



RAPID RESPONSE



Vice-chancellors should start planning their climb-down strategies



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AGEING AND DYING ARE A CONTINUUM

By [discoversociety](#) February 06, 2018 1 Comment 2018, Articles, DS53



Naomi Richards

When I submitted my first article to an international ageing journal (Richards 2012), I was genuinely perplexed to receive a review asking me to justify that 68 counted as 'older' and also to be asked why I had assumed that people of that age might be more likely to be contemplating their own death.

I had thought the logic of my argument was obvious, but, **given that 70 is the new 60**, for the journal reviewer 68 was just 'not that old'. Presumably for her, someone was no more or less likely to be thinking about death at 68 than at any other age in their life. I wonder now if the reviewer was herself older and was personally affronted by the link I had made between ageing and thoughts of death.

Statistically, a man in the UK aged 65 has on average 18 and a half years of life remaining and a woman nearly 21 years (ONS, 2014-2016). So, the reviewer was *technically* right that, at 68, a person on average has many years of life left. But I would counter that by 68, most people will have experienced the death of family and friends, undoubtedly prompting contemplation of their own mortality. More than this, they will have *experienced* ageing – its physiological but also psychological effects – which is likely to have prompted some reflection on 'time left'.

Perhaps if I reach 68, I will also feel that death is no closer than it is now, as I near 40. I've worked on other research projects that have shown that a 'timely' death may always come at an age older than you are now, even at 90 (Richards et al. 2013). But can it *really* be considered ageist to acknowledge the incontrovertible fact that we all die, most of us (thankfully) in old age?

Is it ageist to acknowledge that preceding that death will be months, if not years, of bodily decline, involving some anticipation of the inevitability of where one is headed? I don't think it is to assume that everyone is gripped with a profound existential anxiety, to accept that many older people will be contemplating their mortality, that the likelihood of doing grows with age, and that along with contemplation might be a desire to talk about what the future holds, without fear of judgement or censor.

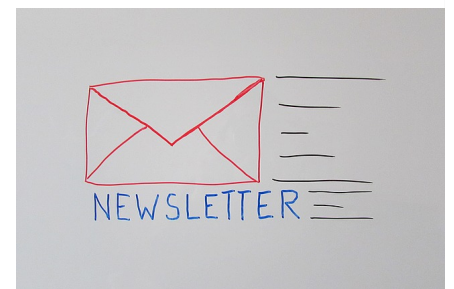
This professional anecdote highlights a broader trend: that ageing and dying are too often artificially separated (Gott & Ingleton 2011). Research about ageing is published in one set of journals and research about dying in another – mostly those dedicated to palliative care.

It seems that discourses about active ageing, about successful ageing – about the added years of *good quality life* that older people can expect at the beginning of the 21st century – can only take centre stage if ageing studies turns its back on the three Ds: Decline, Dependency, and Death.

This trend extends beyond the idiosyncrasies of academic publishing. The compartmentalization of ageing and dying goes on in real life too. The publishing of academic research in a way mirrors this societal separation.

But in failing to acknowledge that ageing and dying are a *continuum*, we become culpable of a perverse form of death denial. We also risk failing to offer the right form of care at the right time, such as palliative care, to frail elderly people. And we limit opportunities for conversations with older people about the dying that they

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Recent research tells us that people in their 90s *are* accepting of impending death and do want to talk about how they will die (Fleming et al. 2016). They don't want to have their questions or reflections dismissed or avoided.

The rejection of separate silos that segregate 'aging' and 'dying' has come to form the backbone of my research career to date. And this brings me on to some of the work I've done on dementia.

In 2016, dementia, became the leading cause of death in the UK. And yet it is commonly *not* acknowledged to be a terminal illness by those caring for people with the disease (Livingston et al., 2012; Robinson et al., 2012). This was my own experience conducting research with people with advanced dementia. As an anthropologist, it was a classic insider-outsider moment for me – when you step into a research field site for the first time, and the outsider notices the elephant in the room. I was repeatedly struck by the fact that caregivers, both professional and family, didn't give any indication that they acknowledged how close death was or that any extensive planning or discussion about it might take place. This isn't to say that these discussions hadn't happened privately but that there was no *public* acknowledgement, no open discussion. And this has been observed by other researchers as well.

Why is this? The average life expectancy after a diagnosis of dementia is 4.5 years (Xie et al 2008), less than for many cancers. And we also know there is no curative pathway. Yet the supportive care services and regular 'goals of care' discussions, routinely mobilized in the case of terminal cancer, are much more limited in the case of dementia. Given that dementia is predominantly a disease of old age, I wonder if this lack of acknowledgement can be considered another manifestation of the artificial separation of 'ageing' and 'dying'? But in which camp does dementia fall, ageing or dying? In many senses, dementia assumes an anomalous or disruptive place between ageing and death studies, essentially rejected by both. Dementia isn't readily incorporated into death studies and only of marginal interest to palliative care, but then neither is it overtly welcomed into gerontology. To the three 'D's' rejected by the active ageing agenda, we could add a fourth: Decline, Dependency, Death and *Dementia*.

The global population is ageing. It is anticipated there will be a **three-fold global increase** in the number of people with dementia by mid-century – from 50 to 150 million. We also know that dementia is a disease that evokes a lot of fear in people, **particularly in those over 50**. As diagnosis rates increase and diagnosis is made earlier, this is going to give *more* people *more* time to contemplate their end of life. The need for open conversations with those newly diagnosed with the disease to my mind is paramount. And these conversations need to be had without censor, judgment or casual dismissal of valid fears.

I started this article discussing the artificial separation I see being made between ageing and dying. There is no clearer example of this than the case of dementia – which is routinely not acknowledged to be a terminal illness. As the century progresses, we need to break new ground if we are going to rectify the pitiful amount of research and policy attention that has so far been given to dying of dementia. Acknowledging that ageing and dying are a continuum is a good place to start.

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**Sarah**

February 09, 2018

Great article – very well written and thought provoking. About a month and a half ago I took a clinical research position at a small memory center in New Jersey. We run clinical trials for individuals diagnosed with Alzheimer’s disease. In my position, I am usually the first person that the participant meets because I do most of the cognitive assessments. Out of curiosity, I’ve asked a couple of people about their advanced directives – most people didn’t have them but spoke with family members about it, but a small subset (I’ve found) seem to have this mentality that “well, I’m not going to remember, so why even bother?” It’s the ultimate ‘ignorance is bliss’ move, I guess. I think it would be fascinating to look at this more in-depth, specifically how planning for death evolves after getting a diagnosis of Alzheimer’s.

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