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A Right to 'Dying Well' with Dementia? Capacity, 'choice' and relationality

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Debates about suicide and assisted suicide are vexed and challenging in the context of many different forms of illness and disability. But in the context of dementia, where a person's so-called autonomy and capacity may be compromised comparatively soon in the disease trajectory if diagnosis is not sufficiently early, discussion about dying is especially fraught. The language of a 'living death' (Sweeting & Gilhooly, 1997) is no longer typically used in expert and policy discourse in the UK and elsewhere. Instead an emphasis on 'living well' with dementia (Department of Health, 2009) functions, at least in part, as a counterbalance to the hopelessness often associated with dementia. In galavanising improvements in the quality and delivery of services, care and support for people with a dementia and their families this is undoubtedly a significant and positive step. Yet where in this landscape is the space for people who don't 'live well' with the condition, or don't want to live at all? As a western, (and increasingly global) public health issue, the demographic and cost 'burden' of dementia (sensationalised through terms like 'tsunami', 'time bomb' and 'epidemic', Peel, 2014) presents significant health and social care challenges (e.g., Prince et al., 2013, 2014), but the personal, moral, ethical and often private challenges associated with dementia are similarly pervasive and compelling.

Kitwood's (1997) work, which emphasized personhood in dementia in a transcendental, sacred and enduring way, has been very influential and continues to inform quality dementia care education and practice. The religious influence in Kitwood's notion of personhood that stresses a duty "to treat each other with deep respect" (Kitwood, 1997, p. 8) is difficult to critique from a feminist perspective that acknowledges and respects women's – and men's and intersex and gender-nonconforming peoples' – rights over our bodies and our lives. Yet Sandra Bem's decision to end her life early, rather than continue to live with a likely long and inevitably terminal journey with Alzheimer's disease sits uncomfortably within the dementia care field. As feminists, and as ex-carers for a parent with younger onset Alzheimer's disease, we admire her personal bravery – and acknowledge how her choice was both enabled through, and constrained by, the relational and legal contexts in which she lived. Most people with advanced dementia in the UK live and die in care homes and, at this stage of the illness, are profoundly cognitively and physically impaired – likely bedbound, helpless, and unable to communicate either verbally or non-verbally; they may exhibit signs of pain or distress. The need for better palliative care in end stage dementia has been highlighted (Roger, 2006; Simard, 2007) and our perspective as outlined here, whilst feminist, psychological and socio-legal, is also invariably informed by the multiple ways that dementia and death have touched our lives. Thus, we outline here some thoughts about the assisted dying proposals currently being considered in the UK, consider the limits of capacity and 'choice', and, finally, we briefly emphasise the feminist concept of relationality when engaging with end of life decisions and the messy realities of lives impacted by dementia.

A Right to Die?

According to the European Court of Human Rights (ECtHR) in Strasbourg, an individual has the right "to decide how and when to end his [sic] life, provided that said individual is in a position to make up his own mind in that respect and to take the appropriate action." [i] There

is, however, no legal obligation on EU Member States to provide the means to enable a person to take their own life, nor to assist someone to do so. The legal position in England and Wales is currently in a state of flux, following the Supreme Court's decision in *Nicklinson*[ii] and the introduction of Lord Falconer's Assisted Dying Bill to the House of Lords (Lipscombe & Barber, 2014). In the *Nicklinson* case, Tony Nicklinson, Paul Lamb and a third applicant (known as Martin) all wanted to be helped to die, because they were "suffering such a distressing and undignified life that he had long wished to end it, but could not do so himself because of his acute physical incapacity"[iii] (Nicklinson v MoJ, 2014). Tony Nicklinson had suffered a severe stroke and could only move his head and his eyes; Paul Lamb had been completely immobile, except for his right hand, since a catastrophic car accident in 1990; Martin had suffered a brainstem stroke at age 43, and was only able to communicate using an eye blink computer (Nicklinson v MoJ, 2014). Current English law on assisted suicide means that anyone assisting Tony, Paul, or Martin to end their own life would be guilty of an offence, under s. 2(1) of the Suicide Act 1961. The maximum penalty, if found guilty, for assisting suicide is 14 years in prison.

The Assisted Dying Bill, which received its second reading in the House of Lords in July 2014 would not help Tony Nicklinson, Paul Lamb or Martin. This is because it would only enable medically-assisted dying for those who have a terminal illness, who have the physical capability of self-administering any prescribed lethal dose of medication, and who have a "clear and settled intention to end his or her own life". Similarly, it would not assist anyone with dementia who wanted to end their life rather than wait for Alzheimer's disease to run its full course. It appears that the bill has been drafted in such a way as to head off many of the usual arguments against assisted suicide. For instance, firstly, the limitation to those with a terminal illness diagnosis with less than six months to live is designed to avoid any charge that those with chronic health problems or long-term disabilities that require long

term care (on average £32,250 per person with dementia in the UK for example, Prince et al., 2014) would feel pressurised into assisted suicide to avoid being a burden on either their families or on the state. Second, the requirement that a prescribed lethal dose must be approved by two healthcare professionals, and that the administering doctor needs to remain with the patient until they have self-administered the drug is intended to prevent familial misuse of the provisions. Third, the bill contains not one, but two, capacity-related 'safeguards': first that the patient must have a settled wish to die, which implies that they must have the capacity to make that decision (indeed, s.4 of the Mental Capacity Act 2005 specifically excludes treatment that intends to bring about a person's death). Second, they must have the physical capacity to self-administer the lethal prescription provided by the prescribing doctor. Arguably then, the Assisted Dying Bill as it is currently configured may create more injustice and inequity in death than it would solve, given the significant limitations on its applicability. Instead of providing a solution to all those who wish to end their lives early, it would help only a minority. And many of those who find their lives intolerable would be excluded from its provision of a peaceful and dignified death.

Capacity, 'Choice'and Relationality in Dementia Contexts

Assisted dying, then, under these proposals (which have much in common with other jurisdictions where it is legal) is restricted to those who have the capacity to make a choice. But what is capacity? And what is choice? Which different groups and individuals are included or excluded by the capacity requirement? It is in answering these questions that assisted dying becomes such a vexed issue. According to Article 12 of the UN Convention on the Rights of Persons with Disabilities everyone has right to equal treatment before the law, including those with intellectual and psychosocial disabilities. Theoretically, under this provision people with intellectual disabilities, people with acquired brain injuries, people

with enduring mental health problems, and people with dementia are entitled to support to make their own decisions. But should this extend to the right to be supported to make the decision to die? In the context of end stage or advanced dementia could appropriate frameworks and conditions be created within care home settings where the previous wishes of an individual could be honoured? And, to what extent, if at all, could the spiritual ethos of much of palliative care – for example Namaste advanced dementia care that is based on the power of loving touch (Simard, 2007) – be used to facilitate different forms of 'choice' about death in the absence of capacity? People with dementia are, like all of us, embedded in and supported through relationships. We make decisions with the support of others, and our decision-making is shaped and informed by both proximal and distant relational, social, moral and cultural contexts. Individual life, and the perceived quality of that life is generated through relationships with others, and if we take the feminist notion of relationality and relational autonomy (Harding, 2014; MacKenzie & Stoljar, 2000; Nedelsky, 2012) seriously the lack of contextual sensitivity in the ECtHR's approach to the right to choose to die becomes problematic. The individualized notion of autonomy, that a person is in a position to 'make up their own mind' is, arguably, a fallacy. We need to recognize that agency, making choices, requires relationality – especially with respect to profound notions of ending life. Even someone who makes their "own" choice to die is facilitated to do so by their relationships. It will be easier for a person to make the decision to die if they know that they have the loving support of their family in making that choice than if they do not. Yet even in recognising the inevitability of relationality, assisted dying remains troubling. If people need their informal support networks to choose death, where are the safeguards, how can we protect the vulnerable, the suggestible, the scared?

There is much discussion and emphasis on living well with dementia in Britain, Europe and internationally. For many people with appropriate health and social care, support

and meaningful engagement living well in the early and mid-stages of the disease trajectories is a reality in the UK. But because of the nature and progressivity of most forms of dementia, the possibility of 'dying well' with dementia is thorny, troubled; and autonomy and 'choice' all too often become seen as redundant once an individual's capacity is questioned or questionable. We must find ways to reconcile the right to equal treatment before the law for people with disabilities with the right to choose to die. If we do not, then people with a dementia diagnosis, as in the case of Sandra Bem, may find that if they are to exercise any 'choice' about how their life with dementia will end, then an early end, even earlier than it needs to be, remains their only possibility.

Notes

[i] *Haas* v *Switzerland* (2011) 53 EHRR 33, para 51.
[ii] *R (Nicklinson)* v *Ministry of Justice* [2014] UKSC 38.
[iiiiii] *R (Nicklinson)* v *Ministry of Justice* [2014] UKSC 38 at [2]

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