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# Bioethics Outlook

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## Truthfulness and Respect in Dementia Care

**Steve Matthews**

In looking after people with dementia, the morally troubling choice over whether to be truthful is never far away. Should someone who cares for a person with dementia deceive them, even outright lie to them, when a situation arises giving rise to such a dilemma? Surveyed care-workers report with near unanimity that they have deceived those in their care, and sometimes lied, typically in order to alleviate a situation in which someone is agitated or confused. What justification, if any, can there be for this practice? The position many take, is that in general one should never lie to those in care, but there may be circumstances (often emergency circumstances) where from necessity telling untruths is permitted, though regrettable. It is permitted in order to head off a situation that might be harmful to the person, or at the very least an aid to comfort.

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**In this issue: Steve Matthews explores truth-telling to people with dementia. He examines the claim that going along with a person's false view of the world might be both reasonable and respectful. David Albert Jones explores the pastoral guidance provided by Catholic bishops in different countries for sacramental and liturgical practice in cases of euthanasia or physician assisted suicide. And Bernadette Tobin argues that the logic of assisted suicide and euthanasia laws is such that they must expand their reach whatever legal limits are first enacted.**

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Those cases are well taken, yet there is an additional kind of case, where the reason for a deception goes beyond this utilitarian one to one in which going along with a person's false view of the world turns out, surprisingly, to be respectful of their agency, and of their identity, at least as it once was. This short piece is devoted to explaining why such a deception might be permitted, and permitted in these surprising terms, as respectful. But first some background.

In 2014 a comprehensive report was prepared by the UK Mental Health Foundation into how we should understand the lived experiences of those with dementia and those who care for them in relation to being truthful, and specifically whether it is permitted to deceive or lie. People in care, they said, experience '...a reality or set of beliefs different from those around them', and this leads to dilemmas: should we (the carers) go along with these different realities and beliefs, or not? The report sought to answer a fundamental question about what justifies telling untruths in these situations. The report offered a highly detailed and nuanced answer to this vexing issue. There are many kinds of situation, some involving highly agitated people whose false view of the world is distressing, to cases of people whose lost insight is disturbing (to those around them) but not to the person themselves. As one person from the report commented,

*"...When [people with dementia] find themselves in need of facts which are permanently unavailable to them, making it almost impossible to make sense of what is happening in their life, they very reasonably make the best match they can with intact information from long ago. This can result in their own interpretation of current activity being vastly out of sync with other people around them."*

In one very striking case a woman in a care home refused to leave her room and became greatly agitated in response to the care staff attending to her. She had misinterpreted the voices from outside her room as being the voices of gangsters. In her former life drug-dealing criminals living above her flat had set fire to the building resulting in her being forced out. She thought the care workers were the same or similar people. In another case, a woman became distressed and disgusted by the sight of care workers who were in fact cleaning and attending

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to residents' rooms; the woman came to believe that they were sex workers going into the rooms of clients for sexual services.

The disorientation those with dementia experience manifests in a host of different ways then, requiring nuanced attendance to the very specific clinical and situational elements. A typical case that gets mentioned in these discussions is of a person with relatively advanced dementia who, because of memory loss, experiences repeated distress every time she is told of her husband's death. Each time she is told of his death she is grief-stricken and distraught.

This state of affairs naturally leads, then, to thinking that perhaps it would be better to lie to this woman, go along with the belief that he is still alive and will be visiting later, knowing that she will forget about it all in a few minutes anyway. In these kinds of cases, especially where the distress is intense and there seems no alternative, carers will often, and with some justification, engage in the deceit. The justification is usually based around the welfarist objective of reducing harm and distress. In fact, there is a good question lurking here about whether in fact such deceit counts as a lie given that the speech act in question aims at some good, rather than for some clear advantage to the person lying.

In any case, this is but one of a plurality of case-types that are messy, that is, cases in which all of the details make a moral difference to the decisions to be made. This messiness makes it close to impossible to provide a uniform set of nursing or care protocols that would fit every case. (Even the case just described can have an indefinite number of variations.) So let us leave those cases to address the kind of case mentioned at the start, one in which a person with significant memory loss believes they occupy a role they once had in the past, either a professional role, or perhaps even a domestic role. In these cases the circumstances trigger the person into enacting the role. Let's consider some of these.

Martha has Alzheimer's dementia and is attending the dayroom with several residents in a dementia care facility. It is the afternoon, and coffee has been served by the staff, who now have returned to the kitchen. As things unfold Martha's understanding of the situation is transformed. As Norwegian dementia researchers Linda Orulv and Lars-Christer then describe it:

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*Somewhere along the way [Martha] assumes the status of gracious hostess – a part that has been hers innumerable times throughout her life. Equally innumerable are her stories about how she, like her mother before her, has taken pride in welcoming everyone to her home and in sharing her food and hospitality with other people...These narrative plots occur frequently in the body of material that can be described as variants of one overall storyline that binds together many of Martha's stories. This storyline is of her being a generous and sharing person throughout her life...*

Thus, a previous role-driven self-image – one specifically infused with a moral identity of someone who is 'gracious', 'hospitable', 'generous', 'sharing' – emerges to fit with Martha's current experiences; making sense of the situation is filtered by a self-image that feeds into her agency. Martha's agency is enabled because she is making sense of what is going on in a way that fits with her current self-understanding. To intervene here by correcting Martha poses a risk to her identity and agency. Its effect would be to bring what Martha took herself to be doing to an abrupt halt.

If this is right, the demand for truthfulness in dementia, would potentially disturb a sense-making process that is *prima facie* good for people – one that provides narrative continuity and allows the person, at least temporarily, to act effectively in line with their self-image. The drive for narrative coherence between situation and self, is, in a sense, the drive for restoration of personhood. In acting out her role Martha is restored to herself, and to those who know and care about her. The sense-making process that permits restoration of self, demands respect.

Or consider the case of Winifred, someone who was in the middle to late stages of Alzheimer's and had formed the belief that the aged care home where she lived was an obstetrics and gynaecology department of a hospital. Winifred had once practiced as a health professional in the role of midwife. She seemed to take on this role in the care home, walking about with apparent professional intent, asking questions of "patients" and generally trying to assist by bringing to bear her medical knowledge. It wasn't too surprising that Winifred might

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misinterpret her surroundings as those of a hospital setting and it seemed that in falling into her medical role she did so with an almost complete transformation. The role provided her a guide to what she could and would do, since it allowed her self-image as a person who occupied one of the helping professions a natural outlet. As one of her carers remarked, “My impression was that [Winifred] seriously believed she was still working as a midwife and was still performing an important role in her community.”

Finally consider the fascinating case of Mr. Q, described by Oliver Sacks. Mr. Q was a former janitor who continued to enact this role in his nursing home run by the Little Sisters of the Poor, checking windows and doors so that they were locked, inspecting laundry and boiler rooms to see that all was functioning well, and so on. Sacks takes up the story:

*Another way of seeing the point is to view the Sisters’ response to Mr. Q as one in which they preserved his self-image by respecting his agency. That his self-image as a janitor is “petrified” seems beside the point. His agency depended on his being able to continue in his role, and that role and self-image was what remained to him as an identity that could fit with his surroundings. As the comment above had it, to tell the truth to Mr Q would be crushing since his own interpretation of himself (as janitor) and his situation allowed his activity to remain ‘in synch’. For him to apprehend the objective truth of his situation would destroy this synchronicity, and render him emotionally incapable of proceeding.*

In these cases it is clear that going along with the person’s false beliefs about their role and situation is something a carer ought ethically to be permitted to do. The ethical justification turns out to be respect for that person, at least as they were. For in a sense they are being true to themselves, or at least the selves that remain. One’s self-image, as a certain person occupying a role, gives rise to a drive to enact that role, and that is what we mean here by agency: the drive to make sense of what we are doing, given our self-understanding and of our sense of where we are. This is true of each of the people in our cases. Martha is driven to host the morning tea; Winifred is driven to enact her role as nurse; Mr Q is driven to attend to

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the janitorial duties within his building. As Sacks points out, these roles provide a means by which each of them are organised and oriented within the social world that remains to them.

Respect for agency, and its manifestation in the drive to make sense of what we are doing ought to be our default in the cases of dementia care where truth-telling is an issue. This is of course not to say that relieving distress or attending to the well-being of a person does not count, and indeed in the cases described above it is generally true that in so far as persons with dementia are able to (subjectively) make sense of a situation or act out a role, this narrative connectedness between self and situation provides them with a place in the world and resulting sense of composure. The point is that when the norm of respect for agency is understood in terms of the drive for sense-making carers will be motivated to discover, especially from family and friends, information about the history and personality of the person in order to place themselves in the best position to respond to this demand. The best kind of care tends to be the result of getting to know a person, and who they were, what their interests were and are, and the kind of person they were and are. So understood, nuanced and particularised engagement can take place. What might this person like? What books, music, games, and so on, interests them? Having even relatively minimal information is respectful of the person and their agency, and treats the individual as a person, and not a mere patient to be managed.

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# Last rites for last wrongs

## Pastoral accompaniment of Catholics who have requested euthanasia or physician assisted suicide

David Albert Jones

### Suicide and Christian burial

To take your own life is to take the life of a human being. It is not only an act of self-harm but also has a harmful, sometimes devastating, impact on others. It deprives the world of a unique and irreplaceable person. From a theological perspective, it is both a failure to accept one's life as a gift from God and a failure to accept death when God wills, not when I will. It is a failure to die to oneself. In former centuries, the Church, in an effort to discourage suicide and aware of the spiritual damage that it causes, denied those who died in this way a Christian burial.

Since the early modern period, however, and especially in the twentieth century, there has been a development in the Church's theological understanding and pastoral practice in this area. Theologians have become increasingly aware that suicidal thoughts and actions are typically an expression of a disturbed mind rather than a conscious rejection of the Gospel. In the words of the Catechism (2282-2283):

*Grave psychological disturbances, anguish, or grave fear of hardship, suffering, or torture can diminish the responsibility of the one committing suicide.*

*We should not despair of the eternal salvation of persons who have taken their own lives. By ways known to him alone, God can provide the opportunity for salutary repentance. The Church prays for persons who have taken their own lives.*

Even when the law of the Church prohibited Christian burial for those who had taken their own lives, this rule was not applied where "the act was committed when they were of unsound mind or... they showed signs of repentance before death occurred".[1] In practice,

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Catholic funerals for those who died by suicide had become the norm even before the Second Vatican Council. This shift in pastoral practice was reflected in the 1983 Code of Canon Law which finally removed the prohibition.

## **The rise of euthanasia and assisted suicide**

At the same time as the Catholic Church was adopting a pastoral approach to suicide that better recognised its typical impulsivity and irrationality, campaigners in Europe and America were promoting new forms of intentional self-killing that were ostensibly rational and deliberate.

It was in the late nineteenth century, in England and America, that the term “euthanasia” was first applied to the proposal that doctors be permitted to end the lives of their patients at the patient’s request. This idea was rejected repeatedly but was taken up in the Netherlands in 1984 when the Supreme Court allowed a doctor who performed euthanasia to claim a “defence of necessity”. This later provided the basis for the Termination of Life on Request and Assisted Suicide (Review Procedures) Act, which came into force on 1 April 2002.

Independently, in Switzerland, the law had permitted assistance in suicide, if done for unselfish motives, since 1942. This gap in the law allowed private associations, beginning with EXIT Deutsche Schweiz in 1982, to establish an organised practice of assisted suicide. EXIT was later followed by other associations of which Dignitas, founded in 1998, is most well known in the United Kingdom because it assists the suicides of people who are not resident in Switzerland.

A third model for assisted suicide was Oregon’s Death with Dignity Act which came into force in 1997. This permits a physician to prescribe a lethal dose for someone with terminal illness and who is not expected to live for more than six months but, unlike with euthanasia, the dose must be self-administered.

In summary, in the late twentieth century there emerged three models of medical killing by or at the request of the patient: euthanasia (the Netherlands), unregulated assisted suicide including “suicide tourism” (Switzerland), and physician assisted suicide for the terminally ill (Oregon).

In the twenty-first century, similar laws have been enacted by some other states in the United States (including California in 2015) and by some other countries (including Belgium in 2002 and Canada in 2016) and, on official figures, over 80,000 people have died of euthanasia or assisted suicide since 2015.

Where these practices are legal, the Church faces a real pastoral challenge: how to respond to requests for pastoral support from seriously ill people who are considering or planning



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euthanasia or assisted suicide, and how to respond to requests for Catholic funerals for those who have died in this way.

## **Pastoral responses to euthanasia and assisted suicide**

Canon Law no longer prohibits Catholic funerals for those who die by suicide. However, it prohibits Catholic funerals for “manifest sinners who cannot be granted ecclesiastical funerals without public scandal of the faithful” (Can. 1184 §1, 3). The Catechism states that “if suicide is committed with the intention of setting an example, especially to the young, it also takes on the gravity of scandal.” (2282)

It seems, then, that there is a case for denying a Catholic funeral to someone who seeks to give public expression to their support of assisted suicide or euthanasia. For example, the political activist Piergiorgio Welby sought, by his death, to change Italian law on euthanasia. When he died, in 2006, as a result of withdrawal ventilation at his request, he was refused a Catholic funeral. This action reaffirmed Catholic teaching but was controversial even among faithful Catholics, some of whom regarded it as cruel to his relatives.

The first episcopal hierarchy to set out specific guidance in relation to euthanasia or assisted suicide was the Netherlands in 2005. The document is in two parts, the first covering the sacrament of the sick and viaticum, the second, Church funerals. However, it is noteworthy that the document was restricted to a limited circulation (“*beperkte publicatie*”). It was not made available to the press nor was it possible to order a copy. Only a statement about the guidance was released and excerpts were subsequently made available online.[2]

It is not clear how aware the lay faithful were of the contents of this guidance or how widely it was applied. When, in August 2011, a parish priest in a Netherlands declined to celebrate a Catholic funeral for someone who had died by euthanasia, a course of action seemingly in accord with the guidance, his refusal provoked a storm of protest.

It is only in the last five years that episcopal documents have provided public guidance to the faithful on these questions. Canada legalised euthanasia and assisted suicide in June 2016. In response, in September 2016, the Catholic bishops of Alberta and the Northwest Territories published guidance on the provision of the sacrament of penance and the anointing of the sick and on the celebration of Christian funerals.[3] This was followed, in November 2016, by a document from the Atlantic Episcopal Assembly, updated February 2018.[4]

In December 2016, Gerald Coleman published a reflection on these issues in the journal of the Catholic Health Association USA.[5] However, the first formal guidance from an American diocese did not appear until Honolulu in November 2018.[6] There is as yet no pastoral guidance on assisted suicide from the US Conference of Catholic Bishops.

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In June 2019, the Belgian hierarchy produced a document *I take you by the hand: Pastoral accompaniment at the end of life* [7] which covers the accompaniment of those who request euthanasia. In December of the same year, after almost four decades of organised assisted suicide, the Swiss bishops produced *A pastoral approach to the practice of assisted suicide*. [8]

In July 2020, the Congregation of the Doctrine of the Faith issued *Samaritanus Bonus*. [9] Section V.11 of that document concerns the pastoral accompaniment and (non-)provision of the sacraments to those who have requested euthanasia or assisted suicide, though it does not touch on the question of Catholic funerals.

In addition, there have been occasional statements to the media by individual bishops, and some dioceses have produced “Frequently Asked Questions”. [10] Nevertheless, the only formal guidance available is that from the Netherlands, Canada, the United States (Honolulu), Belgium, Switzerland and the CDF. Taken together, these offer insights into the pastoral challenges of euthanasia and assisted suicide in relation to accompanying the dying and to praying for the dead.

## **Accompanying the dying**

The mission of the Church gives her an obligation to minister to those in spiritual need and especially those in danger of death. Many rules of the Church cease to apply if the person is in danger of death. The sacraments of penance, anointing and the eucharist may be given to those who are not in full communion (Can. 844 §4). Priests who would otherwise be forbidden from hearing confession are now obliged to do so: “In urgent necessity, any confessor is obliged to hear the confessions of the Christian faithful, and in danger of death, any priest is so obliged” (Can. 984 §2).

In countries with assisted suicide or euthanasia, the great majority who die in this way are seriously ill with a condition from which they might otherwise die. What then should be the pastoral response to a someone who is considering euthanasia or assisted suicide and who requests to see a Catholic priest? All the pastoral guidance surveyed here states that the priest is obliged to respond and to offer support. The fact that the sick person is considering or even planning such action makes their spiritual need all the greater.

At the same time, there is a key issue, highlighted repeatedly across all this guidance, which is the requirement for people to be in a proper condition to receive the sacraments. If someone has decided to take their own life or to have their life ended intentionally, this is an obstacle to receiving the sacraments. Furthermore, the sacrament of penance requires that the person be contrite and have a “firm purpose of amendment”. If the penitent remains committed to euthanasia or assisted suicide then the priest cannot give absolution. The same considerations apply to the sacrament of the sick and to viaticum. If the person is not contrite

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the priest should continue to accompany them and pray with them but not by means of the sacraments.

Documents differ in relation to what is needed to manifest contrition. *Samaritanus Bonus* gives an example, “thus a person who may be registered in an association to receive euthanasia or assisted suicide must manifest the intention of cancelling such a registration before receiving the sacraments”.<sup>[9]</sup> This envisages a situation such as that in Italy or Switzerland where people register with an organisation that provides assisted suicide. However, it is not clear why contrition need involve the intention to cancel registration, if the penitent no longer has the intention to make use of it. In contrast, the guidance from the Diocese of Honolulu is more open to diverse signs of contrition: “If a person gives any indication of a willingness to reconsider his or her decision or to learn better the teachings of the Church, the sacrament of Penance may be celebrated, putting hope in the grace of the sacrament to bring contrition to completion.”<sup>[6]</sup> This advice also reflects the guidance provided by the bishops of Alberta and the NWT.

There is consensus across all guidance that, while accompanying the dying person, the priest or pastoral worker should do nothing that implies support for the person’s decision to take their own life. For this reason, the Dutch and Swiss guidance require that the priest leave the room at the time of suicide or euthanasia. In contrast, the Belgian guidance states that the priest, while not approving, should remain present so as to show that he does not abandon the dying person.

*Samaritanus Bonus* states that “those who spiritually assist these persons should avoid any gesture, such as remaining until the euthanasia is performed, that could be interpreted as approval of this action.”<sup>[9]</sup> This favours the Dutch and Swiss guidance but only because remaining “could be interpreted as approval”. What the Belgian guidance seems to require, but has yet to provide, is some way to demonstrate that remaining is an expression of support not of approval.

## **Praying for the dead**

The question as to whether Catholic funerals should be denied to those who die by euthanasia or assisted suicide is not addressed in the Swiss, Belgian, or Atlantic Assembly (Canadian) guidance nor in *Samaritanus Bonus*. It is addressed in the Dutch guidance and in the guidance of the Canadian bishops of Alberta and the NWT and by the Diocese of Honolulu.

The Dutch and the Canadian bishops acknowledge that the Church no longer denies a Church funeral to those who die by suicide, but both point to differences between unassisted and assisted suicide. While those who die by suicide generally may be presumed to be of

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disturbed mind, the laws on euthanasia or physician assisted suicide require that the person be mentally competent. Furthermore, because the decision is made openly and may be discussed ahead of time, more may be known about the person's state of mind.

This question was first raised in a prescient article by Robert Barry OP in 1997.[11] He argued that Catholics should be sceptical of the propaganda that presents physician assisted suicide or euthanasia as a rational and autonomous decision. On the contrary, such actions are internally constrained by many factors and the fears and anxieties that motivate requests for assisted suicide may equally motivate unassisted suicide. Furthermore, depression is under-diagnosed in those with chronic illnesses and yet only 1% of assisted suicides in Oregon are referred for a psychological assessment. It is the advocates of these practices who hide behind euphemisms such as "death with dignity" or "medical assistance in dying" while the Church affirms that these practices are truly acts of suicide. It is precisely because these acts are suicide that the Church should apply to them the laws and customs it applies to suicide and should grant those who die in this way a Catholic funeral.

The guidance of Honolulu Diocese[6] recalls that the penalties of Canon law are "subject to strict interpretations" (Can. 18), that is to say, they should be interpreted narrowly. The law does not prohibit Catholic funerals for those who die by suicide but only for those who cannot be granted a Catholic funeral "without public scandal of the faithful"(Can. 1184 §1, 3). Such cases will be the exception not the rule and this will generally require a decision by the local ordinary.

While it will be rare for the Church to refuse a Catholic funeral for someone who dies by euthanasia or physician assisted suicide, there will remain a question as to how the funeral is celebrated so as not to celebrate the way the person died. This is analogous to the challenges the Church faces in the funerals of those who are controversial in other ways either in life or in death.

*There may also be the case, however, of a family or friends that wish the funeral rites to be an occasion to celebrate the decision of their loved one to die by assisted suicide or euthanasia and thus to promote these practices as acceptable. This would be truly scandalous, as it would be an encouragement to others to engage in the evil that is euthanasia and assisted suicide. Such a request for funeral rites must be gently but firmly denied.[3]*

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**“Choice will not be necessary”**  
**or**  
**“Choice will be all that’s necessary”**

**Bernadette Tobin**

To legalize so-called ‘voluntary assisted dying’ is to legalize a practice which predictably and inevitably expands.

There is plenty of evidence of ‘bracket creep’ already, both here in Australia and overseas.

From 2017 in Victoria through to 2021 in Queensland, the circumstances in which this service has been made available have widened as Bills have been debated in state jurisdictions. So too, within NSW, from 2017 when the parliament of New South Wales debated the Khan Bill to 2021 when it debates the Greenwich Bill: once again the conditions under which the service is to be available have expanded. And there’s plenty of evidence of the same phenomenon from Europe and Canada.

Expansion should not surprise us. More important, however, than acknowledging these empirical facts is understanding *why* they have occurred.

There are, I think, two different forms of pressure which cause this by-now familiar expansion of the laws. I will call the first pressure ‘choice will not be necessary’, and the second pressure ‘choice will be the only thing that’s necessary’.

The ‘choice will not be necessary’ pressure works like this. The patient chooses VAD. Then two doctors assess the person’s eligibility: a medical condition, from which the patient will likely die soon, from which he or she is suffering intolerably. The doctors must judge whether these criteria are met. But, if someone else meets these criteria, why will choice be necessary? Why not expand the availability to people who meet these eligibility criteria but who cannot choose?

The pressure to expand availability in this direction can be seen in the arguments of those who say that euthanasia should be made available for newborn babies (as in Holland) and/or to people with dementia (as in Canada). Indeed, some years ago the late Dr Rodney Syme, a

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proponent of these laws, predicted that, once the service was legally available to those who could choose it, society might come to think that it would be *'unfair'* if it were not available to people who could not choose it. His reference was to people with dementia. Thus the 'choice will not be necessary' prediction.

The 'choice will be the only thing that's necessary' pressure goes in the other direction. A patient chooses VAD. Then the doctors must assess his or her eligibility. But they, understandably, are likely to shy away from making what is mostly a medical judgment (that the patient meets the eligibility criteria) and prefer to rely on the actual choice of the patient.

The pressure to expand availability in this direction, to *anyone* who chooses, can be seen in Canada where they have dropped the requirement that death must be reasonably foreseeable on the grounds that that requirement discriminates against people with serious disabilities who are not terminally ill. Thus the pressure towards 'choice will be the only thing that is necessary' prediction.

These two forms of pressure, which seem to go in opposite directions, in fact share an assumption: that we can know when a life is not worth living. In the former case, that assumption is made 'objectively' by others. In the latter case, that assumption is made 'subjectively' by the person himself or herself.

This is why most of the debate about the (in)adequacy of the 'safeguards' in these Bills misses the point. However humane one's motives in supporting these laws, the likelihood of the criteria of eligibility being expanded cannot be set aside as though it were mere panic-mongering.

Parliamentarians, in framing laws for the well-being of everyone in the community, have a responsibility to deepen and widen their thinking. The social policy before them is not simply a matter of how best to ensure that people do not die in unrelieved suffering. It is also a matter of how to protect the lives of those who, either on their own or at the behest of others, have come to think that their lives are not worth living. Their existential demoralization is a challenge to us all.

Yes, I'm a Catholic. So it will be said that I'm trying to impose my religious beliefs on those who don't share them. Well, any reasonable religion holds out its social teachings as matters which are apt for rational assessment. But, that said, there is nothing religious in the claim that expansion of these laws is both predictable and inevitable.

**Bernadette Tobin**

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