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## Repelling Neoliberal World-making? How the Ageing-Dementia Relation is Reassembling the Social

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### Abstract

Growing old 'badly' is stigmatizing, a truism that is enrolled into contemporary agendas for the biomedicalization of ageing. Among the many discourses that emphasize ageing as the root cause of later life illnesses, dementia is currently promoted as an epidemic and such hyperbole serves to legitimate its increasing biomedicalization. The new stigma however is no longer contained to simply having dementia, it is failing to prevent it. Anti-ageing cultures of consumption, alongside a proliferation of cultural depictions of the ageing-dementia relation, seem to be refiguring dementia as a future to be worked on to eliminate it from our everyday life. The paper unpacks this complexity for how the ageing-dementia relation is being reassembled in biopolitics in ways that enact it as something that can be transformed and managed. Bringing together Bauman's (2001) theories of how cultural communities cope with the otherness of the other with theories of the rationale for the making of monsters - such as the figure of the abject older person with dementia - I suggest that those older body-persons that personify the ageing-dementia relation, depicted in film and television for example, are 'the Sacra' (Turner, 1967) that threaten the modes of ordering underpinning contemporary lives. This is not just because they intimate loss of mind, or because they are disruptive, but because they do not perform what it is to be 'response-able' and postpone frailty through managing self and risk.

### Introduction

In this paper I examine the social and existential significance of an emergent biopolitics around the ageing-dementia relation and argue that this politics represents a shift from emic to phagic strategies for incorporating, assimilating and transforming the Otherness that the ageing-dementia relation is made to represent. Specifically, the play upon the negative and stigmatizing effects and affects of the ageing-dementia relation runs alongside intense media, neuro-cultural and public health discourses that emphasize how ageing, and specifically dementia, are plastic and malleable, and critically, if not preventable, manageable and postponeable.

Public health policy worldwide represents Alzheimer's Disease, hereafter AD, as not only wrecking individual lives, but as a global 'epidemic' that threatens the social order (e.g. Alzheimer's Disease International 2013). Most recently it has been claimed by the UK's Office for National Statistics that AD and dementia has become the major cause of death in England and Wales (Siddique 2016). As Greengross (2014) suggests, the double jeopardy of ageing when it is associated with dementia, is doubly stigmatizing:

We know in many societies that there are strong associations with ageing and stigma and for those with dementia, it seems many are subject to a 'double jeopardy'. While this stigma to a degree is acknowledged and recognised in some communities, we still have much to understand about why dementia remains outside the realm of acceptable everyday conversation even as the profile of dementia rises. (p.6)

The stigma of what I am calling the ageing-dementia relation has become such a truism that recent research suggests doctors charged with early detection of dementia are reluctant to give someone a dementia diagnosis because of its existential potency and potential for discrimination (Gove et al,

2015). As Margaret Lock (2014) asserts, Alzheimer's and other Alzheimer-like dementias personify all that is most feared about growing old, a fear widely expressed in research on ageing and experiences of ageing (e.g. Balzaget et al, 2011). This fear is crystallized in associating the dementia-ageing relation with the hollowing out of personhood (Halewood, 2016; Katz & Peters, 2008; Kontos, 2005), and with representing it as 'a living death' (Behuniak, 2011). Behuniak goes so far as to argue that it is the social construction of those with AD as zombies that:

. . generates not only negative stereotypes and stigma associated with people constructed as 'other', but also the emotional responses of disgust and utter terror. It is this politics of revulsion and fear that directly infuses the discourse about AD and shapes it (ibid. p. 72).

Stigma is not an inherent quality of some aged and/or ill persons – it is a relation. In Goffman (1963) stigmatization, including processes of discrimination, occurs when there is a lack of fit between a body-person and the worlds of others by which they find themselves marginalized. Inasmuch as they have difficulty in passing as 'one of us', their identity is despoiled. As Twigg (2000) amongst others has asserted, the ageing body can be experienced as disgusting and repulsive because it represents deviation from what is most cherished in modernity and contemporary preoccupations with specific forms of personhood:

Modern individualism rests on the construction of persons as self-contained, bounded entities. Incontinence and bodily disintegration threaten this . . Smell and disintegration undermine individualistic constructions of the person as stable, bounded and autonomous. (Pp. 396-7)

Moreover, the parade of 'monsters' (Canguilhem, 2008) or 'revolting subjects' (Tyler, 2013) which invoke 'social disgust' (Lawler 2005) should not be understood merely as responses to the breach in the social order that older persons with dementia invoke. Rather proliferating media representations of older people with dementia are created spectacles of 'othering' that reaffirm the values and modes of ordering that underpin dominant forms of world-making. What is at stake in feelings of social disgust and the making of monsters is the very production and reproduction of values and moral forms. In some [respects](#), the figure of the demented older person resembles the Sacra (Turner, 1967) – figures, whose potency is exaggerated by their magnification, and which are paraded in order to impress those who see them. And yet, in the case of dementia, monsters are figures that somehow contravene what is most sacred. Growing old badly, especially growing old with dementia, thus can be made to represent a deviant act – forms of otherness that are punishable by stigmatization and isolation (Schmidt, 2011) – because it contravenes what is most cherished.

Bauman (2001), drawing upon Levi-Strauss, suggests that there are two ways of coping with the otherness of others: the strategies known as the emic (anthropoemic) and the phagic (anthropophagic). While phagic strategies involve assimilation of some kind, the emic consists of:

. . 'vomiting', spitting out the others seen as incurably strange and alien: barring physical contact, dialogue, social intercourse and all varieties of *commercium*, *commensality* or *connubium*. ([Bauman, 2001:](#))

In the context of ageing, the abject demented older person represents someone who is being spat out on the basis of seeming incurably strange and alien:

. . . personal losses and interpersonal ravages . . . replete with cliched metaphors and representations in which Alzheimer's is characteristically drawn in colourfully dramatic terms that paint vividly disturbing images of a monstrous disease" (Herskovits, 1995: 152).

Such monsters, have to be 'sequestered' (Giddens, 1991) – hidden away, contained. Social disgust and the creation of revolting subjects remain social processes of othering: processes in which there is a moral demand to 'efface the face' (Bauman, 1990; Latimer, 1997), and which pivots around how this 'other' is no longer fully human.

In what follows, I show how the creation of monsters, such as that bodied forth by the ageing-dementia relation, form the background against which dominant versions of what it is to age well are being performed. I go on to suggest that there is currently a global reassembling of the dementia-ageing relation that – as at the same time as it normalizes the stigmatizing effects and affects of dementia – it can also be understood as a second strategy available in the face of breaches to the social order. What Bauman calls the phagic (anthropophagic strategy) aims at the assimilation of *otherness*. So, rather than try to exile the other, this second strategy consists in:

. . . 'ingesting', 'devouring' foreign bodies and spirits so that they may be made, through metabolism, identical with, and no more distinguishable, from the 'ingesting' body. (Bauman, 2001:24)

In the context of the relation between ageing and dementia, and the prediction that 1 in 4 of us will become demented by the time we are 80, emic strategies alone are no longer feasible. This is particularly so in the context of a current political climate designed to reduce rather than expand the state supported care sector. It is not just that there are not enough 'asylums' to go around, there are going to be less and less places of refuge and care for a supposedly growing population of older people figured as potential 'bedblockers' (see also Skeggs, 2016).

My original research focused on 'bedblocking' (Latimer, 1997, 1999, 2000a and b) as a critical site: it illuminated the boundary work and struggles around those older people who have an acute episode of illness and are admitted to acute health services, but whose troubles can be marked as inappropriate for health care, with their needs redefined as 'personal' and/or 'social'. That study was in the 1990's. The availability of care and support in hospitals, residential homes, or in the home, is even more problematic in post-welfare societies (see for example the essays in Ceci et al, 2011), creating even greater problems over who or what is responsible for the care and support of older people, especially older people with dementia. Under these conditions, the stigma of the dementia-ageing relation is being intensified, especially when older people are associated with care reduced, over and over again, to its economic costs (see figure 4 which illustrates how dementia is being figured in term of its costs – there are many, many more). Being old, demented and costly, then, potentiates the stigma of the dementia-ageing relation.

Thus, alongside the making of monsters, associations between different domains in which dementia is being reconstructed mean that dementia increasingly haunts the public imagination, including the endless evocation to age well instead of badly. Through modes of prevention, including technoscientific interventions, the goal is always to transform, even annihilate the 'foreign bodies and spirits' that dementia represents. In contrast to the literature that objects to the medicalization of ageing and of dementia, the genealogy here suggests that biomedicalization is not just helping to

partially deactivate stigma (see for example, Macrae, 1999; Seale, 1999) but is helping to assemble new social formations (e.g. Bond, 1992) through which to assimilate and transform dementia<sup>1</sup>.

I begin with analysis of a short film about Gladys Wilson and Naomi Feil that as at the same time as it appears to parade the abject older person with dementia as all that is most feared about growing old, also helps reveal a conundrum deep at the heart of the dementia-ageing relation and possibilities for the emergence of new social relations through which to reassimilate the ageing-dementia relation. I go on to show how the contemporary dominant classification of 'ageing well' rests upon complex associations. The widespread enactment of dominant notions of what counts as successful ageing (including prolonged productivity, heightened activity, self-determination, mastery of information technologies, competition of all kinds, youthful vigor and glowing health) act as valued forms of personhood alongside actor-networks of public health, biomedicine, neuroscience and cultures of consumption that are bringing ageing and dementia into being as a bioscientific object. Together they establish that ageing is plastic, not inevitable; something to be transformed, or at least have its worst ravages postponed.

### The Old Fools

.....That is where they live:

Not here and now, but where all happened once.

This is why they give

An air of baffled absence, trying to be there  
 Yet being here. For the rooms grow farther, leaving  
 Incompetent cold, the constant wear and tear  
 Of taken breath, and them crouching below  
 Extinction's alp, the old fools, never perceiving  
 How near it is. This must be what keeps them quiet:  
 The peak that stays in view wherever we go  
 For them is rising ground. Can they never tell  
 What is dragging them back, and how it will end? Not at night?  
 Not when the strangers come? Never, throughout  
 The whole hideous inverted childhood? Well,  
 We shall find out.

(Larkin, 1973, *The Old Fools* in *High Windows*)

Media representations of dementia proliferate (Swinnen & Schweda, 2015). They show us monsters

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<sup>1</sup> In this paper I am drawing on my ethnographic study of biology and ageing, which began in 2009 with a study funded by the RCUK New Dynamics of Ageing Program entitled Ageing & Biology (see also Cox et al, 2014), a series of small grants awarded by Cardiff University & the ESCRC Centre for the Social and Economic Aspects of Genetics (CESAGEN) and a Wellcome Trust Project (with Alex Hillman) on Alzheimer's Disease and memory clinics as well as cultural representations of dementia (Hillman and Latimer, 2017). This research has included interviews and site visits with scientists across the UK & the US, participant observation at conferences on ageing; ongoing conversations with different scientists, clinicians and neuroscientists; participant observation at memory clinics, as well as analysis of publically available representations of ageing, biology and dementia.

as at the same time as they are making the experience of the dementia-ageing relation more and more present in everyday lives (Carbonelle, et al. 2009). Martin et al (2013) suggest that:

. . . films generate certain feelings about dementia which then become part of our popular understanding and approach to persons living with dementia. Indeed, they potentially become part of how people with dementia come to see themselves as they draw upon such films as a cultural resource for making sense of their condition. (Martin et al, 2013, p. 284)

But I want to press how the proliferation of books, films, television dramas and soaps which include a character with dementia are helping to body forth dementia, even give it an existence. As Cohen-Shalev and Marcus (2012) assert, these films are often from the perspective of those looking in on a person with dementia becoming other, a stranger, while others help us to get inside the experience of the person becoming-with dementia. Swinnen and Shweda (2015) suggest many depictions portray the ageing-dementia relation as an inevitable process of decline and unbecoming. Recent examples are the UK TV series', *Wallander* (BBC 2016), based on the Swedish TV series, and ITV's (2016) *The Missing*, both of which depict a strong, professional man who occupies a senior position gradually losing his memory and his mind, increasingly unable to work but attempting to cover it up, and eventually becoming fragile, needy and dependent. In *The Missing*, the senior army officer, played by Roger Allam, has to be admitted to a nursing home, cared for 24 hours a day. These are tragic depictions, the decline and fall of a big man, and the gradual slide towards vulnerability, fragility and becoming a non-person. These representations of dementia parade the dementia-ageing relation unproblematically as something to be feared, as shameful and as stigmatizing. This is the dementia-ageing monster on parade – to be vomited up and sequestered.

But this picture of the slide toward a living death is being disturbed by recent interventions, such as those by the well-known neurologist, Oliver Saks (2008) in his and others' work on musicophilia<sup>2</sup>. In particular, I want to draw on one such intervention through analysis of a short film, publically available on Youtube, by Naomi Feil, a US based validation therapist, and Michael Verde, a filmmaker, about Feil's encounter with Gladys Wilson.

At first we see Gladys Wilson in a chair alone, apparently introverted and disconnected, eyes closed, very thin, but tidy and clean, sitting in a wheelchair that has been made to seem like an armchair (fig. 1). She is sitting alone in a barren, impersonal, sanitized setting. On a close up of Gladys' face it is emaciated but peaceful. Her clothes and crooked teeth as well as the paucity of the institutional setting indicate Gladys is not a wealthy woman – not now at least.

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<sup>2</sup> See <https://www.youtube.com/watch?v=tqrNEmuSCis>. In this video we see an older Afro-American man in a wheelchair 'away' like Gladys, someone puts headphones on him and he literally comes awake, starts singing and bopping in his chair, and afterwards he becomes perfectly capable of answering questions and interacting. We are told the music is hearing is a composite of music he liked across his life.



Figs. 1 Gladys Wilson, 2009, with kind permission of Naomi Feil and Michael Verde available at <https://vvalidation.org> and <https://www.youtube.com/watch?v=CrZXz10FcVM> (.)

We are told by Naomi Feil, in the voice-over, that Gladys is in her eighties and that she was diagnosed with Alzheimer's Disease (AD) nine years ago, and now has little language. For many of us seeing Gladys like this represents our worst nightmare about growing old – abandoned, institutionalized, forced to endure a pitiful life that hardly appears to be worth living – a zombie, even perhaps repulsive and disgusting to some viewers. In many ways this figure of Gladys, co-created by us the audience together with Feil and her film team, seems to body-forth all that is most feared about growing old with dementia: the hollowed-out person in a state of 'living death'.

At the same time Gladys seems peaceful even calm. Very different from the representations of the persons *becoming* demented depicted in films such as *Amour*, or TV dramas, like *The Missing* or *Wallander* mentioned above. Gladys seems 'elsewhere' to the present reality of other people. She is perhaps, more or less, absent to their world-making: being *there* and not here, as Larkin's poem expresses it in the citation above. While this withdrawal may be due to her disease, it may also be her retreat, even a refusal, a repelling: a sign that she no longer wants to participate in the social. As in 'The Old Fools' she may be otherwise engaged, looking inward to the fading rooms and faces and moments from her past life. There may be nothing wrong with being in the world like this. Who knows?

Whichever way we want to look at the film, Naomi Feil takes a more radical position. Like Margaret Shlegel in *Howard's End* (Forster, 1910) she insists we should 'Only Connect!' and stresses that Gladys, like everyone else, needs and wants connection. While I'm not sure about the discourse here, what I want to stress is how Naomi finds a way to become competent in Gladys' world and connect with Gladys. What we are shown is Naomi reaching Gladys: by using her body, and her voice, by taking Gladys' hands, by touching and stroking Gladys face, by moving her face into the space of Gladys' face and touching Gladys' forehead with her own forehead, by singing a negro-spiritual hymn with her, and by holding Gladys' hands and arms and beating time together as she sings. Gradually Gladys opens: her eyes open and look into Naomi's eyes, she holds Naomi's hands, pulling her in and pushing her out as if to focus, and then she begins to sing with Naomi.

For a few moments Gladys-Naomi sings and beats time, in their jointness they become face-to-face. This is a material semiotics of bodily connection in a bodily becoming-with (Haraway, 2008). Then they separate and Gladys seems to be awakened – concentrating on Naomi, answering her questions, making a choice, having autonomy, being expressive. Naomi seems to bring Gladys into presence as participant in world-making. And as such Gladys becomes more than the living dead, regaining what most of us would recognize as the attributes of the fully human.

In the perspective that the film unfolds Gladys is refigured: instead of her inert condition as we see it at the beginning being constituted as something inherent - the effects of ageing and AD on her brain and the rest of her body - we can begin to question whether her condition is an effect of a body-self-world relation (Latimer, 2009), and perhaps of the stigmatizing effects and affects of dementia. An extraordinary possibility is created which has the chance to completely shift how we know and understand Gladys – the supposition of her condition being that of a ‘living death’ may be not just an effect of her degenerating brain, but of her emplacement by a world that does not know how to reach her? Or, indeed, a world that deliberately sequesters her as Other. From this different perspective, dementia and AD become distributed, relational and co-created.

### **Biopolitics and Successful Ageing: managing and self-care**

The figure of the abject older person becoming demented is invoked in the legitimation of a new and emergent biomedical interest in ageing. In my ethnography of biology, medicine and ageing (Cox et al 2014; Latimer, forthcoming; Latimer, et al 2011; Latimer & Puig, 2013), for example, the biomedical scientists I have interviewed almost always cite dementia and AD as the worst of what ageing does to people:

So you know the ideal scenario is that you would be able to start taking some tablets when you were 55 or something like this and it would provide protection against dementia, against heart disease, against diabetes, against you know the bewildering diversity of horrible things that go wrong with you when you get older. And that would be marvelous (Biomedical Scientist of Ageing interviewed in 2010)

Biomedicine is a dominant site of contemporary knowledge creation that is constructing and reconstructing ageing and death (Vincent, 2008 p.331), particularly dementia (Bond, 1992). This process is reflected in worldwide programs that are medicalizing ageing by posing ageing as a challenge because of links between ageing, chronic illness, disability and the increasing need for care (United Nations, 2013; Vos et al, 2008). Problems that get highlighted include the prevalence of multiple forms of illness associated with later life (e.g. Barnett et al, 2012; DOH, 2014; Kings Fund, 2012), especially, as I have already indicated, AD and dementia. At the same time biomedicine intensifies the reorganization of health care not just around technological intervention but, increasingly, around modes of prevention and consumption (Clarke et al., 2010; see also Kaufman et al., 2006). This is important to note as an aspect of the political economy of dementia, referred to above in relation to ‘bedblocking’ and the discourse of crisis in health and social care. This crisis party constructed around an idea that ‘we cannot afford dementia’ which is of course partly what is stigmatising about it. Within this perspective the stigma associated with the dementia-ageing relation is not just the outcome of a political regime, it is helping to legitimate the biomedicalization of ageing, in general, and of dementia, in particular. In the context of so-called ‘greying populations’ and the associations between ageing, multi-morbidity and the proliferation of chronic and disabling disease in later life, ageing has rapidly become not just a policy ‘problem’ to be managed (Balzagette et al 2011), but, as Binstock et al (2006) suggest, an exemplar scientific site for understanding ‘all

enhancement technologies'. Specifically, knowledge practices and governmental processes that position life as an object of power in contemporary capitalist societies can be understood as being played out around what constitutes ageing well or badly (Neilson 2012), especially the causes of different ageing trajectories.

The important questions, for economies, persons, families and communities is not mortality - we are living longer than we have ever done - but *how* and *when* will we age. Globalization, individualization, labour market de-regulation and re-structuration of public services (Beck, 2000; Higgs and Jones, 2009; Kohli, 2007) alongside increased longevity have worked to produce what is sometimes labelled a de-standardized life course (Bruckner and Mayer, 2005), including imaginaries of more fluid, post-modern life trajectories (Hockey and James 2002; Turner 2009) that extend 'middle age' well into latter life. This fluidity is reflected in increasing emphases in health and social policy on finding ways to prolong productivity and employability (e.g. Department of Work and Pensions 2005) especially a 'third age' (Lazlett 1989) of activity, youthfulness and health (Featherstone & Hepworth 1993), with baby-boomer hopes and aspirations for 'timelessness' (Katz 2005), and an endless life of consumption and choice (Turner 2009). How people age is thus no longer being seen as the 'natural and inevitable occurrence of growing old' (Butler 2001–2002, p. 64), but as something that is plastic and malleable (Moreira and Palladino 2008) and available to enhancement (Binstock 2003, Binstock et al 2006).

These biomedical and public health discourses are, however, simultaneously circulating dominant versions of 'successful' ageing, which are underpinned by specific notions of value – keeping productive, independent, fit and healthy, including managing risk. Rowe and Kahn (1997), for example, state that the concept 'successful ageing' has its roots in the 1950s, was popularized in the 1980s, with 'success' classified in terms of three features: low probability of disease or disability; high cognitive and physical functional capacity; and active engagement with life. While the life course is being reimagined as more and more fluid, possibilities for successful ageing are increasingly being individualized and reconstructed as a problem of self-care and self-management of risk (Hepworth 1995; Neilson 2008) on the one hand, and as available to techno-scientific manipulation on the other (Mykytyn 2010). Human ageing is thus being reimagined as increasingly subject to reflexive management and manipulation, including a new age of consumers striving to age positively, including the incitement of a rational practice of designing one's own lifecourse through consumption of 'anti-ageing' technology, products and activities (Schweda & Pfaller 2014).

These discourses of successful ageing thus enact what it is to be a full person and a good consumer in late modern capitalism. Furthermore, 'ageing' as a target to be managed resembles the most sacred of 'public secrets' (Taussig 1999). Not only must everyone age and die (eventually) but opening ageing up as a site of enhancement creates opportunities for the enactment of what is most valued and precious in neoliberal forms of modernity – to have a 'future' and be 'ready and available' for whenever the call to do this or that comes along (Latimer & Munro 2015). The call here is to manage aging successfully. More specifically, after Skeggs (2011), ageing bodies can be seen as bodies of value when they body-forth the effects and affects of managing ageing well.

The markers and signifiers of successful ageing thus go beyond just health, fitness and engagement, and involve enactment of active engagement in *managing* ageing. Hepworth and Featherstone (1993) in their ground breaking work on representations of ageing, written at the advent of the current form of capitalism we are experiencing today, helped to illuminate this shift in possibilities around what it is to age well. Through an examination of 'Retirement Magazine' they analyze the emergence of a new discourse with its front cover images not just exemplifying a discourse of

successful ageing, but as helping to construct it.

Specifically, they show how photographs of Mrs Thatcher frequently appear on the front cover, and suggest these images body forth what it is to age successfully. She appears in middle age, full of vitality, exuding not just health, but poise, grooming and wealth, each performed as *achievements*: the fruits of a steely reflexive modern relation to self through which both the world and the body can be *managed* to postpone older age. The irony of course is that Thatcher as the peon of the possibility that the Third Age could be stretched indefinitely was later subsumed by AD. The achievement Featherstone and Hepworth depict involves individuals investing well in their bodies as well as their other possessions as the pinnacle of individualism, and reflexive management of self (see also Callero, 2013). Here I want to stress the term ‘manage’ as extruding any possibility of failure:

In contemporary Western culture, we are encouraged to think of our lives as coherent stories of success, progress and movement. Loss and failure have their place but only as a broader picture of ascendance. The steady upward curve is the favoured contour. (Stacey, 1997:9 in Diedrich, 2007)

This imaginary of successful ageing – as a lifecourse managed as a steady upward, rather than downward, curve – is represented in public health discourse and health promotional media as if it is available to everyone. Indeed, ‘everyone’ is represented as capable of achieving a successful and prolonged third age. Critically, the fulfillment of this utopian project is represented as an urgent issue to ensure sustainable futures for ageing societies, “a future that takes full advantage of the powerful resource inherent in older populations.” (WHO 2011).

Just think for a moment on the images and discourses in the media that endlessly promote the relation between active and healthy lifestyles and successful ageing. We are immersed in images that characterize people in middle age as always *doing* – (running, rambling, going on holiday, smiling, interacting) – they are never static: as if a continuously active, mobile present is what will keep us youthful and postpone old age. This hopeful imaginary is all around and is prolific (Petersen, 2015). It continuously incites people to consume (Hurd-Clark, 2010): to buy or to join – pension schemes, anti-ageing creams and supplements, gyms, ramblers’ clubs, bicycles, five fruits and veg a day, retirement homes – the list is endless. At the same time we are bombarded with new scientific breakthroughs over what will prevent illness and disability (4 hours of intense exercise each week – half an hour’s walk five times a week; just walking!), as well as things to eat (low fat, low calorie; high fat, low calorie; more vit C, less Vit C – superfoods abounding with new types every week) (see also Petersen forthcoming). Even coffee is proselytized as giving us longer life.

Public health and biomedical messages are thus coupled with a culture of consumption preoccupied with health and youthfulness (Schilling, 2002). The effect is to continuously incite consciousness of the relationship between health, ageing and identity by thrusting us into the future at all times, putting us in what Heidegger (2008) calls ‘advance’ of our bodies and ourselves, so that even a stroll in the countryside to a favorite spot becomes a moment for enhancement, health promotion and disease prevention as we contemplate not the extraordinary view but whether we are walking far enough and fast enough.

Neilson (2012) suggests this as a “growing pressure for ageing subjects to perform practices of self-care”, one that involves an existential shift because it is a “process by which the care of self begins to eclipse the care of others.” (p.45). Healthy ageing is thus being increasingly made the responsibility of individuals and families as at the same time as it is a prime marker of positive identity. Critically then,

'response-able' (Latimer 1999; Latimer & Munro 2015) persons need to be seen to answer the incitements and manage their ageing well, with what counts as successful ageing prefigured as specific forms of personhood – active, productive, fit.

The biopolitics of ageing is thus being reassembled in ways that not only cut out how ageing is a relational co-produced effect, but also seem to represent a shift: from the othering of the otherness that the old represent, to a phagic strategy that impels us to manage our ageing, ingest and assimilate it, and so change its very character, to prolong being and seeming to be younger, postponing the onslaught of what the transhumanist Nick Bostrom (2005) calls the ageing dragon. Those who do not conform are not just at risk of stigmatization, they are at risk of being part of the parade of spectacles, revolting subjects, and monsters.

### **The Dementia Monster & Being Irresponse-able**

There are around 36 million people with some form of dementia in the world and this is expected to at least double over the next 20 years, making it one of the largest neglected global health challenges of our generation. The global economic cost of dementia is estimated at over US\$600 billion, and Alzheimer's Society research suggests that in the UK, one in three people over 65 will die with dementia. This is not something any of us can afford to ignore. (Piet, 2012: 18)

As discussed above growing old badly is personified by the figure of the older person with dementia. Until recently dementia has not been of much interest to clinical scientists. This is partly because dementias could not be made visible as located in lesions in the body, until post-mortem, so that diagnosis was clinical, arrived at through processes of differentiation (Bender, 2003). In addition, dementias have been caught up in the inherent ageism of clinical medicine (Oliver 2008), with dementia being constituted as intractable, inevitable and as a policy problem to be managed, rather than as a proper target for high-flying clinical research. But this is changing.

The alignment of the 'apocalyptic' (Robertson 1991) demographic predictions of the cost of ageing populations plagued by dementia (see for example, WHO, 2015 & Fig. 4) together with revolutions in brain scanning technology that allow for the investigation of living brains (Shine et al, 2015) and post-genomic science that enables the genetic profiling of neurodegenerative diseases (Tanzi and Bertram, 2001), mean that dementia is becoming an increasingly potent site for both clinical and for technoscientific research (Milne, 2017). Critically, we are witnessing how dementia is being reconstituted across the biomedical and neurological sciences as well as mainstream psychology to grow differential dementia diagnoses (Hillman and Latimer, forthcoming). The medicalizing of particular effects as different forms of dementia is ongoing with what Beard and Neary (2013) describe as "nosological creep".

More specifically, brain ageing, like ageing more generally discussed above, is beginning to be opened up as a site of prevention and enhancement (Moreira and Bond, 2008). A new frontier of scientific research is reconstituting the brain as much more plastic and malleable than originally thought (Williams et al, 2012), with hopes and expectations that have gone public:

...scientists worldwide, working in many different specialities, have found that the human brain is highly plastic, possessing the ability not only to create new neurons, but to modify networks of neurons to better cope with new circumstances. (DementiaToday, 2013)

Within this imaginary dementia is the effect of reduced brain plasticity due, for example, to biological ageing. Constructing the ageing-dementia relation in this way begins to give it a future. For example, it becomes something that is possibly preventable, with the public being incited to keep exercising their brains as a preventative strategy. Specifically, the tragic vision of the abject demented older person, such as Gladys, legitimates the enactment of specific values, namely the creation and capitalization of troubles and the triumph of endeavor, including the proliferation of science, industry and innovation through which to overcome, manage and transform dementia. It is not just that dementia in the context of ageing undoes the basis of what it is to be fully human, of personhood, in terms of memory and its loss (Katz and Peters, 2008), it is more complex than that.

Within biomedicine dementias are located as progressive or degenerative diseases of the brain in ways that increasingly somaticize mind and personhood (Pickersgill, 2013; Locke, 2014, Moser, 2011). There are disputes around whether different kinds of dementia are the natural consequence of biological decline, or whether they can be reframed as a ‘terminal disease’ or a mental health issue (WHO, 2015) – thereby, like cancer before it, mainstreaming how dementia can and ought to be known and ‘disciplined’. This has meant that the technoscientific pursuit of knowledge about and interventions in dementia and new thinking in neuroscience about the plasticity of the brain align to form a ‘neuroculture’ (Williams et al, 2012) that individuates dementia as preventable disease or, at the very least, treatable.

I want to suggest that this increasing biomedicalization of dementia – including notions that ageing, even the ageing brain, can be *managed* – reinforce a phagic strategy to transform the ageing-dementia relation through ingestion and assimilation. This strategy can be seen in the reorganization of health services and research around a program for the ‘early detection of dementia’ (Swallow, 2016), and the constitution of a new category of prepatienthood, ‘mild cognitive impairment’ (or MCI) (Katz & Peters, 2008; Moreira, et al 2009). It also includes, like ageing itself, a notion that dementia can be modulated, postponed or even prevented, provided individuals live the right way (Peel, 2014). So, *there* is the rub – the call for lifestyles and self-management strategies through which to nullify the potential of the ageing-dementia monster.

The shift towards reforming ageing, and even the ageing-dementia relation, as manageable depends upon individuals responding to this call to the future and to ‘care for themselves’ (as opposed to others). In this sense then the phagic strategy depends upon people responding to the call to master their futures through their ‘strategic conduct’ (Giddens, 1984) of the present. The figure of the aged demented subject, such as Gladys, is thus also a subject that bodies forth the figure of someone who has not responded to this call, and managed their ageing well.

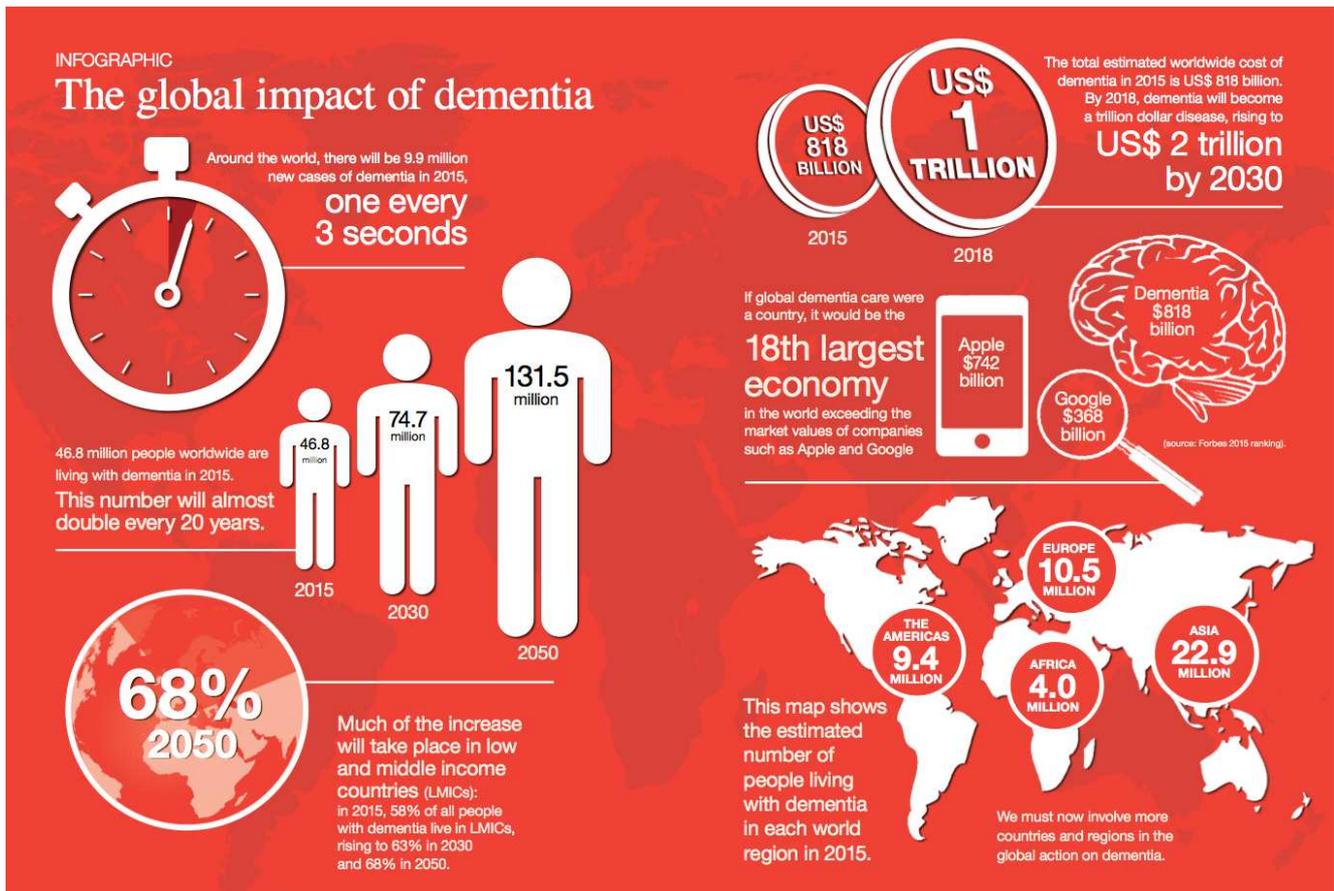


Fig 4. The Costs of Alzheimer's Disease (Alzheimer's Disease International, 2015:3)

Dementia is frequently described as a neuro-degenerative disease. I want to suggest that in the contemporary moment the ageing-dementia relation enacts a profound sense of *immorality*. Specifically, the dementia-ageing relation's monstrousness, its repulsiveness, comes from how it is *constructed as if it* threatens what is most sacred to Euro-American notions of personhood: not just the imaginary of the sovereign subject, or even one who is merely reasonable, but of the subject who is *response-able*. So for example, to be a good somatic citizen (Rose and Novas, 2004) requires someone to be response-able.

Here I am building on my own earlier work that I referred to earlier (Latimer 1999, Latimer & Munro 2015) and the notion of personhood as situated and relational, including an effect of being 'response-able'. If we accept that personhood is not a possession, but situated, then we can also suggest that personhood is an *effect* of being 'response-able': and as I have suggested above, in terms of the relationship between ageing and persons, response-ability has very specific connotations. Being response-able involves what Goffman (1958) describes as presentation of self, which depends upon strategic conduct and reading and doing the social to get along and go along (Giddens, 1984); what Garfinkel (1967) shows as doing member, including being accountable and making actions visible and observable as rational and reasonable; what Foucault and others have shown as being positioned & being emplaced by modes of ordering as well as having the know-how of when and how to resist & transform these through negotiation, agonistics, persuasion (Foucault, 1991; Lyotard, 1984; Rabinow, & Sullivan 1979).

But as I am pressing response-ability here it has an added cache: it includes being ready and available to fold into the next call to the future. From this perspective some older people classified as having

dementia can be regarded as ‘socially abject’ (Tyler 2013) not because of anything essential or inherent but because of how they are not performing themselves as response-able, of how they seem to refuse and repel late modern modes of ordering by ageing unsuccessfully. To put it another way their sensibility and experience has not been sufficiently attuned and exercised to what Adam et al (2009) call the mode anticipation:

As much as speculative finance has become both a dominant mode of capital accumulation, spawning its own material and discursive effects of disaster prediction, anticipation has become a common, lived affect-state of daily life, shaping regimes of self, health and spirituality. (2009: 247)

A conundrum then – through being response-able and maintaining their performativity in relation to neoliberal world-making, for example, through self-care and the reflexive management of risk, people as they age can maintain their ‘status honour’, to use Weber’s terminology. But as Minkler and Holstein (2008) suggest this then acts to denigrate and throw into perspective those aged subjects that can be made to seem abject.

Following Skeggs, Tyler (2013) helps us to see how abject subjects are the effects of classificatory mechanisms through which specific body-persons become systematically defaced and devalued. What she goes on to show is how the rubbishing of particular kinds of body-persons is because of how they stand against particular neo-liberal institutions of identity and personhood, not least in terms of the individuation of persons as discrete, body selves in ways that obscure how persons are affected and effects of their ‘body-person-world’ (Latimer, 2011) relations. Within this view people who appear as abject subjects are not just the effects of complex entanglements in the alignments between media, public health discourse, and forms of governmentality working on behalf of capital. We can see how the prospect and anticipation of ageing, and the creation of monsters such as the figure of the aged person with dementia, both unconceals and intensifies the precariousness of contemporary social existence.

### **Dwelling Alongside Dementia as ‘a Figure Seen Twice’**

The figure of the older demented person represents something sacred that has become despoiled, what is lost is even more precious than the hollowing out of the person, the mind, the individual, their self. As Taussig asserts, this despoiling is ‘attractive in its very repulsion’, because ‘it creates the sacred even in the most secular of societies and circumstances’. Specifically, at moments what affronts neo-liberal world making is the abject figure of the old demented person as one who has not managed their ageing, its repulsiveness attracts because it helps recreate what is most sacred. The figure of the old demented person is both an infraction of the sacred: it helps to recreate the possibility that man can and should manage his or herself – body, mind and all – as a phagic strategy to eliminate the otherness that ‘bad’ ageing represents.

Bad ageing, like poverty, is performed as the *failure* of the individual because of how they fly in the face of contemporary neoliberal agendas: in Bev Skeggs (2011) terms they are unable to (or do not want to?) embody or body forth neoliberal values. In this sense then, stigma is the effect and affects of complex alignments: political, medical, cultural. Ageing, and the extraordinary proliferation of concern and excitation of interest around ageing is an event that brings to the surface the antithetical relation between growing old and neoliberal forms of personhood.

The inversion I want to propose requires us to *'dwell alongside'* (Latimer forthcoming, and Latimer 2013) dementia. Dwelling alongside is a way of being with and becoming with the ageing-dementia relation and be affected by it in ways that challenge dominant forms of what counts as successful forms of personhood. At the same time we need to hold onto the possibility that we can reassemble the social in order to find ways to bring the older person with dementia back into presence. To return for a moment to the film about Gladys Wilson, discussed earlier in the paper, maybe Gladys is just as fully human at the beginning of the film, but simply different? In other words, it may be *us*, and even Naomi, that are *elsewhere* to Gladys' present reality – to her way of being in the world. Within this inversion it is we who are 'other' by virtue of the *long duree* (Giddens 1984) of contemporary forms of personhood. The anthropologist Clifford Geertz (1973) may help us to some extent here. In his initial encounters with the Balinese the locals seem to look at him and his wife as if it is they 'who are away'; they see through them as though they are naught but the air. Yes, at the beginning of the film Gladys seems 'away', in the sense that the Old Fools, in Larkin's poem, are away – they are *there* rather than here. But, contrastingly, drawing on Geertz's work, we have to consider that it may be 'us' that are elsewhere. Us, with our projects and our futures who are really away?

The opening for care that the film conveys thus constitutes what Rudge (2011) calls a rupture of certainty. It is not just that there is no way of knowing for sure how Gladys feels about what is going on. Of course, we do not know whether she wants to be refolded into the present, 'awakened' as Saks (2008) might put it. Rather, what I want to press is how the deep ambiguity at the heart of the ageing-dementia relation is revealed – for a moment – through Gladys and Naomi becoming differently to how they were previously shown to us. On the one hand then can we cherish those with dementia as 'other' than us? And on the other can we begin to see, with Naomi, that the effects of dementia that produce the figure of Gladys as isolated and disconnected are not so much the inevitable consequences of the decline and deficit caused by ageing and dementia, but perhaps the effects of stigma and her emplacement? To use [Donna](#) Haraway's (2005) terminology – this is a moment of 'reworlding' in which the dementia-ageing relation gets figured differently. So what we need to acknowledge, even celebrate, is how this kind of radical relationality entails a possibility of 'dwelling alongside' (Latimer, forthcoming) those figures that seem most stigmatized – and so open up the figure of the ageing-dementia relation to broader perspectives.

With [Michael](#) Halewood (2016) in his recent paper on dementia, I am pressing the need to see people like Gladys differently and rethink "what kind of selves we all think we are" (p.3). This may involve getting beyond old binaries, and 'double crossing' (Munro 2016): going back and forth, one moment seeing ageing and dementia as relational, and as 'things' we can affect and change; and, in the next, celebrating other forms of sociality that involve different ways of being in the world to those that dominate.

## Conclusions

I started the paper by suggesting that there is a proliferation of media representations that parade the abject, aged dementia subject, to bring the dementia-ageing monster into existence as a part of the everyday. The ageing-dementia relation is stigmatizing because it 'breaches' as Harold Garfinkel (1967) would say the markers and signifiers of what makes someone up as a full person. Growing old and becoming 'demented' can seem to put someone beyond the pale.

After Bauman I proposed that the parade of the dementia-ageing monster can be thought of not just as an emic strategy for vomiting up and sequestering the otherness of the abject older person with dementia. Rather the alignment of the parade with a changing biopolitics of the dementia-ageing

relation that I have described can be understood as a phagic strategy to know, ingest, and transform the dangerous and monstrous otherness that the older person with dementia is made to represent.

The phagic strategy involves the creation of a *dispositif* (Foucault 1980), an actor-network of associations for knowing, detecting, managing and transforming dementia: public health discourses promoting healthy ageing associate with policies such as early detection and diagnosis of dementia, a proliferation of technoscientific research, media representations and an anti-ageing culture of consumption – through which the effects identified as dementia can be known, transformed or even just postponed, providing individuals are response-able. Being a full person in late modern times, I have suggested, goes beyond memory and reason – it includes health, fitness and engagement, and the capacity to respond to the call to transform the future by participating in the active and strategic management of ageing.

The ‘thinging up’ (Larsen 2013) of the dementia-ageing relation as something available to enhancement is I am arguing occurring against a background of the parade of monsters. Critically, I suggest, this ‘double helix’ is shifting dementia from simply being an object of disgust – to be shunned and excluded in processes of emesis – into a present day reality, an imminent and present danger, which can and will be ingested and assimilated: transformed by biomedicine and the social body, as at the same time as it is transformative of the social body. On the one hand then the ageing-dementia *dispositif* includes incitements for people to be response-able, stand in advance of their ageing bodies and be proactive to prevent and/or postpone both ageing and dementia. On the other it is the relation – between the older person with dementia and the world in which the older person finds themselves - that needs reordering to find ways to dwell alongside dementia.

I showed you Gladys and Naomi Feil, and how they become with each other in ways that mean that dementia is different from what it was before: that it is as much a body-world relation as it is a state of becoming other. Perhaps the ambiguity and conundrum of the ageing-dementia relation mean that it needs to be a figure seen twice (Riles, 2000): the figure of Gladys – isolated, alone and disconnected – ‘elsewhere’ as I have put it - can be seen as an effect of a disease, or as the effect of stigma: a body-world relation where becoming the living dead of dementia is an effect of how a person is stigmatized, emplaced and sequestered by the biopolitics of late modern capitalism. As such as Feil shows us we need to find ways to reincorporate people like Gladys.

But I proposed that there is yet another way of seeing the figure of Gladys – as someone who is elsewhere, different, but still fully human, even if they are like the Old Fools, ‘away’. Franco Berardi Bifo (2014) in his essay “Exhaustion and Senile Utopia of the Coming European Insurrection” suggests that our way of being together has become apathetic, with modern culture and political imagination emphasizing “the virtues of youth, of passion and of energy, aggressiveness and growth” (p.537). He suggests that capitalism relies on the exploitation of physical energy, with ‘semicapitalism’:

. . . subjugating the nervous energy of society to the point of collapse. The notion of exhaustion has always been anathema to the discourse of modernity, of romantic Sturm and Drang, of the Faustian drive to immortality, the endless thirst for economic growth and profit, the denial of organic limits.” (p.537).

Thus there is the possibility that in our relation to Gladys as we first see her it is us who are elsewhere? By shifting our relations to the characteristics we are being made to see as dementia, we can refigure them as ways of being in the world differently, and as such, as other ways of being human. Here I am suggesting we need to make room for those characteristics and ways of being

human that we are being made to see as the signs and symptoms of dementia. Solidarity with dementia may require then a shift in perspective. What is needed here is very nuanced. Perhaps we can think then how dwelling alongside dementia is about seeing the sense in the reality and world of the person with dementia, becoming more competent in that world and letting the person who they once were, 'go', at the same time as letting the person they are becoming dwell with us, dwelling alongside and cherishing their difference. Here I emphasize the importance of strategies for dwelling alongside the aged as a possible way to resist the dominant forms of personhood mobilized in late modern capitalism, and which "others" those no longer willing or able to be response-able and fold themselves into its demands.

In a phagic reversal of dementia's fortunes the ageing-dementia relation is becoming incorporated into the social body in ways that are helping to reassemble the social in order to transform the future. This involves the partial biomedicalization of the dementia-ageing relation alongside the circulation of hopes, even expectations, that the otherness that marks the abject dementia subject as 'bad ageing' can be postponed and even eliminated. This includes being incited today to be response-able and manage ageing in ways that keep the ageing-dementia monster at the door. The reassemblage of the dementia-ageing relation also includes opening up to dementia's otherness, with new institutions and media representations that help us trouble and even undo specific neo-liberal positionings to help deconstruct the ageing-dementia relation as itself *relational*, so that there are possibilities for finding ways to dwell alongside dementia, give it room, in moments of reworlding. Here I have in mind the ways in which dementia is being partially transformed through how it is reshaping the social body, including such entities as dementia friendly communities, dementia villages, and Alzheimer's choirs. What is interesting here is the extent to which these sequester or assimilate dementia.

Specifically, then I am suggesting a sensibility that does not simply reproduce old binaries between social and biomedical representations and interventions in dementia, especially those that dismiss the biomedicalization of dementia (Lyman 1989). Rather there is a need at the very least to illuminate differences between when it is a disease that is making someone be the ways that they are being, when it is the lack of fit between them and the world-making they are emplaced by and when it is them becoming differently. I want to suggest then what is required by us is to dwell alongside those other ways of being in the world - slowness, immobility, degeneration, confusion, impotency, even chaos. We know from so many carers how dementia disorders the modes of ordering that underpin our living together in the world, and that can include our own as thinkers, scientists and researchers. This means finding ways to dwell alongside what we are being made to see as a clouding of the light of the enlightenment. Attempts to eradicate the otherness of the ageing-dementia relation, and dispose of dementia or at least bring dementia to heel, are not necessarily problematic in themselves, they are problematic when they deny ways to challenge those dominant modes of ordering, and perhaps what positions the aged and the demented, that co-creates or at least intensifies dementia.

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