality theatre. In essence, I suggest that *Sundowner* has been a much more successful production than *MBDJ*, in terms of its spread and its longevity, because it tells the 'right kind' of dementia story in part due to the people behind the story: its sponsors.

The broader context of its funding will be the very lifeblood of any production. Without financial support, most public theatre productions would neither be mounted nor toured. Theatre (especially a show with 10 performers in it as *Sundowner* has) is an expensive art form in this day and age; and touring a

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[99] Ridout argues that there are moments of strong intersubjectivity in the theatre, which he terms its "moments of undoing" (2006: 34), like an audience clapping at the end of a play. In these moments audiences may become conscious of the dissonance between the production as their unwaged leisure and the waged labour of the actors; a dissonance that unsettles the audience, producing shame, embarrassment and fear.

production makes it even more so, particularly in a country the size of Australia. Alzheimer's Australia (AA), Performing Lines and Domain Principal Group, an offshoot company of AMP Capital Investors rebranded as Opal Aged Care[100] since mid 2014, as well as grants from several other private philanthropic groups, largely funded *Sundowner.*[101] I propose that the AA and Domain Principal Group patronage, in particular, is most likely one of the reasons why the story told in this production is the 'right kind'. I do not mean that this patronage would have exerted any explicit pressure for the story to be told in the way it is. However, the sponsorship, in concert with the strength of the master narratives circulating about dementia in the media and elsewhere are undoubtedly at least partly responsible for the resultant rather narrow, private and apolitical representational framing of younger onset dementia in this production. Nevertheless, although *Sundowner* tells a predictable story about dementia as a tragedy, there are redeeming features to be found: the acting and the dancing are of a high calibre and to be extolled; and some of its educative features are impressive, as is the process of its creation (gathering the words and stories of people living with a diagnosis of dementia, as well as their care partners).

"More than dance. Not quite theatre"

On its website, KAGE consistently refers to itself as a "dance theatre" company in preference to a physical theatre company. It adds:

> More than dance. Not quite theatre. Not circus, or poems, or dreams; but like these ... KAGE strikes out for new ground; innovating and reconceiving dance theatre to draw humour, humanity and pathos from the physicality of human bodies (KAGE, 2013a).

According to Christopher Balme (2008: 6), dance theatre is a recent term designating dance forms performed mostly in a theatrical context. Yet, as Balme notes, classical ballet, as well as modern and postmodern dance, are all forms of 'dance theatre', making it a term which not only stretches back to more orthodox

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[100] See DPS News, 2015.
[101] Some of these foundations include The Ian Potter Foundation, the Besen Family Foundation, the Helen Macpherson Smith Trust and the Thyne Reid Foundation. All these organisations are based in Victoria, and provide grants to support and benefit the community across a wide range of sectors and endeavours, including the arts. All have an interest in initiatives that promote positive social change.

practices but one which has also been extended more recently to include the experiments of physical theatre.[102] In Balme's (2008: 7) view, the term 'dance theatre' has arisen to fill the need for a descriptor to encompass the increasing number of forms which fall between drama and dance, but where the moving rather than the speaking body is dominant. Like music theatre, dance theatre shares many features with dramatic theatre (Balme, 2008:7), dealing with a highly complex object whose texts are quite elusive.

Importantly for my purposes here, Balme advises a way to approach the analysis of a work of dance depending on the dominant aesthetic code(s) employed by the choreographer and dancer(s) (2008:162). For example, character and action may dominate; they still feature as much in contemporary dance as in drama and opera. Or there might be a dominance of formal proxemics, citationality and corporeal codes, as is the case in much postmodern dance where the works tend to be self-referential. Balme cautions that, if appropriate, elements, such as movement and dance styles (whether neoclassical, modern or postmodern), figure and story, scenography and costume, should all be taken into account in any analysis of dance. If the choreography is completely new, he advises that the critical approach must be "largely intrinsic" (2008: 163) and it should also incorporate other works by the choreographer or reference other treatments of the same subject matter.

On the whole my analysis in this chapter will not detail choreographic moves and their meaning. Taking Balme's advice in reference to new choreography, I partially look to the way *MBDJ* deals with similar subject matter, even though it is theatre as opposed to dance theatre. This is primarily because the disciplinary location and interests of this thesis do not reside in dance studies but in theatre and performance, specifically in reality theatre and performance. Nevertheless, and as stated earlier, precisely because of the ideological interests I wish to pursue in this chapter, I also acknowledge, following dance studies theorist Susan Leigh Foster writing about empathic connections between dancers and spectators, that many of "the epistemological dilemmas [that] lie at the center of dance studies … have

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[102] Before 1900, dance theatre usually meant ballet alone, which was integrated into opera. With the innovations of the modern dance including Ballet Russes and their experimental integration of visual art, or Martha Graham's styles, "dance has been regarded as an innovative theatrical genre, often more in touch with avant-garde trends than other forms of theatre" (Balme, 2008: 161).

equal relevance for theater and performance studies" (2007: 245). I am aware that dance foregrounds the body and that the body does work, that is, it 'speaks to' or affects other bodies, as so much recent work on theatre and cognition has demonstrated (McConachie and Hart, 2006). However, drawing on Foster (2007: 245), I am also mindful that in Western "concert dance traditions" there is an assumption that the viewing body can and does always sense what the performing body is feeling. This assumption takes for granted some kind of "empathic connection" between bodies "founded in a universal capacity of humans to register the dramatic tension of the motion" (Foster, 2007: 245). With the postmodern troubling of these a-historical and universal assumptions through the work of feminist, gender, sexuality and disability studies, it is critical to highlight that a company like KAGE, which prides itself on "striking out for new ground" (KAGE, 2013a), is very firmly grounded in an eighteenth-century enlightenment tradition of the human, as I will shortly demonstrate through an analysis of its *About Us* page (KAGE, 2013a) and of the epistemology that drives its productions.

Another reason why my analysis does not detail choreographic moves is that in this production it is difficult to identify whether the moving body or the speaking body dominates (not that the speaking body does not move nor the moving body 'speak' in this production, or in life). However, writing from a theatre and performance studies perspective, the movement appears as an adjunct to the speaking, with the dance vignettes interweaving with Peggy's monologues and her dialogue with the other characters, and not the other way around. But my 'subjective' take on the dominance of the speaking body is also supported by a more 'objective' observation that the production, although about the important role that family plays in our lives and in the onset of dementia, has its focus on the story of one woman, and that woman in this production is a well-known Australian actor (Helen Morse) and not a dancer. I hold that this focus on one woman's story positions it as a modern drama despite the dancing and despite the fact that it is a reality piece devised and adapted from community stories and words. Its verbatim roots were well advertised, forming part of its A-effects (Garde and Mumford, 2013: 152). I will return to the ramifications of these matters after I first analyse the production.

Sundowner, the production

Directed by Kate Denborough and written from community verbatim input by her brother David, *Sundowner* is a work built from both the human voice (text) and the human body (dance and movement). In it, danced vignettes from KAGE Company members are interspersed with monologues from Peggy and her grandson. There is also some dialogue between Peggy and her daughter. The dance sequences sometimes allude to the tension and confusion that Peggy is experiencing when Sundowner's takes hold, but they are more often memories: of Peggy's children when they were young and of her romance with her former husband or lover (Stuart Christie or Craig Barry). Whether or not the husband is dead or Peggy and he are now divorced is not made clear in what KAGE states is a feature of contemporary dance, also known as modern, postmodern or experimental dance. In their 'Teacher's Notes' publication, KAGE maintain that contemporary dance addresses "contemporary cultural themes, often in a global context, and is deliberately open to audience interpretation and interaction" (KAGE and Performing Lines, 2012: 27).

Yet little else is open to interpretation in the production, as I will now demonstrate, beginning with the set design, which, as with *MBDJ*, strongly associates the space with the fictional world created rather than disengaging from it. This association together with the choice of a living room/study as the mise-en-scène indicate that, despite its leveraging of the liminal worlds of dementia through the presentation of surreal dream/memory-scapes situated between the past and the present, and fact and fantasy, this production adheres to a mainstream rather than a postdramatic aesthetic to tell a predictable story of the tragedy of dementia.

The stage is a box set: a combined living room and study with wallpaper, all rather old-fashioned in design. All the furnishings suggest the past, in line with the production's theme that memory is the one of the most important parts of being human, that is, a carrier of identity, and even more so for people living with a dementia diagnosis. This is the territory of the 'right kind' of dementia story. There is an older-style desk downstage right, messily furnished with papers and books, as well as a framed photo that Peggy and her daughter both pick up and look at during the performance, but to which the audience is never privy. There is a mirror

over the desk and in one scene Peggy has a conversation with her reflection in it. According to Helen Morse, this scene came directly out of a story gathered from the community forum. One of the carers said that his father, while shaving in the mirror, thought that his reflection was a 75 year old he didn't know. As he thought he was 35, he had a conversation with the older person in the mirror (KAGE and Performing Lines, 2012: 10).

Upstage right is a bookshelf, which contains a TV set, and at one stage of the performance, Peggy switches it on to watch *The Book Club*, hosted by Jennifer Byrne, with whom she has an animated conversation.[103] Byrne calls Peggy by name at one stage. At the back of the set is a window with curtains: when parted they reveal a raised stage where some of the dance scenes take place. Stage left, runs a bookshelf stacked with books, in front of which, downstage left, is a green *chaise longue*. There is also a wall of framed portraits, most likely meant to be Peggy's family members, styled early to middle twentieth century, lending another old-fashioned touch to the design, along with the two doors for side entrances and exits, one of which is partly made of stained glass. The middle part of the stage is empty, cavernous, leaving physical space for some of the dance routines to be performed with numerous bodies (up to 10 at one time). For me, this domination of empty space suggests the cavernous and empty spaces left by dementia in Peggy's mind, thereby perpetuating another tired narrative about dementia, even if there is some truth to it.

The set is realistically furnished in dour colours. Brightness and light are also missing in the lighting choices, which are consonant with the light of the evening and its metaphorical association with the evening of life (Peggy is most likely aged in her late 50s or early to mid 60s). Evening is also character consistent, as Peggy mentions in her letter to her family that it is her favourite time of the day, making her Sundowning episodes, which most people experience in the evening, all the more 'tragic' as they undermine her enjoyment of this time period.

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[103] *The Book Club* previously *First Tuesday Book Club* is televised nationally by the Australian Broadcasting Commission (ABC) once a month. Hosted by Jennifer Byrne (a well-known Australian journalist) with regular panelists Marieke Hardy and Jason Steger, and guest writers, each episode usually covers one new release book and one classic (*The Book Club*, 2015).

Please Credit : Photo Jeff Busby

Figure 4: Peggy (Helen Morse) at her desk in KAGE's *Sundowner*. Photograph by Jeff Busby used with permission from Simone Schinkel, KAGE.

The audience first sees Peggy dressed in a pink and purple patterned kimono (see figure 4). She has her slippers on. The play spans a period of 24 hours, adhering to Aristotle's (1967) unity of time principle in relation to tragedy (in the *Poetics*). Seeing Peggy in her kimono is a design signal that she has just woken up. But it is not just the kimono that functions as a sign. The aria playing as Peggy explores her living room in an obviously confused state is '*Un bel di vedremo*', 'One beautiful day, we will see', the well-known aria from Puccini's *Madama Butterfly*, the tragic story of Butterfly (Ciccio-San), a young Japanese girl who is abandoned by Pinkerton, an American naval officer, and as a result, commits suicide. Both the initial costuming of the lead character in a kimono and the choice of music, with links to a Japanese opera character, underscore that a tragedy is about to unfold. To back up my argument that these costuming and musical choices are part of a clear directorial intention, I refer to 'Memory Play' (*Artscape*, 2011), a documentary about the making of *Sundowner*, in which the director Kate Denborough remarks that the play does not have "a happy ending".

As the play progresses, Peggy changes into a muddy-brown print frock and wears a tawny-coloured cardigan. Interestingly, in 'Memory Play', the cardigan in which Morse rehearses is red. However, red could not be the costume choice for a production wanting to spell out that it is the evening of Peggy's life (and create a thematic link to evening). A disruption to the discursive real is not an option in the 'right kind' of dementia story.

Another interesting costume choice is red for the young woman in the 'Putting on the Ritz' dance segment. Red is often associated with passion and life. Peggy first watches this dance sequence, and then joins in, so the sequence could be a memory of hers, a desire or an episode of her writer's imagination. Whatever it is, the fact that the young woman wears red and Peggy brown is clearly a 'normative age-and-dementia-effect'.

The piece opens, and also ends with, a voiceover from Peggy's grandson,[104] who speaks with a lisp, turning the 'r' phonemes in words into 'w' so that he says 'gwan' instead of 'gran', 'wemembers' in place of 'remembers' and 'witer' not 'writer'. If this type of twee vocal technique is meant to promote an emotional response in audience members ('how cute!'), in my case, this cute child's voiceover did the reverse: it irritated me. I saw it as the use of another "normative age-effect" (Moore, 2014: 2). In the voiceover, the audience hears how much this child loves and appreciates his 'gwan', and at the same time we see her alone in the big empty stage space (her lounge/dining room). This conflation of the voiceover with the cavernous stage space where we first see Morse produces a certain 'atmosphere' or feeling early in the play, along with the choice of the aria and the lighting, or lack of it.

According to theatre studies scholar Erin Hurley, drawing on the work of feminist sociologist Arlie Hochschild in *The Managed Heart: Commercialization of Human Feeling* (2003), theatre does important work in regard to the "making, managing, and moving [of] feeling in all its types … in a publicly observable display that is sold to an audience for a wage" (Hurley, 2010: 9). Hurley has coined the term

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[104] The child, when he appears on stage with his gran at the end of the play, is probably about three or four years old.

"feeling labours" to express this work. Hurley cites a whole raft of machinery and effects:

> to display, create, and incite feeling … most obviously actors train to conjure convincing emotions on the stage … Lighting designers create 'warm' and 'cool' stage washes, descriptors that indicate not only the lighting's colour palette but also its emotional resonance. Sound designers and theatrical musicians likewise strive to convey mood (2010: 8).

Understanding that theatre operates very frequently as a type of 'feeling technology' which manages and directs feelings in order to create certain responses in the audience, makes it difficult to accept the *Australian*[105] theatre reviewer Chris Boyd's seemingly very naïve statement about *Sundowner*: "[i]t succeeds in what it sets out to do: engage, affect, educate and entertain *without manipulation*" (2011; my italics). In *Sundowner*, mood and atmosphere are very strongly evoked through the manipulation of lighting, sound, music, costuming and proxemics. In this production, voiceovers are also a seminal part of this "feeling-labour" (Hurley, 2010: 9).

The first voiceover is also a technique through which certain key facts about Peggy can be quickly established: that Peggy is a writer; that she is middle-class and appreciates high culture (her love of books and music and theatre, for example); and that she is different. This difference is her dementia. Audiences would already know this, although it is not spelled out in the voiceover because of the marketing and promotion of the piece through AA and also because of the title. Peggy's 'difference', as articulated through her grandchild's voiceover, though not directly given a name, is given suggestions for management in the same voiceover: don't ask questions because they make her confused; don't tell her that she is repeating herself because she will get sad; and don't contradict her version of reality as it doesn't really matter if it is not true.

All of these suggestions are good ones for dealing with the deeply forgetful. *Sundowner* also educates about dementia in less obvious ways. For instance, Peggy can still do cryptic crosswords and at several points in the play she solves some very tricky clues. One of these is the clue 'amphibian sport': the answer, which she gets, is 'leapfrog'. This touch helps the audience to understand that the

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[105] *The Australian* is a national newspaper.

loss of faculties in dementia is not total, although Peggy resumes the crossword several times during the production and always gets this clue right so the point might be that she is relying on her long-term memory in doing the crossword and that her short-term memory is not functioning because she forgets she has already got this clue. Another example of how *Sundowner* educates is the way Peggy exhibits many of the mannerisms of dementia processing 'disorders' — she puts on her cardigan back to front; when she can't work out how to tie her shoelaces, she cuts them off as she stands in her shoes. These suggestions, both explicit and implicit, reveal the educative mission of the piece with its focus on dementia as memory loss and strategies for how families can cope with this.

Memory is a seminal focus of *Sundowner*. The play is centred on Peggy's attempts to write her children a letter. The letter is used throughout the show as a unifying device amidst all the independent vignettes of which the piece is constructed, as Peggy writes it or speaks sections of it into a tape recorder. Towards the end of the piece, Peggy speaks out the letter in its entirety. Its substance is Peggy's experience of her loss of memory and the description of the usual process of the earlier stages of dementia in which newer memories tend to be erased. It is worthwhile citing in full because of the way it links the value of the person living with a diagnosis of dementia with who they were in the past rather than who they are now. In other words, memory is lauded as a carrier of identity:

> My dear ones,
>
> It's the strangest thing. No longer being able to tell what is the past and what is the present. It seems that events that took place only minutes ago are now being erased while memories I have been able to hold at bay for decades suddenly come rushing towards me.
>
> No doubt it is only going to get worse. At times now, I am no longer able to tell what is familiar and what is foreign. And that is why I am writing to you today. When it comes to pass that I can no longer hold the memory of who I used to be, will you hold it for me?
>
> I don't want this to be a burden, but if you could remember me perhaps just once a day in the evening light ... that's always been my favourite time. Hold my memory in the evening light my darlings. I don't mean any old, dusty memory of me. I don't mean a time when I was crabby or tired — let others remember those times, or better yet, let them slide into oblivion. No, I'd like you to remember something particular, something luminous.

I guess you should have some say in it, but if I get to choose, how about you remember that day we spent at Rosebud? It was hot that day. Our feet had to skip across the sand to avoid being scorched. And we plunged into the sea together. The others were laughing at us, with us. I recall. We'd all been through so much that summer and somehow we'd found our way through together. Yes, remember me then, if you would.

I wish I could promise to always remember you, but that's a promise I can no longer make. I have loved you the very best that I could for all the years that have been.

Your devoted mother

PS. There is just one more thing, while I remember! When you are with child, please treasure the memories you make together ... that child of yours will live with those memories for a lifetime.

PPS. Why is there always a PPS from me? Why do I always have one more thing to say? I'm starting to come round to the name Spike (KAGE and Performing Lines, 2012: 23).

At the heart of the letter is Peggy's plea to her family 'to hold her memory': "when I can no longer hold the memory of who I used to be, will you hold it for me?" Peggy's plea is one of the many ways *Sundowner* educates audiences about the role family can play in placing and settling someone with dementia within a complex web of the co-creation of self and others through acts of remembering and community stories. But that is only part of the way dementia and its inhabitants can be storied; it is the preferred idea of Alzheimer Associations around the world and it keeps meaning making around the experiences of people with dementia tied to the past and to who they were, which as I have argued in earlier chapters, is a hegemonic notion that is constantly reinforced in dementia. It is also a 'normative age-and-dementia-effect'. Age studies scholar Margaret Morganroth Gullette's caution in regards to the tie between age and reminiscence has value for dementia as well: "[i]t's not just the elderly who reminisce, and even happy people have memories of their earlier life forms" (2004: 149).

Before I turn to an examination of the closing scene of *Sundowner*, I will comment on the use of the Tivoli Lovelies in this production. Early on in the piece, they do a dance sequence ('Putting on the Ritz') and Peggy joins in (see figure 5).

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Please Credit : Photo Jeff Busby

Figure 5: Peggy (Helen Morse) and the Tivoli Lovelies in KAGE's *Sundowner.* Photograph by Jeff Busby used with permission from Simone Schinkel, KAGE.

The function of the Tivoli Lovelies in the production is not well defined, doubtless purposefully. They could either: represent memories of Peggy's; be part of Peggy's imagination; or represent an age-old desire of hers to be a performer. Or their function could be, as one 'astute' reviewer (Boston Smith, 2012) notes, to remind the viewers of "[t]he juxtaposition of their ability compared to the mother's inability" (KAGE and Performing Lines, 2012: 12), a comment which I found to be of the worst kind of ableist discourse. (Ableism is a form of discrimination against people with disabilities which views disability as a failing, rather than as an exemplar of human diversity.) Yet this review was the one chosen from many reviews of the show to be part of the *Teacher's Notes* (KAGE and Performing Lines, 2012), and KAGE was no doubt involved with approving what material went in and what stayed out of this compendium.

In addition, in the section 'About Sundowner', the writer (unnamed) states that "the warmth and tenderness of these women provides consolation and compassion and an affirmation of life and all its cycles" (KAGE and Performing Lines, 2012: 6),

which both age and gender stereotypes these women, as well as excluding those living with early onset dementia from the concept of life and all its cycles (because they are 'the living dead'?). The message is that there is nothing affirming about people living with a diagnosis of dementia. And this is despite a sentence in the next paragraph in the following section of the *Teacher's Notes* entitled 'What's the production about?': "KAGE wishes to confront the stigma attached to the disease and to reveal the life affirming moments in these experiences" (KAGE and Performing Lines, 2012: 6).

These very 'able' women return in the penultimate scene of the show and Peggy dons one of their sparkling black showgirl outfits. This move could mean that she has finally entered a world of total confabulation; or it could be that they represent much older women, likely grandmothers (they are all mostly silver haired), and that when she puts on one of their dresses we are to understand that she has become a grandmother herself, as soon after this there is the final scene with her and her grandson Spike in a garden. For most of the real time of the production Spike has not yet been born.

The final scene of the play is troubling. With the grandson's last voiceover, the back area of the stage opens up to reveal Peggy, dressed in her Tivoli Lovelies sparkling black evening dress, sitting in a garden with her grandson Spike. Given the intimacy of the piece and its location in a domestic space for the majority of the time, I at first assumed that this scene was concerned to show that the loss and grief which dementia brings with it can be mitigated by love and connection. In essence 'all you need is love' in relating to people with dementia.

Love can play a vital part in changing, for the better, the daily interactions that are possible between people living with a diagnosis of dementia and their family and care partners. Love may allow us to enter 'Alzheimer's World' as Bob DeMarco attests in his online blog and newsletter, through choosing to understand and be patient with what is happening for those living with a diagnosis of dementia. Bob DeMarco (2012) set up the 'Alzheimer's Reading Room' when his mother Dotty was diagnosed with Alzheimer's. He writes on changing the way people with dementia are viewed through the insights he gained in caring for his mother. This change he expresses as 'Alzheimer's World'. Love, as Israeli psychotherapist

Hedy Schleifer (2010) points out in a TEDx presentation using a trope of passage, can help us to cross the bridge from our own world to the world of the person with a dementia diagnosis. Both DeMarco and Schleifer reported positive changes in their parents when they moved on from their ideas of how their parents used to be and should be, and tried to connect to their realities now. In Schleifer's case, it resulted in her mother recognising her as her daughter, which she hadn't done for months. Drawing partly on Levinas and Derrida, philosopher Kelly Oliver argues that it is love that will help us to be ethically and socially responsible to those others on whom we, in turn, depend for our sustenance (2001: 19-20).

However, as some cultural studies scholars have argued, emotion is not a politics-free zone: the everyday is also a political realm (Lutz and Abu-Lughod, 1990; Ahmed, 2004). Love, in particular, is not a free-floating signifier but it is tied to relations of power. For example, in Western societies, in traditional Christian marriage ceremonies, women may still promise to 'love, honour and *obey*' their male partner, thereby reinforcing strict gender ideologies of female submission. 'Love' is not a neutral term. It constitutes a set of practices and cultural negotiations that continue to impact narrative meaning making in public representational technologies like theatre. Similar theorisations can be made about the family, another entity upon which *Sundowner* leans heavily in terms of solutions.

Turning to the final scene in the garden once again, on reflection, the garden could be in a nursing home, which is perhaps even more concerning, as the scene painted is quiet, full of light and green and somehow fertile, vividly contrasting with the enclosed gloom of Peggy's lounge-room where the rest of the performance has been played out. If the garden is supposed to reference a care facility, I note how much it sits in scenic contrast to the *MBDJ* set, which had a cold green floor reminiscent of linoleum and harsh lighting capturing much more realistically the reality of the institutions where so many people living with a dementia diagnosis spend their last days. It would be interesting if this last scene were supposed to suggest the garden in a facility, as one of the principal sponsors of *Sundowner* was Domain Principal Group, as I have already noted. Their financial backing most likely impacted the tenor of the piece, as did the involvement of AA. I will consider

these issues in more detail in the final section of this chapter, but for now wish to turn to the issues engendered by *Sundowner's* faithfulness to a modernist dramatic mode despite its postmodernist appearance and flourishes.

Sundowner as a modern drama

In their *Teacher's Notes*, KAGE state that contemporary dance forms (also known as modern, postmodern or experimental dance) address global cultural themes, "reference other cultural forms, especially with visual and contemporary arts, theatre, film, music and lighting" and are open to audience interpretation and interface (KAGE and Performing Lines, 2012: 27). In alignment with this description, *Sundowner* focuses on dementia, a present-day cultural theme globally; it obfuscates some of the details of the main character's story (like whether or not Peggy's husband died or they separated) and refuses closure in the final scene; and it deploys many non-linear elements in the storytelling (like the interweaving of memory and reality in some of the scenes). Furthermore, it references other cultural forms: the music, ranges from opera (Puccini's *Madama Butterfly*), to pop (Australian singer Megan Washington's 'It Wasn't Night or Day' as the closing song); and the dance forms extend from contemporary to tap. In terms of theatrical styles, *Sundowner* ranges from realism or naturalism to abstraction, employing everyday monologue and dialogue to create character and story, as well as movement and non-verbal noises to express hallucinatory states. Many of the above features can also be said to be consistent with the postdramatic. But I argue that *Sundowner* is first and foremost a modern drama, and not postdramatic or postmodern, as its dance styles and its fractured scenes would indicate.

A common marker of many a 'modern' drama is the use of the story of 'one' person to display those unmarked, taken-for-granted signifiers underlying the conception of 'the universal' in dominant Western culture: among these signifiers are an able and often young body, a white race, a male gender, a heterosexual orientation and a middle-class standing. I use the term 'modern' with the understanding that the range of modern and modernist work in the theatre covers a vast range of practices. As opposed to other areas like literature, architecture,

dance and visual art, the terms 'modern' and 'modernist' do not have homogenous meanings in theatre and performance, and are instead strongly contested. And yet, one of the modern drama notions most disrupted in postdramatic theatres, is the notion of character, along with the idea of representation itself, leaving a theatre that is ultimately about itself (Fuchs, 1996).

Sundowner bears some of the above-mentioned hallmarks of a modern mainstream drama, essentially because of its reliance on a central character (Peggy) and her story. In talking about the play, in the documentary 'Memory Play', the cast, the director (Kate Denborough) and the writer (David Denborough) all stress that its central theme is the impact of AD on a family. The *Teacher's Notes* also state that "*Sundowner* tells the story of so many Australian families and the frustrations they face dealing with early onset dementia" (KAGE and Performing Lines, 2012: 6). Though I agree that this production is definitely skewed towards reinforcing the story of the horrors and losses of dementia and thereby creating empathy for care partners in particular, I also argue that in fact it is primarily Peggy's story, which of course, because lives are relational and stories too, does impact others close to her.

I argue this for several reasons. Firstly, there is the amount of time Peggy spends on stage compared to the other characters: she is on stage for the whole 80 minutes of the show. Secondly, she is played by a well-known actor whom audiences would come to see, so her story would be given more time (the dancers are not celebrities). Thirdly, the title of the production focuses on Sundowning behaviour, an episode of which forms the climax of the show.

To an extent, and reliant upon the understanding of the character of modern drama outlined above, I argue that in this production the character of Peggy is asked to represent the experience of all human beings living with early onset dementia. Peggy is white, middle-class and Australian; she is also heterosexual, living in her own home and a published writer. As Peggy is a female, it could be argued that this changes the characterisation of 'the universal', slightly diverting it from the normative signifiers I outlined earlier. She is not able or young which is also another departure. That she is a writer is interesting given that tragic falls from a great height are a favoured dementia narrative and one traced so tellingly in *Iris*

(2001), the film about the renowned writer Iris Murdoch. The onset of dementia for a writer seems particularly cruel as it strips memory, cognition and language, all essential tools for any writer.

As I have already stated, the production showcases a number of theatrical styles. Yet despite the postdramatic inflexions provided by non-realistic dream and memory sequences, an episodic structure and the use of multimedia, *Sundowner* basically presents a teleological narrative pattern operating within a single perceptual frame (Lehmann, 2006); it does not present the kind of multiple framing characteristic of a postdramatic aesthetic (Balme, 2008: 126). It follows, to some extent, a typical narrative pattern in telling the story of one woman and her encounter with Sundowner's. Although it also tells the story of one family (of which Peggy is the mother and grandmother), this still positions it within a single perceptual frame.

In their work on narrative structures, linguists William Labov and Joshua Waletzky (1967) outline a typical narrative structure as abstract, orientation, complicating event, resolution, evaluation and coda. The abstract condenses the whole story. The orientation gives information about the time, place, characters and their activity. Complicating events contain the climax. The resolution informs the audience about how the complicating event was resolved. The evaluation forms the emotional side of the narrative and explains why the story is worth telling. Codas are positioned at the end of narratives and indicate that the story is over. *Sundowner* follows this patterning quite closely though not exactly because it is a performed narrative rather than one that is spoken or written. For this reason, the abstract is not included in the production, but there is an orientation (Spike's voiceover about his Gran's difference); a complicating event (a dramatic sundowning experience); a resolution offered through family love (and possible institutionalisation); and a coda, provided by Spike's final voiceover.

However, and paradoxically, this story of one woman and/or one family was built from many stories and KAGE is to be commended for the process through which it collected the stories and involved the community in the creation of the piece. Over an 18-month period between 2009 to 2011, a series of community forums brought together people with younger onset dementia, carers of those with dementia and

the creative team involved in the development of the show (including the performers, the writer and the director). Participants living with a diagnosis of dementia, as well as their families and carers, offered opinions and stories which fashioned both the philosophy and the direction of the show. Quite a few of the scenes in *Sundowner* were directly crafted from the stories, words and ideas shared within these community forums; so too were many of the characters and their relationships (KAGE and Alzheimer's Australia Vic, n.d: 2).

The resultant production may be termed 'verbatim' but not in any mimetically faithful sense. The company deploy the stories they heard in theatrically innovative ways, rather than just settling for replicating the exact words and stories told in the forums. Possibly as a result, some of the scenes are quite charming, not just tragic (for example, Peggy talking to herself in the mirror). No doubt the cardigan backwards and the shoelace cutting scene also came from the community forums. The sundowning episodes in contrast are tragic and frightening. Sundowning episodes do happen and are not pleasant, either for the person or for their care partners. But recent research has posited that apart from the fact that these episodes do seem to come on at dusk, and can involve delusions and aggressive behaviours, they can be mitigated by the responses of the care partners (Dementia Care Notes, 2015). That is, unrealistic expectations from care partners may add to the problem. But *Sundowner* does nothing towards offering any possibilities for Peggy and this situation. I will now turn to the company and some issues I have with their manifesto; after that I interrogate the performance that I saw in Brisbane in 2013.

KAGE *About Us*

KAGE Company, Victoria, is the original enterprise of Kate Denborough and Gerard Van Dyck who met while dance students at the Victorian College of the Arts in 1992. They launched KAGE in 1997, and have been working on dance theatre initiatives since then. On their website (KAGE, 2013a), they claim that KAGE "uses honesty and imagination to continually explore and redefine what dance can be"; they also assert that KAGE "strives to create work that's felt as often as it's explained." These 'felt' experiences include "the millions of gigantic-

yet-tiny, deeply felt, funny and ultimately connected moments that make up our lives — success, failure, awkwardness, panic, tears and reckless joy." KAGE's manifesto is "to render these, and other *human* things, physical"; and "to draw humour, and pathos from the physicality of *human* bodies" (my italics).

First and foremost, KAGE's manifesto underpins its commitment to using the aesthetic to craft feeling states. I do not have an argument with this, agreeing with disability theorist Tobin Siebers that "aesthetics is the science of discerning how some bodies make other bodies feel" (2010: 10). Aesthetics is an important conduit through which a re-formulation of the disabled body (and the brain/mind which is part of that corporeality) might be achieved. Along with theatre scholar Erin Hurley, I think "theatre's solicitation, management, and display of feelings — … its 'feeling-labour' — is the most important aspect of its cultural work. It is what finally makes theatre matter" (2010: 4).

But it is with the repeated use of the word 'human' (twice on this webpage and 'humanity' once) that I take issue. The human is not an unproblematised notion, as much recent, and not so recent, scholarship has made apparent. Hannah Arendt notes the "abstract nakedness" of the simply human (cited in Rae, 2009: 73). Writing in a post 9/11 context in *Precarious Life*, Judith Butler is also circumspect about the "common notion of the human" (2004: 31). In *Theatre & Human Rights* (2009), theatre scholar Paul Rae argues for a re-thinking of the anthropocentric underpinnings of Enlightenment humanism, that is, the notion of what it is to be human, in order to reconceive the future of human rights in less species-specific ways. He maintains that we, humans, may need to re-think our responsibilities to other creatures and species in the world as well as the environment in order to survive given the poverty, resource scarcity and ecocide of the twentieth century which are linked to human dignity in ways that require this reconceptualisation (2009: 73).

In critiquing what I regard to be an unproblematised reference to the human in KAGE's manifesto, I do not mean to entirely dismiss the usefulness of the notion, as it can delineate an ethical stratum through which our common vulnerabilities can be revealed to each other. Butler herself reaches this conclusion in *Precarious Life* though still suspicious of the ways in which the word 'human' has been used

to justify bloodshed in so-called humanitarian interventions in the world (2004: 31). While arguing for a re-formulation of the traditional foundations of human rights epistemologies to include other species and the environment, Paul Rae also argues for the category of the 'human' to be "defended against those who consider that some people are more human than others" (2009: 74).

But an alternative perspective may have some value here as well. Particular scholars argue that we are all 'post-human',[106] urging movement beyond the term 'human' altogether (Hayles, 1999; Halberstam and Livingston, 1995). Post-human (and postmodern) cultures have been accused of being "inhospitable environments for aging and the aged" (Basting, 1998: 19), offering "disembodied … fantasies of immortality" (Basting, 1998: 23). In disability studies, Tobin Siebers (2008) has accused post-structuralist thinkers like Judith Butler (1988, 1990, 1993, 2004) and Donna Haraway (1991) of presenting the body as "an ideological-textual product" and associating the pain the body endures with "transgressive jouissance" (cited in Berger, 2014:161). Siebers is an outstanding voice in disability studies, validating discussions of pain in a terrain where pain has been seen to undermine the autonomy that disability activism, firmly moored to disability studies, requires. Siebers' discussions of the "blunt, cruder realities" (2008:67) of the disabled body have been missing in disability studies in general given its preoccupation with celebrating rather than mourning, and praising independence over dependence. But when it comes to dementia, autonomy and rationality, which are the markers of human subjectivity in modernity, cannot be the sole criteria of

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[106] The post-human body has been depicted in popular culture as a body of the future in terms of a merging of biology with technology (Hayles, 1999 cited in Jones, 2012: 194). It has also been proposed as a kind of merging of one species with another — like the popular Spiderman who is half human and half spider. But it can also refer to the more quotidian-like effects on bodies working with technologies like gym equipment (enlarged muscles). Cyber theorist Katherine Hayles (1999 cited in Jones, 2012) argues that the usage of a computer (and Facebook or Twitter) implicates us all in the construction of the post-human. Categorising a majority of bodies as post-human allows us to begin to see how much the notion of 'normal' changes over time. For example, IVF babies are proliferating in the world now but when the technology was first introduced, the first baby was labelled a 'test-tube baby' in Time (1978) and there were huge ethical and moral debates about the kind of frightening world these interventions would be hatching. Donna Haraway's cyborg was one of the first post-human tropes to contest the ways in which all things considered natural, like man and woman, person and machine, the human and the human body, are in fact not natural but ideas, socially constructed and fulfilling hegemonic political purposes like the legitimisation of men's dominance over women, whites over blacks, and humans over animals. According to Haraway, it is through an active exploration of liminal spaces and a deployment of borders that an effective (feminist) politics can be mobilised.

subjecthood else people diagnosed with dementia will not be deemed subjects. Because of this I hold that there is some value in the 'post' rubric.

This value lies perhaps in its refusal to re-vivify 'the human', which contains within it traces of enlightenment philosophy and the imperialism which that justified, and still does, through the colonisation and repression of those deemed not human in the pursuit of these ideals. Examples include: the many races oppressed and colonised in the imperialist excursions of the English in the eighteenth and the nineteenth centuries; slave economies; and the imprisonment of the disabled and the mentally ill in the same centuries. The value of thinking beyond the limits of the term 'human' may lie in moving from a term which is loaded down with this historicity to one which has more movement in this particular period of post-modernity. Philosopher Rosi Braidotti asserts that "the very notion of the human is not only de-stabilised by technologically mediated social relations in a globally connected world but is also thrown open to contradictory redefinitions of what counts as human" (2006: 197).

The notion of the post-human may seem to be a stretch from the issues of those cognitively impaired with dementia and their representations, whether theatrical or not. However, I think it could have value as a useful concept for challenging the narratives of abjection so common to dementia and as an invocation to other possibilities. There are new social and biological forms emerging out of clinical practice with people with dementia at the same time as there are old forms being replayed. These new forms include the pharmaceutical, genomic and epidemiological as well as new forms of therapeutic practice that pay attention to personhood (Cohen, 2006: 2). The use of wheelchairs and Zimmer frames as well as the intervention of life support systems as death nears can be argued to be technological extensions that help to situate the person with dementia in the realm of the post-human. As medical anthropologist Sharon Kaufman argues:

> One's biological destiny, and that of one's progeny, is no longer fixed and immutable. Prevention, enhancement and intervention are possible even into advanced age … bio-medical technique has extended choice to every aspect of existence (Rose, 2001: 22) including the timing of death (2006: 28).

Another reason for seeking to find other ways of interpellating people with dementia and moving them away from glib ideas about the human is that for people with dementia, the issue of the human, and in particular its associated issue of personhood, is an extreme site of contestation, as I have pointed out in an earlier chapter. Dementia severely compromises cognition, memory and agency, and as a result, some philosophers have argued that the person with dementia is therefore no longer a person, and more akin to an animal. For example, as I stated in the previous chapter, the philosopher Peter Singer (1996, 2009) argues for animal rights on the basis that there are certain moral features that 'persons' possess (some of these are their aims, their projects and their narrative histories and identities) but that not all human beings are 'persons'. The cognitively disabled are definitely not (Workman, 2008). Therefore, as Singer sees it, there is no validation for giving rights to those human beings who are not 'persons' that are denied to animals.

Given the complexity of philosophical and political issues to do with dementia and the notion of the human and the person, I argue that my disquiet with the unproblematised reference to the 'human' in the KAGE manifesto is justified. Using this word allows a gloss over the acknowledgement of, and arguably an interest in, how 'the human' and the human body/brain is more than biology, and also has a genealogy and a constructedness that has ethico-political callings. The mythical romance of unity resides in the cover-all term 'human' which elides those who do not fit the category and are regularly and systematically marginalised by being the other to this term — the non-human, the non-person, the cognitively impaired.

Along with the references to an interest in the human is the problematic pronoun 'our' in the website sentence, "the millions of gigantic-yet-tiny, deeply felt, funny and ultimately connected moments that make up *our* lives — success, failure, awkwardness, panic, tears and reckless joy" (my italics). This usage references an imaginary collective of humans who, despite differences, are all connected in a common humanity. Post-humanist scholars Judith Halberstam and Ira Livingston (1995), interrogating the use of the phrase "we're all connected" used in an advertising campaign for New York Telephone, argue that the notion of connectedness:

performs an exemplary ideo/topo-logical maneuver. The organicist notion of connectedness — and its most extreme mystification, the Romantic imagination — had been invented as internalizations and de-politicizations of dominant material interests and their power/knowledge grid (1995: 2).

The connectivity assumed by the gloss of the pronoun 'our' perpetuates a fiction of community, which, especially in the case of the lived experiences of people with disabilities, could entail backgrounding and sidelining issues particular to them.

For me these 'fictions' are especially jarring in the face of the photo of the two founders of KAGE, Kate Denborough and Gerard Van Dyck, who are young, fit, slim and white (see figure 6). *Sundowner* is not the only project on which they have worked in the past or will work in the future, and I realise that their work and that of their company is not always focused on disability and dementia. But in the juxtaposition of the photo and the references to 'the human' on their web page *About Us* I contend that what is being foregrounded is the notion of the human as 'normal': "Images in popular culture glorify and highlight some kinds of bodies (for example the young, able-bodied and beautiful) while ignoring or condemning others" (Jones, 2012: 193). What is backgrounded is the vast diversity of 'the human', as well as the diversity of the human body and its brain. In this paradigm, there is no place for the disabled body (especially disabled dancers).
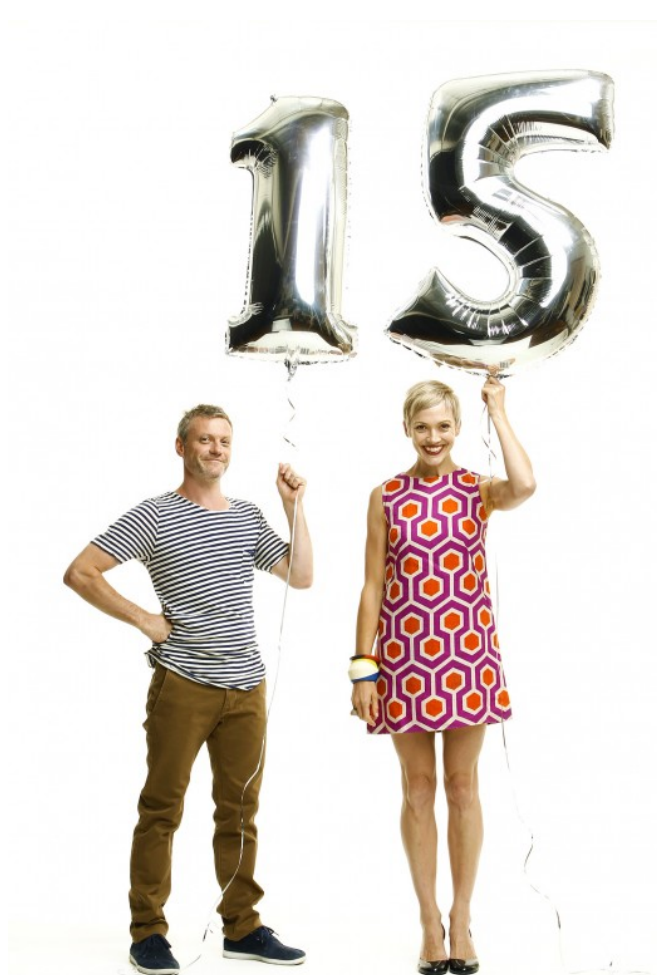

Figure 6: Kate Denborough and Gerard Van Dyck celebrating 15 years since the inception of KAGE. Photography by Jeff Busby used with permission from Simone Schinkel KAGE.

This piece is KAGE's first, and perhaps last excursion into dementia. Financial support for the production was provided by AA and Domain Principal Group. Money is essential in mounting

any productions and allowing the participating artists to live with some dignity because they are being paid for their labour. But at the same time, donations and funding usually entail some compromise and limits to artistic freedom. Producers and funding bodies do not usually just give their money away without checks and balances. The dementia 'industry' in Australia is comprised of the various state chapters of the Alzheimer's Australia Association (AAA) who have a particular agenda; and there are also the numerous nursing home and dementia facilities run by big business with profits on their mind. I argue that the socio-cultural and economic contexts out of which theatrical projects emerge will impact the meanings made in those projects, tempering the political possibilities for re-storying dementia on public stages, whether or not they are made from the stories and words of those with dementia or not.

In the next section of the chapter, I will examine the above-mentioned contexts, firstly, through comments on the program booklet I received when I attended a performance of *Sundowner*; and, secondly, through comments on the lobby banners that greeted me on my arrival at the Queensland University of Technology (QUT) Gardens Theatre Brisbane on Wednesday 17th April 2013 for a 7.30 pm show. I do so to underscore the economic and political realities with which an aesthetic system like theatre is imbricated and to make connections between the aesthetic tenor of a production and the contingencies that underpin, surround, border and in some instances, override it. What happens in the discursive territory around a particular piece of theatre, in its borders or margins, throws vital light on the economy of public theatre productions and the bedfellows that some productions need to tolerate in order to see the light of day. They are its "moments of undoing" (Ridout, 2006: 34). When Nicholas Ridout uses this term, he does so in reference to effects like stage fright, animals and children whose presence may expose the economic underbelly of theatre. However, I am primarily interested in the surrounding contexts in this production: "What we experience as moments of undoing is an apprehension of our own position in relation to the economic and political conditions of our theatre going … under … capitalist modernity" (Ridout, 2006: 34).

Seeing *Sundowner*: 'the right kind' of dementia story

The price of a ticket to *Sundowner* included a good quality cardboard two-sided program in black and white with basic details on it like the names of all the members of the artistic team: the director, performers, set concept, lighting and costume designers and composer (KAGE and Alzheimer's Australia Vic, n.d). This list is then followed by one-paragraph breakdowns of the principal performers, starting of course with that of the well-known Helen Morse. But at the show that I attended, there was also a glossy 24-page colour booklet of good quality paper, replete with a colour photo of Helen Morse taken standing up to her thighs in the ocean (see figure 7).

Morse is dressed in what could be either a nightgown or slip and this would be appropriate attire as it looks like the photo was taken as the sun was going down, in the early evening. Given that the production is focused on and named after the Sundowner Syndrome, the photo shoot was well timed. In the photo, Morse is looking a little lost. The photo is taken in profile. It has a slight sense of danger as she is entering the ocean, alone and confused, and there are connotations of suicide or an ill-fated end. Here the choice for making meaning and creating affect in the use of images to promote a play about dementia is that of tragedy.

At the back of the book (KAGE and Alzheimer's Australia Vic, n.d: 25), there is a long list of acknowledgements to organisations and entities that made financial contributions to the production.

Please Credit : Photo Jeff Busby

Figure 7: Publicity photo of Peggy (Helen Morse). Photograph by Jeff Busby used with permission from Simone Schinkel KAGE.

Among these are government agencies like AA; Performing Lines; the Melbourne Lord Mayor's Charitable Foundation; the Australian Government and the Australia Council; and Arts Victoria. Also listed are a number of private philanthropic organisations whose contributions aided in getting the production up and in mounting its tour around Australia in 2013 (all listed in footnote 99). Another sponsor listed is the Domain Principal Group, one of Australia's largest residential aged care providers, operating almost 60 homes across NSW, Victoria and Western Australia. As I entered the lobby, I noticed two large banners from Domain: one with a picture of two silver-haired elders smiling to the camera under which is the slogan 'Giving You Peace of Mind'. The other is a picture of a very modern facility with the rubric 'Make the Right Choice'.

In aligning itself with this production and providing the kind of money that most likely enabled the production to tour and to produce glossy high quality booklets, Domain involved itself in a public relations and promotion exercise in which it was seen to be actively educating the community through a worthy arts project. In a one-page statement in the *Sundowner* program booklet, Domain notes the educative value of the production in terms of the management of dementia:

> As an aged care provider, dementia management, understanding and education is central to everything we do. It was this core promise of education and understanding which immediately attracted us to the Sundowner production and to KAGE. It is rare that an artistic production is developed with such a deep understanding and empathy to the underlying theme. The painstaking process of collaborative development involving those dealing with the symptoms of dementia serves to demystify the condition and demonstrate the underlying love which goes hand in hand with its effective and dignified management. We are very proud of our association with KAGE and the Sundowner production (KAGE and Alzheimer's Australia Vic, n.d: 24).

Domain may have needed to align itself with the educative value of theatre (the 'theatre of profit' as Horace first termed it)[107] in order to re-make and re-story itself

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[107] In *Ars Poetica*, Horace (cited in Hurley, 2010: 38-39), outlines the two primary functions of theatre as he saw them: to profit or please, with profit implying benefit to its audiences, allied with the mind and pedagogical purposes, and pleasure, allied with sensory and emotional satisfactions, and hence the body. Over the course of Western theatrical and philosophical history, arguments have been made either for or against theatre often on the basis of these polarities. The theatre has been seen to be both morally dangerous and morally valuable (Barrish; 1981; Hurley; 2010). Forming the background to the profit/please declension are Plato and Aristotle's attitudes towards "…'mimesis' (imitation or more broadly representation)" (Balme, 2008:67). Plato used the idea of mimesis to attack the performing arts and to accuse them of untruthfulness. He saw the copy of a

given the history of compliance abuse in its facilities (Besser and Howden, 2011). Domain Principal Group[108] owns the Quakers Hill Nursing Home in the west of Sydney where a fire broke out on the 18th November 2011. Four out of 87 residents died in this fire; five were sent to hospital with severe burns (see figure 8). In a report for the *Sydney Morning Herald* about this fire, journalists Linton Besser and Saffron Howden (2011) also outline a long list of legal and ethical violations perpetrated by the company.

Figure 8: Picture of the aftermath of the Quaker's Hill Nursing Home fire. Photo by Dallas Kilponen used with permission of Peter Lindeman, Fairfax Syndication.

In turn, KAGE's connection to both Domain and AA have both impacted the success of this production, its reach and the kind of intimate, private dementia tragedy that it tells, as well as its promotion of the private solution — the love of family who can remember for you when you cannot do it for yourself. The great paradox is that a company that has a history of abuse in its facilities is a major sponsor of a story that does not touch at all on the theme of institutionalisation and

thing as an impure and debased version of the original. He supported a theatre of reason and truth, in line with what he regarded as the highest aims of philosophy: it was the task of reason to control emotion, so as to retain the rationality and constancy of the human being. On the other hand, Aristotle was interested in a theatre in which mimesis would "teach valid general truths about the world" (Barrish, 1981: 28). Aristotle refused to downgrade imitation as inferior; to him the imitation carried a profound ontological and 'psychological' weight separate from the real thing it referenced, both for those who imitated it and for those who witnessed that imitation. The arousing of the emotions was another one of its valid functions (Barrish, 1981:28).

[108] Domain, now re-branded as Opal Aged Care, is owned by AMP Capital Investors. In 2010, it "reported revenue of more than $198 million and a 9 per cent boost in net profit to $895,000, which it achieved by focusing on cost saving, according to business analysts Company 360. In all, the company received more than $212 million in federal funding in 2009-10" (Besser and Howden, 2011).

its abuses, which is arguably the more important tragedy to be told on public stages given the silence surrounding it. I will now move on to the final section of this chapter where, as a way of concluding, I put *MBDJ* and *Sundowner* in conversation.

Putting *MBDJ* and *Sundowner* in conversation

There are numerous differences between *MBDJ* and *Sundowner*, some of which have already been covered in this chapter, including *Sundowner's* smaller, private tale of the experiences of one person, with memory loss and sundowning behaviours, living in her own home, and the intra-generational effects this has on familial behaviours. In contrast, *MBDJ* is concerned with various stories of race, class and gender set in the broader context of an aged care facility where the elderly living with a dementia diagnosis often end their days.

Although the subject of dementia can and should be treated in many ways in public theatre projects, I think that *Sundowner* attempts to tell a 'universal' story from the fragments of many individual contributions (its process bears this out), a choice which I think helps to present dementia and its contingencies in a more socially acceptable manner. It is also a choice that may have been governed by funding bodies like AA who would have a particular political line (an acceptance of the disease paradigm as can be seen in its campaigns to fight dementia and in its support for the reminiscence paradigm in its Life Story workshops). *Sundowner's* intensely personal and domestic focus is ironic given that a major part of its funding was from Domain Principal Group, a corporation that owns and runs nursing home facilities around the nation. In particular these homes have been complicit in elder abuse infringements around Australia. Fiscal and political contexts will not only affect whether a theatre piece 'travels', or not, but will likely put pressure on the creation of the 'right kind' of dementia story. I am not arguing that the effects of dementia on family life should not be explored in theatre, or that personal stories cannot be political, but I am pointing out what I perceive to be problematic and provocative in certain choices taken by theatre companies in dealing with dementia, especially given their patronage.

Financial support for the life of this production would most likely have been ensured because of its emphasis on the important role that family plays and its message that through love and connection people living with a dementia diagnosis can be held onto, despite losing their memories. This financial support has enabled *Sundowner* to be the face of dementia on public stages around Australia over the last few years, with a reach much wider than that of *MBDJ*. Unlike *MBDJ*, this production toured; and it toured widely in 2013, nearly all over Australia. The website notes that, in 2013, "KAGE presented over 100 performances in 35 different locations including remote and regional Australia as well as Helsinki, Finland" (KAGE, 2013, *About Us*). A staff member from KAGE advised that they actually presented 79 performances, rather than over 100, as one season was postponed. Specific statistics on *Sundowner* are that the show has been seen by over 18,000 people in its live form (across 2011, 2012 and 2013).

Furthermore, KAGE and Performing Lines created a resources booklet for use in line with various school curriculums around Australia. An introduction to the booklet states, "you may be seeing the production as a student of Drama, Theatre, Dance, English, Social Studies, Citizenship or for some other reason" (KAGE and Performing Lines, 2012: 2). So *Sundowner* reached into schools, as well as into the broader community, all over Australia, arguably becoming one of the most widely seen Australian productions to date on dementia. *MBDJ* in contrast did not tour although it was not totally without fiscal support. According to the Kantanka website: "this project has been assisted by the Australian Government through the Australia Council for the Arts, its arts funding and advisory body".

The fact that *MBDJ* did not tour is a pity. In my opinion it is a much more interesting examination of the politics of ageing and dementia than *Sundowner* is, notwithstanding the 'queasiness' that I felt due to core issues around disability representation. Representation issues remain for *Sundowner*, as none of the actor/dancers are cognitively disabled, although publicity was garnered about Helen Morse's experience as a care partner when her mother had Alzheimer's, arguably as a way of promoting the 'authenticity' of the show and its A-effects (Garde and Mumford, 2013).

To sum up, in this chapter, I have unearthed the probable reasons why *Sundowner* has had success in terms of its spread and its longevity, while *MBDJ* has not: essentially that *Sundowner* tells the 'right kind' of dementia story and *MBDJ* does not, which I have argued is connected to the people behind the story (its sponsors). Although partly dressed in postdramatic clothes, *Sundowner* is at core a modern drama using a teleological narrative patterning. It tells the story of one white middle-class woman and her long-suffering family, and trades on the mystery of sundowning episodes to paint a gothic picture of despair, although its educative aspects are to be commended, in part, as too its ethico-political praxis.

In contrast, *MBDJ* includes many voices and many stories: those of men and women, and a range of classes and ethnicities. There are stories from the individuals affected as well as their family members; there are also stories from characters like the facility cleaners and nurses, as *MBDJ* does not shy away from the issue of institutionalisation in dementia representation. *MBDJ* employs a poly-vocal approach to public theatre storytelling in contrast to a univocal approach, which characterises a good deal of mainstream modernist theatre. The poly-vocal is much more in line with a postdramatic, postmodern and feminist theatre aesthetic (Lehmann, 2006; Balme, 2008; and Lyons and Lyons, 1994, in reference to feminist theatre). Yet, although a postdramatic aesthetic has the potential to disrupt the way in which audiences perceive dementia, it might also work to solidify perceptions, stereotypes and biases as audiences might not be able to understand and/or access the meanings lurking within this type of perceptual frame.

This chapter concludes part one of this thesis. In the next three chapters of part two of the thesis, I continue my investigations into the 'right kind' of dementia story, with a particular focus on the kinds of stories favoured in applied theatre.

Part Two

Chapter 4
Charting Applied Performance in Dementia Cultures

As has been pointed out in the preceding chapters, the construction and viewing of any performed stories about dementia and its peoples will inexorably be fed by the 'right kind' of dementia stories which tell of people living with a dementia diagnosis as 'victims' and 'sufferers', amongst other tags, because of their failing memories, faulty cognition and narrative 'incapacities'. In other words, as applied theatre theorist Michael Balfour contends, writing about refugee status and identity, "popular, political and academic definitions … inevitably form the back-story for theatrical practices" (2013: 28). For Balfour this means that in theatrical practices, life stories and other narratives are "framed and defined before a word is spoken or a gesture made" (2013: 28). For these reasons, and as I have been arguing so far throughout this thesis, given that stories may function to control as well as to transgress, attention must be paid in any reality performance endeavour, not only to the stories themselves, but to the funding or commissioning agencies, the intentions of the theatre-makers and their choice of aesthetic modes (such as a realist or a postdramatic style), as well as to their frames of reception. In sum, attention must be paid to the people *behind* the stories.

When applied theatre work is done either for, with, or by people living with a diagnosis of dementia, that is, the 'sufferers' themselves, these factors must also moderate any reductionist ideas about the work, such as any facile connection between the performing of life stories and the implementation of change. That is, the radical potentialities of any applied performance to trigger change for individuals and communities will depend on myriad factors. For example, Balfour maintains that the story is "a site of both negotiation and resilience" (2013: 215); he also argues that applied theatre might facilitate a participant moving from being "victim to agentic self" (Balfour, 2013: 29). But dementia complicates these ideas and many others in the applied performance scholarship. It shows, for example, that agency is neither unproblematic nor a-cultural. In the later stages of a

dementia diagnosis, agency might be expressed through non-verbal means (noises, gestures and facial expressions) requiring any negotiation to be re-thought and/or navigated in ways that might not be easily understandable to the applied theatre practitioner. Furthermore, the highly relational self, whom many dementias produce, will complicate the idea of agency. Likewise, the resilience that people living with a dementia diagnosis do express, might be (mis)interpreted as obstinate or aggressive behaviour.

Part of my aim in this, the second part of the thesis, is to rethink the shape and content of 'the story' in applied theatre work with people living with a diagnosis of dementia. As the first chapter of the second part of my thesis, this chapter provides a foundation to my examination of four specific performed narrative interventions in the two chapters following. These four interventions are all deployed in the closed worlds of institutions and/or their affiliated day care and community centres; they are (mostly) all fashioned in relation to the autobiographical performance genre or have emerged out of a reaction to it; and, they are all created out of verbatim input (or use it in connected theatre endeavours). All these interventions are also either under the aegis of, or created in reaction to, iterations of the 'right kind' of dementia story, which in these environments tends to be one determinedly moored to the past and reminiscence.

In the next chapter (5), I analyse three such narrative interventions: the first and most popular is the recalled life story in RTs; the second, and gaining in popularity, is Time*Slips,* a creative storytelling intervention; and the third is the increasing way facilities are being used as 'narrative spaces' themselves. Another intervention, *To Whom I May Concern* (*TWIMC®)* forms the core of Chapter 6. This is an autobiographical narrative intervention performed, in more public arenas like community centres, by those just diagnosed with dementia, and mostly still living in their own homes. Concerns about how the self is understood and constructed in autobiographical performance with ramifications for dementia sites are also taken up in Chapter 6.

I house all the above interventions under the rubric 'applied', although they could also be termed 'care interventions' or 'therapeutic modalities' or indeed, "cultural performances" (Cohen-Cruz, 2010: 77), as it facilitates an interrogation of certain

controversies in that particular scholarship catalysed when narrative interventions with older adults living with memory loss are analysed, as I have already briefly mentioned. In essence, these are controversies and challenges around "the politics of cultural intervention and the problems of cultural hegemony", as applied performance theorist Nicola Shaughnessy (2012: 7) writes in relation to 'theatre for development' (TfD).[109] When residential care homes are seen as sites and their various patterns of human activity along with their accompanying symbolic structures as cultures, then it can be argued that the challenges Shaughnessy outlines are also as crucial in what I term 'dementia cultures', as they are in those of the 'developing world'. (Although dementia cultures exist in the developing world as well as in the developed, these concerns are not those of this thesis.) In dementia cultures these challenges materialise as the hegemony of narrative recall, and also as ethico-political issues about force, consent, participation and intervention, as well as those of transformation and agency.

My choice to work within the applied theatre and performance domains necessitates the provision of a brief taxonomy of applied drama/theatre/ performance. In the section to come, I first set out the definitions, contexts and aims understood and contested by academics writing about applied performance practices and processes. My arguments against the current hegemony of narrative recall in dementia sites finds support in the work of applied theatre scholar James Thompson (2009), whose theories are outlined in a section of this chapter and applied in the next chapter. In line with the interest this thesis has in the people behind the story, this chapter also provides a discussion of the concept of 'the narrative self', as it is the touchstone against which people living with a dementia diagnosis are often negatively contrasted as non-narrative or part-narrative selves. I then move on to an analysis of specific questions and issues raised by performance practices that pursue social change and interventionist agendas (as most applied performance does), locating the key issues of concern in terms of dementia cultures.

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[109] TfD is an umbrella term describing the various theatre practices undertaken by non-government organisations (NGOs) in developing countries to transform attitudes in terms of health care and affiliated concerns (Prentki and Preston, 2009:13).

Defining the terms and locating the contexts

Although, as British educational theatre practitioner and theorist Helen Nicholson (2005: 2) notes, "[d]rama practitioners have been working in educational, therapeutic and community settings for many years", the emergence, sustained use and popularity of the terms "applied theatre" or "applied drama" (Nicholson, 2005: 2) with academics, theatre practitioners and policymakers has been variously assigned to the 1980s (Balfour, 2009: 348; Landy and Montgomery, 2012: xviii) and the 1990s (Nicholson, 2005: 2). 'Applied performance' now has increasing currency in the literature. Work is sometimes tagged as 'theatre', which refers to participatory workshops with little connection to conventional performance; other work dubbed the same is wholly performance based (Jackson, 2007: 2). Some theorists have insisted on the distinction between 'applied drama' and 'applied theatre', with Philip Taylor (2003) leading this advance, claiming 'applied theatre' as having an element of theatrical product, and 'applied drama' as entirely processual and participatory. Other academics in the field use and argue for the terms 'drama', 'theatre' and 'performance' to be used interchangeably and without distinction (for example, Nicholson, 2005 and 2011a), including the performances of everyday life. Yet again for others, these tolerances only obscure the differences between theatre and performance in particular, levelling everyday life and staged interventions in non-theatrical spaces to the same epistemology of performance, which is a "theoretical laziness" (Bharucha, 2011 cited in Mackey and Stuart Fisher, 2011: 375). Particular critical applied theorists and practitioners recognise the correspondence between performance and participation in many practices, and interpret performance more malleably than just in its application to the work of professional actors on stages (Thompson, 2009; Nicholson, 2005). Very few practitioners are convinced about splitting 'applied theatre' from other forms of contemporary theatre (see Nicholson, in Kramer et al, 2004: 91); several argue about the ethical and political ramifications of placing the prefix 'applied' in binary opposition to an otherwise 'pure' theatre marked as the superior form with all the values usually attached to the idea of a 'pure' aesthetic (Ackroyd, 2000; Nicholson, 2005; Shaughnessy 2012).[110]

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[110] Helen Nicholson importantly directs her readers to a consideration of Pierre Bourdieu's sociological history of 'pure aesthetics' and its social and political ramifications. These are the

What has become known as applied theatre (or drama or performance)[111] is generally understood to reference a wide range of practices and processes sitting on a continuum from games, exercises and other diversions, to hands-on practice-oriented workshops, through to "the creation and presentation of a spoken-word drama or stage play[s]" (Thompson, 2009: 8). Tim Prentki and Sheila Preston, two British scholars of applied theatre, incorporate all of the following as 'applied':

> community theatre, community performance, theatre for social change, popular theatre, interventionist theatre, drama in education, theatre for integrated rural development, participatory performance practices, process drama/ theatre, prison theatre, theatre in health, theatre in education, theatre for development, theatre for conflict resolution/reconciliation, reminiscence theatre (2009: 9).[112]

For the discussions to follow, Helen Nicholson's (2005: 2) cataloguing as 'applied' all forms of dramatic activity intended to benefit communities and societies as well as individuals, including domestic practices of care, trust and community support, seems particularly apt. This is because the narrative practices I examine in the next chapter in particular usually occur in the context of enclosed institutional spaces where people are 'housed' in order to be cared for: one of the meanings of the adjective 'domestic' in the OED online (2014/15) is 'housed'. People are housed in public communities, which are also paradoxically private, as they are not open to the general public, but only to the residents, known intimates of the residents or the workers. 'Care' is also apposite, because in the dementia studies literature, the many practices deployed in dementia sites to improve quality of life are frequently labelled using the noun 'care' (see for example the use of 'dementia *care*' in Brooker and Duce, 2000: 354; Woods et al., 2009: 2; or the phrase 'person-centred *care*' in Dewing, 2008: 3; or Kitwood's 'Dementia *Care* Mapping', 1997: 4; my italics). Furthermore, applied drama, theatre and performance

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'politics of purity' where standards of taste became strongly associated with dominant bourgeois values (Nicholson, 2005: 6-7).

[111] The period of the emergence of the term 'applied' coincided with the withdrawal of the rubric 'community theatre' or its morphing into 'community performance'. This was a period in which the traditional left-wing values of alternative theatres everywhere were called into question through the growth of what has been termed by performance theorist Baz Kershaw a "'new world disorder'"(Nicholson, 2005: 11).

[112] To this compendium, Robert Landy and David Montgomery (2012: 130), two American academics and practitioners, add "action theatre, bibliodrama, engaged theatre, ethnodrama, grassroots theatre, playback theatre, social theatre, sociodrama and drama therapy", as well as forms of theatre that serve the hegemony of Church and State (for example the training of world leaders about change). Many British theorists dispute the inclusion of therapy under the label and would also fight against hegemonic practices being involved (James Thompson in particular).

practitioners usually come to the work as a demonstration of their caring about or caring for the communities with which they are engaged either in a political, ethical or pedagogical sense, making something new out of a variety of elements the context presents (Shaughnessy, 2012: xiv). Nicholson's (2005) emphasis on care practices and community support also works well with the dictionary definition of the verb 'to apply' (OED online, 2014/15). The verb originates from the Latin '*applicare*'. Its discrete meanings are varied but of special interest are the following: "to give one's full and careful attention"; "to bring things in contact with one another"; "to join"; "to connect"; and "to devote oneself to".

The dementia care practices and interventions explored in the next chapter in particular are specifically narratives and, as such, appear to fit well under the precise rubric of applied drama. This is for two reasons: firstly, because drama is a narrative art; and secondly, because narrative is the medium most frequently deployed by applied theatre-makers, as it is understood to be appropriate for both the exploration and the representation of narratives of selfhood, culture and community. By telling 'other' stories or telling stories from a different perspective, many theatre-makers feel that dominant social narratives can be best interrupted, and some kind of balance achieved through changes to these master narratives and the inclusion of other stories in the social palette. As Helen Nicholson maintains, "[i]t is this understanding that narratives can be changed that lies at the heart of practice in applied drama" (2005: 63).

Nonetheless, many recent practices "draw upon the forms, vocabularies, technologies and methodologies broadly associated with contemporary performance: "'devising', 'performance art', 'durational', 'site/place responsive', 'intermedial'" (Shaughnessy, 2012: xv). For this reason, although I do sometimes use the terms 'drama', 'theatre' and 'performance' interchangeably in this chapter, and those following, to underscore their malleability in actual practice, I prefer 'performance' as a descriptor to cover some of the more innovative narrative interventions analysed. As an overarching rubric, it most closely captures work located across and between disciplines and forms, of "hybrid practices which, like performance itself, evade definition, refusing to be constrained by categorical frameworks" (Shaughnessy, 2012: xv). It also captures the embodied and

relational aspects of performed storytelling as Time*Slips* and *TWIMC®* are: out of mouths, through bodies and to and with engaged others who are present in the same time and space.

Before I finish this discussion on definitions of applied theatre and performance, I will note three other staples fundamental to the territory given that the term "is relatively new and links together a number of … practices that might not see themselves as affine" (Balme, 2008: 181). The first is context. Applied performance usually, but not always, occurs in venues not ordinarily assigned as theatre or performance spaces (for example, schools, prisons, community halls or aged care facilities). It also tends to occur in a variety of geographical and social locations that might be particular or relevant to the requirements of the individuals or communities taking part (Prentki and Preston, 2009: 9). It is often led by professionals (Nicholson, 2011a: 241) working with non-professionals. The second staple is that the work crafted, which may or may not be presented to an audience, will, most likely, have a specific meaning to those who participate in its creation, as well as to those who view it. Its audience may or may not be comprised of the participants who created the final 'product', if there is one. Audiences may also be termed participants because they are deemed to be co-creators of what is often more of an interactive piece than a representation. Thirdly, applied theatre and performance has clearly instrumental aims: "[a]pplied theatre is always theatre for a specific purpose" (Balme 2008:182). In all cases, it stands literally and figuratively "outside the framework of traditional Western aesthetics in the sense that art should be non-instrumental "(Balme 2008:182).

As I noted in the introductory chapter, the efficacy of the work usually predominates even if some applied theatre pieces may be framed as art and prioritise aesthetics (Schechner 1988: 129-163). Crucially, applied theatre aims to facilitate beneficial changes for the individual participants, associated communities and societies involved in both the processes and/or the products of its broad church. In sum, the work has "ideological and political objectives that are espoused through practices which have the potential to challenge, innovate and transform" (Shaughnessy, 2012: 3).

However, what these changes entail, how they can be measured, if they should be measured, whether they really happen, and if they do happen, whose agendas or intentions are driving the changes (the participants, the facilitators or the funding bodies), and for what ends, are all questions central to current applied performance scholarship (Honwana and De Boeck, 2005; Odhiambo, 2008; Etherton and Prentki, 2006; Prentki and Preston, 2009; Preston, 2009; Thompson, 2009; Mda, 2009; Coutinho and Nogueria, 2009; Cohen- Cruz 2010). These questions have not to date been taken up in reference to performance interventions that take place in dementia cultures. When applied performance interventions are used in these contexts, these questions are activated in particular ways and will be considered in relationship to both RTs, Time*Slips* and narrative spaces in the next chapter.[113]

These questions and others around making performance in what has been aptly termed a "'new world disorder'" by performance theorist Baz Kershaw (cited in Nicholson, 2005: 11) abound in the scholarship.[114] Concerns arising out of this 'new world disorder' not only test the role of the artists, their relationships with the participants and themselves, and the interactions between process and performance (Shaughnessy, 2012: 5), but also provide fertile ground for a burgeoning scholarship of books and journals.[115]

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[113] I note here that since I began writing this thesis, research on the ways artists use care homes as creative spaces is starting to emerge. Two current examples are Helen Nicholson's (2011b) paper, 'Making home work: theatre-making with older adults in residential care', and Nicola Hatton's (2014) 'Re-imagining the care home: a spatially responsive approach to arts practice with older people in residential care'.

[114] This 'new world disorder' comprises "new temporalities, materialities and ontologies" (Shaughnessy, 2012: 3). Globalisation, diasporic migration, "[d]igital revolution, political revolution and upheaval, global economic anxieties and ecological concerns about sustainability and the environment" are all part of the climate of change (Shaughnessy, 2012: 3).

[115] The academic literature includes two refereed journals: *Applied Theatre Research* formerly *The Applied Theatre Researcher/IDEA* Journal, 2000-2011; and *Research in Drama Education: The Journal of Applied Theatre and Performance*, the first volume of which was published in 1996, focused only on Drama in Education, and was titled Research in Drama Education (RiDE). The journal was re-launched in 2009 with the phrase 'Applied Theatre and Performance' added to encompass the expansion of the discipline, however that might be defined, and its interests (Balfour, 2009: 348).

Applied performance as an academic field

Applied performance as an academic field has grown out of a shift in notions of theatre, drama and performance, influenced by a constellation of factors including the replacement of the focus in theatre studies as the study of literary phenomena only (that is, drama texts) with the study of performance as an embodied live art form; the influence of performance studies itself, with cross-disciplinary feed-in from sociology, anthropology and cultural studies; and the slippage in theatre practice from a strict interest in aesthetics to an involvement with social, cultural and political domains (Balme, 2008).

It has been suggested that the term 'applied' grew out of academia, spreading rather haphazardly "like a rhizome" through the publication of three books with similar titles within a short space of time: *Applied Theatre: Creating Transformative Encounters in the Community*, Philip Taylor, 2003; *Applied Theatre: Bewilderment and Beyond,* James Thompson, 2003; and *Applied Drama: The Gift of Theatre*, Helen Nicholson, 2005.(Nicholson, 2011b: 241- 242). These three seminal texts established applied theatre "as a significant development within the field of theatre studies" (Balme, 2008: 182), setting the context for the ideological underpinnings of the field, and the ensuing debates on terminology and other connected issues.[116]

However, in 2009, James Thompson's *Performance Affects: Applied Theatre and The End of Effect* profoundly revolutionised many of the prevailing paradigms of the field and the practice to that date. Using examples from various performance projects in sites of social disasters and conflict, Thompson (2009) argues for a methodological shift from effect to affect, radically problematising the conventional transformation purposes and practices of applied theatre, previously focused mainly on social change as measured through effects and impacts to the exclusion of aesthetics. Thompson suggests that aesthetics and social efficacy must be

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[116] 'Applied' is also a contested term because, although it has come to prominence over approximately the past two decades, the multifarious practices to which it refers have been running for decades before that, for example in community, educational and therapeutic settings (Nicholson, 2005: 2) under names as diverse as 'museum theatre', 'theatre in health education' or 'theatre in education'. Practitioners have resisted the appropriation of their diverse practices under one rubric, primarily by academics. The argument is that these terms often signify differences of approach, differences in the target market, differences in location and differences in the agendas driving the work that are important to signify (Jackson, 2007: 2).

conjoined in applied theatre performances, contending that "the aesthetic intensity is in itself the propellant of political action" (2009: 128), joining similar calls from Rancière. For Thompson, applied theatre must be valued for its interweaving of both sensation and meaning, so "the joy — the buzz of the participatory arts is inseparable from the total impact of the event" (2009: 131). His book instigated "the turn to 'affect' in applied theatre research and debates about ethics and aesthetics became a focus of concern" (Shaughnessy, 2012: 9). Helen Nicholson's 2011 *Theatre, Education and Performance*[117] and Nicola Shaughnessy's recent *Applying Performance: Live Art, Socially Engaged Theatre and Affective Practice* (2012) have followed in this direction.[118]

But of these three theorists, it is Thompson's ideas I work with in the next chapter with regards to dementia. One idea in particular will take central focus as it shows the most promise for my analysis. This is the hegemony of Western ideas and practices in contexts where they may not be culturally appropriate. Thompson argues that, in particular, the Western model of life storytelling, based on culturally specific ideas about trauma, tends to be imposed on cultures of the South often in disregard of other more locally resonant modes.[119] Like Thompson, I do not seek to disparage storytelling itself, as it is an important event in many cultures, as can be witnessed in community gatherings, numerous therapeutic customs and various theatre and performance events (Thompson, 2004: 151). It is also important to the work of theatre practitioners generally. But I intend to apply Thompson's argument to 'cultures' composed of people cognitively disabled by dementia, as I am

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[117] Nicholson deploys Elizabeth Ellsworth's concepts of the materiality of learning to challenge the mind/body, reason/emotion binaries underpinning the individualism of Western educational paradigms. For Nicholson, interactive embodiment is a key player in learning and agency, and empathy, imagination and social engagement are central to the creation of meaning (Shaughnessy, 2012: 11).

[118] Shaughnessy's book participates in the turn to affect and ethics but through the prism of cognitive theory. In it she challenges the dualisms of the aesthetic and the non-aesthetic, in order to find the space between autonomous art and engaged arts where the role of the spectator and the community in which the art is produced is central to the reappraisal of the worth of these relational and participatory practices (affect theory brings together both aesthetic and socially engaged perspectives). She is particularly interested in live art and the aesthetic potential of place as a stimulus for making performance.

[119] In a similar vein, Rustom Bharucha, a writer, director, dramaturg, and cultural critic based in Kolkata, India, argues that applied theatre is enmeshed with the cultures of the North, that is, "Euro-American traditions, Boalian praxis and the increasingly hegemonic use of English as a link-language" (2011 cited in Mackey and Stuart Fisher, 2011: 378). These models are based on "predominantly urban, secular and modernist notions of individuality and freedom against a spectrum of other modes of living" (Bharucha, 2011 cited in Mackey and Stuart Fisher, 2011: 379).

interested to explore in what ways and situations the application of ideas about the taken-for-granted healing power of life story recall may in fact be oppressive and, in one sense, culturally hegemonic, in this particular cultural landscape. It is also an idea that has not been widely explored in theatre and performance literature, nor in dementia studies. I will now turn to an overview of the key principles of Thompson's challenge to naturalised assumptions in applied theatre practice about the healing power of life story recall.

Narrative recall and healing

James Thompson (2009) makes three main arguments against certain trauma literature claims that provide a very useful basis for then thinking about alternatives to the current hegemony of narrative recall in dementia sites. Firstly, Thompson disputes the unqualified value of telling one's story of trauma in applied theatre practice. Secondly, he argues that there are dubious claims in the trauma literature about how trauma works. Thirdly, he contends that trauma has been universalised, separated from its historical, political and cultural genealogies. Thompson argues that, as a result, the unquestioned alliance between the disciplines of trauma and theatre/performance practice and theory may lead to a neglect of other, perhaps more culturally appropriate and hence more ethically resonant, modes of practice in crisis situations.

Firstly, according to Thompson (2009), trauma relief has not only become a 'master' term in applied theatre discourse and practice, but also an explanation for the moral value of many applied theatre projects. Thompson is sceptical of the way theatre-makers and performance scholars have seen a congruence between theatrical forms of narrative recall and the speaking out of trauma to enable healing. For Thompson, trauma studies:

> has become an important paradigm from which a range of micro-practices, including some theatre and performance projects, find their theoretical rationale … The assumptions emanating from the popularity of the *trauma diagnosis* have led to the prescription of 'telling one's story' as the preferred method and necessary pre-condition for 'relief', 'liberation' or 'healing' … link[ing] *theatre work to story work to trauma relief* in a deeply problematic chain (2009: 44-45; italics in the original).

Secondly, Thompson (2009) argues that there is an unclear elision between the literal and the metaphoric in much of the trauma literature. He notes that, "[a] *trauma* was originally a medical term for a wound made in the flesh that through the course of the twentieth century was adopted by psychiatric and mental health professions as a psychological injury" (Thompson, 2009: 49; italics in the original). In stretching this literal wound to a metaphoric one, trauma theory[120] holds that traumatic events stamp themselves on the brain, overwhelming memory to create either numbness or an uncontrolled revisiting of the traumatic event at other times. The 'engraved' brain then replays the event as an actual return to the moment rather than a representation mediated through recall (Caruth, 1995: 153 cited in Thompson, 2009: 49). But Thompson maintains that there is little empirical evidence to back up many of these claims, citing the work of Ruth Leys in *Trauma: A Genealogy* (2000) (in Thompson, 2009: 49) which, referring to neurobiological literature, disputes that trauma results in a different form of embodied memory.

Thirdly, Thompson (2009) maintains that trauma has been universalised, and in so doing has been made a-political and a-cultural. He is especially critical of literary trauma theorist Cathy Caruth's work.[121] Giving Post Traumatic Stress Syndrome (PTSD) as a main example of this generalising process, Thompson argues that it cannot be seen outside its political and social genesis, which stemmed from the work of psychiatrists and social workers in America in the 1970s as a way of acknowledging the suffering of the Vietnam War veterans. In fact, Thompson contends that PTSD may be a Western artefact linked to a particular historical moment. In other words, if the trauma of the Vietnam War was conceptualised as being seared into memory and then replayed, then the event itself could be blamed and not the innocent victims. He cites research on the dreams of PTSD

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[120] From the 1990s to the present, theories about trauma have been emerging from various disciplines, broadening its research base from its origins in medical and psychiatric research. These theories include: feminist interpretations in psychoanalysis (Herman, 1992, 2010), literary analyses (Caruth, 1996), collaborations between psychoanalysis and literary theory (Felman & Laub, 1992), and work in expressive arts therapy (Linnell, 2010; Hogan, 1997). The interdisciplinary field of trauma studies, which has been postulated as more of a post- or anti-discipline by theatre studies scholar Caroline Wake (2010b: 27), now principally comprises the fields of psychoanalysis, post-structuralism, and Holocaust studies (Wake, 2010b: 27).

[121] Cathy Caruth is a scholar of English and Comparative Literature writing on trauma. In her book *Unclaimed Experience: Trauma, Narrative and History* (1996), she argues, referring to Freud and Lacan in part, and through an analysis of film and narrative, that trauma enables an understanding of history not based on linear reference.

victims, which indicates that instead of having an event focus, these dreams are complex interfaces with the life and numerous quotidian concerns of the person (Leys, 2000: 235 cited in Thompson, 2009: 51). For Thompson, this dream research reinforces the cultural and historical face of trauma, as all dreams must be interpreted within a cultural and historical framework. If meanings attached to a traumatic event are different, any trauma treatment must engage with those differences rather than overlooking them. Thompson's main worry is that PTSD as "a minority response to awful and terrible incidents, based on particular, culturally located events, [has been] transformed into a near-universal set of theories and practices" (2009: 56). Thompson's position is not that appalling events do not cause pain and harm, but that a culturally specific discourse emanating from a particular time in history has overlaid, in many instances, the local responses to traumatic events at specific sites of distress around the world.

Along with Thompson, I hold that the narrative imperative has perpetrated a kind of cultural imperialism of aesthetic form within applied theatre practice, justifying its expansion regardless of the varying cultural landscapes in which theatre-makers find themselves.[122] This imperative can assert the necessity of the story as a way for healing to take place with (sometimes reckless) disregard for the particulars of the site, the community and the culture. In fact, telling one's own story in these endeavours can sometimes be dangerous. In disregarding the particulars of the site, the community and the culture, harm can be perpetrated. As Thompson argues, "[w]ithout extreme care theatre projects that dig up narratives, experiences, and remembrances can blame, enact revenge, and foster animosity as much as they develop dialogue, respect or comfort" (2004: 151). For example, Thompson considers that the massacre of 27 Tamil boys and young men on the 25th October 2000 in the Bindunuwena rehabilitation centre in the hill country of Sri Lanka can most likely be linked to a theatre project with which he was involved

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[122] The imperative to 'tell one's story' is not only bolstered by trauma theory but also, I would add, buttressed by "the language of witnessing" (Wake, 2010b: 25), which goes arm in arm with it. "[T]he language of witnessing", as Caroline Wake (2010b: 25) terms it, has become increasingly popular over the past 20 years or so in both theatre and performance practice and studies. This "language" has been, and still is, most closely associated with the rise of reality theatres, in particular, the documentary and verbatim forms, as well as with social and applied theatre. The critical discourse on these theatres generated through the academy has also been important: among them are Malpede's (1996) "theatre of witness"; Salz's "(1996) theatre of testimony"; Salverson's (2001) "performing testimony" and Farber's (2008) "theatre as witness".

that took place in the centre in July 2000. Thompson does not argue for a direct causal relationship between the massacre and the theatre project; rather, he contends that the project was "embedded in a wider system of practice and discourse that left a group of young men vulnerable to attack" (2009: 16). He urges practitioners and scholars to re-examine and re-articulate the claims of applied theatre for change and transformation by taking into account the adjunct performances and discursive systems in which these projects operate.

It is my contention that dementia advances and complicates Thompson's hypothesis about applied theatre practices. I am aware that applying an argument conceived from work in a war zone to dementia cultures risks being dismissed as inappropriate. A war zone has very different stakes from that of a dementia facility or its offshoots: incidents of "cutting and chopping" (Thompson, 2009: 15)[123] are not likely to happen in these kinds of "total institutions" (Goffman, 1961: xiii) in relation to the impact of a theatre project in situ. Nevertheless murder and mayhem are not uncommon in nursing homes,[124] and the same uneducated, biased or sociopathic attitudes that may have funded nursing home atrocities may be involved (to some extent) in both external applied theatre interventions (whether voluntary or professional) and in internal practices, such as nursing home managers who approve certain projects because they fit particular societal stereotypes or because, for example, they will not disturb institutional regimes by stirring residents up. For those with senile dementia, each residential facility is an institution replete with specific narrative and performance practices which are in turn linked to broader discursive socio-cultural systems and structures. All these tellings, and performances, both specific and broad, may be used to justify, in some instances, behaviours towards those living with senile dementia which are at the very least dismissive of their particular performances of self and, at worst, oppressive and inhumane. Some of these practices include: strapping people

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[123] Thompson (2009) devotes chapter one of *Performance Affects* to the Bindunuwena massacre and his concerns over the dangers of applied theatre practice in war zones. The chapter is titled 'Incidents of cutting and chopping', a phrase taken verbatim from the court transcript of one of the survivors of the massacre.

[124] Nurse Roger Dean's deliberate lighting of the fire at Quaker's Hill Nursing Home in Sydney as discussed in Chapter 3 (Besser and Howden, 2011), and the recent murder of residents by a nursing aide in a North Coast (Ballina) home in NSW are two recent examples. In Ballina, Nurse Megan Jean Haines was accused of injecting fatal doses of insulin to Marie Darragh, 82, and Isobella Spencer, 77, at the St Andrews Village nursing home (Griffiths, 2014).

living with a dementia diagnosis down so that they do not wander; making them wear tracking bracelets or shoes with a Global Positioning System (GPS) installed; leaving them in soiled underclothes which causes urinary tract infections; leaving them without enough food because they have difficulty eating; telling them how they will spend their days; governing their sex lives with rules; and over-medicating them to make them more pliable (Yule, 2011: 42).

In order to demonstrate the oppressive nature of performance practices in certain homes, I refer to Tom Kitwood (1997) in *Dementia Reconsidered*. In this book, Kitwood recounts a vignette told to him by a care worker in a nursing home in England in 1984, which is worth quoting at length as evidence of my point. Admittedly the incident on which the vignette is based happened in 1984 and Kitwood's research was published in the late 1990s: practices in some nursing homes are being radically overhauled in the present day. However, in the following vignette, Sandra and Mary's 'feeding' of two of the women calls up several scenes from Theatre Kantanka's *MBDJ* discussed in Chapter 2, which were based on more recent research into homes in 2008-2009:

> In this residential home, the 'babies', as people with dementia were often called, were given their lunch before the other residents were served in the dining room. For all residents, mealtimes were highlights in their day. After feeding Mrs G. her lunch in her own room, I went along to the ward to see if any assistance was needed there. This was a large room with four beds, four chairs and four commodes; it was home to four ladies with dementia. As I entered the door was wide open; all four ladies were sitting on their commodes and the smell of faeces permeated the air. There were no curtains or partitions to screen the ladies from each other or anyone else walking past. My colleagues Sandra and Mary were feeding two of the ladies, and talking about the night out they had just spent together. Sandra was feeding Mrs T. As soon as there appeared a little room in her mouth, more food was inserted. Her cheeks were bulging with food she hadn't had a chance to swallow. Mrs T. started to gag; food began to spill from her mouth then she coughed, and sprayed Sandra with half-chewed food. Sandra proceeded to clean herself up, while leaving Mrs T. with food debris all over her clothes and exposed thighs. Sandra berated Mrs T. for being a 'filthy old woman'. She then commented to Mary that she hoped if she ever 'got like that' someone would shoot her. 'After all', Sandra said, 'if it was a dog it would be put down by now'. Neither lady received the remainder of her lunch. To my offer of help, Sandra and Mary told me I was too late; they had finished; and why had it taken me so long to feed one lady? They had fed two each. We left the room, leaving the door open; all four ladies were still sitting on their commodes (Kitwood, 1997: 45).

Many of these oppressive performance practices, in Australia anyway, are related to understaffing levels or the employment of staff not trained in understanding dementia. In many instances, the facility owners may be big corporations making a lot of money with profits going to the shareholders, not to the nurses and workers: for example, some listed corporations involved in dementia care include Ramsay Health Care and Aerum. Banks are also involved in aged care corporatisation: Macquarie Bank is one example. Some of the restraining practices like the use of GPS tracking devices might also (understandably) be condoned or used by families genuinely concerned about a loved one in the more advanced stages of dementia who might wander off and put their lives at risk. But still, all these practices have social and political connotations within a broader framework that should not be overlooked. This broader framework is composed of the extant social and political attitudes towards ageing and dementia, which are usually narratives of loss and decline (Gullette, 2004).

As a performance practice, I argue that the life story as a 'one size fits all' or a 'cure-all' needs to be rethought in dementia cultures, as does its necessity. So too, the story should be reconfigured and reconceptualised depending on the different cultural locations and needs at dementia sites. Assuming that it is better to get people living with senile dementia to tell/perform a complete, narratively coherent and 'truthful' life story may be as problematic as the deliberate fracturing of complete and singular narratives by a theatre-maker in war zones, where these types of singular opposing narratives often sustain conflicts. For example, in Sri Lanka, in 2002, Thompson came to a project he did there, training professionals who worked with young children affected by civil war between the majority Sinhalese and the Tamils, with a ready-made idea of working with a plurality of stories and an aesthetic of fragmentation. This was a theoretical decision made away from the site: its rationale was to gain distance from the notion of one true story in the conflict in the hope of highlighting discursive constructions of ethnicity and culture, and bringing social change and healing. But Thompson (2005: 155) discovered that, in fact, the complete oppositional narratives of the majority Sinhalese and the Tamils provided comfort to selves already fractured by war and violence and, conversely, fractured narratives added to their suffering. What I take

from Thompson's example is that applied theatre-makers entering any site with unthinking assumptions about how 'good' it is for people to tell stories, and particular kinds of stories, on the basis of which assumption theatre projects are then undertaken, could be acting recklessly and unethically.

This is not to say that applied theatre and related arts practices do not matter. They do. The telling/performing of alternative stories on stages and elsewhere can be important and valuable, especially for older adults living with a diagnosis of dementia:

> People who have edited themselves into silence for fear of saying the wrong thing, or shut themselves down to avoid contact they cannot understand, can use the arts to reconnect with themselves and the people who care for them … and perhaps most important for people with dementia ... to connect with the people who have forgotten them — their communities at large (Basting, 2006: 16).

But life stories in particular, as they are generally understood, rely on certain foundational norms and generic patterns. Key among these are: the idea of narrative and its fellow, the narrative self; notions of authenticity; the necessity of a (reliable) memory; and, the existence of dependable cognitive and rational language faculties. At the hub of all autobiographical narration practices is the concept of the 'narrative self', theorisations about which have been undertaken across many different disciplines as basic to the creation and maintenance of identity. I will now review the major findings and issues to do with this theoretical work, important for this project as people with dementia are often deeply 'non-narrative' or 'part-narrative' selves. I will first examine the evolution of the idea of the narrative self, discussing various theories about its origins, as ontogenetic or phylogenetic. I will then discuss the idea that there are binding links between narrative and identity, disputing this idea and arguing that 'the self' should be more profitably seen as 'selves'.

The narrative self

For more than 25 years, scholars from various disciplines have been paying attention to narrative, not simply as a literary form, but as the foremost organising principle in human cognition and phenomenology. A resurgence of interest in

narrative can be attributed both to the 'interpretive turn' in the social sciences (Geertz, 1973, 1983; Rabinow and Sullivan, 1979, 1987) away from a positivist and descriptive view of the world, as well as to developments in European theory (Bahktin, 1981; Ricoeur, 1988). Clearly the study of narrative "does not fit neatly within the boundaries of any single scholarly field" (Reissman, 1993: 1).

The notion of a narrative self has been variously postulated across sundry disciplines: anthropology, artificial intelligence, cognitive science, communication studies, history, law, linguistics, literary theory, philosophy, political science, psychology, psychiatry, religion and sociology (Hardcastle, 2008: 18). The resultant consensus appears to be that a narrative self at its widest definition is a self that humans somehow create "by narratively interpreting a subset of [their] life events" (Hardcastle, 2008: 18). Its function is to marry the ephemeral and transitory perceptions experienced by the self into a 'single' self.

The fact that the narrative mode has dominated over other kinds of methods for the telling of life events has prompted questions about the extent to which its origins may be ontogenetic or phylogenetic (Cobley, 2001: 21). Narratologist Jerome Bruner (1990) builds an argument that there is a developmental link between the psychological functions of narrative and its evolutionary neurobiology. Bruner suggests that there may be a human "readiness" for narrative, in other words, that there could be a tendency to consolidate variegated experiences into narrative forms, plot structures and so on (1990: 45-56). He insists that a key role played by narrative is in the:

> framing or schematizing of human experience [which] provides a means of constructing a world, of characterizing its flow, of segmenting events within that world, and so on. If we were not able to do such framing we would be lost in a murk of chaotic experience and probably would not have survived as a species (Bruner, 1990: 56).

In this view, narrative may have survived precisely because it offered evolutionary benefits.[125] Isochronous with what is known about 'human consciousness', the

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[125] Simple organisms like paramecia and amoebas can react to dangerous stimuli in their environments in the present moment but they are not able to document their experience of these reactions nor to record the location of this stimuli in order to circumvent future recurrences. More complex organisms have this ability to map actions for any given moment. Progression further up the evolutionary scale sees organisms able to make comparisons of present behaviour with past and to make predictions about the future (Hardcastle, 2008: 19-20).

development of the narrative self has been linked to a period in evolutionary history when the human brain ceased to be 'bicameral' and became more focused on one or the other of its hemispheres and the mental functions associated with them (Jaynes, 1990 cited in Cobley, 2001: 23). 'Narratisation' was probably favoured for its ability to structure perceptual experience, organise memory and shape life events (Bruner, 1987: 15). Philosopher Valerie Gray Hardcastle explains the workings of the narrative self as:

> pick[ing] out certain past events as important, [and] highlight[ting] those over others. We use those events to understand and explain what our bodies are currently doing and we use past and present circumstances to envision what is to come … This is essentially all the narrative self amounts to — using our interpretation of our past to explain the present and predict the future (2008: 20).

In addition to these ideas about the likelihood of the origins of narrative being ontogenetic or phylogenetic, other work in neurology has gone a step further, claiming binding links between narrative and identity. In 'The neurology of narrative', Kay Young and Jeffrey Saver (2001) investigate the syndrome known as global amnesia. It presents itself in individuals as arrested narrative (recall up until or a few years before an injury) and it manifests physically as lesions in the frontal lobe structures and in the amygdalo-hippocampal system. The hippocampus is where memories are stored. This, they affirm as proof of an "irreparable connection between narrativity and personhood" (Eakin, 1999: 124).

The connections between neurological disorders, behaviour and identity construction have also been well theorised in the ground-breaking work of neurologist Oliver Sacks (1985). In *The Man who Mistook his Wife for a Hat,* Sacks exemplifies these links using the case of Mr Thompson, diagnosed with Korsakov's Syndrome, a neurological disorder typified by memory loss, amnesia and apathy. Mr Thompson was a person compelled to invent himself and his universe each minute: to 'perform' himself over and over, as he had no recall of his past. In this case study, Sacks traces the link between body (brain) and identity, concluding that "[i]t might be said that each of us constructs and lives, a 'narrative', and that this narrative *is* us, our identities" (Sacks, 1985: 105; italics in the original).

Mr Thompson's frenetic antics to recreate himself every day because of memory malfunction and its coeval self-story impairment may point to the human need for

autobiographical selves. They may also underscore Eakin's claim that "narrative is not merely *about* the self but rather in some profound way a constituent part *of* self" (Eakin, 2008: 2; italics in the original). Along with the above-mentioned scholarly explorations in evolutionary biology, psychology and neurology, they seem to leave little doubt that, self-narratives are an impulse bred into us through our evolution as biological animals or, at the very least, that acts of self-narration aid in the formation of identity. Individuals tell stories of past events and actions to claim identities and construct lives:

> How individuals recount their histories — what they emphasize and omit, their stance as protagonists or victims, the relationship the story establishes between teller and audience — all shape what individuals can claim of their own lives. Personal stories are not merely a way of telling someone (or oneself) about one's life; they are the means by which identities may be fashioned (Rosenwald and Ochberg, 1992: 1).

However, there are two main problems with these views, which I will first raise and then discuss. My first main objection to the idea of the narrative self as being constitutive of the whole of selfhood comes from sociology, psychology and neuroscience, where it has been speculated that narrative cannot be co-extensive with all of selfhood and from this, that the self is in fact not a singular entity, but a group entity. My second main objection to the idea of *the* narrative self is that any normalising notions of selfhood risk marginalising those people who do not fit neat paradigms, such as those living with a dementia diagnosis.

My first main objection to the idea of the narrative self is that this self cannot encompass all of selfhood. For a start, the self is understood and has been theorised in various and often conflicting ways across many disciplinary locations in the contemporary academy. It is such a 'big story' that it is not possible to do it justice here, nor is that the charter of this thesis. Nonetheless I will trace a few key ideas to situate my arguments.

Conventionally, in everyday parlance, the self is seen as a loose grouping of corporeal properties like skin colour, height, weight, gender and so on, as well as mental or emotional features like intelligence and empathy (Strickling, 2003). The self is also denotated as "a person's *essential* being that distinguishes them from others, especially considered as the object of introspection or reflexive action" (OED online 2014/15; my italics).

On top of this, in sociology, expressly with the early pragmatists and symbolic interactionists, an empirical self has been posited as: "a socially shaped, interpersonally responsive, yet constant agent of everyday life" (Holstein and Gubrium, 2000: 56). In opposition to this idea "affirmative postmodernists" argue that the self is constructed if still experiencing; "radical postmodernists" argue that the self is merely an image for conveying identity (Rosenau, 1992 cited in Holstein and Gubrium, 2000: 56-57). Sociologists James Holstein and Jaber Gubrium argue that the idea of the single self must at the least be a compromised entity because, even if it is an individual's "*project* of everyday life [its] local by-product is more properly articulated in the plural, as 'selves'" (2000: 13; italics in the original).

Adding to this work in sociology, multiple registers of selfhood have been proposed in psychology. Ulrich Neisser (1988) proposes five to be exact: the ecological (the self in the physical environment), the interpersonal (the self in human interchange), the extended (the self of memory and anticipation), the private (the self with unique experiences not shared with others) and the conceptual (self-information). In this paradigm the narrative self, impaired by the failure of explicit memory, is the extended self only. The self is likely "a colony of Possible Selves, including some that are feared and some that are hoped for, all crowding to take possession of a Now Self" (Markus and Naurius cited in Bruner, 1990: 100).

In neurobiology, Antonio Damasio (2000, 2012) argues that self is a "feeling of what happens" embedded in the physiological processes necessary for survival; it is first and last about the body (2000). Damasio posits three main levels of selves in every human being: a core self linked to perception; an autobiographical self linked to identity and comprising an awareness of relatively stable "facts" of an individual's life (2000: 17); and underlying these two, a pre-conscious proto-self. This is "a coherent collection of neural patterns which map moment by moment the state of the physical structure of the organism in its many dimensions" (2000: 174). Different stimulus inputs to different parts of the brain are bound together so as to produce a single unified *experience* generating *a sense of* some central perceiving entity distinct from the experience perceived. But in fact there is no such single perceiving entity. Scholarship in neuroscience refers to this as "'the binding problem'" (Eakin, 2008: 72-73).

There are also social, historical, environmental and relational dimensions of selfhood(s) which need to be taken into account when theorising the self: "We have as many selves as we have social relationships; and as many selves as there are sites whose local cultures specify the substance of self and subjectivity" (Pollner, 2000: 408). Moreover, selves are endlessly *performed* by the narrative arrangement and re-arrangement of biographical details inscribed by local cultures within particular contexts, both institutional and interactional. Selves also rework cultural materials in ways specific to the individual person fashioning them (Pollner, 2000: 408; Eakin, 2008: 117).

My second main objection to the idea of the narrative self is that any theories that normalise notions of the self and personhood risk the marginalisation of those people (and their experiences) who do not fit neat paradigms, like the cognitively impaired. There is something fundamentally disturbing about the way autobiographical memory has been perceived to be the sole source of personhood in the work of Oliver Sacks. Sacks talks of Mr Thompson's identity-seeking improvisations as "ultimately tragic " (1985: 104); his interpretations lean towards seeing Thompson as less than human. Likewise, attempting to define the difference between a person and a self and which of these can have a story and which not, Valerie Gray Hardcastle cites the example of her aunt declining with dementia:

> Her brain will continue to deteriorate until she no longer can believe much of anything at all, much less complex fabrications about the nature of life. She will become infantile, comatose and then she will die. The question is: at what point along the continuum of her slide, *does she stop being a person*? At what point is 'nobody home' anymore? When does she move from being eccentric but normal to being incompetent but still a person *to no longer being a person at all*? (2008: 2; my italics).

In sum, the ability to tell one's story has been linked to the creation of an identity (Rosenwald and Ochberg, 1992; Kerby and Bruner cited in Eakin, 1999: 21) to interpersonal and cultural bonding (Eakin, 1999), and to physical and mental health (Sacks, 1985; Hardcastle, 2008). Conversely, the lack of a story has been wedded to pathology, sickness, loss of soul (Sacks, 1985: 108) and, in some instances, a perception that those without stories are somehow less than human

non-persons (Sacks, 1985: 110; Hardcastle, 2008: 2). Connected to the idea of the narrative self are problematic issues to do with life story accounts to which I will now turn.

Life story accounts

Research in narrative inquiry, taking dementia into account, has identified that a rational, linear and chronological tale about oneself is only one of the ways remembering and accounting for oneself proceed in life story accounts. As Suzanne England states:

> Irrespective of whether one has dementia … in many cases we 'tell' our lives with other structures — by our relationships, thematic threads, achievements and setbacks, and stories within the larger story (2010: 204).

Indeed, life stories are not always and only bound by the demands of chronology, or authenticity. However, it is likely that a working cognition and memory will give these life stories some kind of acceptable shape which is most likely missing in later stage dementia stories at least, and which Arthur Frank (1997) therefore dismisses as 'chaos' stories. Furthermore, England's use of the universalising "we" troubles me, exposing her argument as one likely based on assumptions of normalcy.

To better unpack what I mean when I refer to normalcy and narrative, I look to philosopher Galen Strawson who argues against what he terms the "*psychological Narrativity thesis*" (2004: 428; italics in the original).[126] For Strawson (2004), the conception that human beings characteristically understand, live or experience their lives as a narrative or story or compendium of such stories, and, most importantly, that this is a normal or natural state is widely and problematically prevalent in Western cultures. Strawson contends that this first thesis is usually paired with a second, what he calls the "*ethical Narrativity thesis*" (2004: 428;

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[126] Strawson (2004) distinguishes Diachronic and Episodic self-experience to be radically opposed although not absolutely discrete: that is, a Diachronic may forget segments of the past or connections between events; an Episodic may remember embarrassing memories or fear death in their future. These two types can be found across all cultures; further, a culture may also have a predilection for one over the other and thence influence the psychological development of one of its members tending to the other trait (Strawson, 2004: 431). Strawson emphasises that the Diachronic and the Narrative cannot be unproblematically equated.

italics in the original). In this thesis, "experiencing or conceiving one's life as a narrative is a good thing; a richly Narrative outlook is essential to a well lived life, to true or full personhood" (2004: 428).

Strawson goes on to argue that there is a prevailing notion that all 'normal' human beings have four properties connected to narrativity: a temporal self who will be there in the past and there in the future; the tendency to form finding or pattern seeking over one's life, of which story-telling is a "species" (2004: 442); and the tendency towards a falsification of life stories, which happens both consciously and unconsciously when we tell our stories (2004: 446). Strawson takes issue with normal humanity (or personhood) being equated with these properties stating that, "I think that some normal human beings have none of them" (2004: 446). Strawson also makes a clever argument in relation to falsification. He argues that as narrative recall always involves revision and is an inexorable outcome of the neurophysiology of remembering, then "the more you recall, retell, narrate yourself, the further you risk moving away from accurate self-understanding, from the truth of your being" (Strawson, 2004: 447).

What I take from Strawson's (2004) discussion is the further troubling of any ethical reckoning between narrative recall and personhood, an important argument for people living with a dementia diagnosis whose lack of narrative authenticity renders them vulnerable in this regard. Strawson (2004) argues for an episodic self who may have no particular tendency to see life in narrative terms of which he sees himself as one, and I gather that he has a working cognition and memory. "There are deeply non-narrative people and there are good ways to live that are deeply non-Narrative", writes Strawson (2004: 429).

Aligning Strawson's (2004) argument to older adults living with a diagnosis of dementia in the later stages, I underscore that these people may be deeply 'non-narrative' or 'part-narrative' selves who may struggle to remember and to tell their stories, and could feel further marginalised in attempts made by (likely well-meaning) applied theatre-makers (or care staff or family members) to get them to heal by telling their stories. People with senile dementia may not be able to remember parts, nor indeed all, of their life stories (especially short-term memories or memories from the middle parts of their lives). They may: dip in and out of the

past, present and future; struggle for words; repeat phrases incessantly; make nonsensical sounds; sing instead of talk; and change their life stories to incorporate 'actual', fictional and borrowed memory fragments in order to make sense of their current situation (McLean, 2006: 172). Their understanding of time will not fit into the chronological time structures that pervade so much of the present global culture. Living in a culture where narrative acts as a mark of the normal and the natural will then mark these 'non-narrative' or 'part-narrative' selves as pathological and abnormal (Eakin, 1999: 140), and perhaps no longer even persons, as certain philosophers propose (Hardcastle, 2008: 2; Singer, 1996, 2009; McMahan, 1996, 2003, 2008). They may be perceived as somehow deficit, and seen in terms of what they cannot do, rather than in terms of what they can do (Hickey-Moody, 2009).

My argument here is that the imperative for the traumatised to tell their story in the construction of much applied performance, regardless of the varying and specific cultural landscape of that trauma, is both limiting and controlling: it needs to be contested and reformed. Broader ways of defining narrative practice in relation to dementia selfhood(s), cultures and communities, need to be canvassed: a range of practices which open up to the relational, affective and creative foundations of dementia personhood in the creation of theatre and performance projects. Some of these practices might include the reconfiguration of the notion of the life story to include imaginative and fictional offerings; others could be to accept and incorporate a repertoire of "noises, gestures and facial expressions" in order to tell these stories in a different way, as applied theatre researcher Rea Dennis (2002: 240) writes in regards to the narratives of people with severe intellectual disabilities. Drawing on Blotzer and Ruth (1995: 174 cited in Dennis, 2002: 240), Dennis also notes that the story could be drawn from "their bearing and tone" or "what they show as much as what they say" (2002: 240).

But even if narrative practice is reconfigured in various creative ways, applied performance practitioners will probably bring to their practice ideas about the benefits and transformational possibilities for people living with a diagnosis of dementia of participating in theatre-based practices. But the radical possibilities of participation in a project will depend on myriad factors like intention, whose interests are being served, the range of the work, and the scope for creative

strategies. In other words, we are back yet again to the issues around the people *behind* the story and not just the story itself, or even those who tell it. I will now turn to an examination of these ideas, first unpacking the problematic assumptions embedded in notions of social intentionality which are connected to ideas of change, transformation, participation and benefit. Then I will narrow my focus to transformation, a naturalised idea widely prevalent in applied performance thought.

Narrative interventions and social intentionality

Applied theatre has a "central commonality of social intentionality," as applied theatre scholar Michael Balfour (2009: 347) so succinctly expresses it. However social intentionality, and its associated notions of change, transformation, participation and benefit, are not neutral terms devoid of ideological implications. In the past, and in some pockets of practice still today, change is assumed to be of 'benefit' to the people and cultures for whom theatre projects are initiated, either by the agencies commissioning the projects and/or by the theatre companies engineering them. But this assumption is highly value-laden, a fact many scholars are aware of and which has been well analysed in reference to TfD (Odhiambo, 2008; Saldaña, 2005).

Applied theatre practitioners in TfD often come from 'first-world' countries to do work funded by NGOs, and/or AIDs relief, human rights or church-based agencies; the people and countries whose workshops and projects they facilitate are from countries designated 'third world'. First-world practitioners (the developed) drive the changes in the third world (the developing), mirroring the destructive economic and cultural drive of global neoliberal capitalism as it marches across local borders. But the obvious linguistic hierarchy in the descriptors of regions as 'first' and 'third', 'developed' and 'developing', is only a surface pointer to the values entrenched in these kinds of projects. Many occurring in, for example, post-colonial sites, may be engineered in a participatory way (based on Boalian praxis[127] about erasing declensions between the audience and the actors, and

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[127] Brazilian theatre-maker Augusto Boal (1979) developed his system, 'Theatre of the Oppressed', in Brazil in the 1960s. It was based on Paolo Freire's educational pedagogies. From Brazil, it went to Europe and then the world, along with Boal. 'Theatre of the Oppressed' uses performance as a way to fight hegemony and also to fight for political and social change. Practices within its domain

democratic educational theories about annihilating declensions between teachers and pupils). More than likely, the intentions of the facilitators, and possibly of the agencies funding the projects, could be mired in left-wing ideas about opening up the minds of their participants to the colonial histories and neoliberal globalised market oppressions in which they are enmeshed and to which they are 'victims'. In these contexts, notions of change and transformation could be accompanied by ideas of 'saving' people from poverty or disease. Applied theatre in this situation may perform a moral role where the underdeveloped poor, perceived as victims, sufferers and unfortunates, are rescued and transformed by the civilising influence of the Western privileged (Preston, 2009: 304), reinforcing a first-world hegemony, even if that comes clothed in human rights agendas.

Transformation is the "unavoidable fault-line" (Etherton and Prentki, 2006: 141) in much applied theatre and performance practice. Many practitioners see themselves as facilitators of change agendas, which they believe will improve or transform people's lives and the societies in which they live (Shaughnessy 2012: 7-14). Debates about transformation and how it can be achieved are common in both applied theatre practice and theory. But the term is also contested in certain quarters, as it seems to suggest that it is the practitioners or the commission agencies directing and determining the changes, rather than the participants.

One theorist problematising the idea of transformation is Michael Balfour (2009: 347). Balfour argues that while the value of applied theatre might rest in its social efficacy, which is also central to its aims, transformation is in fact "commission[ed]" by the donor agencies contracting the work rather than by the participants. Donor agendas are shaped by a complex economic, religious, political and social web comprised of: government and NGOs, charities, religious organisations and arts councils, among others (Balfour, 2009: 347). Because of this, Balfour looks for a 'theatre of little changes' rather than a theatre of transformation. Following Tony Jackson, Balfour argues that this theatre can "shift the focus from persuasive,

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include: Legislative Theatre, Invisible Theatre, Rainbow of Desire, Newspaper Theatre, and the renowned Forum Theatre. Forum Theatre performances position audience members, or what Boal calls "spect-actors", as active analysts of events on stage who are encouraged to come onto the stage themselves and act out the changes they would like to eventuate (Boal, 1996).

coercive, objectives-driven work" to a greater emphasis on the art form itself (Balfour 2009: 356).

Another theorist who contests the idea of transformation is Helen Nicolson. Nicolson contends that embedded in the notion of transformation through performance is a problematic assumption that the dramatic act will inspire audiences to shift from one kind of society or person into another (2005:12). But for Nicholson, transformation in this dispensation could be as much about what is being done *to* the participants as *with* them or *by* them, serving the needs of the applied theatre practitioners over those of the participants (2005:12). For this reason Nicholson (2005: 12) prefers Schechner's notion of transportation (1985) where performance becomes a site to experience another way of being *provisionally*, rather than permanently.

I agree that there are many issues with the notion of transformation. One major concern I have is that the idea is so widely accepted in applied performance ideology that it has been, to an extent, naturalised. For example, Anne Basting's role as a facilitator of a change agenda can be seen in her statement, in reference to Time*Slips:* "[t]he question that haunted me was whether the power of performance could *transform* the lives of older men and women with dementia as it clearly did the lives of those without cognitive disabilities" (2009: 95; my italics). These types of (no doubt) 'good' intentions do raise many issues, several of which are directly connected to dementia sites and concern any therapies used therein, not just Time*Slips*. Some of these problems are connected to assumed ideas about change and its value, together with issues of participation and intervention that circumvolve around ideas about agency and choice. I will unpack each of these assumptions in the following paragraphs starting firstly, with ideas about change, arguing that it may be imposed on people who do not want it. I then move on to a second major issue: that change hinges on choice and participation which in turn both depend on intervention, and that in this regard, issues of force come to the fore, making choice an idea needing to be problematised. The third major problem I investigate is that of participation which is made more complex by issues of agency. All these concerns will be expanded and complicated in dementia cultures and sites, which I also explore in regards to all three assumptions.

Turning to the first issue: applied practitioners may be motivated to use their art to prompt change in communities who may not want this change. For example, they could either be seen as agents of values at odds with local preferences; or on the other hand, they may be promoting a change agenda mired in a politics (for example, left wing) and/ or an ideology (such as a religion) in opposition to that of the community with whom they are working. Recent research on youth in Africa today (Honwana and De Boeck, 2005 cited in Etherton and Prentki, 2006: 149) has revealed that the change they want is access to the same consumer items to which their first-world facilitators have access. This example demonstrates that local circumstances and cultural differences may butt up against imported ideals for a just and inclusive democracy, which often, but not always, are part of the cultural and conceptual baggage that many (first-world) theatre practitioners bring to the environments where they work.

The issue of change in dementia cultures is complex notably because, depending on the kind and stage of the dementia, the issue of the desire for the change on the part of the participants will be clouded by cognitive disability. How can it be known whether or not the participants really want to tell their life stories in a reminiscence therapy or Time*Slips* session? When Basting says, "[w]e began each session by inviting participants to sit in a circle of chairs" (2001: 80), one wonders how much choice the participants had in attending the sessions, either because of their inability to make fully cognisant choices or because of institutional force and regimentation. Choice itself will likely be curtailed in many aspects of life in facilities by the regimes of the institution and the demands of the diseases. Choice may not even be an appropriate idea to bring to dementia sites given that for some people living with a dementia diagnosis, choices may not be expressed in language or ways comprehensible to people used to normative communication. However, it cannot be assumed either that their expressions will be non-normative at all times. Moreover, there are other ways in which decision-making can be comprehended in dementia which will be discussed shortly.

Secondly, as I have demonstrated, discussions about change necessarily circumvolve issues to do with choice and participation which both hinge on intervention. The etymology of the word 'intervention' derives from the Latin '*interventio*' meaning a coming between (OED online, 2014/2015). Applied theatre

theorist Tim Prentki (2009:181) argues that intervention implies the arrival of some external force to alter the dynamics of a stationary, closed system. It is commonly used to describe the coming of applied practitioners as outsiders who enter and work in communities not their own. The response offered by participants to the proposed project could be affected by whether or not this intervention is imposed by force, or was chosen. Many facilitators and companies work by invitation only, which does seem to provide the best results. However the invitation might be offered by the powerful and not those marginalised from power, as it will most likely be in dementia facilities, highlighting that the context in which the practice occurs may have fixed inequities structured into the formation of the group or community (Thompson, 2003). For instance, prison theatre is normally undertaken in response to an invitation by the prison governor rather than the prisoners. In dementia facilities, the manager and/or the diversional therapist will usually decide on narrative interventions, not the residents.

I agree with Tim Prentki's (2009: 181) argument that the very idea of intervention is implicated in issues of power and the right to speak on behalf of others, which enters political and ethical territory. These arguments become even more pressing in dementia cultures where people may have lost the ability to think and speak in accepted ways; or, in contrast, assumptions may be made that these faculties are entirely and permanently missing, when they might not be, or might be temporarily absent. In dementia cultures, issues of invitation, consent and participation are terribly complex, as the self in dementia is highly relational. Because of this, 'interventions' on behalf of, or with those, whose voices are not normally heard can also be vital, acting as some kind of ballast to the reach of institutional control and domination (Prentki, 2009: 181).

The third important issue I wish to consider is the interdependent relationship between intervention and participation. In the literature of TfD, African applied theatre studies scholar Zakes Mda (2009: 196) notes that when one increases, the other decreases. Participation is core to the rhetoric of applied theatre practice. Central to the challenge Augusto Boal (1979) mounted in his *Theatre of the Oppressed* was to the (perceived) passivity of the spectator. Participation is also a seminal concept widely used in the discursive territory surrounding applied theatre practice: that is, in the fields of education, development and health. It is a taken-

for-granted assumption that involving people in their own change behaviour, whether of knowledge, attitude, behaviour or health, is both a pragmatic and an ethical pedagogic strategy. Drama has proved itself a useful medium for attracting people to participate in developmental, educational and change agendas.

However, in actuality, participation is complex. Any idea seen as 'common sense' most likely contains a naturalisation of hegemonic ideologies (Preston, 2009: 127). Ideas of participation, especially of a 'genuine' type, can mask a myth of origins, and evade power relations and competing ideological interests. For example, the popular Freirian notion of co-intentionality is presently making the rounds in the literature (Coutinho and Nogueria, 2009). Co-intentionality is a concept based on educational theorist Paolo Freire's (2000) ideas about how teachers and students can attain knowledge through common reflection and action. However, co-intentionality does not take account of the fact that participants are themselves embroiled in the culture and may support hegemonic practices. Nor does co-intentionality take account of 'cultures' (dementia) where intentionality may be sporadic or even absent, or may manifest in ways theorised as behavioural or emotional problems rather than as examples of agency. People with dementia, even when it is advanced, may exercise basic agency and/or decision-making capacities, if in rather distinctive forms: that is in habituated, embodied, emotional and creative forms, as opposed to deliberative forms like speech, intentional action and goal orientation (Boyle, 2014: 1131). For example, they often use non-verbal communication to clarify their speech or as an alternative means of communication.

A good demonstration of the point I am making is in the findings of applied social science researcher Geraldine Boyle. Boyle's (2014) research involved five people with dementia in a facility in the north of England who had considerably impaired speech and who also lacked the capacity to make both minor and more major decisions, including the capacity to consent to taking part in her research. She investigated capacity retention and ability by seeing, for example, whether they were able to identify their food preferences even if they could not decide what to eat, by observing non-verbal communication (such as facial expressions or gestures) where speech was a problem and by interacting with them one to one with the help of sensory aids, and attentive listening. Boyle (2014) concludes that

the concept of agency in social science theory needs to be expanded to cover cognitive disability, thereby embracing a broader notion of capability (see Burchardt, 2004). This would involve: factoring in communication other than language, accepting emotional forms of social 'action' and permitting imaginative agency even when the potential for social change is limited. Boyle (2014) contends that acknowledging the socio-emotional, rather than cognitive, basis of reflexivity would enable the agency of people with advanced dementia to be more readily recognised (see Burkitt, 2012).

The ability to acknowledge agency in dementia, or not, is related to Western cultural thinking which generally views the self as 'divided': reason is positioned as superior and emotion as inferior (Burkitt, 2008). The biomedical model is based on this same divided view of the self and is partly responsible for the under-recognition of the extant cognitive abilities of people with dementia and the pigeonholing of their emotions and behaviour as symptomatic of their illnesses. On the contrary, these behaviours and emotions (such as resistance to prescribed routines, aggression or wandering) may be indicative of agency, particularly in response to "the structural constraints imposed by institutionalized care regimes, low societal expectations and a lack of opportunities for social participation" (Boyle, 2014: 1131), as well as conflicts of needs and interests between them and their carers, and wider social inequalities (see also Oliver and Barnes, 2012).

Boyle's research shows that agency in advanced dementia in particular may manifest in non-verbal communication, in what staff or family may see as behavioural or emotional problems and/or in relational over individualistic forms of communication. Examples of the latter include the way in which 'personal' stories of those living with a dementia diagnosis may need to be told with others rather than by just the individual person on their own. This has three main implications for Western applied performance practitioners in dementia sites. Firstly, practitioners may enter dementia sites with ideas about agency theorised in ways that privilege language (Madhok, 2013 in Boyle, 2014:1131), which then makes it difficult to apply the concept to people with dementia who frequently have impaired speech.

Secondly, practitioners may enter dementia sites with ideas about agency leaning towards intentional action and neglecting habituated or embodied agency (Velleman 2000; Cleaver 2007). Habituated or embodied agency is demonstrated in habits, routines or body language rather than through consciously negotiated or articulated actions (Boyle, 2014:1133-1134). In other words, agency in this dispensation is exhibited and expressed via material existence: actions that are consistent and unified without narration through recognizable skills that cohere even without deliberative consciousness directing them (Hansen 2013: 72 cited in Potter, 2013:75).

Thirdly, practitioners may enter dementia sites with ideas about agency that over-emphasise individualism, such that relationality and interdependency are under-recognised (Hemmings and Treacher Kabesh, 2013). The idealistic conception of agency as a deliberative process involving clear and intentional action is rarely achieved in practice in individuals who do not have dementia (McDowell, 1979; Reader, 2007) let alone those who do. Therefore, for applied performance practitioners to bring an unproblematised and a-cultural idea of agency into dementia sites[128] (where these ideas are also often reinforced by management, staffing and care partners) can be just as much of an issue for concern as to enter a so-called third world site with first-world ideas.

Locating and exploring the ways applied theatre can best respond to people living with a dementia diagnosis when there is a very real risk of drawing on and repeating the 'right kinds' of dementia stories, is both a challenge and a puzzle, which can possibly only be resolved in "moments of potency and hopefulness that appear fleetingly" (Balfour, 2013: 28) in the processual spaces of creating the work between the practitioners and the participants. The relationship between applied theatre practice and the radical possibilities of participation in a project depends on numerous factors like intention (and within this, as has already been discussed, whose interests are being served), the scope of the work and the openness of the creative strategies being offered.

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[128] Boyle (2014) reports that some researchers have found that agency is affected by gender and its social constructions. Women are more likely to be deemed unable than men. 'Wives' who are care partners will more actively promote their partners' capacity than 'husband' care partners.

In this chapter, I have argued that the potentialities of applied performance interventions to trigger change for individuals and communities depend on many factors but when dementia is involved, any taken for granted ideas in applied performance practice, and its scholarship, will be made complex (for example, the idea of agency). I have also argued that there is a vital need to rethink the shape and content of 'the story' in applied theatre work with people living with a diagnosis of dementia, finding support in Thompson's (2009) ideas about the hegemony of narrative recall. I have argued that the life story as panacea, in this dispensation the 'right kind' of dementia story, needs to be rethought in dementia cultures, as does its necessity. Broader conceptions of narrative practice that respond to the interactive, emotional, sometimes non-linguistic and creative foundations of dementia personhood need to be investigated. As the first chapter of the second part of this thesis, this chapter has provided a basis for my study of four specific performed narrative interventions in the two chapters following. In the next chapter, I look at the most common form of narrative intervention in dementia sites, Reminiscence Therapy, and one of the least well-known ones, Time*Slips,* as well as the emergence of what I term 'narrative spaces'.

Chapter 5
Narrative Spaces: Re-Storying Older Adults Living with a Diagnosis of Dementia

A principal argument of this thesis is that most narratives about dementia in public circulation are tales of abjection and woe: that is, they are the 'right kind' of dementia story. The Western world is saturated with anxiety about the 'diseases' of forgetting and the forthcoming 'crisis' they occasion as the world's population increasingly ages. However, what is told about the dementia experience does not usually emanate from those living with it, in all their complexity, although autobiographies by people living with a dementia diagnosis have been appearing with more frequency since about 1989.[129] When these stories emerge from institutions where older adults reside or are connected, they tend to be stories about their pasts. Reminiscence Therapies (RTs) have a durable grip in these locales. There are many types of these therapies but in essence they can be defined as activities that engage older adults in discussions with another person or group of people, about their pasts (incidents, activities and experiences), typically with the assistance of physical stimuli recognisable from the past, for example, photographs or kitchen items. I provide a brief case study of an RT in the next section of this chapter, the popular 'My Memories Book' (Alzheimer's Australia ACT, n.d). As dementia usually leaves long-term memories intact, past memories are thought to be the conduit through which selves can be remade or reclaimed, if only temporarily. Claims are made for the efficacy of these therapies and there is some weight to them.

But to what extent do RTs reinforce what can be destructive master narratives about the personhood of older adults living with a diagnosis of dementia, like that the 'real' person is not the one in the present moment but the one from the past? How much do they keep these older adults controlled and locked in to performances of personhood, which might suit others, but be distressing for them?

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[129] Among them are: Robert Davis's (1989) *My Journey Into Alzheimer's Disease*; Diana Friel McGowin's (1993) *Living in the Labyrinth* and Richard Taylor's (2007) *Alzheimer's From the Inside Out*. In most cases, these authors had early onset dementia (under 65) and early diagnosis, which is a fraction of the dementia experience — well under 10 per cent (Basting, 2009a: 147), and not the focus of this chapter.

How much do they reinforce and naturalise the redemptive power of what is in fact a very narrowly focused conception of narrative, without any qualifications? Stories, as sociologist Ken Plummer contends writing about gay and lesbian coming-out stories, "have conservative, policing control tasks — as well as transgressive, critical, challenging tasks" (1995: 176).

In this chapter, I address these questions, arguing that those older adults who cannot perform their life stories with confident veracity, that is, those cognitively disabled by dementia, particularly in the later stages, may be further marginalised by assumptions pertaining to the healing power of life stories, especially where these stories are constrained to literal and chronological renditions. In fact, the 'truth' of life stories from older adults living with a dementia diagnosis, especially when they are used to create paratheatrical projects, may lie in ignoring memory and notions of truth and taking up the symbolic. I seek broader conceptions of narrative than those that, in dementia sites, relentlessly incline towards reminiscence.

What is needed in dementia cultures is a range of stories rather than just a narrow band of life story tellings restricted to particular structures and styles, while other types are ignored (Eakin, 2008; Smith and Watson, 1996, 2001). A broader range of stories would likely help to re-imagine and re-configure the personhood of older adults, especially if they focused on who these older adults are *now*, not just on who they *were*, although the two are obviously connected. My hope is that these selves could thereby be re-membered, not in terms of recall but in terms of being brought back in to community (as members), through a re-assessment of common cultural understandings of story. I also hope that alternative stories may help selves living with a dementia diagnosis be re-storied, given, as I have already argued in this thesis, there is a strong connection between selves and stories.

My notion of re-storying selves is based on the key theoretical principle that persons are multi-storied (Geertz, 1976), which means that persons and events can be understood in manifold ways. This notion embraces new configurations of narrative to more fully account for the narrative capacities and creativities of people living with a dementia diagnosis. Stories could involve multimedia and

digital technologies and move away from a reliance on the word.[130] Stories would not have to be restricted to the creation of a life story, or even a time-based performance modality, but rather could permeate every part of the institution and the lives of its inhabitants: its material and spatial dimensions. Stories like these are beginning to emerge in dementia sites. These new configurations are what I term 'narrative spaces'.

This chapter starts with an examination of the role played by RTs in dementia care settings which I argue, although beneficial in some ways, may uphold the 'right kind' of dementia story, keeping older adults locked into the past and who they were without taking into account that what a person finds deeply satisfying in life will not remain in stasis. This is followed by an investigation into Time*Slips*, a performed storytelling venture that aims to foster and promote creative expression among people living with a diagnosis of dementia. Time*Slips* is a good exemplar of how the 'right kind' of dementia story can be resisted through offering a process-based and performative production of narrative which encourages a performance of self not reliant on memory (Basting, 2001: 79-80). To finish the chapter I turn to an examination of two 'narrative spaces', connecting them to issues of place and space. Both Time*Slips* and the two 'narrative spaces' take up the ethical gauntlet to focus on who these older adults are now, in the present moment, as well as their imaginative capabilities as storytellers, improvisers or role-players, but not without issues.

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[130] One example is Spare Tyre's *Once Upon a Time* which encourages participative storytelling striated through "touch, sound, taste, light, smell" (Randall, 2012: 10) in an environmental and relational interaction with lights, music and multimedia projections. Another is B-Arts, from Newcastle-under-Lyme, a company currently working on a project to research and design "digital *continuing* biographies" (Randall, 2012: 10; italics in the original), which their website calls 'Life Streams R and D" (B-Arts, 2015) to be an alternative to the physical memory boxes or memory books used in many care homes. The final structure of these biographies and their access modalities (whether personal computer, touchscreen device or another interface) is still to be decided (Randall, 2012: 10). However multi-sensory experiences, including video and sound are being considered. What particularly interests me is that B-Arts are considering "the representation of an ongoing set of experiences, memories, photographs, and preferences, rather than being … limited to the past" (Randall, 2012: 10; my italics).

Reminiscence therapies in dementia care

Before I start my investigation into the role played by RTs in dementia care, I will briefly introduce the forms and functions of the closely related practices of reminiscence theatre. This type of theatre has many forms. The founder of the United Kingdom (UK) Age Exchange Theatre, Pam Schweitzer, points out five main manifestations (2007:13). Firstly, it can be a scripted piece performed by actors to a variety of audiences, but principally to older people themselves. In this form it has often relied on verbatim theatre techniques. Secondly, it can be created in intergenerational settings, including schools, with input from all the participants. Thirdly, it can involve the direct creative input of groups of older people as actors, directors and so on, along with professional support. Fourthly, it can also be spontaneous reenactments by actors in eldercare settings. And finally, it can be drama used to recall memories for people living with a dementia diagnosis. Moreover, this type of theatre performs many functions, including but not solely limited to those that are therapeutic. It can be a "sourcework for social history…a rules-based method of devising a dramaturgical procedure in its own right…a form of social activism and even, potentially…a framework for socio-political analysis" (Mangan, 2013: 163). Various iterations of reminiscence theatre exist across the globe: the evolution and contributions of this type of theatre have been notably tracked by Anne Basting in the United States of America (USA) (*The Stages of Age, 1998)*, and by Pam Schweitzer (*Reminiscence Theatre*, 2007) and Michael Mangan (*Stageing Ageing*, 2013) in the UK. Amongst its many progenitors are the growth of an interest in oral history from the 1960s on along with the rise of 'people's theatres' (verbatim and documentary), the evolution of Theatre in Education and the growing recognition, in both elder and dementia care, of the value of a person-centred approach, along with Life Review and RTs (Schweitzer, 2007:14-19).

Currently, RTs are among the most frequently used therapeutic-artistic interventions in dementia facilities and day care programs around the Western world including Australia,[131] although sense-based mediations are also gaining

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[131] See for example the Fight Dementia activities at www.fightdementia.org.au. Reminiscence work is one of the three major therapeutic interventions used in dementia care in Australia. In the

ground, and in some instances being incorporated into reminiscence work.[132] In gaining popularity over the last 20 to 30 years, reminiscence, and its various offshoots, has become one of the "most popular psychosocial interventions … highly rated by staff and participants" (Woods et al., 2009: 1). The lineage of RTs can be traced to the process of life review (LR), with roots in psychotherapy.

LR as a term tends to be used with diverse degrees of accuracy along a continuum to refer to activities which include at one end, clearly defined principles practised in care homes and centres by certified trainers, and at the other end, various narrative modes by which one individual may access, organise and represent themselves in connection to their pasts, in a variety of modes and in the present (Mangan, 2013: 124). As Michael Mangan notes "[l]ife-history discussions, life writing, life reviews, narrative and reminiscence of various kinds have become increasingly embedded in therapeutic and interventional care for the elderly" (2013: 125) as much as they are for those older adults living with a dementia diagnosis.

LR emerged from ideas first articulated by gerontologist Robert Butler[133] in 'The life review: an interpretation of reminiscence in the aged' (1963). Butler defines LR as:

> a personal process by which a person evaluates his or her life as it nears its end. This *spontaneous* psychological event is seen especially when one is confronted by death or a major crisis, although some individuals may not be fully aware of it and may even deny that it is happening at all. The intensity and emphasis placed on putting one's life in order is most striking in old age (Butler, 2013; my italics).

Butler (2013) proposes LR to be a naturally occurring process (a "spontaneous psychological event") where the person looks back on his/her life and reflects on

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'Alzheimer's Australia Therapies and Communication Approaches' worksheet (in the Appendix) the other two main approaches listed are validation therapy and music therapy.

[132] Sense-based therapies include varieties of flora and fauna therapies like gardening and interacting with pets, as well as arts interventions in which the body and the senses are engaged, like dancing or moving to music.

[133] Butler, who also coined the term 'ageism', focused on breaking down the broad concept of senility that had dominated the 1970s and 1980s to distinguish irreversible and reversible dementias and to make funding for AD a priority. As a gerontologist, Butler was among those who created old age as a field of research comprising biomedical and social scientists, policymakers, activists and entrepreneurs. Their forebear was I.L. Nascher, the father of geriatrics, who in the early twentieth century, framed old age as an ethical problem for medicine, in this way finding a voice for older subjects and moving senility into two categories: normal ageing and dementia as a pathology, where unfortunately the normal elder was redeemed as the liberal subject but not so the 'demented' subject.

past experiences, including unresolved difficulties and conflicts. What he assumed to be instinctive was then incorporated into a psychotherapy for older people, where life review was stressed as helpful in promoting a sense of integrity and adjustment (Woods et al., 2009: 2). LR involves individual sessions, in which the person is directed to produce a life story in a recognisably chronological form. Interestingly, when it was first introduced to dementia care over 27 years ago (Norris, 1986), LR was conceived as a methodology for change, whereby institutional and familial care partners could be encouraged to positively reconceptualise people with senile dementia. Up to that point, any reminiscing they did was viewed as a problem, as they were, for living in the past. Butler's work started a change in professional perspectives so that older adults both with and without dementia could be understood to be involved in a lively practice of adjustment. It is also likely that increasing interest in oral history spawned by the rise of 'cultures of confession' in the West made the reminiscences of older people better valued.

In referring to 'cultures of confession' I am suggesting that telling one's own story (or portions of it) has become the zeitgeist of the last decades of the twentieth century into the first decades of the twenty-first century. The West is "a singularly confessing society" as Foucault (1990: 59) argued in 1976. Confessional spaces, from the private to the public, have proliferated and are multiplying. Stories (many of trauma) are told and re-told by individuals in private rooms to psychotherapists, one to one, over and over, and, in some cases, year after year. Confessions from ordinary people instantly transformed into five-minute celebrities by the act of confessing are constantly available in various forms of the mass media. In chat shows like *Dr Phil*, stories (often traumatic) are told one to hundreds of thousands, crossing from the USA to other countries and cultures, like an invading army. Developments in digital technology have allowed the proliferation of blog and webcam confessions broadcasting the private and displaying the 'self' on public platforms, as well as in the theatre. As Deidre Heddon encapsulates: "[i]f we were confessing animals in the 1970s, we have by now surely mutated into monsters" (2008: 160). This growth of testimonial cultures would have helped to make LR more acceptable and seen less as a problematic retreat to a past no longer existing (Woods et al., 2009). Butler's work helped long-term memory recall to be framed as a strength rather than as a weakness.

RTs undoubtedly have worth, depending on the person and the situation. For those not cognitively disabled, life narrative sessions may provide "coherence, resolution, or direction" (McLean, 2006: 158), incorporating a sense of continuity, an aid in the transition towards death, as well as intra- or inter-personal development (Hsieh and Wang, 2003). For those who are cognitively disabled, life narrative sessions may provide ways in which the person's story and identity can be co-constructed with a "vicarious storyteller" (Hyden and Antelius, 2011: 593) using certain questions or prompting certain story lines to re-member them into the family history; or for care partners or volunteers to use as a way of building relationships. Life narrative sessions can be seen as both a repetition and a variation on the autobiographical invitations and injunctions that have no doubt been a staple of the past and present everyday lives of the participants in and through which people's experiences can be valued and heard (Poletti, 2011: 75). In this sense, narrative recall will most likely provide a sense of continuity.

Moreover, reminiscence has a cognitive rationale. People with dementia recall more memories from an earlier life than from other time spans (Morris, 1994). They have difficulty with short-term memories, and, as well, performance across the whole lifespan is impaired, as often memories from the middle years are lost. Recalling memories from earlier times in anecdotes which are well rehearsed and much practised could provide some security to people living with a dementia diagnosis: the disappearance or diminution of their middle-year memories could disconnect their past from their present, and could leave them struggling with personal identity issues (Woods et al., 2009: 3). RT has also governed design choices in care facilities, seemingly to good effect: for example in Hogewey village, various living spaces are designed to suit residents' life histories.

Yet there are also limits to the efficacy of RT when considered as a panacea, particularly given its institutional reach. There are three main matters that cause me disquiet in this regard. Firstly, I am troubled by the increasing interest in conducting reminiscence sessions jointly with families and other care partners (Bruce and Gibson, 1998; Thorgrimsen, 2002), perhaps as part of the move towards co-curation of stories as mentioned above. Although it may also have many positive sides, like any intervention thought to be universally 'spontaneous' or 'naturally occurring', reminiscence could be used to justify unthinking and

potentially oppressive behaviours with different individuals, and involving the families or institutional carers could make matters worse.

Life narratives are used to foster and promote community and family bonds (Poletti, 2011: 76). They have a relational function, part of which is coaxing or coercion. When dementia is a factor in the production of life stories in a reminiscence session, coaxing or coercion will no doubt play some part. But there is a darker side to coaxing or coercion as well, especially in institutional contexts. Determining if older adults living with a dementia diagnosis *want* to tell their stories is a significant issue, but so is the likelihood of pressure for them to tell their stories in *ways* their families or carers expect. Life stories provide 'evidence' of lives shared as much as lived solo; however, people may be constrained by this sharing through pressure to align the evidence into "known scripts" (Smith and Watson, 1996: 12) in terms of the shape as well as the content of the recalled events.[134]

In terms of the shape of life stories, known scripts will most likely present significant impediments to an understanding of the extant meanings of life experiences told by many older adults living with a dementia diagnosis, especially those in the later stages of dementia. Participants could be forced to structure stories in response to the framing discourses of reminiscence and the discursive contexts in which they are produced rather than in a shape that makes sense to them. In terms of content, socially unacceptable life experiences might be denied or eliminated because of these known scripts. For example, there could be pressure for some people to present heterosexual, gender and/or age normative life narratives in ways acceptable to family members or care partners in religious facilities (as one example), which in turn will play a role in the construction and maintenance of socially acceptable and normative subjectivities.

The second main issue of concern I have in regards to reminiscence is connected to the latter point above: the role played by reminiscence in the *construction* of subjectivity and the making of identity, and not just in the *reflection* of it. Educational philosopher John Ambrosio (2010: 739) points out that Foucault critiqued the psychoanalytic subject grounded in the same confessional and

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134 Narrative scholars have convincingly demonstrated this will happen in many different situations and time frames (Smith and Watson, 1996: 17; Eakin, 2008).

autobiographical practices that were designed to discover and liberate the subject. Foucault argues that these practices might in fact produce that subject. I think that the way reminiscence produces subjects has not been given the attention it deserves in dementia care practices and literature.

I will give an example of how reminiscence does this through a brief case study: a look inside the popular 'My Memories Book' (Alzheimer's Australia ACT, n.d.). Alzheimer's Australia (AA) distributes it as part of its Life Story Books workshops for carers, who can fill it in with life history details and photos of their loved one, and use it when they visit them, to prompt conversations and connection. The justifications given for carers filling in this visual diary are quite sound (Alzheimer's Australia ACT, 2014: 1-6). Among them are: reminding health workers of the life experiences of the person; recognising the person's achievements; and honouring the person's life-long traditions. However, there seems to be no room in the book for alternatives to heterosexual and hetero-normative subjectivities, that is, selves married with children. Single and/or childless or de facto heterosexual subjectivities, let alone gay, lesbian, bisexual or intersex, are not considered. For example, throughout the book: the term "my spouse" is consistently used; two whole pages are devoted to "My Wedding" and its photographic records (Alzheimer's Australia ACT, n.d.: 16-17); and another two to "My Marriage and Children" (Alzheimer's Australia ACT, n.d.: 18-19). There are no pictures of more non-traditional families (such as two or more women or men with their children). There are also no people of colour or Indigenous people represented in the book. Moreover, the design choices are reflective of the past: the book itself is a dark green and the pages are cream with an art nouveau floral border. It seems as if dour colours, sepia tones and hetero-normative imagery and language defines, constrains and constructs the subjectivity of anyone diagnosed with dementia.

The third main issue I have with reminiscence revolves around three general narrative devices commonly associated with it. These devices are not necessarily discrete but are often interwoven with each other. These are narrative coherence (temporal and thematic), acceptability (authenticity) and verbal language (Linde, 1993: 3; Eakin, 2008: 32). In regards to coherence, past research on language production in dementia suggests that considerable 'losses' occur, particularly in regards to temporal and thematic coherence (Ellis, 1996; Davis et al., 1997;

Thompson, 1987). This research emphasises that, although speech may be effortless and grammatically correct, it will likely be convoluted and unconnected. In the speech of people with more advanced cases of dementia, these researchers also found that grammatical errors usually occur, along with difficulty in ordering events and their sequence, and the inadequate use of referents.

Other research however, has focused on how coherence is defined, emphasising that contextual and relational factors can make a huge difference to coherence. This research has found that the *conditions* under which speech is produced will generate life stories that adhere to more accepted notions of coherence (Crisp, 1995; Killick, 1999): linguist Charlotte Linde points out that coherence cannot be located in a "disembodied text" but in the "cooperative achievement" of the discourse participants (1993: 18). For example, when people living with a dementia diagnosis are given enough time to find words, organise thoughts and to direct the conversation, as well as when they are in a relationship of trust to the person with whom they are sharing the stories, the type of language produced, as well as its intelligibility and coherence, will be markedly different. There is also the important role played by the listener in this mutual project: empathy, silence and even humility on the part of the listener will better enable older adults living with a dementia diagnosis to produce comprehensible language for creative endeavours like poetry (Killick, 1999).

The next troubling narrative device I want to consider in dementia sites is a reliance on authenticity. The historical authenticity and truth value of many dementia stories will often give way to subjective truths exemplified in often fictional recreations where new selves and stories will be created which have their own logic and do not rely on so-called objective reality. However, these stories may be disputed, rejected or changed by facilitators or families who may not understand the symbolic or psychological value of stories being told without authenticity (and coherence and acceptably structured verbal language). For instance, the inability of some older adults with senile dementia to recount their lives as others remember them, and instead to confabulate elements of their pasts, may be a strategy where they are using their imaginations to justify why their lives have turned out as they have (that is for example, institutionalised). But family members may become distressed by the lack of verifiable facts and put pressure on their loved ones to tell the 'truth'.

A good example of the point I am making above, in regards to affective truth, is provided by anthropologist Athena McLean. McLean writes about the case of a Mrs Fine who told anyone who would listen a tragic tale of her husband disinheriting her and her children because of a photo that was taken of her with an unknown man, a stranger with whom the husband believed she was having an affair. This accounted for her ending up alone in a nursing home. In fact, Mrs Fine had mixed up various pasts and the two men with whom she had been involved at different time periods: her husband and the man in the photo with whom she had had a relationship, years after her husband died. The nursing home staff and her family would vociferously deny the story, as it was not the 'truth'. McLean argues:

> The invalidation, injustice, and particular losses she suffered in her story can be matched in real life by the invalidation she experiences in response to her dementia; the injustice of living in an undesirable situation; and the loss of her freedom, autonomy, and frequent contact with loved ones (2006: 174).

When these kinds of affective truths are not honoured in dementia stories, and insistence is placed on autobiographical accuracy, older adults with senile dementia can become distressed, which can lead to an increase in their symptoms, and further pathologise what are in fact often quite understandable responses to their situations.

What is also interesting about Mrs Fine's story, according to McLean (2006), is that it in fact satisfied the criterion for a reasonable narrative structure, having an orientation, a sequence of events, an evaluation and a coda, all principles described as 'emplotment' by various narrative theorists (Ricouer, 1988; Bruner, 1990; Mattingly, 1998). Social science researcher Jane Crisp (1995) has also reported structure in stories emanating from her mother where others could not see it. Yet these factors can be overlooked because of an insistence on historical accuracy, to which most dementia stories cannot adhere.

The final troubling narrative device commonly associated with reminiscence is the reliance on verbal language. The ability to produce it or to produce it in a socially acceptable manner may be compromised in senile dementia, particularly as it progresses. At just the verbal level, although some narratives may be intelligible to a resourceful listener, others will not necessarily make linguistic sense (Kitwood,

1997: 95). Rather than insist on sense, narratives might be told through gestural and other non-verbal means (Dennis, 2002), or the notion of the life story could be amplified to include artistic forms like music and song. In other words, there could be a reframing of what the story can be and a celebration of the ingenuity that might be shown by older adults living with a dementia diagnosis in creating unique stories with their bodies or gestures.

To finish my critique of RT, I will note that it may be as popular as it is, not necessarily because of its tried and tested efficacy, but because of the rarely questioned supremacy of 'the story' in Western society, making it in turn difficult to disturb or challenge what then becomes fundamentalist and naturalised. Its success for older adults living with a diagnosis of dementia may in fact be traceable to other factors, like sociality and connectedness in the composition of the event itself, rather than the act of telling and creating a life story. Although widely used, and well researched in dementia studies and allied fields like nursing since at least the 1980s,[135] many of the studies reporting positive changes in mood and cognition as a result of the therapy have not finely distinguished whether it is the therapy itself or other factors that are responsible for positive changes (for example, the social environment, working in a group, being paid attention and so on); nor have they proceeded on the basis of consistent definitions or consistent uses and configurations of reminiscence work (for example, group or individual).

These were many of the points made by Bob Woods, Aimee Spector, Catherine Jones, Martin Orrell and Stephen Davies from the Dementia Services Development Centre at the University of Wales Bangor in their 2009 study on RT. Woods et al. conducted five trials of reminiscence therapy with 144 participants, each examining different types (for example, individual and group) and reported "[i]nconclusive evidence of the efficacy of reminiscence therapy for dementia" (2009: 2). This was despite some statistically significant results for cognition and mood (at follow up) and general behavioural function (at the end of the trial). They

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[135] Numerous studies examining RT have been undertaken in dementia service allied fields: amongst them are Kiernat (1979); Cook (1984); Lesser (1981); Baines (1987); Goldwasser (1987); Orten (1989) and Woods (1995) (all cited in Woods et al., 2009: 3). Some studies have noted positive outcomes (for example Cook, 1984 and Gibson, 1993 cited in Brooker and Duce, 2000: 354) because it can stimulate communication, increase cognition and improve mood.

concluded that low numbers and poor quality impacted the efficacy of the results, recommending "more and better-designed trials" (Woods et al., 2009: 2) in the future. They also cautioned against interpreting their results as proving the success of RT in changing behaviours, mood, cognition and communication. Further, they warned against the assumption that memories from a person's earlier life will always be pleasurable (Woods et al., 2009: 3).

Indeed, remembering can be very distressing for some older adults who have experienced trauma and loss (holocaust survivors are one example), underscoring that reminiscence has the potential to be misused in particular cases. Eliezer Sobel told the following story on the Alzheimer's Reading Room blog on Thursday 21st March, 2013 (DeMarco, 2012). It is a story that emphasises that an insistence on reminiscence may not always be appropriate for people living with a dementia diagnosis:

> I went to a psychic and told her I was concerned that my mother was losing her memory, and she replied, "I have a feeling your mother will be a lot happier without her memories."
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> She was right. My Mom is a Holocaust refugee; she arrived in this country at the age of 14 with her immediate family. Although her beloved grandmother had lived with them for years, they were unable to obtain a visa for her, and Grandma insisted they get out while they could. She was taken away soon after on a cattle car to a labor camp where she perished a few months later.
>
> There are many stories from that time, none of them pleasant, but just to say, yes, my mother grew happier without her memories. I have felt thankful for Alzheimer's on many occasions. Not only for the positive changes I saw in her — albeit, not on a cognitive level — but also the changes I saw in me, and in our relationship.

In the comments section of the blog, 'Janet' responds:

> What a delightful piece. I especially enjoyed the part about your mother being happier not remembering. My mother is also happier now than she's been for decades, and she 'remembers' wonderful experiences that never happened — like taking a trip with Birthright (a program for college age students that's only about 10 years old) to Israel. When my girls talked about their trips there, she chimed in with smiles about hers. I'm glad that she sees her life that way. THAT's a happy ending.

When this capacity for the conflation of fact and fiction, past and present, and memory and imagination, is seen and enjoyed as a strength rather than as a weakness in the production of narrative, the creative potential of people with dementia may be able to be harnessed. Time*Slips* is an applied theatre and performance story-making intervention that does exactly this.

Time*Slips* storytelling workshops: genesis and format

Time*Slips* was conceived in 1995 when Anne Basting volunteered as a drama therapist in a Milwaukee nursing home, trying drama exercises that had worked with the 'senior theater' participants she had tracked as part of her PhD. But she found that they did not work with the residents living with a dementia diagnosis. In the seventh week of her drama project, Basting writes that she "gave up on memory, of trying to trigger thoughts of the past" (2009a: 96). Cutting out a picture of the Marlboro man from a magazine and with paper and markers in hand, Basting announced to the participants: "[f]orget about remembering … Let's make it up. What should we call this guy? You can say anything you want and I'll write it down. Anything." (2009a: 96). Someone suggested that he be called Fred Astaire; another that he lived in Oklahoma and ate fish, peppering their responses to her questions about name, place and dietary preferences with song fragments from popular tunes of their day (for example, "Oklahoma where the wind comes sweeping down the plain").

Since that moment, Time*Slips* has developed into a multinational applied theatre project with over 2,000 Time*Slips* facilitators trained across the world online; it is also embedded in over 30 facilities or organisations around the USA. It has created training manuals for facilitators; conducted and published research on the method (Fritsch et al., 2009; George et al., 2011); staged plays and curated art exhibits inspired by the stories; created a 'service learning' program for students in high school, college and medical school, and launched a new website with free, custom storytelling software (Time*Slips*, Creative Storytelling, 2015).

Time*Slips*[136] has two main components. Currently, it is primarily known as a methodology for engaging groups of people living with a dementia diagnosis and also older adults, in productive storytelling workshops. Participants usually create stories from visual prompts in an open storytelling circle in an institution, although the stories can also be created in a one-on-one situation, for example, with a care partner at home. A Time*Slips* facilitator writes the participants' contributions up on paper in front of them. No contribution is regarded as unworthy, even those that have muddled grammar, or are off the point. A frequently repeated mantra in the training materials is "there are no wrong answers" (Basting, 2009b). Training and certification can be achieved face to face in America or online across the world. Certified facilitators are supported through a Facebook page and regular webinar check-ins and check-ups. But the modality is also open to all through internet access. The answer to one of the frequently asked questions (FAQs) on the website "Do I have to take the Training to use the site?" is:

> Nope. The site is free and yours to use to share stories (with decorum and good judgement). If you want to facilitate storytelling with people with dementia, we strongly suggest you take the training, so you can be sure to get the best results (Time*Slips* Creative Storytelling, 2015).

The second and less known component of Time*Slips* is its 'celebrations'. Facilitators are encouraged to use their imaginations in sharing the stories through the creation of books, public readings, public art displays, interactive web sites, theatre pieces and so on.

Time*Slips*: resistance to the 'right kind' of dementia story

In this section of the chapter, I argue that, as a process-based and performative production of narrative not dependent on memory (Basting, 2001: 79-80), Time*Slips* creates discursive spaces of non-compliance to the 'right kind' of dementia story. It allows for re-stor(y)ing experiences in which multiple, contingent,

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[136] In an article written in 2001, 'God is a talking horse: dementia and the performance of self', Anne Basting (2001) refers to both the professional plays and the storytelling workshops on which they were based as Time Slips. By 2009, in her book, *Forget Memory*, she uses Time*Slips* to refer to both. Her website also uses the latter style. For these reasons, I refer to Time*Slips* in this thesis.

discontinuous and incoherent narratives (and their carrier selves) may be celebrated.

As a process-based production of narrative, Time*Slips* resists the 'right kind' of dementia story in two main ways: firstly, it challenges the life story as demanded by more traditional life story formats and reminiscence work, setting memory aside, but not entirely rejecting it. Secondly, it creates new stories rather than replaying old ones and, in so doing, radically celebrates the chaos of dementia stories along with the performativity of the participants.

I will begin with its first point of resistance: against reminiscence. RTs usually rely on memory as an important carrier of identity. Memories are usually talked about or filled into life storybooks chronologically: starting at birth and focusing on major, significant life events that have actually happened (Hsieh and Wang, 2003). Time*Slips*, on the other hand, sets memory aside. As I have already mentioned, when Anne Basting's efforts to create stories out of the memories of the participants in her drama group were to no avail, she made a radical decision to 'forget' memory (Basting, 2009a: 95-96). Despite Time*Slips* being premised on forgetting, as can be seen in its genesis story and in the title of Basting's (2009a) book *Forget Memory*, it does not actually dismiss memory outright. In fact, long-term memories, along with imagination, play a vital role in the intervention. Long-term memories are often strong in people diagnosed with senile dementia, as I have already noted.

In analysing some of the stories produced through Time*Slips*, the role that memory and popular culture plays is, in fact, very obvious. In what Basting credits to be the first story that emerged from Time*Slips*, a reference to Fred Astaire and the deployment of the theme song from the musical *Oklahoma* surface as two examples. There are numerous other examples from all of these early workshops,

including stories with remembered songs or snippets of songs like '*Que sera sera*', '*Cera luna mezza mara*', 'Too fat polka', 'Beer barrel polka', 'Daisy, Daisy give me your answer do', and 'Abide with me' as well as characters like the Three Musketeers and Gina [sic] Autry (Basting, 2001: 84-87).

Rather than dismiss memory entirely, what Time*Slips* seems to be asking is for an expansion in cultural understandings of memory, exposing the hubris that personal memory is a large part of selfhood. As identity is always both personal and social, so too memory can never be a solely individual act. Memories are formed within culture and triggered through culture (Halbwachs, 1992). Memory, therefore, can be used to affirm and define the self, but always in relation to others. Time*Slips* is a process-oriented performance of narrative in which the teller can form social bonds with staff and other group members. Social bonding involves having shared memories of culture and communicating them with other participants and staff.

The second important factor in Time*Slips*' resistance to the 'right kind' of dementia story is its elicitation of "new stories" from visual prompts, in which all contributions from all participants are included, complete with "missing words, repeated sounds, and hazy memories" (Basting, 2001: 80). This type of open-form storytelling sets up a radical challenge to certain theories about the healing power of narrative, where claims are made that telling illness stories is always an ethical and political act of healing, if not a literal cure for the bodies of the marginalised and ill (Frank, 1997, 2010). This type of open-form storytelling in effect sanctions and celebrates what social narratologist Arthur Frank (1997) would term a 'chaos' narrative.

The chaos narrative is one of three main types of illness narratives catalogued by Frank (1997), in *The Wounded Storyteller: Body, Illness, and Ethics*: the other two are the restitution and the quest narrative. Frank (1997: 75) argues that people tell their own stories using these culturally accepted narrative genres. The restitution narrative has a basic storyline of "[y]esterday I was healthy, today I am sick, but tomorrow I'll be healthy again" with medicine featuring triumphant (Frank, 1997: 77, 1998: 115). In quest narratives, suffering is met, accepted and used, but it is the storyteller's perspective that holds illness at bay (Frank, 1997: 115). For Frank, chaos narratives are anti-narratives: "time without sequence, telling without mediation, and speaking about oneself without being fully able to reflect on oneself … these stories cannot literally be told but can only be lived" (1997: 98). Frank argues that these types of stories cannot be curative as "no sense of sequence redeems suffering as orderly, and no self finds purpose in suffering" (1997: 105). Giving an example of a chaos narrative, Frank uses a story told by a chronically ill daughter caring for her mother who has AD: "[h]earing the story in Nancy's talk is

not easy … the story has no narrative sequence, only an incessant present with no memorable past and no future worth anticipating" (Frank, 1997: 99).

There are two main issues with Frank's dismissal of chaos stories as curative. The first is that it ignores the fact that these types of stories are often richly experimental and imaginative. Their non-linearity is a valuable marker of their creative abundance, with potential to open up the storying of lives in a way that more accurately reflects the lived experiences of the participant storytellers. The second issue is that Frank's definition limits remediation through narrative to text only (Basting, 2006: 182). As a process-based production of narrative, and underneath its seeming chaos, Time*Slips* presents its participants with the opportunity to experiment with language and narrative and to partake in the joys of creative experimentation.

In experimenting with language, Time*Slips* asks that all answers be accepted, and even individual word fragments be folded into the production of these community narratives, including sounds, if this is the limit of the participants' language. For example, in the original projects Basting writes about in 2001 and 2009, some storytellers would add their own names as characters in the stories, often doubling as tellers and, for example, a bear who dances the cha-cha (2001:83). Staff and facilitators worked with the participants on the stories by laughing and singing along with the groups, occasionally in what seemed like complete verbal nonsense. "Babababababa" was one contribution that became part of every story at that time (Basting, 2001:81). One staff member said to Basting that, "[b]y doing the story telling, it's like they are telling their own life story. They are putting it together and they are loving it" (2001: 82). Crucially, the Time*Slips* stories were not cleaned up; they remained in the list-like form in which they were gathered, revealing common themes like longings for freedom or acceptance. According to Basting (2001), as language was freed to carry emotional rather than literal meaning, staff and facilitators also gave up looking for symptoms of the disease in the spoken word, and the social identity of older adults living with a dementia diagnosis was improved.

My argument is that it is this *process*-based production of narrative that supports the unique performativity of older adults living with a diagnosis of dementia, rather

than trying to change it. Performativity here refers to the way these adults perform their lives and voice their stories (Basting, 2006: 182) as well as to the constitutive effects of these narratives on their lives. Time*Slips* gives a performance space to these seemingly chaotic and incoherent stories rather than suppressing them through efforts to make these older adults tell their stories in a more socially acceptable manner. Time*Slips* also celebrates this chaos, which is the real story that heals, and not necessarily the autobiography rooted in the past and ideas of linearity. It also gives the participants an esteemed role to play in their institutional setting (that of storyteller), so that the chaos is framed as creative expression and, in a sense, licensed.[137]

In sum, as a creative storytelling intervention, Time*Slips* is both aesthetic expression (the production of wildly imaginative stories that tell a world) and therapy (individual creative expression assumed to be of personal benefit to the participants, as well as the enhancement of their communication skills). It carries the possibility of bearing not only on the well-being of the individuals involved, but also on that of the communities of which they are a part. If, as a result of the project, staff interactions with the group participants change for the better, as Basting claims, (because of the way a reframing of capabilities is allowed), then the project can be said to have political as well as ethical outcomes. In other words, an aesthetic system (Time*Slips*) works in particular communities (a day centre in Milwaukee, among others) to disrupt and reframe the normal perceptual coordinates operating in that community.

This makes it a political project in Rancière's schema, where the institutional recognition of these people not just as bodies in need but as people functions as a valuable and important disruption of the "distribution of the sensible" (2004: 12). Time*Slips* can also be categorised as an ethical project given that it is premised on a challenge to the whole notion of what it is to be human, both through the workshops in situ and through the disruption to the quotidian performances of selves in institutions or para-institutions. When naturalised assumptions to do with

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[137] This underscores Erving Goffman's (1959) ground-breaking notion in *The Presentation of the Self in Everyday Life* that the self results from society and not its own machinations. Goffman argues that the "self is a *product* of a scene that comes off, and is not a *cause* of it" (1959: 252; italics in the original).

thinking about, discussing and interacting with older adults living with a diagnosis are challenged, then there is a chance to reposition them in new words and worlds. Through a re-conception and re-materialisation of people with senile dementia in Time*Slips* performances, "another world [may become] possible" (McRuer, 2006: 71) as ideas of deficit and lack are replaced by relational and embodied understandings affirming their humanity. Performances of possibility may then be actualised.

Time*Slips*: problems of control, power and regimentation

However, the picture I am painting looks far less 'sunny' when one looks to the relationship between Time*Slips* and issues around social intentionality (as articulated in the previous chapter). Regardless of its idealistic purposes, problems of control, power and regimentation are likely to butt up against the positive intentions of theatre practitioners and volunteers applying this intervention, especially within the multifaceted contexts of aged care facilities, with all with their accompanying institutional performances and constraints.

Institutional constraints are a normal part of life in aged care homes. Aged care work is usually highly task-oriented with demands on care staff to support large numbers of people in tightly repetitive and regulated regimes like washing, dressing, feeding and so on (Hatton, 2014: 356) particularly in state-funded and/or not-for-profit care homes. Therefore it is likely that the presence of theatre artists or people engaging in theatre-based practices could be seen as disruptive to these routines. For example, Time*Slips* workshops rely on chair circles and places where the flip charts on which the facilitators write up the residents' stories can be accommodated. In some institutions, the only places available might be rooms where changes to the proxemics would disrupt the routine: for instance, if the storytelling was situated in a dining room, and lunch or dinner settings were displaced to make room for the workshop, or if the workshops were held at meal times. Positive intentions may encounter all kinds of obstructions in institutional contexts where multiple and contradictory motivations and power relations are present, although this applies to any intervention, not just Time*Slips*. For example, there may be those who have benefitted from a power difference in the past, which

could mean that they would begrudge and, consciously or not, work against the empowerment of the participants in the projects. These kinds of realities underpin the need for change to be considered at levels other than grassroots or personal. Applied theatre and performance needs to be more regularly engaged with those people who can bring about structural transformations, that is, those in power (Thompson, 2009). The changes wrought at Starett Lodge, which is a Uniting Care aged care facility in Wyong, New South Wales, Australia through the work of its manager Colin McDonell, are an example of the effect which top-down changes can bring to an aged care facility.

These changes at Starett Lodge, as well as numerous other creative ventures, which are increasing across various countries (Hatton, 2014), were not in play when my mother was institutionalised. Currently, dementia care is being rethought and changes are being implemented in more and more aged care facilities. Some of these changes recognise the role of the arts in promoting the health and well-being of older people. Along with this, new ways of working with older adults living with a diagnosis of dementia are being canvassed. In the final section of this chapter I introduce ways in which narrative can work appropriate to the needs of specific sites, cultures and individuals in care homes and also in ways that do not restrict the application of narrative to life stories only, nor just to the word as Time*Slips* does, even if that word is deployed in a process-based performance of story that is also performative*.*

Narrative places/spaces

This section of the chapter reflects on the significance of specified narrative practices in care homes wherein certain applied theatre artists and care home staff have created embodied, immersive and relational performance spaces. These spaces, which I term 'narrative', weave material, sensory and imaginative objects and qualities into a layered ecology for older adults living with a dementia diagnosis. The actual *place* of the care home is thereby not just determined by its bricks and mortar, nor by its institutional regimes, although these play a role to a greater or lesser degree, depending on the particular facility. But the home may also become a metaphorical *space* of possibility where selves are allowed to be

both who they are now and who they were once, and even selves they have never been, involving play-acting and improvisation, as the real and the imaginary are happily conflated in day-to-day interactions. I start with an examination of ways both age and illness have been theorised by a variety of writers as metaphorical places, before moving on to a brief exposé of a select number of narrative spaces.

Referring to American writer, playwright and Jungian analyst Florida Scott-Maxwell's memoir, *The Measure of My Days*, written when Maxwell was 85 and first published in 1968, as a fiery testament to age as "an intense and varied experience" (Scott-Maxwell, 1979: 5 cited in Fuchs, 2014: 72), Elinor Fuchs maintains that age is often envisioned in terms of landscape as "a series of 'places'" (2014: 72). Illness has also been theorised as a 'landscape' of biological disease with all people having "dual citizenship, in the kingdom of the well and the kingdom of the sick" (Sontag, 1991: 3). Just as the ill person may be literally taken out of everyday social life and moved to a place reserved for the unwell (a hospital), so too the person living with a dementia diagnosis is often moved into a care home or moved metaphorically, from the moment of diagnosis, into what Kate Swaffer has theorised as a place of "prescribed disengagement" (2014). Whereas with the sick, this separation may have a practical rationale (such as minimising the risk of infection), with dementia, although the motivation may also have practical elements, it will also most likely have a symbolic rationale where the removal presents the minimum disruption to social life for the care partners (Frankenberg, 1986: 616). Although other markers like gender and race may rate, a crucial feature in this literal realm of the care home will be the person's diagnosis, and through this they could tend to be assigned to yet another and metaphorical realm, already discussed in the introductory chapter, that of the 'living dead'.

Place and space are frequently theorised in opposition, with place seen as local, inhabited, socially determined, and space as disembodied and abstract; or with place as secure, closed, fixed and stable, and space as open, free, mobile and risky, which has led some theorists to posit place as reactionary (Massey, 1997 [1991] cited in Heddon, 2008: 94). Space and time have also been conceived in opposition: "Space was treated as the dead, the fixed, the undialectical, the immobile. Time, on the contrary, was richness, fecundity, life, dialectic" (Foucault,

1980: 70). As geographer Doreen Massey describes it, "[o]ver and over again time is defined by such things as change, movement, history, dynamism; while space, rather lamely [sic], by comparison, is simply the absence of these things" (1993: 148). Time is gendered as masculine; space as feminine (and disabled).

The postmodern disruption of these oppositions has led to a more refined evaluation of space not as a "passive, abstract arena on which things happen", but rather as constitutive of the social and thus a site for political change (Keith and Pile, 1993: 2). Lives are lived both in space *and* time. The term 'TimeSpace', as pressed by human geographer Nigel Thrift, captures the idea that temporality and spatiality are in fact not discrete but in dynamic interplay (May and Thrift, 2001), especially for older adults with dementia who may be moving in and out of the present and the past while living in a space that may be more restricted than the homes they lived in before their move into residential care (Nicholson, 2011b).

Places and selves are also interconnected. As Deidre Heddon notes, all lives are 'located': embodied as gendered, raced and sexed subjects and also in and through specific spaces (2008: 88). She also contends that identity arises from place. In other words, who we are is often conjoined with where we come from (or have been), thus linking the private self to the public or communal (Yi-Fu Tuan, 1974 and 1977, cited in Heddon, 2008: 93). Moreover place has always been important in the experience of persons with disabilities. The politics of location has been a constant theme in disability history, including the difficulty of accessing civic spaces and incarceration in institutions because of physical and mental differences to normal individuals.

Disability and age studies, hand in hand with theatre and performance studies, have a critical contribution to make to theorising the potential of 'narrative spaces' for those living with dementia in care homes and like facilities. These spaces are areas of possibility which work counter to notions insistently theorised in dementia cultures about loss and deficit. What I mean by this is that when it comes to dementia, the biomedical gaze tends to predominate. People are seen as embodiments of an impaired brain and their behaviours as symptoms of awful diseases for which there are no cures. But place, space and how people are treated within these spaces can make a difference to the experience of dementia,

and even alter brains, as Tom Kitwood theorised in his idea of "rementing" (1997:4). The social model of disability has long argued that disability is constructed in the environment and not (just) in the materiality of bodies. Where older adults with dementia live, and how these places are designed and organised socially and environmentally, will play a vital role in making life better for those living with a dementia diagnosis.

Place and space, as cultural geographer Yi-Fi Tuan (1977) argues, are constantly permeated with values and beliefs. If, as I have been arguing throughout this thesis, dementia is already a 'site' where certain assumed values and beliefs are steering its popular conceptualisations, then physical places like care homes too will be driven by these values, whether consciously or not. As journalist Sanjay Gupta writes, people with dementia "live in non-descript buildings and anonymous wards with lots of white coats, non-stop blaring television, and superfluous sedation" (2013: n.p). The conclusion reached by social science researcher Michael Meacher, after his 1972 study of residential homes, still holds true in many care homes today: that "the social psychology and general arrangements were virtually sufficient in themselves to actually 'drive people demented'" (Kitwood, 1997: 46).

In the following examples, some from innovative approaches to the organisation and management of care homes, and some from specific applied theatre practices, ethics emerges as central to the work that space is allowed to do, in concert with theatrical narrativisation, person-centred care principles and the notion of capacity building through agency. The revisioning of space through theatrical and performance based narrativisation becomes a resistant tactic that not only gives voice to those who might be usually silenced or thought not to be able to speak, but also a way in which the subjectivity of those living with a dementia diagnosis can be reimagined. In the following paragraphs I first discuss Starett Lodge and its Bucket List, and then Hogewey village in the Netherlands. These case studies are interesting because they show how some institutions are making changes in dementia care and are playing a different role to the past (and the present, in some instances). They also show the important link between the construction of disability and the environment.

Starett Lodge: the Bucket List

My first example of a 'narrative space' comes from Starett Lodge, where the manager Colin McDonell is committed to the prevailing discourse of personhood (Kitwood, 1997), but recognises that in order for 'personhood' to operate effectively in any institution, there needs to be a commitment from all parties, so that it can move from being just an idea to which 'lip service' is paid, to an active, living and embodied concept. At Starett, it appears that the concept of personhood is not just tied to personal storying, but to the roles played by both the physical and the social environments in which life is lived there.

In a 16-minute documentary made about some of Starett Lodge's practices entitled *Finding the Why: Enabling Active Participation in Life in an Aged Care Facility* (easily accessible on You Tube), McDonell talks about how the physical environment was changed to bring in more light, known to be very effective in treating depression, commonly co-morbid with dementia. Communality is also stressed. Many of the activities in the home are not done *for* the person with dementia but *with* the person, so that they become "participants" rather than "recipients", with the staff "on tap rather than on top" as McDonell so effectively expresses it; there to help out the residents if need be. He expresses a keen awareness of the fact that so many people in care homes lose agency and choice because of risk-aversion strategies. Care in this home is defined as much about capacity building as about monitoring risk.

Starett Lodge, like many other care homes is both a physical place and a space of transition, and in this way it is also a liminal space. It is a place/space where the person will most likely not go back to normal life, but to further debilitation and death, with all the affiliated terrors and dreads that this vulnerable state engenders (Becker, 2011). And yet, any liminal space will also be imbued with possibility, even if just in small moments. This idea of the liminal as a threshold experience bursting with the possibility of transformation comes from the writings of anthropologist Victor Turner (1979) on ritual as 'social drama' for groups and individuals. Turner identifies the liminal as a reflexive time in which what he terms "neophytes" are between realities, not who they were, but not yet who they are going to be (1987: 4-5). Between time and space apart from daily duties, and

disconnected from everyday social interactions, Turner's liminal may include the reversal, destabilisation and disputation of quotidian roles, as well as playful performances of unorthodox realities as a way to evaluate the individual's social role and that of others. The liminal period is "a time of enchantment when anything might, even should, happen" (Turner 1979: 465). It can also be a 'TimeSpace' (May and Thrift, 2001) of empowerment.

"It's amazing the things that Colin cooks up for us to do that makes us feel part of the outside world as well as part of here ", says Violet Kelly one of the residents in *Finding the Why*. I will use one of these "things" to demonstrate a very specific 'narrative space'. It is called the 'Bucket List'. It originated when some of the residents decided that they wanted to achieve a few of their dreams, long since assigned to the dustbin because of how their advanced age and their dementia were viewed, by others, as much as by themselves. They decided to start a 'Bucket List', a colloquialism containing a lovely tongue-in-cheek nod to the death they are keenly aware is coming. In this activity, residents write lists of what they want to do before they die, and then do it; who goes first depends on names drawn out of a hat. One 85 year old wanted to skydive, which he had done when younger. After some resistance from his family and after finally gaining permission, he was taken on his skydive.

Apart from demonstrating very soundly the principles of person-centred care, the Bucket List, also allows a space where people can take on roles involving both some pretence and some actuality, and where they can become selves they have never been, or selves with some immediate power in a context where they have likely lost it. The 'narrative space' in this scenario operates through the appointment of two of the residents as managers of the Bucket List (see figure 9). The two women are not managers, they are residents, and it would be highly unlikely that they would have any of the usual responsibilities accruing to such positions. But in this 'narrative space' they take on the roles of the managers within the care home and do organise something to do with the list (it is not explained in the video): the real and the imaginary are combined in this wonderful example.
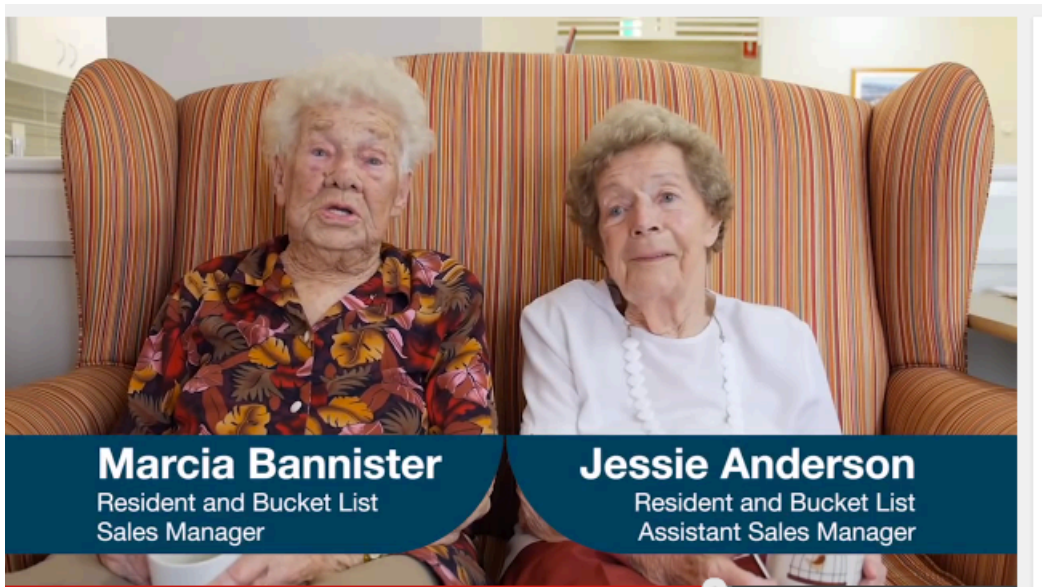
Figure 9: Video still from *Finding the Why; Enabling Active Participation in Life in an Aged Care Facility* (Uniting Care Ageing) available on YouTube at:
http://www.unitingcareageing.org.au/services/dementia-care-short-film

Hogewey

I will now discuss the second example of a narrative space, Hogewey, a village just outside Amsterdam in The Netherlands, given over to the creation of one large narrative space interwoven with various smaller ones. Hogewey demonstrates that the care home can function as a space of possibility, and not just as a place holding terror and dread, either for the care staff or for the residents. It reinforces, as does Starrett Lodge, that "space and environment, light and sound, affect us [all] bodily, emotionally and cognitively, and create the weather[138] of the horizon" (White, 2010: 167). Theatre theorist Gareth White posits that space in more traditional theatre settings offers invitations, suggesting "activity and roles" (2010:167). He argues that: "[s]pace offers its affordances: walls define possibility for motion, doors present opportunities for exit, furniture and props are choices made manifest, corridors demand motion" (2010:167-8). As in theatre performances, Hogewey offers its inhabitants invitations to perform in roles and activities that accord with the particular ways in which their dementias manifest, as I will now outline.

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[138] White uses 'weather' as Martin Welton does in *Feeling Theatre* (2012) to allude to the preponderant affect in which performers do work and audiences receive it.

Hogewey was originally a conventional care facility with wards, and common rooms where people would watch TV and wait: for medication, for meals, for death. Yvonne van Amerongen, one of the founders of the village says:

> It wasn't living. It was a kind of dying. This isn't how I'd like to spend my last days, how I'd wish my father to spend his last days. So we asked the question: How would we want to live? (Fernandes, 2012).

In 1992, van Amerongen and six other people began to research and brainstorm answers to that question, opening the new Hogewey in December 2009. It is a gated 'village' built on four acres, where its 152 residents are free to roam, even at night, without shackles or locks (up to the borders). Discreet 24-hour audio and visual surveillance minimise the risk of harm. Based on the idea that people with dementia have long-term memories that can be harnessed through efficacious and creative reminiscence strategies, Hogewey has been described as a "step back into the 1950s boasting pretty, manicured streets, a grocery, cafe, coffee shop, restaurant and even a beauty salon and barber shop" (Archer, 2012). The barber at the local salon, the chefs in the restaurants, the shopkeepers and the bus drivers are, in reality, all specialised health workers. Here residents wait at bus stops where the bus does come, with a nurse or a care assistant driving it, fostering an illusion of independence and a sense of integration in village life, but both of which are based on the pursuit of a fiction.

The 'Bus Stop', used in some care facilities for a while now, is an example of a 'narrative space' where fiction and improvisation ease the distress of dementia. In *MBDJ,* which I discussed in Chapter 2, there is a vignette where a woman in a hounds-tooth jacket waits patiently at a bus stop for a bus, which does not come. A nurse, complicit with her fantasy, tells her that because they have missed the bus, they should now have a nice cup of tea, providing a distraction from the woman's desired reality so that she doesn't get upset. At Hogewey, the 'Bus Stop' has been extended into a series of such spaces within one overarching space, a village.

At Hogewey, theatre and therapy also intersect in the yet smaller 'narrative spaces' called lifestyle options, where people are placed with others of similar backgrounds, experiences, values and interests. Residents live in one of seven different 'lifestyle' categories: religious, cultural, urban, homemaker, trade/craft,

upper class and Indonesian,[139] where moods are evoked by the furnishing, decoration, and art in an insistence on the creative revisioning of reminiscence. The life narrative of each individual's formative years is not told but rather lived: "The doctors' and 'carers' job is to make those seven worlds as real as possible: through the way the home is decorated, the food, the music, even how the table is laid" (Fernandes, 2012).

One example of the intersection between theatre and therapy at Hogewey comes from journalist Edna Fernandes (2012). In the vast living room of the workers' group she saw two carers: one ironing and chatting; the other preparing dinner. A resident, Jo Verhoeff, 86 years old, was helping one of the carers, whom she thought was a friend, by peeling potatoes with a small knife. Jo said to Edna: "I live here with my friends, the food is good, the people are lovely. My girlfriends are lovely [she point[ed] to the carers]." A former office worker, Jo told Fernandes that she is married, has two young children and is in her 40s. Fernandes later found out that Jo's husband died some time before and her children are grown-up. van Amerongen says :"It's so important we don't correct her. It is the fake reality that keeps her well." As Gupta says, "It's the only place of its kind, on its scale, anywhere in the world" (2013).

Hogewey has been nicknamed a 'Truman Show for the elderly and sick', after the Jim Carrey film in which reality turned out to be the set of an elaborate TV show (Henley, 2012). Eloy van Hal, the facility manager, admits there are some issues:

> Sometimes the illusion falls down; they'll try to pay at the hairdresser's, and realise they have no money, and become confused. We can still do more. But … you don't see people lying in their beds here. They're up and about, doing things. They're fitter. And they take less medication. I think maybe we've shown that even if it is cheaper to build the kind of care home neither you or I would ever want to live in, the kind of place where we've looked after people with dementia for the past 30 years or more, we perhaps shouldn't be doing that any more (Henley, 2012).

Hogewey's success can be attributed to its use of the basic building blocks of performance to create a narrative space. As with performance, Hogewey is:

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[139] The 'Gooise', or aristocratic Dutch; the '*ambachtelijke*', or working class; the 'Indische', or those of Indonesian origin who migrated to Holland from the former colony; the 'Huiselijke' or homemakers; the '*culturele*' who enjoy art, music and theatre; the urban sophisticates who relish city life, and the 'Christelijke', for whom religion is paramount — whether Christianity or another faith.

a special world set aside from everyday life by contractual arrangements and social suspensions, not entirely hermetically sealed, but a devised world, all the elements of which – site, environment, technology, spatial organisation , form and content, rules and practices –are conceived, organised, controlled and ultimately experienced by its order of participant (Pearson, 2001:27).

Other 'narrative spaces' are being created all around the world through the work of specialised artists in health care, most of whom work in pairs and distinguish themselves through the use of red noses, the international symbol of fun, for example Jovia in Canada, Big Apple Circus Vaudeville in the USA and the Elderflowers in Scotland. The red noses provide an immediate visual sign for both the residents and the staff that these are artists and not medical staff. The noses are also clear visual markers that their purpose is fun. In Australia facilitators operating 'The Smile Within' wear red uniforms and caps to distinguish their clown work.

In sum, the relevance of play in dementia, creative adaptations of reminiscence, as well as interventions other than reminiscence, are now being explored in some dementia care settings. For one Starett Lodge resident lucky enough to live in a care home where the vital relationship between the environment, performance and health is well understood, "life is just one experience after another". As disability and performance scholar Arseli Dokumaci argues (2014: 114), when the environment is not seen as a fixed entity but:

> in its own becoming then it becomes impossible to sustain a moral boundary that presents health and illness in opposition. For when life is not considered as 'a principle that is separately installed inside individual organisms' but as 'what is going on in the generative field' — a field that is 'constituted by the totality of organism environment relations' (Ingold 2000: 200) — illness does not stand for something 'below' or 'fallen'. Instead 'the possible abuse of health', as Canguilhem says in alluding to Valery, appears as 'part of health' (1989: 200).

Dokumaci's argument is paralleled by Tom Kitwood's reference to the "ecology of [dementia] care" (1997: 93) which refers, not to a "fool's paradise" (1997: 95), but to an environment where the "illusion of incapacity" (1997: 95) is challenged because the whole environment, including spatial, temporal, material and interpersonal dimensions, supports what older adults diagnosed with dementia are capable of, rather than focusing on problematic behaviours and non-normative

communication styles. This will hopefully put into jeopardy the moral boundaries that create a 'them' of dementia worlds and an 'us' of supposedly normal cognitively intact worlds, seeing how our worlds are not separate but strongly interconnected and interdependent.

In summary, I have argued in this chapter that it is vital for applied theatre artists working with older adults diagnosed with dementia to create new stories and, if not to actually move away from reminiscence, then at least to move away from unimaginative renditions of it. Only conceiving of people living with a dementia diagnosis in terms of who they were rather than who they are now or who they could be may be constricting, not only their possibilities, but those of the narrative form itself. Performed narratives that deviate from a reliance on the word and take seriously the whole environment where older adults live, need to be promoted, including new stories or ways of performing them that more fully understand and build on the narrative capacities and creativities of people with a dementia diagnosis. These reconfigurations of narrative could include the creation of narrative spaces where narrative is not restricted to the creation of a life story, nor even a time-based performance modality, but rather permeates every part of the institution and the lives of its inhabitants: its material and spatial dimensions.

Having used this chapter to deliberate on a number of narrative-based paratheatrical interventions deployed in institutions and mostly not seen by publics, in the next chapter, I consider a particular form of performed first-person narrative where people diagnosed with dementia do perform to publics, even if those publics are mostly their family, friends, carers and doctors, or on occasion, the general public, via the internet. An exploration of this modality provokes questions as to whether or not the autobiographical (verbatim) form is appropriate for people diagnosed with dementia, as well as catalysing issues in the theatre and performance and disability literature.

Chapter 6
"I Don't Want to Disappear": Dementia and Public Autobiographical Performance

In this chapter, drawing on Anne Basting's question, "Might certain forms of narrative and modes of performance actually support ideals of independence and selfhood that fuel fears of disability in the first place?" (2001: 78), I examine both ideas about, and practices of, public autobiographical performance for people living with a dementia diagnosis in applied theatre settings. The shortage of this type of performance from people diagnosed with dementia, either in professional or applied theatre circuits, seems to uphold the idea that the form, as it is commonly understood, is inappropriate for them mainly because of its reliance on memory and words to tell a life story, or part of one, on their own. However, although it presents almost insurmountable challenges for those people in more advanced stages of dementia, the form may also provide possibilities for others who are at earlier stages of their 'diseases', although it will still most likely be a venture fraught with risks, for example, in chancing the exposure of fallible memories.

Autobiographical performances foreground some aspect of a life story and are usually performed by the same person whose life story it is.[140] The etymology of the adjective 'autobiographical' reflects this. Its core segments are all derived from the Greek: auto is from '*autos*' meaning self; bio from '*bios*' denoting life; and graph from '*graphia*' for writing (OED online, 2014/2015). Autobiography, however, may be a contested prefix for the performances I consider in this chapter. Disability narrative theorist Thomas G. Couser (1997) might see them as "illness narratives". Performance scholar Leigh Anne Howard would probably argue that, when staged, these narratives become "*performed* illness narratives" (2013; my italics).[141]

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[140] However, personas are adopted by some performers, and in some recent "meta-autobiography", the autobiographical lives represented are those of fictional characters who create themselves "via performative means in the provisionally real worlds of the plays in which they appear" (Martin, 2015: 137).

[141] Although I am aware of it, I do not use the term 'autopathography' (Tembeck, 2009). 'Autopathography' is generally used to reference biographical accounts of illness or suffering that take a literary form, although Tamar Tembeck, in her PhD thesis, expands its usage to performances, choreographies and photographs in order to denote a given aesthetic form through which an experience of illness is related firsthand (2009: 5).

Nevertheless, I position my case study as autobiographical from a range of possible terms,[142] because my arguments in this chapter rest on the way both the self (the auto) and the life (the bio) are relegated as non-existent in many discursive constructions of people living with a dementia diagnosis. Using the term autobiography foregrounds this point. Bringing into play the term 'autobiography' is to stress the "unique authorship" of the work (Basting, 2003: 88), despite the fact that many issues arise from its associations with the "literary expression of the self-determined life" (Couser, 1997: 182; my italics). I consider some of these issues later on in this chapter.

I also deploy the more recent term "autobiographical *performance*" (Heddon, 2008; my italics) in order to apprehend a wide range of direct address practices in which, through the immediacy of performed storytelling, performers engage with audience members using their own life as the prime material (Heddon, 2008: 10-11). I prefer 'performance' to 'theatre' as it embraces the fullest range of practices originating in both the theatre, as well as the visual and other arts (Pearson, 2010: 1). However, in this chapter I will sometimes use 'performed dementia first person testimony' to capture particular characteristics of one such practice which is the major case study of this chapter, *TWIMC®.* Another focus of this chapter is an investigation of the issues likely engendered by this type of performance for people living with a dementia diagnosis.

TWIMC® is an interactive theatre project where stories of living with a dementia diagnosis are performed to an audience of peers, friends, care partners and professionals. In this chapter, I argue that *TWIMC®* enables its participants to move out of the silence and invisibility expected of or imposed on them by virtue of living with a dementia diagnosis in order to simultaneously: craft work despite memory loss and declining cognitive competencies; actively construct their identities through performative telling; and advocate for change. But they also perform in groups, not alone, and have the assistance of a director/dramaturge who does not have a dementia diagnosis and who writes up their scripts for them.

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[142] A selection of the terminology used or still in use includes: "personal narrative performance" (Hantzis, 1998: 203; Langellier, 1998: 207); a sub-genre of the "performance art monologue" (Peterson, 1997: 12); "autobiographical personal narrative performance work" (Gingrich-Philbrook, 2000: vii); "solo autobiographical performance" (Sandhal, 2003: 28); "documentary solo performance" (Kalb, 2001: 13); "the testimony of autobiographical performance" (Park-Fuller, 2000: 38).

Performing in groups importantly challenges current understandings of the autobiographical performance form and its possibilities, also likely destabilising claims for 'membership' in the genre. At the same time, group performance operates as an ethico-political statement contesting the nature of selfhood as it is popularly conceived in a number of social, legal, ethical and scholarly environs, as well as in many theatrical representations, that is, as autonomous and independent. However *TWIMC®* also activates problems in relation to selfhood as in many ways it works to uphold current paradigms of able-bodied performance, such as a coherent narrative voice, and clarity and consistency of expression, many of which exclude those with cognitive disabilities who may have an incoherent or atypical voice, expression and style.

I will start with an overview of the complexities of self-representation in general, which have been well considered in the autobiographical performance literature to date. I will then argue that these complexities, deepened when disabled subjectivities take to the stage, are even further intensified when people living with a dementia diagnosis do so, especially when the form is conceived and used as a mouthpiece for disability rights activism. Given that, in Western cultures, selfhood is symbiotically linked to narrative identity, rationality and autonomy, I argue that dementia exposes and critiques certain fundamental assumptions about selfhood embedded in both the practice of autobiographical performance, and its scholarship. These are assumptions about what it is to be a 'real' person, that is, assumptions about what it is to have an 'auto' and a 'bio' and the relationship between the two (Eakin, 1999, 2008; Damasio, 2000, 2012).

Dementia as provocateur in autobiographical performance scholarship

In current scholarship, any 'common sense' generally understood notion of the self (or 'auto') as authentic, unified and 'real' has been productively challenged for a while now. It has been argued that although the self of the life story is usually on stage in the here and now, that self can only perform a version of itself. Theatre academic Gabrielle Griffin notes "performance is, of course, always citation, and as such instantly troubles the I-dentity of … [the] performer " (2004: 155). It has also been argued that there is always a sub-text (Madison, 2005). Another

argument is that the 'I' that performs is often strategically complex and layered and a result of the many collaborations which usually occur in performances (Heddon, 2008).[143]

In addition, any uncritically accepted presence of the 'bio' in autobiographical performance has also been well contested and problematised. Many scholars agree that in this genre, the fictional and the real create an unstable binary impacting both ways for several reasons (Langellier, 1999; Heddon, 2008; Nicholson, 2005; Bordo 1995). One of these reasons is that, despite the political significance of the 'bio' behind the performance, we can never be absolutely sure that the material presented is autobiographical, as the binary between the fictional and the real is extremely volatile in all autobiographical performances and indeed in all life stories. That is, "behind the story I tell is the one I don't" (Allison, 1996: 39 cited in Langellier, 1999: 131): certain parts will be omitted; others added; yet others fabricated. The relation between a life (the real) and its performed representation (the referential) is also not transparent: all autobiographical productions involve processes of selection, writing, editing and modifying (Heddon, 2008: 9). Autobiographical productions are just that: *productions* mediated through the creative assistance of other lives. So too, other lives are 'behind the story *I* tell': yet another reason for the unstable binary between the fictional and the real in autobiographical performances. All lives interweave with other lives, right from the early stages. Parents likely 'make' us in more ways than just biologically, given that they are the ones who tell us the minutiae of our early lives which are beyond our ability to recollect (Couser, 2004: 57 cited in Heddon, 2008: 182, footnote1). These are tales that lose their truth-value as time evolves and stories to which details are added and subtracted.

To capture many of these complexities, Deidre Heddon makes a useful distinction between 'autobiography' and 'auto/biography' where the latter refers to the "explicit presence of the *bio* in auto/biographical performance" (2008: 9). This declension pinpoints the relationship between the 'auto' and "the wider cultural and social

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[143] For example, Spalding Gray's *Rumstick Road* was in fact group devised; Elizabeth Le Compte, the director, structured the monologues and Gray's performance (Heddon, 2008: 8). *TWIMC®'s* script is produced in the group and edited and written up by both the group members and the director, Maureen Matthews. In many verbatim and applied theatre performances, versions of scripts will be shown to audiences who will also give feedback, changing the original script.

context, making references to others almost inevitable- mothers, fathers, lovers, friends, enemies" (Heddon, 2008:127).

Yet another reason for the unstable binary between the fictional and the real is that we always understand the real through the mediation of representation and discourse and vice versa (Phelan, 1993: 2). Finally, stories that are supposedly fictional will also have an impact on 'real' stories. The fictional narratives of myth or the stories already written in public discourse will interweave with narratives of the self and that self's experience (Nicholson, 2005: 66).

In response to all the above concerns, many of them 'border', certain performers have deliberately played with boundaries creating ambivalent and unsettling rather than precise and clear-cut representations of themselves and their lives. Yet, when it comes to *performers* living with a diagnosis of dementia, these 'border' issues will be deepened and complicated by their *lived experiences* in daily life. At certain stages of its progress, and depending on the type, dementia may mean that its peoples are always performing versions of themselves to which others may object as not true or not real. They may also *not* be performing these versions in the here and now, but between the past and the present. Fluctuating boundaries between the fictional and the real will most likely be everyday lived experiences for them. They can be confined to institutions for publically displaying or confusing the lines between fictional and real life experiences, which, as a direct consequence of failing memories, may not always match the understandings others have of their life experiences.

This means that, when it comes to autobiographical performance, the stakes will most likely be much higher for people living with a diagnosis of dementia than for many other marginalised identities in regards to the status of and relationship between the self, life, identity, reality and representation. For example, playing with ideas about the borders between reality and fiction and creating ambivalence about the status of their work, and by implication themselves, may not be an option when they take to the public stage. Beyond invisibility, and likely relegated to biosocial death because of the symbiotic association of selfhood with narrative, memory and rationality, they will most likely have been wiped off access to public stages of all kinds, not just the theatrical, from the moment of their diagnosis.

Therefore, and as has been the case for many other marginalised identities, autobiographical performance may be seen as a way for people living with a diagnosis of dementia to reclaim their damaged subjecthood, to assert their 'rights' to social recognition of their personhood, to seek redress for injustices suffered by creating a temporal link between these injustices (such as inequality) and the future possibilities, which changes to these conditions could bring about (Park-Fuller, 2000), as well as to exert some agency, rather than as an opportunity to unsettle identity and expose issues to do with self-representation. Concepts of rights, justice and agency are tenets fundamental to identity politics and disability rights advocacy. These underpinning precepts include speaking for oneself from inside a particular condition; speaking back to a history of negative cultural representations; and speaking back and claiming agency. But notions of rights, justice and agency are deepened and complicated by dementia, as is the supposed creation of subjecthood through performing life testimonies, as I will now demonstrate.

To start with, notions of rights and justice are based on certain performance criteria embedded in the philosophical underpinnings of "the (Lockean) social-contract tradition" (Bérubé, 2010: 99), among them independence, equality and rationality. This is a "capabilities approach to theories of justice" (Bérubé, 2010: 97). Moral philosophers judge what it is to be a person by these criteria, and the cognitively disabled, including those with dementia, will often be found lacking. Bioethical discussions frame Alzheimer's and other dementias as principal "limit case[s]" (Burke, 2007a) in appraisals of personhood, in debates about the worthiness of life, in discussions about where meaningful life begins and ends, and in decisions about whether the concepts of 'person' and 'human' (as a designation of species) should be distinguished (Burke, 2007b: 65).

Personhood debates in moral philosophy have been theorised by the bioethicist Theodore Fleischer as "wars", and delineated into two main strands: "personalism", where the human being can claim life if cerebral capacities and self-consciousness are present, and "physicalism" or "vitalism" where every human even those missing certain faculties is allowed to have a life (1999: 309). For Peter Singer (1996, 2009), an advocate of personalism, personhood is the capacity to see oneself as existing in different times and places by having wants and plans for

the future, rationality and self-awareness. According to Singer, there is an interrelationship between 'brain failure' and 'person failure', shaping which lives are, and are not, considered to be worth living. Those who fail to be considered persons are consigned to the standing of non-person (or a subordinate primate).

Debates over personhood in moral philosophy inform the social, cultural, moral and interpersonal ecologies in which cultural artefacts are produced about people living with a dementia diagnosis. They will also provide a crucial context for any theorisations of autobiographical performances, let alone the performances of people living with dementia. Additionally, they will most likely attenuate the desires of performers thinking about taking the stage to "talk back, talk out, [and] talk otherwise" (Heddon, 2008: 3).

Apart from notions of rights, justice and agency being intensified by dementia, the question of how the subject is realised through performing is likewise complicated. If subjecthood through performing life testimonies is secured to social and political recognition, those incapable of constructing and performing their own narratives will be eliminated in a 'Catch 22' situation. Expectations of autobiographical performance will likely include a single performer at its core who can clearly articulate his/her story in a memorised presentation. Theatre critics may tend to focus on features like coherence of the narrative, 'Shakespearean' vocal clarity and eloquent expression as measures of the 'right' to claim continuing personhood in this genre. This raises the issue of whether or not notions of agency and self-determination are the most appropriate ways of construing the politics of first-person representation in this kind of disability life performing. For it is precisely "these fictions of autonomy that render the vulnerable and disabled beyond the pale of social, political and often legal recognition" (Burke, 2007a: n.p). Performed life narratives can actually be "a barrier to further progress" in furthering disability rights as they may override people with cognitive disabilities (Shakespeare, 2006: 202). As disability scholar Michael Bérubé argues, "It is easier to speak of a barrier-free environment when one is speaking of wheelchairs and ramps than when one is speaking of cognitive disabilities" (2010: 102).

In sum, this section of the chapter has identified and explored the provocations dementia poses to autobiographical performance practice and its literature. These

include the fundamental assumptions made about selves, lives and performer capabilities in the current literature on autobiographical performance; the formulation of the category of self and person in moral philosophy and its exclusions; the impact this formulation of self has, or should have, on debates in the theatre and performance literature; the role of telling a recognisable life story (biographia) on formations of the self; and the role played by autobiographical performance for those who live outside normalising identity categories and also outside recognised identity politics movements. In this latter instance, the challenge is as to whether the form is of any value and whether other forms would be more suitable.

To deal with these provocations in further detail, I will now turn to an analysis of an autobiographical applied theatre performance modality, *TWIMC®*. I first outline its origins and its format, followed by a discussion of the political, ethical and aesthetic implications of first-person testimony it raises. I categorise *TWIMC®* under the rubric of autobiography, as I stated earlier in this chapter, as dementia provides a particular experience in which that 'I' is almost automatically denied from the moment of diagnosis (Swaffer, 2014). It is not 'auto/biography' (Heddon, 2008) as the people performing in *TWIMC®* normally read their own stories, although this is not always the case. Analysing TWIMC® under this rubric also enables a continued engagement with and a problematising of particular conventions of the genre. In doing so, I press the autobiographical performance project to its limits, reframing ways of conceptualising autobiography in performance.

To Whom I May Concern: origins and format

Figure 10: *To Whom I May Concern* Stage Play. Photo used with permission of Maureen Matthews.

TWIMC® materialised from Maureen Matthews' 2005 PhD dissertation in nursing. During her candidature, she conducted support groups for people in the beginning stages of memory loss in New York City and environs, interviewing them to find out what commonly ensues after a diagnosis (To Whom I May Concern, 2013b). With the data she collected, she created a play, which was never staged.[144] Soon after, she created a new script based on interviews with 10 people from two Alzheimer Association support groups. These 10, along with Matthews and Lauren Volkmer, a New York based director, met once a week for four weeks, sharing their experiences with early memory loss. Their accounts were edited into letters. The participants then rehearsed once a week for four weeks. The first production was in the auditorium at the Cuny Graduate Center, Manhattan, in May 2006. A second production was mounted in 2007, funded by a grant from the Society for the Arts in Healthcare and Artists for Alzheimer's.[145] Numerous others have followed.

There is a multi-part structure to the staged endeavour as it now stands (all information and quotations are cited from Maureen Matthews, To Whom I May Concern, 2013c). Matthews invites members of an Early Stage Dementia Support Group to share their experience with others outside the group. Next, a focus group is formed, comprised of volunteers who are willing to share their stories. In the

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[144] The use of data to create plays is gaining popularity in health studies (Mitchell et al., 2011).
[145] This is a program comprised of volunteers wishing to work in dementia services in New York City (Basting, 2009: 92).

focus group, Matthews and her colleagues repeat the same question: "What is it like to live with dementia?" The responses of the participants are first audiotaped and then reviewed for stories that support the particular themes decided on for the production: "past groups have told stories of the diagnostic process, impact on self perception, the reactions of friends and families, coping strategies, hopes and concerns". Matthews then transcribes the focus group responses and from the shared stories, creates a script. The script is brought to the group for validation and drafted repeatedly until the group feels "a sense of ownership of the script. Each script is unique because it reflects the people in the group though the script always follows a letter format." After this, volunteers are recruited from the group to be the readers on stage. The decision to "come out" as a person with dementia can be a difficult one, and Matthews says that she allows the decision to be given the ethical weight it deserves. Four or five readers are regarded as sufficient for the performance, but at the end of each show the whole group is invited on stage to be part of the Talk Back session, which is the last phase of the project.

In some recent productions, performers read letters from people who have now died or are in such late stages of dementia that they are not able to read themselves. As the project has developed since 2006, some stories from earlier productions have been carried over into current 2015 scripts because of their perceived power in describing the experience of living with dementia. In these few instances, the production becomes auto/biographical in Heddon's terms (2008), as outlined earlier in this chapter. The ethical challenges of reading for others are resolved by the performers acknowledging both that the letters are not their own and whose they are. The political value of airing these bios is that what is being acknowledged is the continuing importance of the lived experience of people with a dementia diagnosis. Their necessary dependence on others to tell their stories for them has ethical overlay as well. There are now also interactive online performances of *TWIMC®,* described by participants as a "travelling stage", with a similar format. One of these, *Our Side of the Fence* (To Whom I May Concern, 2013a), will also be discussed in this chapter.

"I don't want to disappear": the politics of the 'I' in *TWIMC®*

As I have already noted, for people with cognitive disabilities acquired through the onset of one of the dementia group of diseases, issues to do with identity are central. Fluidity of identity may already be an everyday state, a lived experience; or it may be a threat looming in the future. Beyond abstract theorising, people living with a dementia diagnosis may have fragmented and disoriented experiences of their selves. Perhaps because of this, in *TWIMC®*, people who have recently been diagnosed, use autobiographical performance to actively fight for their 'I' not to disappear, that is, to be seen and heard as 'themselves', and not just as symptoms of a disease. (The phrase "I don't want to disappear" is from a participant in *TWIMC®*: see To Whom I May Concern, 2013b). This is one of the major reasons why the 'I' takes centre stage in *TWIMC®* as an occasion for a re-staging of subjectivity and a staging of resistance (Smith and Watson, 1998: 434).

The title of the project is one of the seminal ways in which *TWIMC®* demonstrates its relationship to the politics of identity (the 'I'). *TWIMC®* was birthed in part as a support response to people struggling through the indignities of being seen as disappearing selves from the very start of their diagnosis. In the first 2006 stage production, John, an actor with past stage experience, opened the show as the narrator, reading a letter next to a large mailbag overflowing with letters. His role was to introduce the letters as a framework for the play. He read:

> To whom I may concern:
>
> I know you think I've made a mistake. You think I meant to write 'To Whom *It* May Concern'. But don't worry. It's not a mistake. This is not just any letter to some unknown person or persons, a form letter that complains or advises.
>
> No, this letter is not about an 'It' that may concern you, but of an 'I', that is, me. I am writing to you today to let you know what it is like to be me these days (Basting, 2009: 89; my italics).

Lodged in the title of the *TWIMC®* project is a conceit, which accentuates the importance of the politics of the 'I'. The common phrase 'to whom *it* may concern' is a typical way to address a letter when the writer does not know the recipient. Substituting the 'I' for the 'it' functions to accentuate that the letters, or the 'conversations' in *On Our Side of the Fence* (To Whom I May Concern, 2013a), are

not about an unknown recipient but the known writer (as the audiences for *TWIMC®* are usually family members, caregivers and staff doctors). But this substitution also functions to highlight the relationship between the elided pronoun and the substituted one. Selves living with dementia do become 'its' to many parts of society, especially in the course of everyday encounters with medical personnel. In this way, the rubric of the project can be said to highlight political and ethical issues to do with the self. It has special reference to the often dehumanising biomedical apparatuses with which anyone diagnosed with dementia will become embroiled. *TWIMC®* can therefore be seen to follow in the tradition of identity-based reality performances where the marginalised are uttering their own concerns, speaking out or talking back through defying, and questioning and problematising dominant ideas and representations spread about them in their communities (Heddon, 2008: 20). When subjectivity is disputed in this way "autobiography, spoken or written, offers an affirmation of selfhood" (Caster, 2004: 111).

But *TWIMC®* also operates within a therapeutic framework that could counter its politics, given that therapy is often conceptualised as focused on the treatment of an individual's perceived shortfalls over systemic social, political and environmental deficits. According to Maureen Matthews, *TWIMC®* aims "to s*upport* the dialogue between people with dementia, and those that accompany them" (To Whom I May Concern, 2013b; my italics). The word 'support' points to Matthews' nursing background and the initial and primary therapeutic aims of the project. With an emphasis on free expression, *TWIMC®* 's focus is on improving the lives of people with dementia through this expression, and through the reception of this expression by an audience. Those involved may enjoy the therapeutic benefits that creating a script, collaborating with others, and performing before an audience can bring. Their therapy may also reside in their pioneering of new identity formations necessitated by the trauma of the diagnosis often experienced as a brutal rupture between their private and public selves and between ideas of who they thought they were and who they now feel themselves to be. In this way, authoring their own work in the theatre space may also lead to a situation where they can take back some agency and authorship in their own lives, especially in regards to their treatment by doctors and other medical staff. It is in this way that the therapeutic parameters of the project in fact return *TWIMC®* to the politics of the 'I' again.

For example, in the first production of 2006, many issues of concern to the players were covered (God, caregivers, assessment teams), but the production started with issues around the experience of diagnosis, as so many of the first performers reported trauma, not only from the diagnosis itself, but from the way they were treated by doctors delivering the diagnosis. Complaints about treatment by medical staff and family and friends predominated. Both the following letters (cited in Basting, 2009: 90) were addressed to doctors. Margaret urged her doctor for more consideration:

> Dear Doctor
>
> Today was terrifying. I felt so alone. I couldn't believe those words were coming out of your mouth: " you have probable Alzheimer's disease … come back in 6 months" … I wish you could have told me more about what to expect … I'm enclosing the phone number of an Alzheimer's chapter. When I asked you for it, you couldn't find it. It might be a good thing to hang on to because it might be the only thing someone like me can hang on to.
>
> See you in 6 months.
>
> Margaret.

Richard was more scathing about the way his diagnosis was confirmed:

> Dear Doctor,
>
> I just spent $5,000 to learn what I knew when I came into your office in the first place: I have probable Alzheimer's disease. Do you think I got my money's worth?
>
> Sincerely,
>
> Your probable patient,
>
> Richard.

From the examples cited above, it can be seen that *TWIMC®* is a type of communal therapy with strong political colourings, also functioning as first-person testimony and witness. Testimony is here defined as "a transgressive political act performed without repentance … given by a witness despite restrictive taboos" (Park-Fuller, 2000: 22).[146] *TWIMC®* is testimony because it evokes an absent

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[146] *TWIMC®* is testimony, not confession. Testimony is "personal or documentary evidence or attestation in support of a fact or statement; hence, any form of evidence or proof" whereas confession is "the disclosing of something the knowledge of which by others is considered humiliating or prejudicial to the person confessing; a making known or acknowledging of one's fault" (*OED Online*, 2014/2015).

event in support of a deed ("let me tell you what happened"). It is witness because it encompasses a present speaking of a truth ("now"), which at the same time is a creative telling in the moment of a past event, with resonance for both speakers and listeners. The performers' desire to testify is compelled by three main factors: the trauma of diagnosis, the therapeutic benefits of writing and performing their stories, and the wish to construct their selfhood in the face of the diagnosis and the profoundly negative cultural representations of the disease. Importantly, they are speaking "*from* disability" and not "*about* disability" (Stramondo, 2014: 36; italics in the original). The performers involved, whom I do not call actors because they do not adopt personas, are speaking their testimony of living in the early stages of AD and other related dementias from a subject position that is quite often seen to prevent or impede first-person narration (Burke, 2007a). For this reason and for many of the others that I will now catalogue, *TWIMC®* transgresses borders and presses the autobiographical performance project to its limits.

A boundary phenomenon

As communication and performance theorist Kristin Langellier argues, personal narrative is a:

> boundary phenomenon: between literary and social discourse, between written and oral communication, between public and private spheres of interaction, between ritual performance and incidental conversation, between fact and fiction (1999: 138).

TWIMC® follows in this transgressive tradition. Firstly, its form (in both its staged and virtual incarnations) does not fit any traditional categories. It is not quite a play, not quite public speech, not quite literary narrative. The *TWIMC®* stage project is literally autobiographical: separate letters written by people diagnosed with dementia are performed on stage. On the internet in *Our Side of the Fence* (To Whom I May Concern, 2013a), the participants construct a 'conversation' between members of a support group who have been meeting online and sharing their issues for some time. Yet the 'conversation' they have is referred to as a 'script' in the end credits, which also roll with the names of "The Cast" who are in fact not actors but people telling their "personal stories of life after diagnosis": Sue

Stephens from Canada, and Joe Potocony, John Sandblom and Jan Pitts from the USA.

Secondly, *TWIMC®* is performed with other bodies, and not solo, as much autobiographical work usually is. Putting all these 'autos' in a group is a radical dramaturgical move which also quite drastically challenges the genre, as one for solo performers only, bringing it to what could be called a multi-cultural mode where individuals of different genders, class backgrounds, sexualities and with different dementias all talk together about their individual experiences with dementia, which of course share some commonalities. For example, in *Our Side of the Fence* (To Whom I May Concern, 2013a), John is on disability support and Rose has a female partner. These are different selves performing in groups and yet arguing for the consideration of being seen as individuals; they all stress their individuality in phrases like "we are all unique". However, personal narrative performance in this instance cannot privilege the individual over the community, because it is pushing the genre into communal territory. Thirdly, *TWIMC®* is not performed in traditional theatre venues (Park-Fuller, 2000: 22). For all the reasons noted above, *TWIMC®* transgresses, disrupts and blurs the boundaries between art, activism and therapy, and between performance, literary narrative and public speech.

TWIMC® is also transgressive because it performs a rupture to the distribution of the sensible in Rancière's (2004) terms. For philosopher Jacques Rancière, the "sensible fabric" (2004: 64) is those associative and practical configurations characterised by particular ways of organising who can speak, be visible and participate in society, which are simultaneously cultural, social and economic. Communities are drawn together by common ways of acting in a shared, sensible world, influencing both politics and art practices. Politics "revolves around what is seen and what can be said about it, around who has the ability to see and the talent to speak" (Rancière, 2004: 13). Artistic activities are "ways of doing and making [that] intervene in the general distribution of ways of doing and making" (Rancière, 2004: 13). For Rancière, both the public and the private are political, and artistic practices can affect both ethics and politics (Thompson, 2009: 174).

TWIMC® activates a rupture to the distribution of the sensible because people who do not even count as beings, let alone speaking beings, are writing and performing their stories, addressing audiences and making themselves visible (Kelleher, 2009: 68). *TWIMC®* provides a platform for "the unspoken-the absent-*word*- as well as an aesthetic space in which to evoke an absent *world*" (Park-Fuller, 2000: 23; italics in the original). The absent word, solidly at the centre of these productions, is from people who struggle to tell, and for whom words do not come easily, or in the manner in which they are expected, or at all. For example, on the internet, in *Our Side of the Fence* (To Whom I May Concern, 2013a), one part of the conversation is devoted to the problems all four cast members have with words. Joe and John both have problems with understanding and answering questions; Sue drops words; John takes his time to enter a conversation by which time his wife has answered for him, which he finds very frustrating.

Another example comes from the first stage production when the narrator, John, lost his place in the script. Matthews notes that she saw him flipping back and forth through the script trying to find his place. The audience became very aware of this and there were many moments of tension as a result. When a fellow performer rescued him by physically walking over to him and showing him his place in the script, John turned to the audience and quipped, "Sorry about that, I have Alzheimer's." According to Matthews, the audience's tension was swept away with laughter and applause for this rescue (Basting, 2009: 90). In the act of taking control of words, *TWIMC®* performers are doing something regarded as impossible or difficult, and in the process they are claiming a political voice in the presence of an audience who witnesses them and ideally galvanises with them to stop the forces that work against the realisation of this subjectivity (Jeffers, 2012: 130). The word has been corralled into service through the medium of a letter which, together with the presence of the other members of the group on stage, provides a safety net in case of loss of memory.

Another rupture to the distribution of the sensible is through audience members listening to people with dementia who have 'the stage' to tell largely untold stories. In *TWIMC®*, people stigmatised because of a diagnosis of dementia are telling their stories at the risk of being publically identified; they are telling their stories at the risk of fear and shame; they are telling their stories at the risk of a threat to

established thinking. The indignity of the diagnosis and the disease needs witness (speaking and listening), which in fact may be more disruptive than the disease itself. For all of the above reasons, *TWIMC®* moves into ethical territory. Its performers risk exposure and vulnerability face to face with partners, friends, strangers and medical staff so that untold stories are brought into view. But the staging of the 'I' engenders other problems and issues to do with truth, authenticity and credibility. These issues have been, and still are, deliberated over in the autobiographical performance literature and it is to these that I will now turn.

In the next section I start by outlining how autobiographical performance has been evaluated in the literature, provoking both positive and negative responses. I then examine the commitment that *TWIMC®* performers have to appearing 'real' through the use of a neurotypical presentation style that relies on certain 'reality' mechanisms, or effects, to guarantee the performers some security. I then move on to consider specific issues around the presentation of the self on stage for selves not considered to be 'I's.

Staging the 'I'

Autobiographical performance has been both praised and deprecated in the literature. Celebratory appraisals of autobiographical performances will often credit them as 'hopeful projects' with a potential for self-transformation (Spry, 2003; Park-Fuller, 2000, 2003) and with a unique potential to contribute to political change for these subjects (Madison, 1998). When marginalised subjects "talk back, talk out, [and] talk otherwise" (Heddon, 2008: 3), it is argued that the self may be re-storied, and move from the periphery to centre stage, gaining agency in the face of oppression (Spry, 1995; Madison, 1998; Alcoff, 1991/2). Other creditable characteristics noticed include its empathic present-ness, that is, the potential afforded to both performers and spectators by the fact of sharing the event in time and space: "let me tell you a story … now … here" (Langellier, 1999). In addition, it has been praised for its shunning of experts (Dolan, 2001, 2005; Heddon, 2008).

Yet criticisms about the genre also abound. One seminal criticism about the staging of the 'I' is that autobiography serves as a kind of authenticating symbol endorsing an underlying and often unproblematised truth and authority in relation to identity; put another way, "I become the evidence" (Heddon, 2008: 26), silencing problems engendered by autobiography as representation. The autobiographical performance project "can sanctify experience, render the narrative sacred, and exempt the personal from critique, thereby bracketing the problematics of the self" (Langellier, 1999: 138). Here the authority of 'truth' (real words, real people, real stories) works in tandem with the 'authentic' presence of the human subject: an 'I' speaking out in the here and now of a temporally shared space, in the stage productions at least, through defying, questioning and problematising hegemonic representations of themselves in the world. Personal narrative performance in this sense can be understood to be "the expressive act of a pre-existing, autonomous, fixed, unified, or stable self which serves as the origin or accomplishment of experience" (Smith, 1994 cited in Langellier, 1999: 129). However, this conceptualisation of the self denies that the self not only produces its own stories but is as much a production of personal and communal stories (Hantzis, 1998). Culture comes already narrated with canonical stories of how our lives may and should be lived, as I demonstrated in the introduction to this thesis.

Despite these criticisms, and possibly because dementia selves are commonly framed as not 'I's in popular and medical discourse, the performers in *TWIMC®* present themselves as 'real' people. They do this firstly, through their personal presentation style, and secondly, through the minimalist production values of the set. In terms of presentation, people do not dress up; they wear their own clothes; they do not adopt personas or use deliberate mannerisms or vocal inflections. Likewise with the production values, the stage set is underdressed. No deliberate aesthetic is employed to distract from the message. No visual or aural pleasure can be found in the production values. Big money is not behind these productions; they are community efforts. Tables and chairs face the audience. In *Our Side of the Fence* (To Whom I May Concern, 2013a), the sets are bedrooms, or lounge rooms as shown by the webcams: in Joe Potocny's bedroom, the set includes a cat eating food from a small a plate on the bedside table in the background.

The presentation and production values of *TWIMC®* are likely thought to aid cast members to be 'real' people. To back up my point I cite John Sandblom's statement from *Our Side of the Fence*: "we want to be real" (To Whom I May Concern, 2013a). But what exactly is this 'real' which they want to be? The answer is expressed in the last part of his statement, in the negative: "not bumbling idiots"! To be 'real' is to be a "neurotypical" 'I' as opposed to being an 'I' in line with preconceived ideas about dementia (Burke, 2007a). The term 'neurotypical' was coined by people diagnosed with one of the disabilities on the autism spectrum (such as Asperger's Syndrome) to refer to people not on it, and was later adopted by the medical community. Though not highly regarded by many neuro-diverse activists, neurotypical presentations seem to be very important for the *TWIMC®* cast members when performing their stories to an audience, especially to strangers on the internet, and even if the audience is comprised of known faces.

But to be neurotypical, many safety nets must be put in place in the production in order for the cast not to be exposed as "bumbling idiots". For example, the letters in the stage production are pre-scripted with the help of Maureen Matthews, who also directs. The letters are also read out rather than memorised, and so on. In *Our Side of the Fence* (To Whom I May Concern, 2013a), computer screens open to word documents and become the substitute for the letter, and the webcam is the way in which each member of the group can see each other. Another safety net present in all the staged productions of *TWIMC®* is the presence of several people on stage at once sharing their stories. In the online groups, the same group format prevails. This last protective measure has a paradoxical side. Though being together in a group creates a safe space for these selves with dementia, in *Our Side of the Fence* (To Whom I May Concern, 2013a), the four cast members argue at the same time for their uniqueness: Joe Potocny contends that once a diagnosis is received, people with dementia are all clumped together when in fact "when you've met one person with dementia, you've met one person with dementia".

All these safety measures absolutely do need to be in place. As Anne Basting argues:

> by the time a person with memory loss pulls together thoughts and the courage to share them, the conversation has already moved so far downstream he or she doesn't bother to enter it (2009: 87).

Nevertheless formatting the internet piece as a conversation, as happens in *Our Side of the Fence* (To Whom I May Concern, 2013a), turns these safety measures into mechanisms that work against a sense of authenticity, as the reality presented is so obviously constructed, despite the many mechanisms in place that point to how 'real' the project and its people are.

One example of these reality mechanisms is the clothes, another is the 'sets' or mise-en-scène, and yet another is the script, which is a deliberation in dialogue. The conversation is 'read out' by what are in effect non-professionals, mostly in a self-conscious and sing-song tone, despite or perhaps because of hours of rehearsal, undermining the fiction of a spontaneous casual conversation between people on which the production rests. Cutting across has been rehearsed and when one group member forgets that it is his turn to (spontaneously) cut in, another group member reminds him. He then makes the (obligatory?) joke about having Alzheimer's as an excuse for his forgetfulness. Despite these lapses in rehearsed authenticity, the paradox is that in fact the lapses point to how 'real' the performers are, exactly because they do not have the professional acting skills to effect a more 'genuine' presentation.

In the presentation of the self on stage in the same time and place as the audience and in the presentation style described above, the physical person will most likely be seen as the 'real' person. The reasons for this are understandable. But the performer both is and is not real in the liminal space which performance enables of personal narrative. Equating these categories to Schechner's (2013) "not me" and "not not me" in performance, the "not me" self can be understood not just simply as a presentation. It is a re-presentation and often strategic (Heddon, 2008). Behind the story told is the one that is not; behind the chosen and edited experiences are the ones not told; behind the truthful accounts of a remembered event are the creative acts in the present which telling stories of the past always invoke given that personal stories change with each telling. Memory is as much connected to the present as to the past. With each telling, remembered events get shifted and rearranged depending on whom the story is being told to, where and why.

But the self in autobiographical performance is crucially also 'not not me', underlining the paradoxical relationship between fiction and authenticity in

autobiographical performance. The relationship between the 'not me' and the 'not not me' of performance is parallel to the way dementia itself troubles notions of an essentialised self. People with dementia are frequently framed as double selves: the person who is (the essential self) and the entity the disease creates. The essentialised self is propped up in some autobiographical performances, but it is this self that is commonly thought to be lost or to disappear in people with dementia.

In *TWIMC®* the 'I' is dominant because that 'I' is perceived to be a not 'I' in social vocabulary, an 'I' denied in social and institutional encounters, or, for the people with early stage dementia, an 'I' that is facing this not 'I' status in the near future, but most likely experiencing it in some measure from the moment of diagnosis. In *TWIMC®,* people in the early stages of dementia still have the ability to write down and speak out from the daily incidents they encounter in their lives. They choose to do so: to audiences of their friends, family and caregivers. It is this still functioning 'I' that feels the need to tell the community about what matters to them in the now. Advocating for the acknowledgement of themselves as 'I's' has been a crucial factor in the evocation of *TWIMC®.*

But all these gestures could potentially de-stabilise the subjects despite the safety nets in place. If, as medical philosopher Stephen Post (1995a cited in Basting, 2003: 96) argues, memory and its control substantiate the composition of the human being as rational and autonomous, those who disclose memory failures will not qualify as whole people. For someone to reveal that they have dementia with its mistakes, forgetfulness and fragmented language, is to hazard losing the standing of a whole person as is commonly understood in the world and in autobiographical performance.

So in working to uphold current paradigms of personhood, *TWIMC®* may unconsciously work to exclude those with cognitive disabilities as 'real' persons and selves because there will inevitably be memory slips, dropped lines and along with them, dropped ideas of fully functioning autonomous beings who can be called 'selves'. Moreover, these selves could be unwelcome to the *TWIMC®* performers (Dennis, 2012: 4). If performance can be catechised as intrinsically about the double negative — 'not me' and 'not not me' — what are the implications

if the performer is worried about the 'not me' side which they may have to display in their performances of self? This also involves the "talk otherwise", which Heddon has written about (2008: 3). The *TWIMC®* performer is bringing into being a self as "a way to talk out, talk back" but how comfortable would they be with this self who "talk[s] otherwise" (Heddon, 2008: 3)?

To sum up, when it comes to the performance of identity, dementia presents some interesting tensions. For some people living with a diagnosis of dementia issues to do with identity are central. Fluidity of identity is a lived experience. They may actively fight for the anchoring 'I' of identity not to disappear. For these people it may be of the utmost importance for the self to be staged as a subject. The staging of their stories could be a way to re-stage themselves as people, gaining agency in the process. For these performers, personal identity and experience matter a lot. They, who are facing the future possibility of the legal removal of their rights as citizens, along with access to their bank accounts, want to claim the identities they feel will disappear, not only through their memory losses and difficulty with processing skills, but in the way others treat them. Here their making identity claims in performance would rightly need to be confirmed as political: as an act of activism, a fight for their rights. *TWIMC®* is one such act of autobiographical agency.

However, for certain other performers, the affirmation of identity in this manner is too difficult. In these instances, renouncing identity might be a better fit; embracing otherness and the distinct cultural markers of dementia could be a more productive way for performances to be created (most likely in concert with others in joint storytelling enterprises, which could still be seen as forms of autobiography). Here memory could be deployed as a creative act rather than one of biographical precision; language could become free of its demands for literalness; the whole gamut of the body's available resources, linguistic, non- verbal and gestural, could be put to use. The performers could say it and do it differently (Kearney, 1999). Time*Slips*, which was discussed in the previous chapter, is one such example of this methodology, although it does not involve public performance. For these selves, the ontology of performance itself could be deployed to think about ways autobiographical performance could work for them. Performance is as much about absence as it is about presence, as much about disappearance as appearance. It

knows that the truth is slippery, that selves are not static, that there are multiple 'mes', that performers can be both themselves and other than themselves on stage.

I will now turn to an examination of the challenges of creating and staging works by people living with a dementia diagnosis, whether they are professional or community, as evidenced by *TWIMC®.* These challenges are connected to the effects of the 'right kind' of dementia stories, or what autobiographical performance theorist Kristin Langellier terms "ghostly audiences" (1999: 127), as much as to do with the way in which the genre itself has come to be understood.

Ghostly audiences

The absence of people living with a diagnosis of dementia from public life narrative performances is undoubtedly connected to, and limited by, discursive understandings. These are entrenched webs of power relations that operate through systems like medicine, the law, the media and the family, that both fashion and regulate the perceptions, situations and worlds in which people diagnosed with dementia could perform life narratives to audiences. The "forces of discourse that shape language, identity and experience" have also been termed "ghostly audiences" (Langellier, 1999: 127). Whether or not people living with a diagnosis of dementia can partake in and be heard and seen in an autobiographical presentational/representational system may be as much to do with the constraints of these 'audiences' and/or "malignant social psychology" (Kitwood, 1997: 45-49), as with 'reality'.

Unsurprisingly, the relationship between the real and its representation/presentation is notoriously complex and rife with feedback loops. As performance studies scholar Peggy Phelan notes: "the real is read through representation and representation is read through the real" (1993: 2). Phelan goes on to state, within a Lacanian frame of reference:

> within the diverse genre of autobiography the real is considered the motivation for self-representation … [believing] itself to be the Real-real … [However] the very proliferation of discourse can only disable the possibility

of a Real-real. The visible itself is an unmarked conspirator in the maintenance of each discursive real … employed as a truth-effect for the establishment of [the] discursive and representational notions of the real … by seeing the blind spot within the visible real we might see a way to redesign the representational real (1993: 3).

The "blind spots"[147] in the visible real of dementia are the taken-for-granted, normative and modernist discourses about the self as stable, cohesive and rational, overlaid by tropes of disappearance and gothic horror in relation to dementia selves (Matthews, 2014; Burke, 2007a). Performers diagnosed with dementia do not often appear on stages to tell their stories because these discursive formations about their selfhoods impact how both they and others view their capacities. They also do not appear on stage very often because of the way these discursive formations have infiltrated understandings about the genre itself.

Autobiography as a literary form is implicitly bound up with gender. The genesis of critical writing about autobiography was developed by a group of male critics writing in the 1960s and 1970s (see for example, Olney, 1972 and Weintraub, 1978 cited in Anderson, 2001: 3) studying works by men in the public sphere whom they regarded to be 'great', that is, men having the kinds of experiences that were significant enough to be written about according to these theorists. This in turn promoted a view of the universalised subject as masculine, Western and middle-class (Anderson, 2001: 3).[148] They deduced abstract critical principles for autobiography based on the ideals of autonomy, self-realisation, authenticity and transcendence, reflecting their own cultural values (Anderson, 2001: 3): the 'I' and the 'we' of this genre implicitly carried these qualities. Women did not have these types of experiences and so women's autobiographies (private letters and diaries), along with their experiences, were excluded from the way the genre came to be understood as autobiography (Jay, 1987: 50). People with cognitive disabilities were similarly excluded, although a growing genre of stories from people living

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[147] This is an example of the way in which negative disability metaphors are used without question by radical scholars.

[148] The work these critics did was established on the foundation of eighteenth- and nineteenth-century thought about autobiography. There is evidence that the word was first used in the late eighteenth century in William Taylor's review of Isaac D'Israeli's *Miscellanies*, where he pondered the use of the term as preferential to 'self-biography'. It is commonly thought that the poet Robert Southey first coined the word in 1809. In the 1830s the term was established and in the nineteenth century it came to be associated with authorship, in particular those humans capable of self-reflection and those not (Anderson, 2001: 6-8).

with a diagnosis of dementia have been appearing, some of which were mentioned in the previous chapter (footnote 127).

Furthermore, recent scholarship has revealed (for example, Whitlock, 2007; Jolly, 2008; Smith and Watson, 2001; Miller, 2002; Poletti, 2011) that all autobiographical acts, from the literary to the performative to the quotidian, can be usefully studied as contextual and relational occurrences of self-representation that both respond to and reflect an array of ideas and philosophies about the uses of life narrative, as well as being attempts to construct and manage affective relationships with their audiences. 'Ghostly audiences', ideas about the uses of life narrative and efforts to manage audience impressions will all impact performer/audience interactions and put into jeopardy facile ideas about the way the genre can transform audience perceptions of the lived experience of dementia.

Selves whose faulty cognitive processes and patchy memories have landed them with the label of non- or part- narrative selves, not adept at remembering, telling or performing their life stories on public stages, have generally been locked out by not being the kinds of selves supposed to be able to partake in the autobiographical performance genre. They have then not generally deployed this practice. It is then thought that people living with a diagnosis of dementia are not capable of appearing on public stages to tell their stories, so that when they do appear on public stages, as they do in *TWIMC®*, relationships with audiences become paramount. If as Deidre Heddon contends, "the relationship that autobiographical performances (… about some 'self') attempt to forge with the spectator (some other 'self') seems … particularly crucial" (2008: 6), I would argue that this already crucial relationship is all the more crucial when the performer is a person living with a dementia diagnosis and the audience members are carers, medical and institutional staff, and families, partners and friends.

Performers and spectators

When people living with a dementia diagnosis do appear on public stages, as they do in *TWIMC®*, the audience/performer relationship is imbued with political potential. Autobiographical performance is particularly suited to a political agenda

partly because in a shared public space in now time, it is capable of staging a direct address to a spectator (in extremis, "do something now about me"). In *TWIMC®,* the present-ness of the performers in concert with their present concerns (to do with the immediate past, and current worries) means that the political potential of theatre as a 'de-pathologising gesture' (Cvetkovich, 2003: 47) may be realised.

For a start, *TWIMC®,* like Time*Slips*, takes the present as its starting point and not the past. In so doing, stories beyond reminiscence are allowed life. People with dementia can complain publically about their treatment — by doctors, family and others — thereby eluding the abjection so common in dementia narratives. The expressions of the participants in *TWIMC®* are not pigeonholing the dementia narrative down to a medical tragedy being told in the search for a cure. Rather, the stories are told in an active search for the construction of a community through dialogue, which is where the real therapeutic outcomes lie, ironically. This realises the political potential in theatre displacing the dyadic and hierarchical relationship between doctor and patient with a public sphere in which audience members can address specific traumas (Cvetkovich, 2003: 282-286). Indeed, experience is always mediated in performance (as Derrida argued), but the performers are in the same space as connected others capable of staging a direct address to those spectators which, as many performance theorists have argued, is suited to political (and ethical) agendas. Phelan (2001: 29) claims that live performance removes the representational structure of art; Dolan argues that we are gathered together in this space apart allied with others (2001: 473 and 459); and Miller, that live performance becomes a container in which consciousness can be raised and direct action prompted (2000: 89). In this shared space, political power relations can be reversed, if only momentarily. Medical staff and carers in the audience must listen in a passive role, while people with dementia have the stage and talk. They have not been disappeared or silenced: by their disease, by their carers, by discursive understandings.

To demonstrate the points I have made above I will give an example from the second stage production of *TWIMC®,* mounted in 2007. The play followed the same format as the first production, including a narrator who in this show was a woman, Anne. Some letters in this script took a mocking tone and others were

grateful to services like Access-a-ride and their support groups. One of the players, Adele, read a letter to her husband who was in the audience, and while directly looking at him asked him not to be so helpful and "to stop watching over me like a hawk … you're being so thoughtful. But sometimes it can be infantilizing" (Basting, 2009a: 92). It is likely that Adele had not expressed these sentiments before. In the post-show discussion her husband stood up and thanked her for making him aware of her feelings (Basting, 2009a: 92). Adele's address to her husband and his response bears out both the political and the ethical potential of *TWIMC®* and underscores the fact that "[t]he autobiographical impulse can only be fully realised by the dialogic act of speaking and listening because the audience is as much a part of the process as the actors" (Jeffers, 2012: 136).

However, whether or not Adele's husband's behaviour actually changed shows the difficulty of determining the level of translation that occurs from potential to actuality in judging the politics and the ethics of any performance. The composition of the audiences listening to these narratives will be different, and the likely consequences of these narratives for them will also vary: for example, as witnesses, as unconditional therapists, as critics, as the criticised (for example family, health professionals and caregivers) (Langellier, 1998: 210). If audience members are deliberately made to feel uncomfortable and exposed, then anger or resentment could as likely be generated as sympathy and understanding. Hostile audience responses may or may not result in better outcomes for the performers in *TWIMC®*. Specific venues will also construct audiences and construct them differently. The internet may decrease the political potential of live performance but increase other kinds of political potential, for example reaching audiences in other states and countries.

TWIMC® mainly intends to serve the interests of the performers and not the audience members through educating and informing audiences, in part by confronting misunderstandings based on myths about dementia and the people who live with it. However, some of the audience members have a relationship to the performers on stage, charging the relationship with extra significance. *TWIMC®* asks audience members to reflect on their relationship to those on stage ('not I's') as well as to their own identity in relation to their position as 'I's' (although in some instances other 'not I's' will also be in the audience). It asks audience

members to be active participants in changing their attitudes and behaviour, and in so doing, it makes ethical and political demands on them. In other words, it makes the treatment of people living with a diagnosis of dementia a problem that can be solved together and not just one inherent in the disease label. It also refuses the audience the distance of aesthetic spectatorship. The represented body is the material body known, seen and making demands on the audience. The audience can also answer back in the post-show discussions that are a typical feature of the productions, even as they occur on the web (Talk Back session, *Our Side of the Fence,* To Whom I May Concern, 2013a). With a nod to Boal's forum theatre, this move is a chance "for people who are silenced to speak" (Basting, 2009a: 92) to an audience who can participate in the outcomes; an audience who can answer back and address some of the concerns and criticisms levelled at them, promising change. The boundary between the spectators and the *TWIMC®* objects of the gaze is crossed.

In summary, in this chapter I have analysed *TWIMC®,* both play and therapy, operating both virtually and live, arguing its value for discussion because of the ways in which it galvanizes issues in the autobiographical performance literature to do with the self and its relationship to narrative, identity and representation. I also investigated the dearth of public life narrative performances from older adults diagnosed with dementia suggesting that it is undoubtedly connected to and limited by generalised discursive understandings of dementia as well as to discourses about their *capacities*, which both generate and regulate the worlds in which these people live and perform. I suggested that partaking in an autobiographical representational system may be as much to do with these estimations as with 'reality'. It will also be connected to the impact of the countless iterations of the 'right kind' of dementia story sifted through the media and other discourse systems.

In the next and final chapter, I conclude the thesis by investigating performance as a "mode of power" (McKenzie, 2001: 25), focusing on how dementia 'performs' in the twenty-first century, particularly in residential care homes. After that, I rehearse a theory of dementia as performance, summarise my arguments and track future imaginaries for the work this dissertation has started.

Conclusion
Revisiting My Mother's Story, My Story

In the introduction, I divulged a story told to me by the nursing staff of the facility where my mother spent her final days: a story about her escape attempt. As is the way with all stories, that they are told and retold to different people at different times and in different places, so with this one. I was retelling it yet again the other night to my sister when she added another piece to the mosaic. For me, seeing memory as a mosaic captures a sense of the pieces making up the whole and of the fragments collaged together to form a bigger picture, both consciously and unconsciously, when we reminisce (Fox, 2010). My sister told me that my mother had indeed dressed for the occasion, and not just by donning yellow rubber gloves. She had put on a very large sunhat and dark glasses, and a trench coat, all atop her tiny figure. As my sister was boosting the details of my memory-story (which was also hers), I had a flash of insight: if this was an escape attempt as I had conceived it, then it was likely that my mother had cast herself as the key player and was dressed accordingly. The sartorial details added by my sister carried such important dramatic qualities. Was my mother playing the part of an interned spy who was trying to disguise herself for the escape attempt? Or, in a more plebeian interpretation, did she know about the security cameras in the facility, and did she intend to avoid punishment for the damage she was obviously intent on doing with the hammer in her hand? I will never know exactly why she dressed up like this, but what I can be sure of is that she had readied herself for a performance of some kind: whether it was as part of a performed hallucination, a smart move on her part to disguise her anti-social activity, or recourse to a well-practised way of being, my mother was playing a role.

I feel sure about this for several reasons. My mother was a lifelong theatre-lover: drama was in her veins. Even in her late 70s, she was a member of the University of the 3rd Age drama group. When she was a young woman, she would make herself up to look like a very glamorous movie star: a Veronica Lake, her blonde hair parted to one side and curled to her shoulders. Film star look-a-likes were common in the 1940s and are just as common now (along with top model and TV star looks). As I argued in Chapter 1, reality is mediated, with feedback loops

functioning between representation and our everyday lives, making it difficult to know what 'the real' really is. Our dress and appearance keep representations we are fed in various mainstream media circulating in the choices we make in everyday life. And media is in turn informed by various trends in everyday life: the grunge look appropriated from the homeless and the down-and-out is one such example.[149] Moreover, as Erving Goffman (1959:111-112) so clearly saw, when we leave our "backstage" worlds (Goffman also used the term "back region[s]") we ready ourselves to 'perform' front of stage (in the "front region[s]").

Both the notions, that life is theatre and that we are performers in everyday life, are now well established, although both have also been strongly contested in the performance literature: for example, Read (1993) and Davis and Postlewaite (2003). In this regard, and as I have already argued in this thesis, people living with a diagnosis of dementia have been assigned restricted 'roles', for example as 'zombies', 'strangers' or 'sufferers'; and dementia itself is usually framed as a 'tragedy'. But in Richard Schechner's concept of "performance consciousness" (1985: 6) there exists the possibility of change, affording other ways to conceptualise these roles and performances. As I stated in the introductory chapter, if Schechner's notion of 'performance consciousness' was more widely accepted it could allow the actions, verbal speech and stories of people living with a dementia diagnosis to be framed as imaginative variations rather than solely as signifiers of ghastly diseases of forgetting. 'Performance consciousness' could also allow for the reality they inhabit, which exists somewhere between imagination and reality, and the present and the past, to be accepted as one form of reality, as opposed to it having to be remade in a fashion more in accord with general conceptions of what reality is or should be.

In this concluding chapter, I first look to the proliferation of the performance paradigm in the twenty-first century as a "mode of power" in Jon McKenzie's (2001:25) dispensation. As stated in the introduction, I contend that this mode currently predominates others, including Schechner's transformative options, regulating both the manners in which, and the situations where, people living with a

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[149] The documentary film on the New York fashion photographer Bill Cunningham makes this point: *Bill Cunningham New York* was directed by Richard Press and released in theatres on 16 March 2011.

dementia diagnosis 'perform' their stories and selves. I pay particular attention to health science knowledge(s) and practices, which have resonance for how dementia 'performs' in the twenty-first century, particularly in residential care homes. After that, I rehearse a theory of dementia as performance. Along with various other meanings including "to repeat", the verb "to rehearse", in relation to performance means "to practise something for later public performance" (OED Online, 2014/2015). The noun "rehearsal" is defined as "[a] practice performance of all or part of a play or other work, in preparation for later public performance" (OED Online, 2014/15). In defining what a rehearsal is, Richard Schechner contrasts the many possibilities that unfold in a rehearsal to the comparatively few actions performed in any finished performance work (2013: 238). In deploying the term 'to rehearse' then, my aim is to explore the range of possibilities that might exist for future work in theatre and performance scholarship in regards to dementia as performance. This work could be mine, or that of others. What unfolds in the rehearsal undertaken here could play a part in future performance work or scholarly research where the 'gaze' of theatre and performance could be a key player in reframing some of the negative conceptualisations of people diagnosed with dementia which abound in both popular and medical environments. After rehearsing my theory of dementia as performance, I then summarise the main arguments I have made in this thesis, as well as proposing other avenues where the research I have undertaken can and should be extended.

Situating performance paradigms

> Today … work, play, sex and even resistance — it's all performance to us.
> (McKenzie, 2001: 3)

Performance today has many registers, not just the theatrical or the artistic. In the West, at this point in time, the idea of performance has a 'cultural' life in the widest sense of the term: in other words, it has spread well beyond the confines of theatres, movie houses, art galleries and even personal and social rituals. Today performance, as McKenzie argues, is the nascent stratum through which power

and knowledge can be best understood (2001: 18),[150] as opposed to discipline, which was the regnant episteme of power operating in the eighteenth and nineteenth centuries (Foucault, 1991). This "mode of power" operates through "the reading machines of Performance Management and Techno-Performance" (2001: 25) with organisational and technological profiles respectively. The organizational is linked to profit and loss, efficiency and achievement: the technological to the completion, effectiveness and measurement of tasks (2001: 13). Of specific relevance to the interests of this thesis, McKenzie also claims that contemporary health science knowledge(s) and practices are now required to 'perform'. In other words, they have to deliver results, and the effects of any interventions have to be able to be measured (McKenzie, 2001: 13): in medicine, science and many other health areas.

McKenzie's idea is supported by the development in some Western economies, like the United Kingdom (UK) (Brodzinski, 2010) and Australia, of certain types of health 'performance' frameworks, within which 'performance' indicators are nestled. In Australia, The National Health Performance Framework (NHPF) first emerged in 2001 (and was revised in 2009). Its main purpose is to provide a structure for reporting on the performance of the Australian health system at the national level, and for developing sets of performance indicators for describing and measuring particular programs or specific target groups (AIHW, 2014).[151] As taxpayers fund the Medicare system of national health care in Australia, this means that overarching moral and political sensitivities around cost-effectiveness and accountability of spending, as well as task measurement practices, will operate in government-funded care homes and home care practices for people living with a diagnosis of dementia (Nicholson, 2011b) in line with the government's performance framework.

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[150] In his seminal *Perform or Else*, McKenzie (2001) draws on Foucault's (1977) concepts of discipline, as well as the performance theories of Judith Butler (1993), Jean Francoise Lyotard (1984) and Herbert Marcuse (1955), to argue that performance produces a new subject of knowledge, one that is fragmented, decentred and virtual, and that this ontological formation is historically located, having emerged after World War II and thriving now in a specific tempo-historical frame where digital media, the internet and globalisation are dominant.

[151] The NHPF has nine main areas: better health, prevention, access, safety and appropriateness as quality, patient-centred, efficiency/value for money, sustainable, integration and continuity of care. These nine further cascade down into key performance indicators. An example is the area of efficiency and/or value for money, which has two main performance indicators: out-of-pocket costs as a proportion of cost of service, General Practitioner (GP) and specialist medical services, pharmaceuticals and dental services and deferment of required treatment due to cost.

The success of these government-funded care homes, both in Australia and in the UK, is usually measured through 'Techno-Performance'. They will be judged by how they prioritise tasks, such as bathing and dressing, as well as by their time-efficiency with these tasks and their achievement of targets in terms of tasks (Hatton, 2014: 358). Privately run homes may also have similar pressures from shareholders rather than the general public. Managers in care homes might also have to relate performance to efficacy, or paradigms of 'Performance Management', which "echo business models of efficiency and productivity rather than the immaterial labour of compassionate care" (Nicholson, 2011b: 48). Managers will also likely promote the construction and maintenance of the care home primarily as an institutional space (Hatton, 2014: 358) over other perhaps more creative utilisations. These frameworks could constrain the work done by sincere and caring health professionals in the homes, as well as work against ideas of social efficacy that applied theatre artists working within these homes could bring to these sites.

The arts too are currently being asked to play a role in meeting core health performance indicators within a performance culture of accountability and measurement (AIHW, 2014). For example, in 2013, the National Arts and Health Framework (MIM, 2014) was developed to enhance the profile of arts and health in Australia and to promote greater integration of arts and health practice and approaches into health promotion, services, settings and facilities, as well as to appraise current programs.[152]

The aim of services like these, McKenzie (2001) notes, is not to explicitly normalise or discipline. In an epoch where chronic 'diseases' like diabetes, cancer and dementia are proliferating, it is clear there are not many able and/or disease-free bodies left to 'discipline', in the terms in which Foucault (1991) first theorised. Rather, these services are interested in how the body 'performs' and in measuring

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[152] The National Arts and Health Framework (MIM, 2014) contains many information links (for instance, to examples of approaches to arts and health), as well as resources and research findings. The Framework provides guidance for state and territory governments to appraise current programs, study new directions and distinguish new partners to support arts and health initiatives appropriate to each jurisdiction.

and evaluating these performances, often with the unequivocal aim to empower, liberate and diversify those bodies, but in fact operating to control them.[153]

Performance then, as I stated earlier, has many registers in all of which the self is also performed, presented and managed in front of others to whom the term 'audience' can be applied. (And of course theatre audiences also perform their own versions of an audience as they watch a show, as well as versions of themselves as individual audience members.) Applied theatre scholar Gareth White's definition of an audience is worth quoting at length, as it underscores the historical and cultural contingency of the term and its relationship to context:

> An audience is both a socially constructed practice, and a notional position in relation to internal and external phenomena: we become audiences and understand what we do as audience members because of traditions that we inherit and adapt, but we also go through our lives taking the position of spectator to the world around us, our own actions in it as well as those of other people (2013: 5).

For White (2013: 4), audience participation is the involvement of an entire audience or member of that group, in the action of the performance. All social action can be seen as participation, on a continuum with dramatic and performance action (White, 2013:6). In performance theory, an approach that sees performance as much about the audience or the spectator as the performer has intersected the traditional emphasis on the performer. This can be demonstrated in the re-examination of the writings of Aristotle on catharsis, in the promulgation of identification theories in the production and reception work of the last two centuries, as well as in the more recent mirror neuron theories emerging out of

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[153] Diversity is the regnant paradigm of the twenty-first century, argues disability theorist Lennard Davis in *The End of Normal* (2013). For Davis, diversity is overtaking the rule of normalcy, about which he argued so cogently in his earlier *Enforcing Normalcy* (1995). According to Davis, diversity is well suited to the core beliefs of neo-liberal capitalism, emphasising malleability, free play and choice. Choice in turn underscores individuality and difference. However, as Davis argues, this difference paradoxically works to normalise: we are all the same in our difference, but in fact difference must be suppressed to achieve the diversity by which we are all the same. For instance, there are the advertisers who offer a range of 'different' bodies in order to sell their products. Davis (2013) exemplifies by referring to Dove soap advertisements that showcase black, plump or ageing women. But, writes Davis (2013), they do not offer us the comatose or the homeless, those whom Giorgio Agamben would see as "zoē" or "bare life", those not worthy of "bios" or life (1998: 8). Difference or diversity then is an ideological formulation promulgated with force in Western societies, a seminal way in which power is exerted and maintained. But, as Davis (2013) goes on to argue, disability is not a choice: it is the state of exception that undergirds our ideas of diversity, even in health care scenarios.

both the cognitive and affective fields of spectator response theories (Balme, 2008: 34). Spectating in this view is an active participatory process of analysis, appraisal, and interpretation where meanings are continually being interpreted, re-interpreted (Rancière 2007: 277) and co-created (Schneider, 2000: 26-27).

Drawing on White's (2013) direction on audience and participation, and their relationship to historical and cultural contingency, Schechner's (2013) continuum of performance, and new ideas about the active role of the spectator in performance (Rancière, 2007), I will now rehearse a theory of dementia as performance which articulates people living with a diagnosis of dementia as performers and their care partners as spectators or audiences. Through this lens, incoherent speech, memory loss and repetitive speech and behaviours, among others, can be seen as deliberate, if shifting, constructions of identity and/or as creative adaptations to corporeal and neurological changes, rather than just as signs of vanishing self-identity in the progress of incurable and disabling illnesses (Beard, 2004: 417). When perceived through the gaze of performance, people who live with a dementia diagnosis can be seen in terms of possibility by spectators, who are co-creators of this field of possibility, responsible for interpreting deficit behaviours in a new light. We can then ask: What ethical compunctions does spectatorship entail?

Rehearsing a theory of dementia as performance

> Rehearsing a … theory of performance we must … create concepts, initiate models … our rehearsal … must seek out other sites, other premises, other performances
> (McKenzie, 2001: 53)

> We are all, in a manner of speaking, performers (States, 2003: 108)

To conceptualise this section of the concluding chapter as a 'rehearsal' means that I am trying out, seeking, and possibly finding, the relationship and usefulness of a theory of dementia as performance, an enterprise fraught with risk and discovery. This proposal is, necessarily, broad and general, and because of this, wide open to criticism. Generalisations are often anachronistic abstractions and usually do not sit well in a field like performance studies which has been strongly influenced by the 'posts', in particular postmodernism and post-structuralism, and is therefore

wary of grand narratives and metanarratives (Lyotard, 1984). Nevertheless, as Jon McKenzie argues:

> Performance theory cannot do without movements of generalizations …The task of theory is not to dismiss generalization, but to situate its movement within a matrix of sociotechnical and onto-historical forces, while also allowing it to deviate itself into idiosyncratic passages of experience (2001: 20).

My aim is not the presentation of a finished product, but rather an investigation without necessary closure, a line of flight with emergent and processual qualities also consonant with some theorisations of performance (Bauman, 1975, 1986). Conceiving of dementia as performance means looking at dementia not as an object, as one might with a theatre studies perspective, but as a practice, event, behaviour or action with attention to the circumstances in which it has been created and in which it is exhibited (Schechner, 2013: 2). This is Schechner's (2013: 38) "as" of performance: where actions, events and practices can be perceived to be performances, including gender, sexuality and ethnicity, among others.

Schechner defines performance as a "continuum" (1985: 37) of human actions. All performances are "restored behaviours" or "twice-behaved behaviours", for which people practise and rehearse (Schechner, 2013:28). These behaviours are also regulated in the face of different individual and social situations (Schechner, 2013: 28-29). Schechner's (1985, 2013) concept of restored behaviour points in two directions: the first is connected with the exhibition of skills, as in acting (the "is" of performance), and the second, with the exhibition of recognised and culturally coded patterns of behaviour (the "as" of performance). The latter suggests that all human activity could potentially be called a performance, which in turn raises the question of the difference between doing and performing. In his earlier work, *Between Theater and Anthropology*, Schechner (1985) argues that for the operations of restoration to function, even in everyday life, there must be some kind of *consciousness* of performing a social role operating (for both the performer and the audience). In the third and latest edition of *Performance Studies: An Introduction* (2013), which was first published in 2002, Schechner writes that "[a] person may not be aware that she is performing a strip of restored behavior" (2013: 29), moving *consciousness* out of the earlier definition and into the realm of any doing, physical, verbal or virtual that is not for the first time. In my view, this

permits restored behaviour to be used to theorise people living with a dementia diagnosis, who may not be aware that they are performing.

Scholars have mounted arguments against the idea that social performance can be positioned along a continuum with artistic performance. In trying to determine the extent to which performance can move on this continuum and continue as performance and at what point performativity begins, theatre phenomenologist Bert O. States (2003) argues, contra Goffman (1959) and Schechner (1985, 2013), that social performance cannot be explained using exactly the same terms as artistic expression: he argues that the relationship of 'real life' performers to, and the degree of control over, their performances, are not equivalent to those of an actual stage performer. He takes umbrage with Schechner's (1985, 2013) notion of performance as repetition or *twice behaved* behaviour, as it creates a situation where almost anything in the world "done more than once" (States, 2003: 119) is performance, positing that in this declension, spousal and workplace behaviour would be included on these grounds and executions or hostage crises excluded, because they only happen once. However, States thinks that the idea of restoration has valence because "something is always restored in performance, even if the restoration comes through a simple framing device" (2003: 123). For States, "framing and performance are … conterminous principles" (2003: 125), which, when done by a spectator might release everyday performance from "its empirical invisibility" (2003: 125). According to States, this type of bracketing or framing is not performance per se but the *first step* towards it, and should more properly be called performativity. In sum, he maintains that performance begins with everyday behaviour, gets polished in Schechner's repetition process and is completed in Phelan's (1993) interaction of the work and the spectator (States, 2003: 126), that is the 'presentness' of performance about which she argues in *Unmarked: The Politics of Performance* (1993).

In rehearsing my theory of dementia as performance, I do take into account the specific differences between cultural performances and the performances of everyday life, as does States (2003). But unlike States, I also seek for what they closely share, and the degree to which performance and performativity interleave with each other. Following Schechner, my rehearsal is based on the idea that "performative thinking needs to be seen as part of cultural analysis" (Schechner,

2004:8). Accepting Schechner's very broad definition of performance as a foundation (and in particular his concepts of restored behaviour and the double negative) enables this chapter's venture into two main sites: some of the common everyday behaviours of, and some of the stories told by, people living with a dementia diagnosis.

I will start with an example of how 'performance consciousness' can reframe certain behaviours. To do this, I look to the often incessant repetition of linguistic phrases and/or body movements of some people living with a dementia diagnosis. In speech they may reiterate questions because, in the trajectory of many of the 'diseases', their short-term or declarative memory fails and they forget they have asked the question earlier, or they become adept at repetitive communication 'hooks': for example, 'How's things'? In terms of movement, they may 'rehearse' walking, sometimes wandering around and around in circles or up and down corridors. They have been known to repeat former life scripts, for example, if they were managers in their jobs, they may rehearse this role out of context using both movement and words.

Research indicates that many caregivers become frustrated and uncommunicative when faced with repetition and forgetfulness (Miller et al., 2008). A medical view of this behaviour would see repetition as a problem to be solved and managed. But in fact, repetition of phrases or actions can be interpreted differently. Verbal or non-verbal repetitive behaviours may be read as a cue for care partners to become primary storytellers in an exchange, or redirect the conversation to another topic, time, person, or place for access to more pieces of new conversational mosaics. These behaviours may also be seen as communication behaviours, which facilitate engagement for the person living with a dementia diagnosis in standard and socially well-mannered interactions (Rhys and Schmidt-Renfree, 2000). Phrasal repetition may indicate the connection people living with a dementia diagnosis can have to the "structural norms of conversational behavior such as turn taking … [where they are able to provide answers that] … satisfy the requirements of the question" (Rhys and Schmidt-Renfree, 2000: 537-538), thus preserving the organisational level of communication even though they may show difficulty comprehending the gist or substance.

An example of a son recognising this communication ploy on the part of his father is told by Ragan Fox (2010) in his article 'Re-membering Daddy: autoethnographic reflections of my father and Alzheimer's disease'. Fox reports that his father could perform "greet, smile, and friendly question" (2010: 10) but not distinguish fundamental conversation prompts when spoken by other people. For instance, his father would repeat the question "What's new and exciting?" whenever he saw Fox (Fox, 2010: 10). Eventually, after a lot of frustration, Fox started to understand that the question acted to give shape and conversational balance to exchanges between them that would otherwise be lacking in content. For Fox, his father's question functions like "muscle memory … [or] our body's ability to subconsciously engage in activities after several repetitions" (Fox, 2010: 10). Fox relates the importance of repetition in memory retention to performers who know this well; and his father was a performer (2010: 10). Repetition is what actors and performers do before a show, many times over to get the production ready for a showing. They also do this night after night when the show has its run. Everyday life is also full of repetitions in the demonstration of learned behaviours. But these repetitions may not be as condensed in temporal terms as they can be for people living with a dementia diagnosis, making them more apparent. Fox (2010) also writes about how his own involvement in performance and communication scholarship greatly influenced how he approached and interpreted his father's behaviour, alluding to how interpretive decisions are always made by any 'spectator'. Seeing ourselves as spectators, we can interact differently and assume responsibility for our role in the mutual interplay between performers and audience. How the spectator responds is of great importance to the outcome of successful communication ventures between care partners and those living with a diagnosis of dementia. In this way spectatorship can be demarcated as an ethical project.

Another common 'issue' is the back-and-forth 'double' performance of identity between confusion and lucidity, which people living with a dementia diagnosis as well as their care partners may find difficult. For care partners, some of the difficulty may be attributable to the placing of all the speech acts of their loved one in mental comparison with a potential, an ideal, or remembered original (Carlson, 2004: 5). Omissions and fabrications in life stories will also add to the view of those living with a diagnosis of dementia as deficit, because they will be compared

to the original person from the past who told the story in a coherent manner. As a result, the person with dementia in the present moment then becomes a 'stranger', because they are not now who they used to be.

However, if Schechner's (1985: 110) theory of "double-negativity" is deployed, their stories, as well as their identities, could be allowed to be both not true, but not-not true. For example, through this lens people who are exhibiting symptoms of forgetfulness or changes in their personalities can be understood to be both who they are now and who they are not now (who they were): still becoming selves, if also disappearing selves. They are not exactly 'themselves', but this should not prohibit possibilities for being other selves. Theatre and performance both understand doubleness: its operation on stage and in life. Some people with more advanced cases of dementia may be making themselves up at every minute (as does, Mr Thompson in Oliver Sacks' (1985) *The Man who Mistook His Wife for a Hat*), but this can be seen to be an artful improvisational response to an unreliable short-term memory, a social performance similar to those all social actors play out depending on the context and the other roles being played around them. Personhood itself can be said to be performative, as it is collaborative, negotiable, contingent and interdependent. Also in this view, the adaptation of life stories by some people with dementia, as outlined in the case of Mrs Fine in Chapter 5, could be seen in terms of twice-behaved behaviour. In this light, the fabrication of life stories could be seen as shaping learned behaviour to suit new circumstances, which most people do throughout their lives, not just people diagnosed with dementia.

Many other so-called negative 'behaviours' and issues emanating from a dementia diagnosis could be seen differently through the prism of 'performance consciousness' (in terms of its 'this' and 'that-ness'). In this way, the emphasis on what people living with a diagnosis of dementia are doing 'strangely' or 'wrongly' can shift to one which is interested in the responses of the spectator and how these feed into the problem, or not. Social psychology tells us that our identities and senses of personhood are partly a result of how others see and interact with us, so the responses and behaviours of others (the spectators) are certainly one of the key influences in determining the identity of people diagnosed with dementia. It is not neuropathology alone that leads to the loss of selfhood typically associated

with the decline of a person diagnosed with dementia, but what has been termed by Tom Kitwood a "malignant social psychology" (1997: 4). Here the person is *positioned* socio-culturally as infantile, incapable, zombie-like, the living dead (Behuniak, 2011: 71) in and through a complex range of determinants such as: the power of medical discourse in our culture; the socio-cultural construction of dementia in the media and other cultural products, including theatrical and filmic representations; institutional agendas, and the behaviour of others towards the person, to name but a few. In general, our media, our cultural products and our minds are saturated with constructions of dementia as a "hideous, debilitating condition … the disease of the century" (Fox, 1989: 58). Medical marketing strategies encourage these views of dementia as a ghastly epidemic, coming for all of us, playing on cultural anxieties, and generating fear and disgust of the disease and, as a byproduct, its people. This is often in order to achieve financial targets for medical research which, in alliance with the financial incentives provided by drug companies, is usually focused on slowing the progression of the disease through drug interventions, and not in looking at the bigger picture of the interrelationship between dementia, values, politics and social psychology. There is a "politics of revulsion and fear that directly infuses the discourse about AD and shapes it" (Behuniak, 2011: 72), so much so that we generally do not question it, uncritically accepting this politics and its correspondent ethical and aesthetical dimensions.

An unquestioning acceptance of the taken-for-granted characteristics thought to be part of the progress of dementia could help to reinforce behaviours in those relating to people living with a diagnosis of dementia, which in turn fortify those behaviours in the people diagnosed that facilitate viewing them as 'the living dead'. When speech is seen as meaningless, memories as defective and repetitions as senseless, people will then be allocated a restricted range of social roles (Kitwood, 1997). Assumptions will often be made that everyday interaction is no longer of use or interest (Beard, 2004: 419). In turn, this will likely feed into states of disengagement rather than engagement for those living with a dementia diagnosis. Work has been and is continuing to be done in clinical trials and studies which give credence to the idea that if people living with a diagnosis of dementia are treated as people with feelings, creative capacities and a right to some control over what happens to them rather than as walking manifestations of a ghastly disease, then

in fact their self-esteem and other related attributes may also improve (see Kitwood, 1997; Gillies, 1997, 2000; Allan and Killick, 2000; Hedman et al., 2013; Tanner 2013). Changes in how people are treated not only impact their psychological health but in turn their neurological and endocrine systems, which are all systemically related. In addition, nerve function may improve and some degree of neuroregeneration may also occur (Kitwood, 1997: 101). In this way spectatorship as a co-creation of meaning can have a strong impact on the lives of people living with a dementia diagnosis.

In this section, I have sketched a picture of the ways in which 'performance consciousness' could likely transform how people living with a diagnosis of dementia are conceptualised in intrapersonal, interpersonal and broader social domains. In the last section of this concluding chapter, I draft a vision of the ways in which my research may open up other avenues of scholarship in the field of dementia and performance. But before I do that, I will summarise the main arguments and contributions made in this research enterprise.

Encore

The chief question that has guided my research has been how theatrical and paratheatrical performance can most effectively represent and/or respond to the figure of the person living with a diagnosis of dementia (senile dementia in the main) when that figure is produced partially in and through cultural performances, of which theatrical performances are one measure. This question has been used to assay a select group of verbatim art theatre and autobiographical applied theatre case studies in order to narrow the question to an investigation of the relationship between stories, words and the materialisation of 'reality' as 'normalcy' in relation to how stories constitute selves.

As there are particular concerns that become apparent when the aesthetic demands of a piece and its reception outweigh therapeutic and/or community concerns, or vice versa, I structured this thesis into two main sections. In part one, a foundation chapter preceded two verbatim 'art' theatre case study chapters; in part two, an applied theatre and performance literature review was followed by two

chapters considering both verbatim and autobiographical case studies. Arguing that there is a strong connection between the construction of public, medical and institutional discourses and the enactments of both creative and therapeutic 'performances' about, with and by people living with a diagnosis of dementia, part one of the thesis was concerned with an analysis of some of the ways dementia and its peoples have been represented on public theatre stages using the verbatim technique; and part two, with how they are dealt with in seminal applied theatre interventions in care homes or associated facilities. All chapters considered to what extent these representations and interventions tell the 'right kind' of dementia story. When people with dementia tell their own stories or actors use them to make and perform theatre in verbatim theatrical and paratheatrical endeavours, these discourses will most likely be operative.

My introductory chapter laid out the personal, political and theoretical underpinnings of the thesis. I began by telling my story about being a care partner to my mother, a story of being thrust, by her diagnosis of "probable" Alzheimer's disease, into a topsy-turvy world for which I had little preparation other than the available stories, media myths and 'sticky' metaphors (Ahmed, 2004) about dementia and ageing, commonly propagated by medical personnel, public discourses, cultural representations and the media. These I argued to be elements of the 'right kind' of dementia story: one telling at the macro level of crisis because of the coming dementia tsunami, and at the micro level of loss, abjection and tragedy in the face of a person's declining memory, cognition and narrative fitness. Despite the fact that there were some devastating aspects to the diagnosis, and to the later stages of the progression of my mother's disease, I found that the limited repertoire of the 'right kind' of dementia stories, did not in fact match my own experience of travelling with my mother through much of her dementia experience.

In the introduction, I also probed the usual consequences ('de-I-dentification' and marginalisation) of the loss of narrative capabilities for people living with a diagnosis of dementia, given that the social recognition of 'normal' personhood rests partly on the ability to remember and produce coherent narratives. I argued that the connection between narrative and 'normalcy' has not been widely investigated in reality theatre or performance studies scholarship and also that, in applied theatre scholarship, the hegemonic function of the narrative imperative in dementia cultures

has been generally and paradoxically overlooked. Both are omissions rectified in the thesis. I proposed that, through the analysis of a distinctive group of verbatim and autobiographical projects using the stories or words of elders as textual content, dementia could advance new perspectives on reality theatre and performance practices in regards to the self, the relationship between identity and performance, the role of the actor/performer, and ethico-political praxis and spectatorship. I suggested that, when verbatim input from people who are commonly understood not to be 'real', or even 'people', is put together with any performance initiative (either theatrical or paratheatrical) popularly understood as able to present or represent the 'real', or some connection to it, the extant but often obscure fastenings between the word, the story, identity and the social recognition of 'normalcy' in Western cultures will be drawn into sharp focus. In this chapter I also asked: How might theatre and performance studies shift or add to popular and theoretical conceptions of dementia and people diagnosed with dementia? In answering this question, I suggested that the 'gaze' of theatre and performance could dislodge the primacy of the medical gaze, and even that of personhood, to offer new ways of seeing people with dementia in terms of possibility rather than deficit, and in terms of the present not just the past.

In Chapter 1, I reversed the question asked in the introduction by inquiring: How might dementia shift or add to questions, debates and issues in theatre and performance studies? This question was asked with specific reference to verbatim theatre and performance. I proposed that dementia might shift debates and issues in relation to the ontological, relational and performative properties of verbatim theatre products and processes, animating certain debates in the literature. This chapter began an investigation into the connection between stories, words, identity and the materialisation of 'reality' as 'normalcy'. It investigated the difficult relationship between reality, representation and reality theatre in order to unpack foundational issues to do with the 'real' in reference to people who are usually marginalised from conceptions of the accepted 'real'. I coined the term 'normative age-and-dementia-effects' to denote the effects of discursive representations of older adults living with a dementia diagnosis, and the prejudices and norms behind these representations. I also examined if and how the 'right kinds' of stories can be disrupted through the postdramatic aesthetic as a resistant strategy in reality theatre.

In Chapters 2 and 3, also focusing on how dementia might shift or add to questions, debates and issues in the relevant scholarship, I examined two verbatim productions about dementia devised in Australia, in which performers living without dementia play the roles of people living with dementia: Theatre Kantanka's *MBDJ* and KAGE's *Sundowner*. The productions were used as optics through which ethical, political and aesthetic problems to do with disability and age representation were revealed. My particular interest in these chapters was to assess to what extent the 'right kind' of dementia story was being told and how resistant these productions were to 'normative age-and-dementia-effects' in the representation of dementia and ageing.

In Chapters 4 and 5, I also focused on how dementia might shift or add to questions, debates and issues in the relevant scholarship. In Chapter 4, I undertook a literature review of issues to do with cultural intervention and hegemony in applied theatre and performance scholarship with relevance to dementia. In Chapter 5, I analysed two paratheatrical storytelling interventions: RT and Time*Slips.* With RT, I directed James Thompson's (2009) challenges to narrative hegemony toward chronological life story narrative when conceived as an unquestioned practice of late life therapy. With Time*Slips*, I argued that it extricates storytelling from reminiscence but still accepts and works with long-term memories in a creative way. In this chapter, I also evaluated certain applied theatre claims about the benefit of intervention for change in regards to dementia cultures and proposed the worth of what I termed 'narrative spaces'.

In Chapter 6, I investigated issues in the autobiographical literature, especially the construction of the self and its relationship to narrative, identity and representation. I also examined *TWIMC®,* a transgressive mixture of both drama and therapy, with both virtual and live manifestations, which allowed me to assemble many debates about the value of theatre when identity is in decline. I also made the argument that the absence from public life narrative performances of older adults diagnosed with dementia is undoubtedly governed by generalised ideas about dementia and the capacities of people living with it, which both generate and regulate the worlds in which they perform their narratives and their audiences listen to them. I argued that participating in autobiographical representational systems may be as much to do with these limitations as with 'reality'. This is

different from claiming that individuals diagnosed with dementia will suddenly either want or be able to craft their stories for public consumption, as it is different from claiming that there is something distinctively subversive, liberating and/or oppressive in dementia diseases.[154]

In studying the main ways dementia is represented in the theatre, what becomes apparent is the strong connection between the construction of public, medical and institutional discourses and the enactment of performances in dementia facilities, and/or the creation of theatre for public stages. Master discourses affect all theatrical and paratheatrical practices, as they impact the way theatre-makers respond to the subject. These theatre-makers have a role to play in either facilitating these common master narratives of abjection and tragedy or in distinguishing and rejecting them in favour of alternative stories. Through resistance to the 'right kind' of dementia stories and through dissemination of alternatives, narrative transformation and the transformation of subjectivities becomes likely. This is because dementia and its peoples are produced in and through cultural performances, largely depending on narrative underpinnings, as much as in and through biology. Changing cultural attitudes through performing different stories on stage or in institutions, and through their mutual interplay, could allow for the production of a newly reconfigured subject. Doing this, I have argued, is to bring "performance consciousness" to the situation and to have "activate[d] alternatives" (Schechner, 1985: 6) to contest the governing discourses of abjection and loss around dementia and the people who live with a diagnosis (elders in the main) in Western cultures. Compromised memory and cognition in tandem with the ability to tell a 'normal' life story are associated with identity loss, with the consequences being confinement in institutions and the removal of the many rights and privileges afforded 'normal' people. The political and ethical stakes of change have much riding on them.

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[154] This is exactly what some disability studies' scholars (see Siebers 2006:177 and Wendell 1996: 169) have argued that contemporary body theorists like Butler and Haraway have done (Dokumaci, 2013:114).

Future imaginaries

There are many avenues of future exploration for which this thesis has laid the foundations. What this thesis could not do due to its scope and time restrictions calls out to be done. Most obviously, productive conversations with people who are living with a diagnosis of dementia themselves need to be mobilised: about their experiences of acting on stage, for example in *TWIMC®,* or in other community arts or applied theatre projects. Broader and more far-reaching investigations of dementia representations in the theatre and of paratheatrical interventions in institutions right across the world also need undertaking, not just in verbatim or autobiographical theatre. Even in this regard, my project has been so focused that further extensive work could be done. Cataloguing theatrical and paratheatrical project histories in Australia or around the world would do vital work. Taking a more radical stance on the hegemony of reminiscence in dementia cultures and theatre traditions is also an area deserving of further research.

Another area only very marginally touched on in this thesis is dementia activism. If a broad definition of the theatrical is maintained, then the genesis and efflorescence of the dramaturgy of theatrical structures and gestures in this area could be tracked. There is also clearly more work to be done at the intersection of theatre, performance and dementia studies. Where do theatre and performance appear within dementia studies, and what work are they being asked to do?

I hope that this thesis will open up the closed, taken-for-granted and often unquestioned assumptions running discourses of dementia to position relational, affective and ethical discursive spaces in their stead. The grip of bio-medicine on dementia debates needs to be softened and new ways of understanding and looking at possibilities for people living with a diagnosis of dementia embraced. Performance may help to change this discursive space, orienting the debates towards possibility and away from the hegemonic tropes of catastrophe, crisis, loss and abjection running them at the current moment. This thesis lays the foundation for futures imagined differently for people living with a dementia diagnosis.

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Appendix