
Bioethics Outlook

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On truthfulness and dementia

Philippa Byers

I had a few hours to spare on a recent Sunday so I looked up the listings at my local cinema. *The Leisure Seeker* starring Donald Sutherland and Helen Mirren was starting in twenty minutes. I love Donald Sutherland's acting, so off I set. I was a naïve viewer. I'd read no reviews and didn't know that Sutherland would play a person living with dementia. If I'd known I may have stayed home. I volunteer at a dementia specific residential facility in my neighbourhood, and I also have an academic interest in dementia. Further, dementia is currently affecting a member of my family and has done so with several others in the recent past. Dementia is not one thing, and for this reason I'm wary of popular dementia stereotypes.

If you would prefer not to know how the movie ends, stop reading now. I thought the movie was appalling so I looked for reviews when I got home later that afternoon. The reviews stressed the point that *The Leisure Seeker* is a corny film unworthy of its lead actors. But no review mentioned the moral landscape of the movie. I looked for, but did not find, reviewers' comment on what I felt were the malign moral perspectives on dementia that the movie promotes or, at the very least, normalises. For me, two were striking. First, that the life of a person living with dementia is over or may as well be. Second, and my concern here, is that due to cognitive decline and memory loss, such a person is no longer owed the truth in day-to-day conversation, nor owed the truth of their loved ones' intentions.

<p>In this issue Bernadette Tobin summarises a new explanation of the reasons why organised medicine cannot be, and should not be, 'neutral' with respect to physician assisted suicide, and Pope Francis greets members of the Pontifical Academy for Life.</p>

Sutherland plays an elderly man called John who is a well-educated retired teacher with what we are meant to believe is mid to late stage dementia. Helen Mirren plays his capable wife, Ella. The story begins in 2016 with the two leaving home for a road trip in a Winnebago they've owned since 1975. The story of their mostly happy marriage and their many Winnebago holidays unfolds as they travel along, in the way you expect from road trip movies.

The last scene in the movie is John and Ella's adult children walking from two newly-dug grave sites, set side by side with huge white funerary bouquets. It's a road trip with a very final finale. This scene has a voice-over from Ella. It's a few lines from a suicide note left for her two children. She seeks their understanding and asks them not to be angry with her.

Two scenes before this, we see Ella in the Winnebago asking a trusting John to drink what we later assume is a potent sleep-inducing pain medication. Throughout the movie Ella has been downing medication and alcohol to deal with the pain of an advancing cancer she never discusses with John. At her request John drinks the medication and lies down, unaware of its knock-out effect. In a while, Ella turns on the Winnebago engine and quickly undoes masking tape she had placed over seams in the flooring carpet early in the trip. We now realise the taped-down carpet was insulating the cabin from the monoxide fumes of the old and un-serviced Winnebago's exhaust system. Ella then consumes the remains of the medication and lies down with John one last time.

During the movie I sat amongst people my age—later middle age—and people considerably older. Not a young one in sight. Throughout the movie I was a little irritated and distracted by an older woman sitting next to me. She and her friend arrived ten minutes into the movie. She continually wiggled and fidgeted with necklaces, and from time to time spoke loudly to her friend. I was tempted to say something but refrained. I wondered if perhaps there was an early stage issue, that perhaps she and John were fellow travellers. After all, the presence of dementia in the cinema was not entirely unlikely, given the numbers and the age demographic.

As the scene I've described was unfolding I had a strong urge to shout 'murder-suicide'! I'm not writing these words just to ramp up the tone here. The scene hit me like an assault. And although Ella's actions were flagged from the beginning they were entirely out of whack, morally speaking, with the portrayal of John. Sutherland had played him as a delightful person. Although he occasionally forgot exactly who Ella was, John's emotional atunement with her and with others was the only genuine or charming part of the movie. There were moments when Sutherland's flickering facial expressions reminded me of someone I care for and love very much. I've heard that in the 1920's moving picture audiences boo'ed and hissed at a villain's antics. But a direct moral response, like the shout I suppressed, would be considered silly these days. It would show that I don't get that movies are make-believe. If I'd

shouted, I would have disturbed the rest of the audience, who are of course entitled to draw their own moral and aesthetic conclusions without a prompt from me.

The movie ended and the older audience quietly filed out. If anyone else was upset, it wasn't on show. As I've said, I was furious. Was I supposed to see Ella's final actions as an assertion of her autonomy, by dying at a time of her choosing with the man she loved? Was this her way of respecting John's request earlier in the movie? He'd said that when the time came for him to go to one of "those places" by which he meant a residential aged care facility, Ella should give him a rifle, tell him what to do with it, remind him that this was his request, and then leave the room.

In light of such a request, other viewers of the movie may interpret Ella's actions as respecting John as he was at an earlier stage of disease progression. Although he certainly had dementia at the time of this request, was he autonomous then but no longer autonomous a few weeks later? John had also wet his pants on this final evening, were we supposed to think of Ella as sparing him from further incontinence and thus from indignity, albeit by dying? I don't buy any of this, which I'm aware puts me at odds with others.

The belief that residential aged care facilities are so bad that suicide is a reasonable preference strikes me as apathetic and alarming. If a person truly thinks they are that bad—that preferring to die rather than go to one is reasonable—there is surely an alternative moral imperative. This is to do something about such a state of affairs. Agitate for more funding, go and visit one on a regular basis, or even go and work in one. Make a difference that counts.

And why does some kind of autonomy justification mean that it's fine for Ella not to tell John of her intentions, and not tell him that drinking the medication will be a fatal move? If John is able to choose what he likes for lunch—"I want a hamburger"—surely he could have a say in this? To pass over the fact that a person living with dementia is owed the truth no less than anyone else doesn't seem like respect for autonomy or love to me. If the scene in the *Winnebago* was a necessary confrontation with the realities of elder autonomy and a senior romantic moment, this was entirely lost on me.

It should be clear that I found Ella's decision objectionable: that a particular 'now' would be the time that she and John would die, she knowingly and him not. I've also dismissed autonomy justifications for the decision. And in this I've replayed some objections to the position of liberal rights theorist Ronald Dworkin. Dworkin's argument is that a competent person should be able to specify life-limiting measures in the event of later dementia onset, even if they turn out to be content and happy despite their dementia. My concern here is one step prior to this loaded topic. I'm concerned about what happens when we assume a person living with dementia has no need of the truth, about what happens when we release ourselves from truth-telling as a moral obligation.

Moral quandaries concerning truth and truth-telling to people living with dementia are both common and painful. Should you tell Mary that her husband died five years ago each time and every time she forgets it? Should you remind Frank that his son is now a reclusive alcoholic and no longer a seventeen-year-old sports star? There may be occasions when it is not so important to keep the facts exactly in order. And things can be really tricky if a person living with dementia has a persistent and delusional belief, say that the honest son who loves his mother Bonnie is stealing her money. Here, an incorrect belief hurts Bonnie and her son. Navigating these quandaries requires sensitivity and practical wisdom, rather than a release or reprieve from a general obligation to be truthful with words and intentions.

People who live with dementia are a part of us. They sit next to us at the movies, they are our relatives, in some cases they are our future selves. Popular representations of people who live with dementia as those we can lie to ('they'll forget anyway') or misrepresent ourselves to ('they won't know the difference') perpetuate the conditions of a specific kind of vulnerability. Intentionally or otherwise, lies and misrepresentations, and the assumptions underlying them, render them vulnerable by situating them outside the moral bonds of community. These are bonds we jointly maintain by fidelity to the truth. People living with dementia need truth no less than anyone else in their families and their communities. And, in my view, they don't need the popular stereotyping on offer in movies like *The Leisure Seeker*.¹



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Neither neutral nor appropriate

Why the profession of medicine should reject physician-assisted suicide

In a recent article in the *Journal of General Internal Medicine*, six experienced and highly-regarded doctors argue against the idea that medical organisations should adopt a position of neutrality with respect to ‘physician-assisted suicide’ (PAS) and euthanasia. Their arguments deserve serious attention.² I summarise them in what follows, adding just a few ‘Australian’ connections.

The claim that medical organisations should adopt a position of neutrality has arisen in the context of the legalisation of these practices in some jurisdictions around the world. These doctors point out that the legalisation of physician-assisted suicide followed the adoption of an officially neutral position by medical societies in California, Colorado and the District of Columbia. Both the American Medical Association and the World Medical Association have recently been asked by some members to consider revising their opposition to physician assisted suicide, and that some medical organisations are being asked to move beyond ‘neutrality’ to ‘engaged neutrality’ on the issue, that is, to provide advice to those doctors who do participate in the practice where it is legal.

The authors do not mention Victoria’s *Voluntary Assistance in Dying Act 2017*, presumably because their article was submitted for publication before that Act was passed. But when in a Position Statement on Euthanasia and Assisted Suicide was published by the Australian Medical Association in 2016, a statement which said that doctors should not be involved in interventions that have as their primary intention the ending of a person’s life, Dr Rodney Syme, the Vice President of Dying with Dignity, claimed that he could discern in the Statement a subtle shift from complete opposition to neutrality, a shift he welcomed, adding that most doctors’ associations did not back euthanasia laws before governments introduced them overseas!³ Are there any persuasive arguments in favour of neutrality? For instance, does neutrality become necessary in a jurisdiction when the jurisdiction legalises the practice?

² Physician-Assisted Suicide: Why Neutrality by Organised Medicine Is Neither Neutral Nor Appropriate. Sulmasy D P, Finlay, I, Fitzgerald, F, Foley, K, Payne, R, Siegler, M. *Journal of General Internal Medicine*, 2018; 33,8: 1394-1399

³ The Age, 24th November 2016

No. The fact that the American Medical Association is opposed to capital punishment even though it is legal in 30 states in America shows that the legality of a practice does not require neutrality with respect to it from the profession.⁴ Does disagreement among doctors require a position of neutrality? No. The fact that doctors disagree about, for example, whether healthcare should be funded by taxpayers or by the market does not require the professional association to be neutral on that subject. In fact, as proponents of the legalisation of PAS like Dr Syme rightly imply, the adoption of a formal position of neutrality is not *neutral*. When he welcomed what he took to be a subtle shift from complete opposition to a position of neutrality on the matter of physician-assisted suicide in the Statement of the Australian Medical Association in 2016, Dr Syme was welcoming what he recognised to be a political green light! What then is to be said on the matter?

The arguments in favour, and against, legalisation

A good way to start is to understand the overall shape of the debate; that is, to understand the *bases* of the three main arguments in *favour* of legalising PAS and the *basis* of the three main arguments *against* a permissive stance. The basis of the three main arguments in favour of legalising PAS are self determination, the relief of suffering and the denial of any real difference between forgoing life-sustaining treatment and suicide. (In addition, it is claimed that, in jurisdictions in which the practice has been legalised, there is no evidence of a 'slippery slope'.) The basis of the three main arguments against are the meaning of medical practice; the importance of the doctor-patient relationship; and respect for the common good.

Autonomy, suffering, voluntariness

Autonomy does not mean 'I want, therefore I must get'. One person's autonomy ought not to undermine another's. For this reason, any claimed obligation to respect someone's autonomy has to be evaluated in the context of other professional principles such as beneficence, non-maleficence, the internal rationality of medicine, justice and respect for the common good. And, though some suffering is amenable to direct medical intervention, much (loneliness, existential distress, etc.) is not. It is beyond both the ken and the expertise of doctors to assess whether such suffering is adequate to fulfil the criteria for the provision of lethal drugs. The same is true of assessing voluntariness: most doctors have limited knowledge of the lives of their patients beyond the examination room, limited knowledge of family dynamics and other internal pressures experienced by the patients. This problem is exacerbated by the fact that, since the majority of doctors refuse to participate in providing PAS, the requests of patients who seek that service are assessed by doctors who have had no prior relationship with the patient. PAS laws have a medical dimension, verifying diagnosis

⁴ Nor has the profession felt that it has to give instructions on how execute prisoners *well* to those few members who do participate!

and prognosis, but the most important criteria are beyond a doctor's sphere of professional competence.

Healing and its limits

Medicine's purpose is to heal. Healing is more than curing. Symptom relief heals. Forgoing treatment acknowledges the limits to healing. But it makes no sense to claim that patients have been healed by having been assisted to end their own lives. Indeed, since Hippocrates' time, the pledge not to kill has been one of the structural features of the doctor-patient relationship. Since modern medicine gives doctors far greater power over patients' lives than they had in the past, patients, made vulnerable by disease, need to be able to trust the doctor upon whose skills they depend. Things are further complicated by doctors' own discomfort with death, dying and the limits of medicine. Inadvertently, where it is legal, doctors can steer patients in the direction towards assisted suicide.

Killing is never ethically justifiable: allowing to die is often justifiable

Commonsense confirms there is a medical and ethical difference between forgoing a heart transplant and ingesting a poison. Deliberately ending a life creates a new lethal pathophysiological state with the direct intention of making the patient dead. This is what a patient does in PAS, with the aid and consent of the doctor. Allowing to die means to forgo an intervention that is thwarting or would thwart the progression of a pre-existing lethal pathophysiological condition. That may be done for good reasons, such as respecting the patient's judgment that the treatment is too burdensome or because the treatment has proved to be futile.

Laws are more than mere regulatory instruments: they send social messages. A law permitting PAS send the message that, if one is seriously ill, then taking one's own life is something to think about. If it becomes socially acceptable for people to commit suicide because they find loss of control and dependence on others intolerable, then the value of the lives of all those who are dependent on others is called into question. That is why there is so much resistance to PAS in the disabled community: not that they fear they will be disproportionately persuaded to undertake PAS but because their dignity is deeply disrespected by the very fact that society legally endorses the idea that people like themselves can be considered better off dead.

Approaching death

Is the choice one between a gruesome death, strapped to machines, sickened by drugs, stabbed with needles, or a peaceful death via a lethal prescription? No. Progress in symptom management belies this picture. In addition, it is routine for patients to refuse life-sustaining treatments such as ventilators, feeding tubes, cardiopulmonary resuscitation when they

judge them more burdensome than beneficial, and then to be cared for and supported in their dying. There should be no need for PAS for uncontrolled symptoms: the response of the profession should be to ensure that doctors become skilled in providing good care at the end of life and ensuring that all patients have access to that care.

Normalising demand, and avoiding discrimination

Public support for PAS seems to be motivated by a fear that doctors will not adequately relieve pain. Those who actually seek PAS do so because of fear of diminished autonomy or dignity or the fear of being a burden. Those who receive PAS have a distinct personality type, fixated on issues of control.⁵ But when PAS is normalised, it is short step to say that those who cannot self-administer the drug are being discriminated against on the basis of their handicaps and that this requires a move from PAS to euthanasia. Similarly, to avoid discrimination, those who are unable to speak for themselves (children, those suffering from dementia, the severely retarded) will need to be eligible for euthanasia on the basis of surrogate judgments. So too will those suffering from refractory depression and autism, and others not terminally ill. The evidence from Belgium shows how all this happens.⁶

Control

Everyone wants some measure of control in the face of the overwhelming reality that no one can control: the fact of mortality. Control can be exerted over decisions to forgo life-sustaining treatments, decisions about how to organise one's affairs, decisions about how to make best use of the time available. But dying brings unavoidable uncertainties, for both patient and doctor. If control is the ultimate value and duty, then professional judgment about prognosis, etc. is irrelevant: there would be no principled way of withholding *any* requested treatments!

To summarise, there is more at stake than meets the eye in the debate over legalising PAS. In adopting a 'neutral' position, organised medicine just avoids taking responsibility for its own ethical principles. But, as a 'profession', medicine should define its ethics independently of the state, the market and the vicissitudes of public opinion.

⁵ Oldham RL, Dobscha SK, Goy ER, Ganzini L. Attachment styles of Oregonians who request physician-assisted death, *Palliat Support Care*. 2011; 9; 12-8. As cited in Sulmasy et al, op cit.

⁶ Sulmasy et al, op cit, page 1398

Equal beginnings, but then?

Ethical issues in a globalised world

Opening address to the Pontifical Academy for Life,
Vatican City, 24th June 2018.

Pope Francis

I am pleased to offer my greetings to you all beginning with your President, who I thank for his presentation of the Program of this General Assembly, where the question of human life will be considered in relation to the globalised world we live in today.⁷

Each of you is relying on the wisdom that must inspire your approach to “human ecology” as you examine the *ethical and spiritual quality of life at each of its phases*. Think of human life at its conception, human life growing in the womb, life just born, life as a child, a teenager, an adult; think of life that has grown old and is ready to pass away – into eternal life! There is life that is family and community, life that reaches out with hope. There is life that is frail and sick, wounded, insulted, humiliated, marginalised and cast aside. But all are still human life, the life of human persons that live on God’s Earth, and who share a common home with every living creature. In our life-science laboratories we study life with instruments that let us explore life’s physical, chemical and mechanical aspects. This is an activity that is important and cannot be ignored, it must be integrated into a wider and deeper perspective, one that concentrates on human life specifically – life that has entered the world with the miracle of words and thought, affections and spirit. Today it is fair to ask what recognition the *human wisdom of life* receives from the natural sciences. What political culture inspires us to nurture and protect real human life? The “beautiful” work of life is the generation new persons, the education of their spiritual and creative qualities, their introduction into the love that is found

⁷ <http://www.academiavita.org>

in the family and the community, in care for weakness and wounds; and in new life's initiation into the life of God's children, in Jesus Christ.

When we give children over to poverty, the poor to hunger, the persecuted to war, and the elderly to abandonment, do we not ourselves do the "dirty work" of *death*? Where does this dirty work of death come from? It comes from sin. Evil tries to convince us that death is the end of everything, that we have come into this world by chance and that our fate is to end up in nothingness. If we exclude "the other" from our thinking, each life thinks only of itself, and life itself becomes simply a consumer commodity. Narcissus, the character of ancient mythology, who loves only himself and ignores the good of others, is shallow-minded but does not even realise it. Meanwhile, he is in a way the source of a very contagious spiritual virus that turns us into reflections in a mirror who see only ourselves and nothing else. We become blind to life and its power – to life as a gift that is received from others and that to others must be passed on responsibly. The *global vision of bioethics* that you are preparing to re-launch in the field of social ethics and worldwide humanism will, strengthened by Christian inspiration, strive with greater commitment and rigour to break free from complicity with the dirty work of death that draws strength from sin. It will bring us back to the covenant with grace that God has destined to be part of our lives. This bioethics will not begin with a consideration of sickness and death in hopes of reaching an understanding of the meaning of life and the worth of the individual. Rather it will begin with a profound belief in the *irrevocable dignity of the human person* as loved by God – the dignity of *every* person, in *every* phase and condition of existence – as it searches for those forms of love and care that must address the vulnerability and frailness of each individual.

First of all, your global bioethics will be a specific development of the vision of *integral ecology* set forth in the Encyclical *Laudato si'*, in which I emphasised the following points: the intimate relationship between the poor and the fragility of the planet, the conviction that everything in the world is connected, the critique of new paradigms and forms of power derived from technology, the call to seek other ways of understanding the economy and progress, the value proper to each creature, the human meaning of ecology, the need for forthright and honest debate, the serious responsibility of international and local policy, the throwaway culture and the proposal of a new lifestyle (*Laudato si'*, 16).

Secondly, in a holistic vision of the person our task is to express with even greater clarity the connections and differences that the universal condition inhabits, and that involve us – *starting with our own bodies*. In fact our body places us in a direct relationship with the environment and other living beings. The acceptance of our bodies as God's gift is vital for welcoming and accepting the entire world as a gift from the Father and our common home, whereas thinking that we enjoy absolute power over our bodies turns, often subtly, into thinking that we enjoy absolute power over creation. Learning to accept our body, to care for it and to respect its fullest meaning is an essential element of any genuine human ecology.

Also, valuing one's own body in its femininity or masculinity is necessary if I am going to be able to recognise myself in an encounter with someone who is different (*Laudato si'*, 155).

It is necessary to proceed with a careful discernment of the complex *fundamental differences of human life*: between a man and a woman, fatherhood and motherhood, filiation and fraternity, social factors and all the different ages of life. Likewise, between all the difficult conditions, and all the delicate or dangerous situations that require particular ethical wisdom and courageous moral resistance: sexuality and the transmission of life, sickness and old age, handicaps and disabilities, poverty and exclusion, violence and war. *"The defence of the unborn, for example, needs to be clear, firm and passionate, for at stake is the dignity of human life, which is always sacred and demands love for each person, regardless of his or her stage of development. Equally sacred, however, are the lives of the poor who are already born, the destitute, the abandoned and the underprivileged, the vulnerable infirm and the elderly exposed to covet euthanasia, the victims of human trafficking, new forms of slavery, and every form of rejection."* (Apostolic Exhortation, *Gaudete et Exsultate*, 101) In the texts and teachings of Christian and ecclesiastical formation, the subjects of the ethics of human life will have to be given their proper place in a global anthropology, and not be confined to the borderline areas of morality and law. It is my hope that an acceptance of the centrality of integral human ecology, that is, of a harmonious and comprehensive understanding of the human condition, will find in your intellectual, civic and religious commitment, both strong support and effective resonance.

Global bioethics calls us to the wisdom of a profound and objective discernment of the *value of individual and community life*, which must be preserved and promoted *even in the most difficult circumstances*. We also state strongly that, without the adequate support of responsible human closeness, purely legal regulation and technical assistance cannot, on their own, guarantee conditions and relationships with the dignity of the person. The vision of globalisation that, left to its own devices, tends to increase and deepen inequalities, invites an ethical response that favours justice. Attention to social, economic, cultural and environmental factors that affect health is part of this commitment, and it becomes a concrete way to implement the right of every people "to share, on the basis of equality and solidarity, the enjoyment of goods intended for all." (St John Paul II, Encyclical *Sollicitudo Rei Socialis*, 21)

Finally, the culture of life must look more deeply into the "serious question" of life's "ultimate destination". This means highlighting with greater clarity whatever directs man's existence towards a horizon that surpasses him: every person is freely called "as a son to commune with God and share in His happiness. [...] a hope related to the end of time does not diminish the importance of intervening duties but rather undergirds the acquittal of them with fresh incentives." (Second Vatican Ecumenical Council, Pastoral Constitution *Gaudium et Spes*, 21)

We need to question ourselves more deeply about the ultimate destination of life, in a way that makes us capable of restoring dignity and meaning to the mystery of life's deepest and most sacred affections. Human life, beautiful beyond words yet terrifyingly fragile, takes us beyond ourselves. We *are* infinitely more than *what we can do for ourselves*. But human life is also incredibly tenacious, certainly thanks to some mysterious Grace that comes from above as it boldly calls for justice and the final victory of love. And man is able – hoping against all hope – to sacrifice himself for life, until the end. Recognising and appreciating this faithfulness and dedication to life gives rise in us to gratitude and a sense of responsibility, and it encourages us to offer our knowledge and our experience generously to the whole human community. Christian wisdom must recognise with passion and boldness that the destiny of the human race is the life of God, who has promised to open, beyond death, the infinite horizon of loving bodies of light, with no more tears. And to amaze human kind eternally with the ever-new charm of all of the “visible and invisible” things that are hidden in the womb of the Creator.

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