



# *Dignity in Living: Addressing Euthanasia by Affirming Patient Personhood in Dementia*

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## About the Author



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## Summary

Organisations like the Alzheimer's Society have made it their mission to transform the landscape of dementia forever so that those affected by that condition are supported, accepted and able to live in their community without fear or prejudice. There has been a concerted effort to change perceptions about dementia and a significant part of this mission has been the move to change the narrative around it. Talk of 'suffering from' dementia, of being 'warehoused' in care homes, has given way to 'living with' dementia, being cared for by 'dementia friends', and many strategies have been put in place to enable people to live well.

This work risks being undermined by those who have returned to the old narrative and who claim that the very visceral fear of dementia is justification enough for people with dementia to be eligible for euthanasia and assisted suicide (EAS). The depersonalising language that feeds into demands for EAS focuses on people being a burden, of existing

in a living death, of being a husk of their former selves, of suffering a miserable and undignified existence, of living a life not worth living. This negative narrative of depersonalisation results in what Kitwood calls 'malignant social psychology', a self-reinforcing set of conditions which erode the patient's sense of self-worth and well-being. Though malignant social psychology may not necessarily be premised on malintent, its effects are nonetheless negative for people with dementia and their families, and it reinforces the notion that EAS is the only solution.

Instead of going backwards, strategies such as those adopted by the Alzheimer's Society, and the excellent care already being provided in many care homes and families, show how it is possible to both live and die well with dementia. This alternative narrative enshrines the real dignity deserving to those with dementia and their loved ones.

# Dignity in Living: Addressing Euthanasia by Affirming Patient Personhood in Dementia

## Fear of dementia

Commenting in 2018 on a Guernsey bill to legalise assisted suicide, [1] the journalist Polly Toynbee argued that ‘the ban on assisted death ignores the reality of illnesses like dementia’. To reinforce her argument Toynbee spoke of a visceral fear of dementia, fear fuelled by the prospect of people with dementia ‘warehoused in miserable nursing homes’, a burden on their families and on society. [2] As with all the bills in the UK for assisted suicide to date, the Guernsey bill was defeated. [3] Notably, it had proposed a law similar to that which operates in the USA state of Oregon, under which, in theory, people with dementia would not be eligible for assisted suicide, a factor to which Toynbee did not allude in her article. [4] Even though dementia is regarded as a terminal illness, [5] a person with early-stage dementia and mental competency is unlikely to receive a prognosis of less than six months to live; given the progression of the illness, a person with end-stage dementia is unlikely to have the requisite capacity, or ability to self-administer medication. Proposals to expand the Oregon Act to give access for assisted suicide to patients with conditions such as dementia and Parkinson’s [6] have included removal of the six-month requirement or the use of advance directives. However, evidence from the Dutch experience of the use of Advance Euthanasia Directives (AEDs) suggests that AEDs are not an adequate response to the vulnerabilities experienced by people with dementia and their families and carers. [7] AEDs ultimately rely on others to interpret and carry out

instructions. Moreover, euthanasia requests in dementia place ‘an ethically and emotionally heavy burden’ on Dutch GPs and physicians not least because of ‘pressures from relatives’ and society’s negative views of dementia. [8]

## Fear of dementia and the threat of depersonalisation

Toynbee’s approval of the failed Guernsey bill is representative of many who think that current proposals to change English law will give access for EAS to people with dementia. But Toynbee’s argument is more than simply a failure to appreciate the nuances of the law. Toynbee highlights what some people do have – a visceral fear of dementia. As Peter Singer puts it, ‘beyond a certain stage of dementia, the person we knew is gone’ and all that remains is a ‘husk’, and if the person did not want to live in that condition they should have access to EAS. [9] As Mary Warnock says, ‘if you’re demented, you’re wasting people’s lives – your family’s lives – and you’re wasting the resources of the National Health Service... the real person has gone already and all that’s left is the body of a person, and nobody wants to be remembered in this condition’. [10] According to Warnock, even if their ‘very nice’ family disagrees, people with dementia know that they are a burden and a ‘great expense’ to the family or the National Health Service. [11]

## Reframing the old fearful narrative

However, the tired narratives of dementia as a 'living death', as a waste of healthcare resources, of caregiving being a 'burden', has long given way to a reframing of dementia with a view to reshaping attitudes. [12] With the help of campaigns from dementia charities, organisations and government, the new narrative is about living well and fully with dementia. And the veracity of this reframing has shown itself clearly in the experience of the COVID pandemic. Certainly, the Care Quality Commission has long recognised that more can be done to improve care for people with dementia, especially at the end of their lives, and there are many strategies to build up and disseminate good practice. [13] Nevertheless, the outcry at how elderly people and people with dementia have been left behind during the COVID-19 pandemic reveals that a real concern for their human dignity and welfare is widespread in society. [14] Media coverage of the ravages of covid in care homes explicitly demonstrates that people with dementia are not 'warehoused', nursing homes are not 'miserable'. The at times unsung and heroic efforts of care home staff to help their residents with dementia to live happy and flourishing lives, even in challenging times, soundly indicates that their residents are people who, like all people, deserve to be treated appropriately and with full human dignity. Moreover, as many carers and relatives have testified, their loved one is not a burden still less a 'husk'. Each one is someone's mother or father, wife or husband, brother or sister, friend or neighbour.

## The fear of depersonalisation: a vicious circle

The challenge to eradicate depersonalising language and attitudes in relation to dementia is not new. In the 1990s Tom Kitwood, a lecturer in psychology and pioneer in dementia care, identified an 'old culture' of understanding dementia and care. The depersonalising language of 'warehousing' and inevitable destruction of personal identity, attitudes that there is little to be done positively for the person, or that there are limits to effective care, all belong to this old culture. [15] Kitwood acknowledges that the real fears of becoming 'frail and highly dependent' and of having to endure 'a long drawn-out process of death' cause many to 'shrink' from the prospect of developing dementia. He points out that these fears form part of the dynamic that 'excludes those who have dementia from the world of persons', and he argues that depersonalisation is one strategy to try to make anxieties bearable. [16] Kitwood further observes that the personhood of people with dementia can be undermined by what he terms 'malignant social psychology'. [17] While Kitwood is keen to point out that 'malignant' does not imply 'evil intent' on the part of caregivers, he highlights that certain attitudes produce a harmful environment both for the person with dementia and for those holding such attitudes. Ultimately this creates a vicious circle where depersonalising attitudes are reinforced. Kitwood's principal interest is in sensitising staff in formal care settings to the presence of malignant social psychology, something he thinks can be remedied by appropriate training. To illustrate malignant social psychology at work, Kitwood presents a vignette that is especially pertinent to EAS. He describes a person with dementia being fed by a caregiver who is not paying proper attention



to the process and keeps overloading the person's mouth, with the result that the person accidentally sprays the caregiver with food. The caregiver comments to her friend that she hopes 'if ever she "got like that" someone would shoot her. "After all... if it was a dog it would have been put down by now"'. [18]

While malignant social psychology entrenches the attitudes of others, it also insidiously damages the person's own sense of self, worth and well-being. [19] Attitudes and behaviours that infantilise, disempower, deceive, or impose, reinforce in the person with dementia the belief that dementia has stripped them of human dignity and that they are a burden to others. [20] Singling out people with dementia as wasting healthcare resources in a way not applied to other people with long term or complex healthcare needs further entrenches malignant social psychology. When it comes to EAS and dementia, the significant point about malignant social psychology is that a set of attitudes, including those motivated by misplaced good intention, can spread and infiltrate thinking to the extent that it becomes normal to view and treat people with dementia in a particular and negative way. [21] Moreover, people with dementia themselves may come to view radical loss and depersonalisation as inevitable outcomes of their illness. Depersonalisation and fears of being treated as less than a person drive fears over good care at the end of life and negatively inform decision-making.

Kitwood's influential reconsideration of dementia has initiated an important conversation and inevitably has also provoked further evaluation, critique, reinterpretation and development. [22] Controversially, Kitwood suggests that malignant social psychology may actually cause organic damage to the brain of a person with dementia

since it stunts learning and experience: [23] the person who is repeatedly told they cannot remember comes to believe this and it becomes a self-fulfilling prophecy. Nevertheless, it is accepted that the social environment can 'either construct or deconstruct the self with dementia'. [24] Kitwood's call for a 'new culture' of understanding and care where the priority is the day-to-day existence of people with dementia and 'how to maintain personal well-being', [25] has brought a revolution in dementia care and notably a challenge to discriminatory ways of representing people with dementia. [26]

## Changing the narrative

Another example of a challenge to the old dominant narratives around dementia comes through the work of the Alzheimer's Society (AS). While the AS recognises that 'dementia can devastate lives', one of their main strategies is to 'change the conversation on dementia'. [27] Published in 2017, the AS's strategy 2017-2022, *The New Deal On Dementia* aims to 'transform the landscape of dementia forever' by creating 'a society where those affected by dementia are supported and accepted, able to live in their community without fear or prejudice', and to ensure that people with dementia get 'the care, support and hope for the future they deserve'. [28] The AS realistically accepts that a diagnosis of dementia can leave a person in 'the loneliest of places' where 'the road ahead looks frightening'. But, in an inclusive society that understands dementia, the person knows that 'however hard the road ahead', the person does not 'walk it alone'. The AS's promise that the sufferer and loved ones are, 'not alone' is a pledge of support from pre-diagnosis to the natural end of life. Pillar one of the new deal is

working towards better community support and improved care so that people can live full lives. Pillar two is 'changing the public conversation' so that people with dementia are treated as 'equal members of society'. This pillar also encompasses being positive about change by creating dementia friendly communities and capturing the 'wishes and aspirations' of people affected by dementia. Pillar three is helping people live better through investment in research. The whole tone of the New Deal is improving lives not hastening death.

### Living well with dementia

Central to the AS's strategy is listening to the voices of people affected by dementia. In its 2017 report *Turning Up The Volume: unheard voices of people with dementia* the AS confidently states that with 'the right level of support from government, professional care providers and society' people with dementia can be enabled to live well. [29] Moreover, the report notes that 'people affected by dementia still have an incredible amount to offer to their community. If appropriately supported they can continue to play an active and valuable role even years after diagnosis'. [30] As the dementia activist Helga Rohra observes, 'life is beautiful, even with dementia'. [31]

Additionally, a significant change in language has come about through attending to the experiences of people affected with dementia. [32] Notably, there has been a shift away from describing a person as 'suffering from' dementia to 'living with' and also 'living well' with dementia. [33] However, it would be a mistake to present only a positive account of dementia or to deny any suffering in the condition. People do live well with dementia, but dementia does involve suffering at some

point; perhaps at diagnosis, or when a person begins to realise all is not well, or when the person senses a lack of control over life, or is subject to social suffering or perceived stigma. People do not want a diagnosis of dementia. Some people do not live well with dementia. It is important to recognise this suffering so that people with dementia and their carers receive appropriate care and support. [34] Acknowledging both the living well and the suffering of dementia is to take a realistic approach to the everyday experiences of dementia and to address the person's actual needs. To deny any suffering would be akin to a form of malignant social psychology.

### And dying well with dementia

For all people, living well also encompasses thinking about dying well. As a natural extension of its living well programme, the AS and other dementia organisations have produced material on end-of-life care. Notably, in its promotion of good quality end-of-life care, the AS is clear that it is 'not calling for a change in the law on assisted dying or euthanasia'. [35] Given that one aspect of living well with dementia involves enabling people to continue to have choice and control in their lives, the AS frames its end-of-life care within a framework of planning ahead to ensure that the person's needs are met. [36] Although, as the AS recognises, planning ahead is not simply about legally binding advance decisions, there has been significant discussion on the difficulties involved in decision-making and these discussions have bearing in some countries on the working out of AEDs. Alzheimer Europe's Dementia in Europe Ethics Report (2020) highlights the real difficulties in legal capacity and decision making for those affected by dementia, including the problem of bias or unconscious projection of those who support people with

dementia in decision making. [37] Although Alzheimer Europe's report concentrates on decisions that involve varying degrees of risk these difficulties are further increased when the stakes are high – life or death. Noting especially the continuing dignity of the person as the illness progresses, Alzheimer Europe points out that 'the experience of having a condition, such as dementia, can lead to significant changes in priorities and wishes and there is a risk of trapping people and failing to recognise their right to change'. [38] Problems of an advanced directive include the explicit intention that the person's preferences when competent override preferences when incompetent. Moreover, advance directives do not take account of scientific advances. [39]

## Dementia, autonomy and good end of life care

In a paper reflecting on the Oregon legislation on assisted suicide, John B. Mitchell, Emeritus Professor of Law at Seattle University, points out that acceptance of physician assisted suicide is about autonomy. [40] Moreover, Mitchell argues that a depersonalising narrative makes it easier to see dementia as a personal, social and healthcare burden. [41] According to Mitchell it is impossible to create a workable regulatory regime which safeguards people with dementia in a jurisdiction where EAS is legal because contemporaneous consent is not possible and living wills simply delegate 'unbounded discretion' over the life or death of the person with dementia. [42] Mitchell explains that to make a decision the person must be fully informed and have capacity. However, he questions whether the person can be fully informed because in dementia 'you are literally considering how you would think if your mechanisms for thinking and communicating were radically different'. [43]

Furthermore, in mid-to-later dementia the person's wishes may be influenced by underlying issues such as depression or poor care experiences or indeed malignant social psychology factors.

The first reported case of a British person living with dementia and choosing EAS at the Swiss Dignitas facility took place in 2013. The man and his family had been guided in the process by Dr Michael Irwin, known as 'Dr Death,' for his views on assisted suicide. According to Dr Irwin the man was in the early stages of dementia and did not want to suffer from dementia, nor let his family see him suffering. The man took with him to Switzerland a psychiatrist's report saying that he had sufficient capacity. Dr Irwin firmly believes that dementia provides a stronger case for assisted suicide than does terminal illness. The AS's response was clear: 'no one with the condition should have to accept a poor quality of life. Instead we need to be driving up standards to ensure everyone can enjoy a good quality of life today... and when the times comes, people with dementia deserve a dignified death and good quality end of life care – no less than everyone else.' [44] Good end-of-life care includes timely planning discussions, the provision of supportive care including spiritual and emotional care, proper and adequate attention to pain relief, sensitivity as the person nears the end through creating a peaceful environment, and ideally the opportunity to die in their usual place of care. Professional care should be co-ordinated and there should be support of families with appropriate bereavement care. [45]

## Affirming dignity

There are many different types of dementia and dementia affects people in different ways. However, a person's experience of dementia is

affected by the people around them and by their social environment. As the AS's initiative Dementia Friends [46] demonstrates, people affected by dementia can be offered positive and caring support and accompaniment, enabling them to live well. And as the Art of Dying Well initiative [47] shows, dying well is possible for everyone without recourse to EAS. The AS's reminder that 'you are not alone' and that no one should have to walk the long road of dementia alone are calls to support and care for people affected by dementia, not to hasten their death. This support includes affirming that the world is not better off without a person even if that person has come to see their life as redundant or burdensome to others. Such an affirmation is a real witness to the person's dignity, dignity that can not be lost no matter the person's situation.



## Endnotes

[1] For definitions of terms, see David Jones's first paper in this series, *Defining the Terms of the Debate: Euthanasia and Euphemism*: [https://www.bioethics.org.uk/images/user/Defining%20the%20Terms%20of%20the%20Debate%20%E2%80%93%20Euthanasia%20and%20Euphemism%20\(Prof.%20David%20Albert%20Jones\).pdf](https://www.bioethics.org.uk/images/user/Defining%20the%20Terms%20of%20the%20Debate%20%E2%80%93%20Euthanasia%20and%20Euphemism%20(Prof.%20David%20Albert%20Jones).pdf)

[2] Polly Toynbee, *The ban on assisted death ignores the reality of illnesses like dementia*, The Guardian, 22 March 2018: <https://www.theguardian.com/commentisfree/2018/mar/22/assisted-dying-dementia-alzheimers-guernsey>

[3] *Assisted dying: Guernsey rejects proposal to move towards legalisation*, BMJ 2018;361:k2236: <https://www.bmj.com/content/361/bmj.k2236>

[4] Oregon's Death With Dignity Act applies only to those with mental capacity and with a prognosis of less than six months to live. See: <https://www.oregon.gov/oha/ph/providerpartnerresources/evaluationresearch/deathwithdignityact/Pages/index.aspx>

[5] End-of-life care and dementia: An introduction, Social Care Institute for Excellence: <https://www.scie.org.uk/dementia/advanced-dementia-and-end-of-life-care/end-of-life-care/introduction.asp>

[6] Oregon Lawmakers Consider Expansion Of "Death With Dignity" Law, KLCC, 08 March 2019: <https://www.klcc.org/post/oregon-lawmakers-consider-expansion-death-dignity-law>

[7] See Carlos Gómez-Vírseda, Chris Gastmans 'Euthanasia in persons with advanced dementia: a dignity-enhancing care approach' J Med Ethics 2021: 20 May; medethics-2021-107308. doi: 10.1136/medethics-2021-107308.

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[9] Peter Singer, *Choosing Death* (2014): <https://www.project-syndicate.org/commentary/peter-singer-makes-the-case-for-allowing-patients-to-decide-when-to-end-their-lives>

[10] Jackie Macadam, *Interview with Mary Warnock: A Duty to Die?*, Life and Work, Church of Scotland Magazine October (2008), pp. 23-25; Martin Beckford, *Baroness Warnock: Dementia sufferers may have a "duty to die"*, Daily Telegraph, 18 September 2008: <https://www.telegraph.co.uk/news/uknews/2983652/Baroness-Warnock-Dementia-sufferers-may-have-a-duty-to-die.html>

[11] Rick Lewis, *Interview, Baroness Mary Warnock*, Philosophy Now, Issue 55 (May / June 2006): [https://philosophynow.org/issues/55/Baroness\\_Mary\\_Warnock](https://philosophynow.org/issues/55/Baroness_Mary_Warnock)

[12] Daniel R. George, *The art of Medicine: overcoming the social death of dementia through language*, The Lancet vol.376 (2010) 586-587.

[13] *People with dementia: A different ending ending: addressing inequalities in end of life care*, Care Quality Commission, May 2016: [https://www.cqc.org.uk/sites/default/files/20160505%20CQC\\_EOLC\\_Dementia\\_FINAL\\_2.pdf](https://www.cqc.org.uk/sites/default/files/20160505%20CQC_EOLC_Dementia_FINAL_2.pdf)

[14] See Xavier Symons, *Care Homes and Older Members of the Community COVID-19 Briefing Paper 4*: <https://bioethics.org.uk/research/covid-19-briefing-papers/care-homes-and-older-members-of-the-community-dr-xavier-symons/>

[15] Tom Kitwood, *Dementia Reconsidered*, Berkshire: Open University Press, [1997] (2012), pp. 45; 135-137.

[16] *Ibid.*, p. 14.

[17] *Ibid.*, p. 4.

[18] *Ibid.*, p. 45.

[19] *Ibid.*, p. 46.

[20] See also, malignant positioning as described by Steven R. Sabat, 'Mind, meaning, and personhood in dementia: the effects of positioning', *Dementia: Mind, Meaning and the Person* edited by Julian C. Hughes, Stephen J. Louw, Steven R. Sabat Oxford: Oxford University Press (2006), pp. 288-290.

[21] Pat Hobson, *Enabling People With Dementia: Understanding and implementing Person-Centred Care*, Switzerland: Springer Nature (2019), p. 5.

[22] See for instance *Tom Kitwood on Dementia: A Reader and Critical Commentary*, edited by Clive Baldwin and Andrea Capstick Berkshire: Open University Press, (2007).

[23] *Op. cit.*, Kitwood, pp. 16-19.

[24] Carmelo Aquilina and Julian C. Hughes, 'The return of the living dead: agency lost and found?', *Dementia: Mind, Meaning and the Person* edited by Julian C. Hughes, Stephen J. Louw, Steven R. Sabat Oxford: Oxford University Press (2006), p. 147.

[25] *Op. cit.*, Kitwood, p. 137.

[26] Trevor Adams, Ruth Bartlett, 'Constructing Dementia', *Dementia Care: An Evidence Based Textbook*, edited by Trevor Adams and Jill Manthorpe London: Arnold, (2003), p. 3.

[27] Alzheimer's Society. *Our Strategy 2017-2022*: <https://www.alzheimers.org.uk/about-us/our-strategy-2017-2022>

[28] *The New Deal On Dementia*: [https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/alzheimers\\_society\\_2017-2022\\_the\\_new\\_deal\\_on\\_dementia.pdf](https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/alzheimers_society_2017-2022_the_new_deal_on_dementia.pdf)

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[migrate/downloads/turning\\_up\\_the\\_volume\\_unheard\\_voices\\_of\\_people\\_with\\_dementia.pdf](#)

[30] *Ibid.*, p. 35.

[31] Alzheimer Europe, *Living with dementia*, Personal experiences of living with dementia: Helga Rohra (Germany): <https://www.alzheimer-europe.org/Living-with-dementia/Personal-experiences-of-living-with-dementia/Helga-Rohra-Germany>

[32] Pia Matthews, *Changing the conversation: from suffering with dementia through dementia as a disability rights issue, to a deeper theological perspective*, *Journal of Disability and Religion* 23/2 (2019).

[33] Dementia Engagement and Empowerment Project (DEEP), *Dementia words matter: Guidelines on language about dementia* (October 2014): <http://dementiavoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf>

[34] Ruth Bartlett *et al*, *Suffering with dementia: the other side of "living well"*, *International Psychogeriatrics* 29:2 (2017), pp.177-179.

[35] Alzheimer's Society, *Alzheimer's Society's view on end of life care*: <https://www.alzheimers.org.uk/about-us/policy-and-influencing/what-we-think/end-life-care> It is regrettable that NHS England directs people with dementia and their carers to Compassion in Dying, a sister organisation of the voluntary euthanasia society Dignity in Dying, as one of the resources for advanced care planning (pp. 16, 25): <https://www.england.nhs.uk/wp-content/uploads/2018/04/my-future-wishes-advance-care-planning-for-people-with-dementia.pdf>

[36] Alzheimer's Society, *End of life care for a person with dementia*: <https://www.alzheimers.org.uk/get-support/help-dementia-care/end-life-care>

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capacity on the lives of people with dementia (2020), p. 16. <https://www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice/2020-Ethical-issues-linked-to-legal-capacity-and-decision-making-full-report>

[38] *Ibid.*, p. 21.

[39] *Ibid.*, pp. 33-34.

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[41] *Ibid.*, 1091.

[42] *Ibid.*, 1092.

[43] *Ibid.*, 1123

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[46] Dementia Friends:  
<https://www.dementiafriends.org.uk/>

[47] The Art of Dying Well, *What is dying well?:* <https://www.artofdyingwell.org/what-is-dying-well/>



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