Survival and the citizen: Micro-dialogues on key challenges

No. 1

End-of-life care and the right to die
Introduction

This the first in an occasional series initiated by the Royal Irish Academy's Ethical Political Legal and Philosophical Studies (EPLPS) Committee to stimulate debate on a series of topics within the Academy’s theme of “Survival and the Citizen”. The micro dialogues draw upon a format where two leading experts in the field set out an initial position on a topic of interest and, over a short period of around two weeks, respond to the views expressed by each other. The exchange is moderated by a member of the EPLPS Committee. Future topics to be covered will include the survival of the Irish language and the idea of citizenship in the digital world.

**Professor John Morison, MRIA**
Chair
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Foreword

People everywhere hope for a peaceful, pain-free death. The reality is often very different and advances in medical technology have led to the increasing medicalisation of the dying process. Many people spend their last days surrounded by the invasiveness of machines, tubing and noise. This inevitably raises ethical and legal issues concerning the dignity and autonomy of the patient, including the question of whether physicians should accede to a patient’s request to facilitate her/his own death, or end the life of a patient at her/his own request.

The right to die with dignity was the focus of discussions at two meetings of the Oireachtas Joint Committee on Justice and Equality on 22 and 29 November 2017. Some jurisdictions such as Holland, Belgium, Luxembourg, as well as some states in U.S.A, and Canada, have enacted so-called ‘right to die’ legislation that makes it legally permissible for physicians to assist patients to end their own lives or to have their lives ended by a physician. Should Ireland enact such legislation?

Professor Mary Donnelly of the Faculty of Law, University College Cork, and Professor David Albert Jones, Director of the Anscombe Bioethics Centre, Oxford, explore the issues pertaining to death with dignity and the right to die for this micro-dialogue in the Survival and the Citizen project. Each of them makes an opening statement on the topic, followed by responses to each other, arguing the case for and against the legalisation of assisted dying by medical means. Taken as a whole, this micro-dialogue challenges readers to reflect on the issues related to the question of whether legislation permitting medically assisted death should be enacted in Ireland.

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End of life care and the right to assistance in dying

Mary Donnelly

The way we die is a fundamental part of our life story, even if, most of the time, we prefer not to think too much about it. Yet there comes a time when, as Terry Pratchett said, ‘we must all shake hands with death’. When this happens, most of us privilege an ideal of dignity, comfort and the presence of loved ones. Appropriate palliative care (physical, psychological, emotional and spiritual) plays an essential role in delivering this ideal and such care should be at the moral heart of any healthcare system. Yet sometimes, for some people, whether because of pain, fear, feelings of indignity, a desire for peace or a need for control, such care cannot suffice. Gloria Taylor, who successfully challenged the legal prohibition on assisted suicide in Canada, explained to the court, ‘I live in apprehension that my death will be slow, difficult, unpleasant, painful, undignified, and inconsistent with the values and principles I have tried to live by .... What I fear is a death that negates, as opposed to concludes, my life’. Ms Taylor, who was living with Lou Gehrig’s Disease, sought a ‘right to die peacefully, at the time of my own choosing, in the embrace of my family and friends’.

The question of whether Ireland should introduce legislation to allow a right to assistance in dying is both difficult and important. It speaks to, and reflects, the values and beliefs that underpin our society. My argument in favour of such a right is based on three principles: autonomy, dignity, and beneficence (or easing suffering). These principles justify the right but they also set necessary perimeters around any attempt to give it legal effect.

The principle of autonomy underpins all liberal political traditions and is legally protected by the Constitution and the European Convention on Human Rights. Autonomy is sometimes (mis)represented as no more than ‘mere, sheer choice’ (as caricatured by the philosopher Onora O’Neill). However, to provide principled support for a right to assistance in dying, a stronger (or ‘thicker’) conception of autonomy is required. On this understanding,
respect for autonomy enables each person to pursue the projects, relationships and goals that are important to him or her, thus allowing for the creation of his or her best moral self. If we are prepared to recognize that this matters during a person’s life, it is difficult to see why it should lose significance at the end of that life.

The second underpinning principle is dignity. Human dignity is at the core of the Constitution and of international and European human rights instruments. Like autonomy, dignity is multifaceted. It is not just concerned with objective (or outside) categorisation and how a person is treated (although this is of course an important aspect of a right to dignity). However, the principle of dignity also encompasses a subjective understanding of each person’s own view of the conditions of his or her (continuing) life. In this way, respect for dignity looks beyond a person’s projects and goals to the minutiae of their day-to-day living. Marie Fleming, the Irish woman who unsuccessfully petitioned the Supreme Court to be allowed ‘assistance in having a peaceful and dignified death in the arms of her partner’, described her life to the court. She was unable to control an electric wheelchair; had no bladder control; required help to eat and drink and to be washed, dressed and repositioned; she suffered frequent choking episodes which were frightening, distressing and exhausting; and she endured severe, at times unbearable, pain. She was clear that these myriad problems left her feeling ‘totally undignified’. While Ms Fleming described her subjective feeling, it is a feeling that many (possible most) of us can recognise and empathise with, even if we cannot know how we might feel in the circumstances described. In this way, we can recognise and in a sense authenticate Ms Fleming’s subjective feeling of lack of dignity without in any way suggesting that, she as a person, lacked dignity or worth.

The third principle is that of beneficence or the easing of suffering. This has been at the ethical core of healthcare provision since at least the time of Hippocrates. However, until the development of analgesics, providers of healthcare were limited in how much ease they could bring. Instead, it was death, often through infection, which brought a natural end to suffering. So it is that Keats, who died from tuberculosis at the age of 25, wrote of being ‘half in love with easeful Death’. However, technology has changed how we live and die. We live longer with more complex health conditions; antibiotic treatments are available for most infections; we can provide assisted ventilation as well as tube feeding and hydration. This progress has saved countless lives but it also delays, sometimes for long periods, the prospect of a natural end to suffering. Recognising this, most legal systems allow a person to refuse treatment even if the effect is to bring about the person’s death. However, the quality of such a death may be very far from the person’s ideal. Refusal of ventilation can result in breathlessness and distress; withdrawal of tube feeding/hydration results in a slow death from starvation/dehydration. Analgesics may ease the symptoms but they are less effective in addressing feelings of fear or the existential distress that a person may feel at ending their life in this way. It is difficult to justify visiting this needless suffering on a person who has decided to die when the means to ease this suffering are available.

The Japanese novelist Haruki Murakami writes that, ‘Death is not the opposite of life, but a part of it’. People at the end of their lives should be afforded the space to die in a way which is best for them. Taken together, the three principles described here provide support for a right to assistance in dying and a robust basis for legislation to give effect to this right.
Maintaining the bright line against medical homicide

David Albert Jones

Why have most countries continued to reject proposals to legalise either the intentional administration of a lethal injection to patients at their request (voluntary euthanasia) or the prescription of lethal drugs to enable patients to kill themselves (physician-assisted suicide)?

Such proposals are opposed by most representative bodies of the medical profession including the World Medical Association, and rightly so. The goals of medicine are to restore health, improve physical and mental function, and palliate symptoms (even if palliation were to shorten life as a foreseen though unintended side effect: palliative medicine seeks to kill the pain, not the patient). Many questions in medicine are matters of degree but there are also some bright lines that are central to medical ethics, not least the prohibition of voluntary euthanasia and physician-assisted suicide. Such practices not only contradict key goals of medicine, they also breach a fundamental principle of the common law. The prohibition on intentionally killing patients has been described as the ‘cornerstone of law and of social relationships’ that ‘protects each one of us impartially, embodying the belief that all are equal’.2

The disability rights movement is another source of opposition to voluntary euthanasia and physician-assisted suicide.3 4 Although ‘right-to-die’ campaigners often claim that their proposals would be limited to patients who are ‘terminally ill’ and who are suffering intolerable pain, the data from Oregon (which provides physician-assisted suicide for those expected to die within six months) consistently show that the three main reasons for accessing physician-assisted suicide are loss of autonomy (91%), loss of enjoyable activities (90%), and loss of dignity (76%): only a minority (26%) cite concerns about inadequate pain control.5 An increasingly common reason (given by over half in 2017) is fear of becoming a burden to family, friends or caregivers. Predominantly, then, these are concerns not
about dying in pain but about living with dependence or disability.

In Belgium, the proportion of patients seeking voluntary euthanasia who have diseases other than cancer is increasing (from 17.5% in 2003 to 32.3% in 2015). More and more euthanasia deaths are of people with non-terminal illnesses (from 20 cases in 2003 to 299 in 2015).\(^6\)\(^7\) These include people who seek voluntary euthanasia/physician-assisted suicide for psychiatric conditions.\(^8\) Also, in 2016, the Dutch government announced proposals to extend its law allowing voluntary euthanasia/physician-assisted suicide so as to permit elderly people who feel their life is ‘completed’ to access assisted suicide. All this reinforces the discriminatory view that life with disability or dependence is a life without dignity such that death is a reasonable option.

In the case of young and physically healthy individuals, society makes great efforts to prevent suicide. These efforts express and sustain social solidarity with those whose distress may be very real, but who can be helped with positive support.\(^9\) Such support is needed no less by people who are elderly and isolated or are severely ill. (I have personally known someone with disability who took his own life and can attest that this was a tragedy that affected many, though, in his distress, he was unable to foresee this.) In some jurisdictions the law mercifully makes some allowance for the emotional pressures which might lead a relative or a friend reluctantly to assist in someone’s suicide.\(^10\) However, to legalise assisted suicide would be to send out a very dangerous signal and would be largely to abandon efforts in suicide prevention for certain categories of people, especially those with disabilities.

Those few jurisdictions that have legalised voluntary euthanasia and/or physician-assisted suicide have some form of ex post facto ‘review’ procedure which, it is claimed, brings previously covert practices ‘into the open’. However, evidence from the Netherlands and Belgium shows that a significant proportion of cases (20% and 50% respectively)\(^11\)\(^12\) are not reported. Furthermore, even when, occasionally, breaches of the law do come to light, prosecution is a rarity. Laws that rely on self-reporting, after the fact, by the very physicians involved, are intrinsically ineffective.

There is also good evidence from Belgium that the legalisation of voluntary euthanasia has adversely affected other areas of medicine. For example, sedation is sometimes used with intent to end life, as a less overt form of euthanasia.\(^13\) Such cases of disguised euthanasia escape even the pro forma review procedure. Furthermore, in 70% of cases sedation at the end of life occurs without the consent of the patient.\(^14\) If these deaths are acknowledged, cases of life-ending without request have increased significantly since voluntary euthanasia was legalised in 2002.\(^15\) The actual level of life-ending without request in Belgium is thus much higher than—perhaps double—the ‘strikingly high’ figure that so alarmed the Irish High Court in its careful examination of the experience of Belgium and the Netherlands in 2013.\(^16\)

Another disturbing illustration of the porous distinction between voluntary euthanasia and life-ending without request (also termed ‘non-voluntary euthanasia’) comes from the Netherlands. In 1984 the Dutch courts declared voluntary euthanasia lawful. In 1996 they declared non-voluntary euthanasia lawful, in the case of disabled infants.
Both the expansion from voluntary to non-voluntary euthanasia and the expansion of voluntary euthanasia and physician-assisted suicide to those not ‘terminally ill’ were foreseen sixty years ago. These trends are each driven by the underlying logic behind voluntary euthanasia and physician-assisted suicide. If their rationale is the duty to relieve suffering, is it not cruel to withhold relief from those unable to request it? If a doctor could decide that death would benefit a patient, why could the doctor not make the same judgment about an incompetent patient? On the other hand, if it is only the patient who could assess the extent of his or her own suffering then, logically, voluntary euthanasia and physician-assisted suicide cannot be confined to categories like ‘terminally ill’.

The evidence shows that once the ethical bright line against intentional killing and assisting suicide is abandoned, remaining limitations are arbitrary and will inevitably be eroded away, sooner or later.

Notes

1 World Medical Association ‘Resolution on Euthanasia’. Adopted by the 53rd WMA General Assembly, Washington, DC, USA, October 2002 and reaffirmed with minor revision by the 194th WMA Council Session, Bali, Indonesia, April 2013 https://www.wma.net/policies-post/wma-resolution-on-euthanasia/.
13 Fleming -v- Ireland & Ors [2013] IEHC 2, paras, 102, 104.
Mary Donnelly

David and I agree on the significance of human dignity and that a life which involves a high degree of dependence should not be regarded as a life without dignity. We agree too that States have an obligation to protect people whose life choices are restricted, whether because of disability, age, infirmity or other forms of vulnerability, and that this should extend to meaningful protection from overt (and covert) pressure to end their lives. However, we disagree in two respects. First, I dispute that there is an ‘ethical bright line against intentional killing’. Rather, I suggest that the line is decidedly blurred. Secondly, we have different views of what the law can deliver, in ensuing the avoidance of arbitrary conclusions and preventing the erosion of human rights.

The ‘ethical bright line against intentional killing’ draws on the principle of double effect, most famously propounded by Saint Thomas Aquinas, to provide a justification for killing in self-defence. This principle proceeds from the argument that it is permissible to cause harm as a side (or ‘double’) effect of bringing about a good result, even though it would not be permissible intentionally to cause such a harm. This is increasingly difficult to defend in the situations where modern technology is employed in end-of-life care. The withdrawal of assisted nutrition and hydration from a person in a persistent vegetative, or minimally conscious, state is, by any standards, an action intended to cause the person’s death. Yet, since the decision of the Supreme Court in In re a Ward of Court (1995), this is not just legally acceptable but constitutionally approved under Irish law (and indeed in most legal systems).

As more jurisdictions adopt a variety of measures to allow for assistance in dying, there is now a growing body of literature to draw on in assessing the law’s capacity to deliver a sufficiently robust protective framework. Inevitably, the ‘objectivity’ of data presented will be challenged, based on the normative standpoint of the observer. One of the most rigorous attempts at an objective evaluation is that of Justice Lynn Smith in the Supreme Court of British Columbia in Carter v
Canada (2012). Reviewing data and direct testimony from expert witnesses regarding the position in Oregon, the Netherlands and Belgium, Justice Smith concluded that it was possible for a State ‘to design a system that both permits some individuals to access physician-assisted death and socially protects vulnerable individuals and groups’. Endorsing Justice Smith’s position, the Supreme Court of Canada concluded that ‘the risks associated with physician-assisted death can be limited through a carefully designed and monitored system of safeguards’. Canadian legislation, with tightly circumscribed safeguards, came into effect in June 2016. Irish legislators could (and should) consider adopting a similar position, legislating for assistance in dying on the basis of respect for the principles of autonomy, dignity and the easing of suffering. As argued, these provide both justification for the right and perimeters for the operation of any system to give it effect.
David Albert Jones

‘Yes’ to assisting the dying person, ‘No’ to assisting their suicide

Professor Donnelly is right to say that respect for a person’s autonomy, dignity and wellbeing (including their freedom from pain) applies not least to the way someone dies. Those who are dying are living and have the right to medical and social assistance during this final phase of life. However, the euphemistic language of ‘assisted dying’ obscures the element that makes the issue controversial: whether assisting a dying person should include assisting their suicide. The question at issue is precisely: should Ireland maintain ‘the legal prohibition against assisting suicide’?

Respect for autonomy implies a preference for liberty except where this would do harm to others. But if ‘no man is an island’ then the death of anyone diminishes us all and more so when it is caused deliberately. Death is inevitable but death by suicide is not inevitable. Once a principled opposition to assisting suicide is abandoned then broad concepts such as autonomy and beneficence offer no credible limits to the practice and directly threaten the dignity and the lives of people living with disability and chronic illness. Perhaps someone who seeks ‘assisted dying’ might otherwise have died by (unassisted) suicide, but overall the legalisation of assisted suicide demonstrably increases the number of people who die by their own hand.

Prosecution policy on assisting suicide for England and Wales was first articulated in relation to Daniel James, a young man who, as a result of injury, was paralysed from the chest down. He took his own life at a clinic in Switzerland at the age of 23. In common with many who take their own lives, ‘he could not envisage a worthwhile future for himself’. His parents helped reluctantly. They were spared prosecution but his suicide ‘caused them profound distress’.

In contrast, while the disability activist Alison Davis had wanted to die for years, several times attempting suicide, her ‘greatest piece of good fortune was that I had friends who did not share my view that my life had no value’. They helped her to ‘give life another try’ though it was another five years before she was able to say, ‘Do you know, I think I want to live.’
The bioethicist Nicholas Tonti-Filippini, who lived with chronic illness for many years, warned that ‘the fear of being a burden is a major risk to the survival of those who are chronically ill’. Without the protection of the legal prohibition on assisted suicide, the lives of disabled people are made disturbingly ‘contingent upon maintaining a desire to continue in the face of being classified as a burden to others’. Over half of assisted suicides in Oregon cite fear of becoming a burden as a reason for seeking death.

The prohibition of assisting suicide signals a determination to value and protect all citizens irrespective of their mental or physical health. Individual cases of reluctant assistance should be treated with discretion but the prohibition is needed to prevent the encouragement, social sanctioning or institutionalisation of suicide for certain categories of people.

Notes
2 Donne, J. 1623 Devotions upon Emergent Occasions, Meditation XVI.
6 Davis, A. 2013 Why euthanasia/assisted suicide would have robbed me of the best years of my life, Catholic Medical Quarterly 63(2). http://www.cmq.org.uk/CMQ/2013/May/Editorial-Euthanasia-Alison-Davis.html
Mary Donnelly

Like David, I think that terminology is significant. I adopt the term ‘assistance in dying/assisted dying’ because this is the right which I have been defending. The right to assistance in dying (i.e. where a person has a determinate life-limiting condition) is distinct from the right to assistance in suicide (i.e. where a person chooses to die but without necessarily having a life-limiting condition). This more limited right is recognised by legislation in Canada (where the person’s death must be ‘reasonably foreseeable’) and Oregon (where the person must be diagnosed with a ‘terminal illness’ that will lead to death within six months) and can be contrasted with the more expansive right recognised in Belgium and the Netherlands.

I would argue that this boundary (between assisted dying and assisted suicide) is important for more than terminological reasons. It also raises the issue of proportionality which, I believe, is at the core of this debate between David and I. As I understand, David asserts the importance of a principles-based, bright-line around the provision of assistance (whether in respect of assisted dying or assisted suicide), although he accepts that individual cases of reluctant assistance should be treated with discretion. I assert both a principles-based requirement for a proportionate approach to assisted dying and the possibility that such a response can be delivered.

A proportionate response recognises that rights, such as autonomy or dignity, are not absolute and that, as David quotes from John Donne, ‘no man is an island’. However, it also recognises that the more profound the impact of failure to respect a person’s rights, the greater the justification required for interference with these rights. The rights of autonomy and dignity are at the core of what makes us human and these rights are engaged in a fundamental way in the context of assistance in dying. Denying a person control over the manner of his or her death or requiring a person to face his or her death in conditions which he or she experiences as undignified constitutes a significant violation of that person’s fundamental rights. For such a violation to be justified in the interest of protecting others from harm, it must be clearly established that the violation is necessary in order to prevent certain
(or at least highly probable) harm. This does not diminish in any way the requirement to protect vulnerable people who may feel pressured to end their lives. However, it shifts the onus for protection to encompass questions of appropriate limits and the provision of positive alternatives. This is why a right to assistance in dying is best delivered through legislation, which is best able to take account of the competing interests and deliver a proportionate solution. Developing an appropriate solution is not easy; however, it is possible if it is based on the fundamental principles of autonomy, dignity, easing of suffering as well as the protection of people who are vulnerable.
David Albert Jones

**Assisting or encouraging the suicide of those who feel their life lacks dignity**

There is a medical-ethical (and a legal) bright line against intentional killing. That is precisely why lethal injections for patients on request (voluntary active euthanasia) and prescribing lethal drugs to help patients kill themselves (physician-assisted suicide) have been contrary to medical ethics since Hippocrates and are illegal in the great majority of countries. Even those few states that have legalised them define them as involving an intention to hasten death or an intention to help patients to end their own lives.

Mary’s three reasons for crossing that bright line are: easing suffering, autonomy and dignity. However, if easing suffering justifies voluntary euthanasia, why not provide lethal injections for non-autonomous patients, like those with dementia, whose suffering may be at least as great? We should not, then, be surprised by the ‘strikingly high’ level of assisted deaths without explicit request in the Netherlands and Belgium, noted by the Irish High Court in Fleming. Crossing the bright line logically leads to a blurring of the line between the voluntary and non-voluntary ending of life. The same line could, indeed, be crossed by endorsing the withdrawal of treatment or of tube-feeding with the intention to hasten death. However, the withdrawal of treatment or tube-feeding, as in the Ward of Court case, need not involve this intention. Cases such as this provide no precedent for the legalisation of voluntary active euthanasia or of physician-assisted suicide.

If an autonomous request is required (however arbitrarily), how can we reasonably limit euthanasia to those dying of a physical illness? No European state that permits euthanasia or assisted suicide requires even a physical, let alone a terminal, illness. In Oregon, there is evidence of undiagnosed depression in up to one in three cases. Crossing the bright line thus leads to a blurring of the line between ‘assisted dying’ and facilitating suicide of people with psychiatric illnesses, which is permitted overtly in both the Netherlands and Belgium.
Most parliaments, courts and expert committees that have considered the arguments and evidence have rejected calls for legalisation. The evaluation of the evidence by Justice Smith in *Carter*, far from being ‘one of the most rigorous attempts at an objective evaluation’ was exposed as unreliable in *Fleming*. The Irish High Court judged her evaluation ‘altogether too sanguine’. Moreover, Justice Smith simply evaded the argument that it is the inherent logic of euthanasia and assisted suicide that drives their expansion once legalised. (Nor is the Canadian legislation ‘tightly circumscribed’, as Mary claims. When, for example, is a patient’s death ‘reasonably foreseeable’?)

Mary’s third principle is human dignity. I wholly concur that ‘a life which involves a high degree of dependence should not be regarded as a life without dignity’. How, then, can someone’s ‘subjective feeling of lack of dignity’ be a good reason to encourage or assist that person’s suicide? Of all the arguments for legalisation, it is this that poses the greatest threat to the values that underpin society, and to all those who are disabled, dependent or disadvantaged.

Notes
2 Fleming -v- Ireland & Ors [2013] IEHC 2, para 104.
6 Bill c-14 section 241.2(2)(d)
Mary Donnelly

Mary Donnelly is a Professor of Law at University College Cork. Her work in healthcare law and ethics focuses on the interplay between individual autonomy and State intervention/protection and on the intersections between legal and medical systems and the implications of law for medical practice. Her books include Consent: Bridging the Gap Between Doctor and Patient (Cork: Cork University Press, 2002); Healthcare Decision-Making and the Law: Autonomy, Capacity and the Limits of Liberalism (Cambridge: Cambridge University Press, 2010) and she is co-author of End-of-Life Care: Ethics and Law (Cork University Press, 2011) and co-editor of Ethical and Legal Debates in Irish Healthcare: Confronting Complexities (Manchester University Press, 2016). She has collaborated on projects funded by the European Commission, the Irish Research Council for the Humanities and Social Sciences, the National Children’s Office and the Irish Hospice Foundation and has acted as consultant for public agencies and legal firms. She was a member of the Expert Group to review the Mental Health Act 2001, which reported in 2015. She is a member of the Health Service Executive National Consent Advisory Group/Assisted Decision Making Steering Group; the Ministerial Working Group to develop a Code of Practice on Advance Healthcare Directives; and, the Legislation Committee of the Mental Health Commission and she is Chair of the National Disability Authority Expert Technical Group to develop Codes of Practice for the Assisted Decision-Making (Capacity) Act 2015.
David Albert Jones

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