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# Bioethics Outlook

## Plunkett Centre for Ethics

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To thine own self be true:

## Dementia, citizenship and authenticity

Julian Hughes

Dementia is not a new phenomenon, although the use of the word “dementia” has had different meanings over the millennia.

At the risk of upsetting medical historians, I'm going to point to Alzheimer's discoveries at the start of the twentieth century as a turning point: tangles and plaques were identified in the brain of 'Augusta D', a lady with early onset dementia, and the term Alzheimer's disease was coined; and then I'm going to ride roughshod over further historical developments to highlight the work of Sir Martin Roth, who with colleagues Sir Bernard Tomlinson and Gary Blessed from Newcastle University published in 1970, “Observations on the brains of demented old people” in the *Journal of Neurological Science*.

A few years later, in 1978, some of the same group, but now featuring Professors Elaine and Robert Perry, published in the *British Medical Journal* a paper entitled, “Correlation of cholinergic abnormalities with senile plaques and mental test scores in senile dementia”.

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### In this issue

**We start with the text of Julian Hughes' Annual Plunkett Lecture. The lecture has since been broadcast on the ABC's *Big Ideas* Program.**

**We then reprint an opinion piece which appeared in the *Weekend Australian* five days before the implementation of Victoria's '*Voluntary Assisted Dying*' Act.**

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These papers helped to confirm and establish modern understandings of the neuropathology of the dementias. More than that, the paper by the Perrys paved the way for the development of the cholinesterase inhibitors, which remain the mainstay of drug treatment for people with Alzheimer's disease. By the time I arrived in Newcastle in 1999, it was also recognised, under the leadership of Professor Ian McKeith, as the major centre for research on dementia with Lewy bodies.

Of course, research in old age psychiatry and dementia has also been carried out in other centres around the world, including in Australia where there has been a strong tradition of world-leading research. But what I'm pointing towards is a deeply embedded biomedical understanding of dementia.

There was, and still is, a strongly biomedical way to understand the different dementias in terms of brain pathology, genetics and possible treatments. The progress in neuroimaging has greatly added to some of these understandings. Even psychosocial treatments are evaluated in accordance with scientific paradigms, where double-blind placebo-controlled trials are held up as the acme.

All of this biomedical research is to the good — well, perhaps not all of it. But then there's a lot of research that the world could probably do without. It's just that you can't always tell what might be of benefit. You can't always tell what the effects of research will be.

These days, there's always the infamous search for "impact". This generally does *not* include the kindly manner in which a research participant has been treated by the researchers: someone showing an interest in you, trying to help, treating you like a human being— all these things count.

Similarly, a young researcher may acquire the habit of curiosity, may learn from the focus of a particular project to look at people in a certain way and take interest in facets of the person that might otherwise be overlooked. But these things might happen in a piece of research that changes very little, that hardly sees the light of day.

A larger piece of work may claim great "impact" but use the participants merely as *means* (offending Kant's Categorical Imperative to treat people as ends in themselves) and only instil in the junior researcher an awareness that you need sharp elbows to get to the front of the pack. And there is the worry that a rather scientific biomedical approach fosters attitudes that obscure the person from view and skew the focus of care towards a purely biomedical understanding.

For instance, drugs tend to be seen as the solution to many problems. When the cholinesterase inhibitors — the drugs for Alzheimer's — first came on the market, they were understandably very expensive. There was an imperative to use them. But what we saw and still see is that they convey only a modest benefit. It matters less these days because they're now very cheap. But in those days, for the cost of the drugs we could have employed another nurse or occupational therapist. Might the work of a dedicated nurse have been more beneficial than the administration of one of these drugs to, say, twenty people? I'm not aware of anyone ever trying to work this out. Similarly, for many years we've seen the over-use of

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psychotropic drugs to treat behaviours that are challenging in dementia. For these sorts of reason, while acknowledging the benefits of biomedical research, it's good that a more psycho-social approach has emerged too.

## Person-centred care

Undoubtedly the biggest boost to this was the publication in 1997 of Tom Kitwood's seminal work *Dementia Reconsidered: The Person Comes First*. This year, the second edition of the work, now called *Dementia Reconsidered, Revisited: The Person Still Comes First*, has been edited by Professor Dawn Brooker with contemporary commentaries on Kitwood's original chapters. Kitwood's work ushered in (what was called) the "new culture of dementia care". This was person-centred dementia care, where the person was to be understood broadly "in the context of relationship and social being". Kitwood famously spoke of "malignant social psychology": the ways in which those around the person can undermine his or her standing by strong depersonalising tendencies — disempowerment, infantilisation, labelling, stigmatisation, ignoring, mockery and so forth.

Meanwhile, the idea of malignant social psychology has been developed by Professor Steven Sabat from Georgetown University in his own seminal work, published in 2001, *The Experience of Alzheimer's Disease: Life Through a Tangled Veil*, where he talks of "malignant positioning". In his contribution to the new edition of Kitwood's work, Sabat describes malignant positioning as entailing:

*"a focus primarily on a person's dysfunctional attributes that arise, in the case of people with dementia, due to brain injury resulting from disease ... Once this focus is established, there then follows the creation of storylines about those diagnosed that emphasize dysfunction even where it may not exist at all".*

The practical relevance of this work is easily apparent. If a person living with dementia is malignantly positioned, then when he becomes aggressive it's readily conceived that his dementia has worsened, that there have been changes in his brain state that can be rectified by chemicals perhaps; but at any event, it's not worth taking time to understand the person because the brain changes preclude it.

But in the new culture of dementia care — *person-centred care* — attempts are made to understand the person instead. The mantra is that any behaviour that we might find challenging is the consequence of unmet need. It's not the person's fault; it's that we in the psychosocial environment just do not understand what the unmet need is. And in truth, understanding that need may be very demanding and meeting it may be even more so.

Say the need is to get out of an institution to see one's parents, but one's parents are dead: it will not be possible to meet the need directly. But once we understand that this is the need that we are not meeting, we are more likely to develop other means to deal with the situation: anticipation, comfort, the use of pictures, reassurance, religious ceremonies, reminiscence, validation of emotions — all such means may help to prevent the behaviour we find so challenging; and will generally be better than giving drugs.

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So we need a *biomedical* approach but also a *psychosocial* one. Person-centred care has come to epitomise this approach. But there are two points to make about it. First, conceptually, it's worth asking: what does it mean to be 'a person'? Second, this approach not working.

Tom Kitwood spoke about relationships and social being. His was a social constructionist view of personhood. But there are reasons to think in a way that allows a greater role for biology, too. Pia Kontos speaks of "embodied selfhood" and has written eloquently to demonstrate the salience of the body for our understanding of the person. I've written about the person as a "situated embodied agent", both to emphasise the importance of the body, using the idea from the philosopher Charles Taylor that our understanding itself is embodied; and to stress that the person living with even advanced dementia has agentive wishes and preferences.

But also, this characterisation of personhood stresses that our embodiment and our agency are *situated*. It's their situatedness — as part of a history or narrative, as part of a culture, as part of a moral and ethical system, as part of a whole social embedding — that helps us to understand the person's embodied agency. I know what she wants because I share so much with her in terms of history, culture, memories and so forth. One of the ways in which she is situated or embedded is as part of a *polis*. She's a citizen of a city state. I'll come back to this in a moment.

The second point is that person-centred care is not working. Well, of course, there is good practice here and there. But who of us can say that everywhere we go we see things greatly improved from what they were in the 1980s, when Kitwood was developing his views? Malignant positioning and malignant social psychology are still to be found all over the world. Yet, worryingly, all over the world we'll be told that person-centred care is the norm. I don't want to labour the point. Instead, here is Kate Swaffer, an Australian dementia activist, who herself has been diagnosed with dementia, writing at the end of the new edition of Kitwood's book: "From my experience", she says, "I believe Kitwood's Person Centred Care has not generally been translated into practice, and instead has mostly been a tick-box in an organisations' paperwork." She goes on to say that "self-advocates" are demanding real change. And this, I think, is where citizenship can take a stance.

## Citizenship

I've already mentioned that we are situated or embedded as citizens, as members of a *polis* or city state. Now, one of the things about person-centred care is that it relies on *other people* adopting a new attitude. Citizenship is, among other things, about people with dementia standing up *themselves* and demanding their rights. It's about people like Kate Swaffer speaking out. It's about people like Keith Oliver — who has a diagnosis of Alzheimer's disease, but is an Alzheimer's Society Ambassador in the UK and also contributed to the new edition of Kitwood's book — representing the views of people living with dementia at the United Nations to the Committee overseeing compliance with the UN Convention on the Rights of Persons with Disabilities. People living with a diagnosis of dementia are active on committees, steering groups, boards; they write books and blogs; they speak at conferences; they advise researchers and so forth. In a commentary in Kitwood's *Dementia Reconsidered*,

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*Revisited*, Keith Oliver and psychologist Reinhard Guss point out, “The growing political engagement of people with dementia, and their involvement in advisory and policy-making groups was something beyond the imagination 20 years ago.” Towards the end of the book, Professor Claire Surr, who is Professor at Leeds Beckett University, but who used to be part of the Bradford Dementia Group formed by Kitwood, talks of going beyond Kitwood’s new culture of dementia care to what she terms an “inclusive culture”: “In the Inclusive Culture,” she says, “people are treated as citizens with full rights.”

Citizenship, I’m arguing, is the new kid on the block when it comes to conceptualising dementia. But it’s worth taking a step back and asking *what citizenship is*. It can be defined, and in practice it is often conceived, in a narrow political sense. For instance, Richard Bellamy states:

*“Citizenship is a condition of civic equality. It consists of membership of a political community where all citizens can determine the terms of social cooperation on an equal basis. This status not only secures equal rights to the enjoyment of the collective goods provided by the political association but also involves equal duties to promote and sustain them — including the good of democratic citizenship itself.”*

In other words, citizenship has to do with rights and duties and with voting. I’m sure there’s much that we could say in connection with dementia and these themes. We would wish to assert that people with dementia have rights. They also have duties, but these have been exercised over a lifetime and we’d wish to specify the duties of a citizen. These might include the duty to contribute to the general good of the political community, but different citizens fulfil this duty in a variety of ways and more or less at different phases of their lives. What are the duties of any old ageing citizen and in what ways might the duties of someone living with a diagnosis of dementia differ?

I’m simply going to assert that: it seems to me that people with dementia are often more than capable of fulfilling their civic duties; and that a citizen with dementia should not be expected, any more than anyone else, to fulfil unjustifiable and unreasonable duties.

Voting is a whole subject in itself. Some years ago, in 2010, I contributed to a *British Medical Journal* editorial on the issue of dementia and voting. I’m not going to get bogged down in it here. Suffice to say that there are probably people who are being disenfranchised, through not being registered, even though capable of voting; and there are probably people who vote although incompetent. At the time of our editorial, we wrote:

*“In Australia, where voting is compulsory, an elector may be removed from the electoral roll if a medical practitioner certifies that he or she is of “unsound mind” — incapable of understanding the nature and importance of voting. In practice, it is unclear who is being excluded and what rights of redress they might have.”*

I’d be interested to know what the situation now is in Australia. I know it’s an issue the Australian Law Reform Commission has considered in connection with the UN Convention on the Rights of Persons with Disabilities. It’s obviously complicated partly because no one wishes to impose tests of the capacity to vote (how many Trump supporters in comparison

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with Clinton supporters would have passed the test, one wonders) and in any case the nature of supported decision-making when it comes to voting would be complicated. And yet, when we talk about citizenship, we need not have such a narrow political version in mind. More pertinent to people with dementia is the idea of *social citizenship*. In an important book entitled *Broadening the Dementia Debate: Towards Social Citizenship (2010)*, Ruth Bartlett and Deborah O'Connor have defined social citizenship as a relationship, practice or status, in which a person with dementia is entitled to experience freedom from discrimination, and to have opportunities to grow and participate in life to the fullest extent possible. It involves justice, recognition of social positions and the upholding of personhood, rights and a fluid degree of responsibility for shaping events at a personal and societal level.

*Political citizenship*, one might say, involves voting, rights and duties, while *social citizenship* involves rights, personhood and relationships. The issue of rights is central. In an important paper published in the journal *Dementia*, entitled "Rights in mind: Thinking differently about dementia and disability" (2019), Tom Shakespeare, Hannah Zeilig and Peter Mittler concluded that a relational model of dementia lays the basis for a human rights approach to the condition, based on collaborative partnerships between people with dementia and people from other disability communities.

The disability rights movement, which Tom Shakespeare has contributed to and critiqued over many years, presents a paradigm for dementia. "Nothing about us without us" has been their rallying cry, which has now been firmly adopted by people who live with a diagnosis of dementia. Shakespeare and his colleagues argue that it is vital to situate the individual experience of dementia in the broader social context. We also need to articulate a human rights perspective in which self-advocacy is core. We need to expand our ideas about social models and about human rights in order to incorporate the experience of all human beings, including people living with dementia. We are embarking on a project of cultural transformation.

One of the central moves here is to see dementia *as a disability*. This seems entirely reasonable, given the UN Convention on the Rights of Persons with Disabilities, which defines persons with disabilities as those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

In *The Dementia Manifesto, Putting Values-Based Practice to Work*, (Cambridge: CUP) the book I published earlier this year with Toby Williamson (Toby is an independent health and social care consultant who worked for some time in the Mental Health Foundation in the UK), we set out a manifesto based on three principles, the second being that we should see dementia *both* as disease *and* as disability. This was to emphasise "the rights of people living with dementia to all the usual benefits of citizenship, whilst also recognizing its effects as a physical disease on people's lives." Concerning the duality between disease and disability, we contended:



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*“The duality should not involve choosing one or the other. Both themes are relevant to individuals and families affected by dementia, practitioners, services, policy makers, communities and society. Seeing dementia as disease can provide understanding and some amelioration of its effects in the here and now, and may generate solutions in the future, but still remains limited in what it offers to people currently affected by the condition. Viewing dementia as a disability has the potential to change current perceptions of dementia and peoples’ lived experience of the condition by altering in a positive way how society responds to dementia, supported by legal frameworks requiring institutions and individuals to adapt, accommodate and include people with dementia as citizens like anyone else. But a disability model should not be used as an excuse to reduce efforts to understand the biomedical aspects of dementia or to continue to seek effective interventions. The values underpinning one theme must not be used to deny or marginalize the values of the other.”*

So dementia is both disease and disability, but it’s especially its status as a disability that helps to establish the claim on rights. I should perhaps add the clarification that we were not saying that dementia is *a* disease, which clearly it is not — at least for the mundane reason that dementia is not one thing but many, but also because it is, in any case, a semantic construct rather than possessing any form of unique essence: it’s not *a thing* as such.

I should also add that the other two principles in our manifesto were:

- *that our views about dementia reflect our views about humanity (we wrote: “Dementia is a unique touchstone for understanding disease and disability, self-identity, aspects of the human condition such as ageing and mortality, a person’s place in society, and how we live together as people, families, and communities”); and*
- *inspired by the work of Professor Bill Fulford, we argued that values-based practice (placing values centre-stage throughout the course of dementia), with attention to rights, provides a means to safeguard the rights and humanity of people with dementia.*

In a moving peroration, with which we’d agree, Tom Shakespeare and his colleagues concluded their article on dementia and disability rights thus:

*As a society, if we can assimilate and acknowledge all that dementia implies, and the diverse ways in which people with dementia want to live, then we will also have a more profound understanding of life, and all that it entails — not just decay, loss, transience and difficulty, but also joy, love and friendship. The benefits will be felt not just by those living with dementia, but by people living with disability — and indeed, everyone.*

## **From citizenship to authenticity**

I want to move now from *citizenship* to *authenticity*. But you might wonder why I want to make this move. I can point to three reasons at least.

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First, I just like the idea of authenticity. I think it's a rich notion, having more depth than, say, the much-vaunted concept of *autonomy*. So, however important the principle of respect for autonomy might be, when we're thinking about the agentic characteristics of citizens, my hunch is that authenticity is relevant.

Second, there are good reasons to link authenticity with ageing. I've written elsewhere about why I think the notion of authentic ageing might be a good one and a better one than the very popular notions in the medical literature of successful or active ageing. I don't like those ideas because, actually, according to the criteria for successful ageing (and partly because we can't always remain active), we're bound to fail if it's a requirement of good ageing that we should be successful. Whereas, we can be authentic with or without disabilities and illnesses and even as we die.

Dr Hanne Laceulle, from the University of Utrecht, has written an excellent paper, "Aging and the ethics of authenticity" in *The Gerontologist* 58 (5) (2018) p.970-978, in which she presents compelling reasons to think that authenticity should be used in the sociocultural narratives which surround ageing. She writes:

*"Authenticity discourse is argued to be capable of, on the one hand, acknowledging the positive potentials of growth and development that later life may harbor, while, on the other, providing support for recognizing and integrating the inevitable existential vulnerability and finitude that old age also confronts us with."*

So, if we can plausibly link authenticity to ageing, it's a short step to make the link to dementia; and if citizenship is relevant to dementia, then it is to authenticity.

And the third reason to make the link from citizenship to authenticity is that we find the notion of authenticity embedded in literature about citizenship in connection with dementia. I've recently had published in a journal called *Maturitas* 125 (2019) p11-16 *Citizenship and authenticity in dementia: a scoping review*, of the concepts of citizenship and authenticity in connection with dementia. There are relatively few papers about authenticity and dementia, whereas there are now numerous papers on citizenship and dementia. However, only a couple use both notions — and then only in a tangential manner. Nevertheless, it can plausibly be argued that many of the papers about citizenship and dementia make use of ideas that suggest authenticity.

The plausibility of this claim comes from the work on authenticity of Professor Alessandro Ferrara, who, in his brilliant 1998 book *Reflective Authenticity: Rethinking the Project of Modernity*, (Routledge p80-105) sets out four dimensions or characteristics of authenticity derived from the psychoanalytic tradition, namely: coherence, vitality, depth and maturity. It's impossible to convey the profound and nuanced thought that underpins these dimensions in a few words, but here are some of the ways in which Professor Ferrara characterises matters:

- *Coherence* is "the possibility of summing up the modifications undergone by an identity during the lifetime of its bearer in the form of a narrative";



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- *Vitality* “designates the experience of joyful empowerment,” the “immediate and joyful experience of the self as worthy of love and esteem” as “genuine and spontaneous”;
  - *Depth* suggests “self-knowledge or self-reflection” as well as the “capacity to be alone”;
  - *Maturity* is the “capacity to maintain a certain congruence between our ideal self and the actual potentials of our real self” — it’s also to show “an ironic acceptance of one’s finitude.”

It was these four dimensions that were everywhere in evidence in the papers on citizenship and dementia that I scoped in my review. For instance, a number of studies pointed to the idea of narrative coherence. Professor Clive Baldwin’s work (has stressed the importance of integrating narrative and citizenship approaches to link the personal and the political. Ruth Bartlett, one of the authors of the important book on social citizenship I mentioned before, (*Broadening the Dementia Debate: Towards Social Citizenship*, 2010) has written about how campaigning for social change can be energising for citizens and for their sense of individual identity. Her paper suggests a sense of vitality, that you can become the person you want to be. Pia Kontos has written with colleagues about “relational citizenship” and conveyed the dimensions of vitality, depth and maturity (*Sociology of Health & Illness* 39(2):182-198 February 2017).

Suffice to say that in promoting the need for a sense of citizenship in dementia, these papers also promote the possibility that people living with this diagnosis can be *true to themselves* and that — of course — is the nub of *authenticity*.

So, it seems plausible that talk of citizenship and dementia links with talk of authenticity and dementia. Before I focus on authenticity, for the sake of intellectual honesty it’s worth noting that there is a possible argument that these two notions oppose each other: it may be that the ability to be authentic is impaired by the demands of citizenship. Being a good citizen might pose a threat to the dimensions of authenticity. To be honest, this possibility does appear in the literature, but invariably it appears as a possible threat but not as a reality. Where people with dementia are being, or being encouraged to be, good citizens — especially where this entails social citizenship — the result is invariably a display of narrative coherence, a sense of joyful vitality, psychological depth and mature acceptance. The self is not swallowed up by citizenship.

## **Authenticity**

The Greek *authentikos* suggests the idea of being “genuine”. Recently, in *Authenticity: The Cultural History of a Political Concept*, Maiken Umbach and Matthew Humphrey have pointed to the Greek roots *auto* (meaning “self”) and *hentes* (meaning “doer”), concluding, “*To be authentic is to identify with, or claim ownership of, a narrative of origins, or a sense of original and unadulterated selfhood.*” (2018, Palgrave MacMillan: Cham Switzerland; p 1) More frequently, authenticity is summed up in the advice spoken by Polonius to his son Laertes in *Hamlet*: “*This above all: to thine own self be true*”. This does, however, cause some

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problems, because the immediate question is what it might mean to be true to *your* self, which itself depends on what you *mean* by the self. The tension I'm going to highlight is that between the *inner* self and the *outer* self.

The story of authenticity usually starts with Jean-Jacques Rousseau (1712-1778), although it doesn't appear that he ever used the word. In his book *On Being Authentic* (2004, Routledge), Charles Guignon makes the point that "*all of the core assumptions built into the concept of authenticity are fully worked out in [Rousseau's] writings.*" There is distrust of society, the idea of an inner "true self," nostalgia for the "happy age" when people were unencumbered by social expectations and able to turn inwards to the "noble savage" living the innocent life of a child. According to Guignon, "*There is the idea that our access to the source of our being is achieved not by cognitive reflection, but by feeling.*"

This last idea, but the others too, makes direct contact with themes in dementia, where authentic engagement might well rely on shared feelings rather than on cognitive skill. But the main point is that the self to which we need to refer is the *inner self* — the self separate and protected from the outer world of society with its tendency to corrupt us from the purer natural state.

Jumping forwards to the existentialist philosophers of the early twentieth-century (along with Søren Kierkegaard, before them), the emphasis is on the inner voice of the self. Jacob Golomb, writing in his book *In Search of Authenticity: From Kierkegaard to Camus*, 1995, Routledge, says, "*to be authentic means to invent one's own way and pattern of life*". Thus Jean-Paul Sartre (1905-1980) asserts: "*Man is nothing else but that which he makes of himself ... he is the sum of his actions*".

Concerning Rousseau and the existentialists, Alessandro Ferrara writes that: "*Authenticity becomes associated with [an] attitude of openness and receptiveness towards inner motives in the assessment of the moral worth of action.*" The point being that authenticity becomes the basis of moral deliberation, but it does so as *self-realisation*. The self is something inner and it's here that we'll find how to be true to ourselves.

This is, perhaps, not the whole story for the existentialists, for whom the outer never loses its importance. Certainly in Martin Heidegger (1889-1976), *in*-authentic existence involves being lost in the "they", disappearing into the crowd; but to be authentic means to engage with others, albeit in a deep sense, not just as objects, but at the level of solicitude. His notion of "being-in-the-world" itself suggests the need to look outwards and not just to the subjective inner world.

Meanwhile, Charles Guignon writes: "*What we call our authentic self, the self we access and express when we are being authentic, is at its deepest level something shaped and defined by society.*" He says that we need to see that we draw from and are answerable to "*the shared historical commitments and ideals that make up our communal life-world*". The idea is that the self to be true to is a self that reflects the complexity and depth of the world and not just whatever it is that motivates me at the moment. This, in my view, has been summed up best by Charles Taylor, in his wonderful book *The Ethics of Authenticity*:

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*“I can define my identity only against the background of things that matter. But to bracket out history, nature, society, the demands of solidarity, everything but what I find in myself, would be to eliminate all candidates for what matters. Only if I exist in a world in which history, or the demands of nature, or the needs of my fellow human beings, or the duties of citizenship, or the call of God, or something else of this order matters crucially, can I define an identity for myself that is not trivial. Authenticity is not the enemy of demands from beyond the self; it presupposes such demands.”*

And, actually, it turns out that Shakespeare realised this when he was writing *Hamlet*, for the full Polonius quote goes as follows:

*This above all: to thine own self be true,  
And it doth follow, as the night the day,  
Thou canst not then be false to any man.*

In other words, the reason for being true to yourself is *in order to* be true to others. The focus is not on my inner self; it's on the nature of my relationship with the world, which moreover is inherent.

Having indulged myself in some of the literature around authenticity, I suppose there's a question about what this might have to do with dementia. Having accepted that there's a social conception of citizenship and that there can be a conception of authenticity embedded in our understanding of citizenship, it's at least interesting to note that one way to consider authenticity is as a social virtue.

Moreover, the inner life of the person with dementia is manifest to us through gestures and behaviours. As the philosopher Ludwig Wittgenstein (1889-1951) famously wrote: *“What goes on within also has meaning only in the stream of life.”* The outer and the inner are not two separate things in the person. They are both part of the person who is also part of a framing context. So, to be true to your *self* is to be true to every aspect of yourself, where what has meaning for you, what is important to you, if it's to avoid the triviality of which Charles Taylor made mention, must have the requisite worldly standing. It cannot be a simple whim.

Moreover, people living with a diagnosis of dementia do have such world-involving concerns. There are things that are important to them as individuals and as social beings. We know this because they — people like Kate Swaffer and Keith Oliver — tell us. We know it because people like Steven Sabat have recorded conversations with people with quite advanced cognitive impairment and demonstrated that they remain “semiotic subjects” — people who understand and convey meaning. We know it because there is copious research to demonstrate meaning-making by people with dementia (for example, some of the ethnographic work in care homes carried out by Pia Kontos, *(Sociology of Health & Illness 39(2):182-198 · February 2017)*). And we know it through observation and from the descriptions of families and friends. People living with a diagnosis of dementia live authentic lives; at least, they can live authentic lives if the environment is supportive.

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## The Helix ArCH study

I want to conclude by illustrating all of this with reference to a pilot project, the Helix ArCH study, we carried out in the North East of England (funded by the Wellcome Trust) where we put an artist into an aged care facility and recorded his interactions with the residents. Residents, who had dementia, families and staff were interviewed about these interactions.

There was some evidence of institutionalisation, where residents were not able to be true to themselves. For example, knitting is not allowed in the absence of care staff for health and safety reasons; and meals are regimented. One resident, when asked what being a citizen meant, said, "Well, nothing now." When pushed, the resident replied, "*What does it mean being a citizen? It's gone.*"

But, on the other hand, there was a story from a daughter of her mother showing authenticity. The staff were inclined to put residents into their pyjamas early in the evening. Here's what the daughter said:

*So I think one day when they were trying to say, "Let's put you in your pyjamas," and she said, "My son will be coming. He'll think I'm senile if I'm in my pyjamas" ... So she's been more forceful than I thought. Actually, she is just totally true to herself.*

Here's a resident asserting herself: *No, I'm what I am and that's who I am ... You have a bit more nerve to just do something if you want to.*

And a male resident, similarly: *I'm a quiet man and I don't express myself [laughs]. Never again, never again if I've got something to say that's important I'll ..er.. talk away.*

There was a particular man who had been a singer when he was younger, but this was something staff had not known. Encouraged by the artist, he revealed his singing career and began to sing. One member of staff said: *When he was on about that he used to sing and that singing is the first I've heard [the resident] sing, so that got me.*

Recall Alessandro Ferrara's dimensions of coherence, vitality, depth and maturity. Narrative coherence and vitality emerge in the story of the singer; there's depth in the account of the resident who did not wish to be seen in her pyjamas early in the evening; and a number of residents spoke of death and dying, which was something of a shock to staff, but showed that the residents had a sense of maturity and of the finitude of their lives.

Asked about citizenship, one resident gave a straightforward political reply:

*"To vote, of course. It's a right, you should, I mean it was fought for, voting was fought for and you should do it."* Indeed, their observations could be quite astute. The artist asked, "*What do you think of President Trump*?" The resident replied, "*He's a funny man; he's rather odd though*". And then added: "*... I think he could be a bit dangerous.*"

Others showed a developed sense of social citizenship: Researcher: "*Do you feel part of the community here*?" Resident: "*Oh yes you've got to, you've got to*". Researcher: "*You've*

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got to”? Resident: “You’ve got to make do and mend ...” suggesting you have to make it work. The community was important to the residents.

Another resident said: “I just like to help people. That’s my way of being a citizen ... And I love to walk up that path though [she meant a corridor], and go into the coffee room and have a bit of a chat.”

## Understanding our humanity

I’ve argued that people living with dementia can and *do* exercise both social citizenship and the social virtue of authenticity. Citizenship and authenticity emanate from personhood and rely upon and reflect the embedding contexts that give a person’s life meaning and purpose.

But as I conclude, let me take you back to the first principle of the *Manifesto* written by Toby Williamson and me: “Dementia is a unique touchstone for understanding disease and disability, self-identity, aspects of the human condition such as ageing and mortality, a person’s place in society, and how we live together as people, families, and communities.” Because it seems to me that a really interesting aspect here is the way in which dementia is a touchstone for understanding *our humanity* generally. We all wish to flourish as human beings, but we only do this with the help of others: others to make things possible; others to provide support — food, clothing, entertainment and stimulation; others to provide healthcare; others to educate us, but also to cherish and love us.

Social citizenship is about encouraging the right regard of the other. Authenticity is about being true to ourselves as we engage with the world, by seeing what it is that makes us the people we are. And, again, central to those concerns that define us as *selves*, is a concern — Heidegger’s solicitude perhaps — for the other as one like us. This is true for all of us. But it’s also true for people with dementia. In some ways it’s more starkly revealed when we consider people living with dementia. Nevertheless, it’s a lesson that we need to learn and re-learn that at root our lives tend to flourish in the context of good quality human engagement.

Let me end with a reflection from a member of staff in the facility in which we undertook our research. She said: “I think sometimes, we just forget and need to be stripped back down to basics and you don’t need anything apart from two people and two chairs”.

**This is a slightly revised version of the 2019 Plunkett Lecture, which Professor Julian Hughes delivered at St. Vincent’s Clinic, Darlinghurst, NSW, on 15 August 2019.**

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# Euphemistic ‘*voluntary assisted dying*’ undermines the meaning of medicine

**Bernadette Tobin**

When their patients are dying, the much-loved Catholic hospitals in Victoria assist them to die in comfort and with dignity. That’s precisely what they are doing when they provide their patients with palliative medicine and care. It’s what Catholic hospitals have been doing for nearly 130 years in Australia.<sup>1</sup>

The doctors and nurses relieve pain and other physical symptoms of illness and frailty such as breathlessness, restlessness, anxiety, clinical depression, constipation. They withhold or withdraw life-prolonging treatments when those treatments are medically futile or overly burdensome (or both). And they do what they (as healthcare practitioners) can do to alleviate other non-physical forms of suffering: loneliness, the fear of being a burden on others, unresolved emotion.

Indeed, their active encouragement of the practice of advance care planning (long part of the provision of healthcare in the Christian tradition) reveals their commitment to honour the primacy of the patient’s responsibility for accepting or rejecting life-prolonging treatments.

Why, then, when Victoria’s *Voluntary Assisted Dying Act* comes into force next week, will doctors and nurses in Catholic hospitals not provide the services that, under certain conditions, it legalises? Why will they not prescribe lethal substances to people who have advanced disease that is expected to cause death within six months (or within 12 months for people with neurodegenerative diseases) and that is causing the person “unacceptable suffering”? Why will they not administer the substance to someone who, though meeting these conditions, is unable to “self-administer” it? Note that these are the practices to which the term voluntary assisted dying in the VAD Act actually refers. The act will legalise doctor-assisted suicide.

Reluctance to use the term suicide — including the decision not to specify it as the cause of death — is not surprising. The same use of euphemisms is found in almost all jurisdictions that have legalised this practice. It is not hard to sympathise with at least some of the motivations that may lie behind unease about using straightforward language: a desire to protect the privacy of the patient (and the doctor?), a desire to emphasise the relevance of the circumstances in which the person “self administers” the substance. But if the patient fails

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<sup>1</sup> *The Weekend Australian*, 15 June 2019: <https://www.theaustralian.com.au/inquirer/euphemistic-voluntary-assisted-dying-undermines-the-meaning-of-medicine/news-story/>

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to die, they will have failed to do what they set out (with assistance) to do, something that has always been understood as suicide.

Moral reasoning goes well when it is sensitive to the complexities of human life. But moral reasoning goes badly when it hides from view something that matters. The term “*voluntary assisted dying*” implies that the doctor is simply assisting a natural process.

So the reason doctors in Catholic hospitals will not provide VAD services is explained by their conception of the practice of medicine itself. Medicine’s task is to heal, where healing is a much broader concept than curing. On this view, it makes no sense to claim that patients have been healed by having been helped to end their lives. Symptom relief heals. Forgoing treatment acknowledges the limits to healing. But assisting a patient to suicide undermines the meaning of medicine.

How will doctors and nurses in Catholic hospitals respond if someone asks them about the VAD services? They will have open, respectful and compassionate discussions about that person’s end-of-life treatment and care options. And if a patient wants to access VAD services, the hospital will release the patient or transfer the patient to another facility.

The Victorian Act protects conscientious objection on the part of individual doctors. In addition, the Victorian Department of Health and Human Services has reiterated the reassurances made by the parliamentarians during debates about the Bill in 2017; that is, that healthcare institutions will not have to participate in the provision of VAD services.

The government acknowledges that one reason a healthcare institution may decide not to participate in the provision of VAD is because it does not align “with the values of the health service”. In putting it this way, the government acknowledges that individuals and institutions have consciences. That said, it is ironic that healthcare professionals in Victoria are described as “conscientiously objecting” when they provide excellent medical care but refrain from doing something that, on their view, undermines medicine’s healing ethos.

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