Right to die?

Medicine changes—not just in the accumulation of scientific knowledge but in the responsibility the profession has to acknowledge the expectations of society and adjust our attitudes and behaviour accordingly. Just as rigid opposition to all change is wrong-headed, so too is uncritical bending in the breeze of public opinion on matters of high ethical and clinical complexity. One such area where society is said to be changing and where, in turn, the medical profession may perceive a pressure to change, is that of assisted dying and euthanasia. Hardly a week goes by—at least in the British press—without the subject being aired. Reform is called for, of our laws relating to euthanasia, and of the position of medicine and of the medical ‘establishment’ (often seen as a pejorative phrase in itself). The progressive media argue with a single voice in favour of change. Commonly, such press coverage concentrates on one individual, of his or her story of suffering, desire to die or be killed, and consequent battle with ‘the system’. One such person, a sufferer with multiple sclerosis, is Ms Debbie Purdy.

In 2008, Ms Purdy, anxious about the consequences of asking her husband to help her travel abroad for legal euthanasia, should she so choose in the future, requested the Director of Public Prosecutions for the Crown Prosecution Service of England and Wales to set out the circumstances in which her husband could be prosecuted. The Director of Public Prosecutions refused her request, a decision ratified in the Court of Appeal, but then turned over in her further appeal to the House of Lords. Mr Keir Starmer QC was therefore required ‘to prepare an offence-specific policy identifying the facts and circumstances which he would take into account when deciding, in cases such as Ms Purdy’s, whether or not to prosecute’. The judgment emphasized that the Suicide Act of 1961 decriminalized suicide but explicitly did not decriminalize assisting suicide; therefore, under extant law, ‘a person who was present at the suicide of another and who assisted or encouraged the suicide, was guilty of murder as a principal in the second degree’. Additionally, ‘as a general rule, English criminal law does not extend to acts committed outside the jurisdiction’—but, ‘since the time of Henry VIII, murder [including manslaughter] has been recognised as an exception to this rule’, and so ‘if a British subject accompanies a relative, who is also a British subject, to Switzerland and assists in Switzerland the relative to commit suicide…that person will under English law commit the crime of murder and will be subject to the jurisdiction of the courts of England and Wales in relation to that offence’. Furthermore, it was pointed out that in order to protect ‘the vulnerable or the easily led’, the principle must apply that an act commenced in the UK falls within the compass of English law.

Consequently, a Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide was issued for consultation by the Director of Public Prosecutions in September 2009, amended, and the final policy put into effect from 25 February 2010. The Guidance points out that when an offence may have been committed, ‘it has never been the rule that a prosecution will automatically follow’ but ‘it remains murder or manslaughter to cause the death of someone who wishes to commit suicide but is unable to do so’; and ‘even genuine and clear expressions of intent from someone who wishes to end his or her life’ do not legally permit such acts of assistance. The comments relating to whether prosecution would be ‘in the public interest’ form the core of the document. Favouring prosecution would be ‘in the public interest’ form the core of the document. Favouring prosecution would be circumstances where capacity and intention are in doubt; coercion and pressure to act were used; the person could have taken their own life without assistance; and where evidence that assisting with suicide was motivated other than by compassion. There might also be a tendency towards prosecution if ‘the suspect was acting in his or her capacity as a medical doctor, nurse, other healthcare professional, a professional carer (whether for payment or not), or as a person
in authority, such as a prison officer and the victim was in his or her care. Factors against prosecution include clear intent by the patient; acting entirely through compassion; evidence that the suspect played a minor role in assisting the patient to die, argued against assisted suicide or only acquiesced reluctantly; and that any mitigating circumstances were operative close to the time when assistance to die was provided.

Unsurprisingly, Ms Purdy’s story, and then the publication of these guidelines, gained the subject yet further media coverage. Outside the UK, several countries, or states, have already embraced change, and the reality of such change in Holland, Belgium and Oregon fuels the fires of reformists elsewhere. So is the momentum for such change now irresistible; and indeed, should it be resisted if that is ‘the will of the people’?

There is certainly no doubt where medical orthodoxy lies in relation to assisted dying or euthanasia. One could start, as virtually all Western medical ethics must start, with Hippocrates: ‘I will give no deadly medicine to anyone if asked nor suggest such counsel’ [which pre-Christian position might also immediately give cause to doubt the common current assertion that ‘most opponents of assisted dying are in a minority driven by faith’ (Lord Joffe, 2009)]. Scrolling rapidly forward to the 20th century, the Declaration of Geneva, Article 2 of the European Convention (‘everyone’s right to life shall be protected by law; no one shall be deprived of life intentionally’); the World Medical Association (‘assisted suicide, like euthanasia, is unethical and must be condemned by the medical profession’); and the American Medical Association (‘physician assisted suicide is fundamentally inconsistent with the physician’s role’) — all leave little room for confusion, individually, let alone collectively.

It is worth asking why so strong a tide of opinion has formed in the first decade of the 21st century AD, contrary to so clear and consistent a position held for the preceding 2.4 millennia. Arguably, the opposite might have seemed more likely. At no previous time has medicine been better able to deal with disease, either at a mechanistic or a symptomatic level. Surely the ‘need’ now for assisted suicide is far smaller than with the practice of medicine in (say) the 16th century and before, when nothing could be done for almost anything? The popularity of this cause does not seem directly related to increased deficiencies in the therapeutic efficacy of medical practice.

If not the success or otherwise of medicine, what are the arguments in favour of or against ‘helping’ patients to die? Perhaps (to start with the negative) one of the most telling and important counter-arguments is semantic. ‘Helping patients to die’, along with ‘mercy killing’ and ‘euthanasia’ itself are euphemisms. Legally, and far more importantly morally, these all describe some form of deliberate termination of human life, something (outside the theatre of war or judicial killing) that has never previously been considered licit, in any form, direct or indirect, active or passive and perpetrated by anyone, doctor or otherwise.

More positively, what arguments are now offered in favour of changing the status quo? Principal amongst these are the questions of autonomy and the prevention of suffering and of indignity. Autonomy assumes the often articulated ‘right to die’. Patient choice is paramount. It is for the patient alone to decide whether his or her life is worthwhile, and not for others to override this judgement. Respect for human dignity licenses the right to make autonomous decisions. And if a patient is suffering, is terminally ill, and has made clear his or her wish is to die, is it not merciful to acquiesce with and enable this to happen?

Despite the most articulate efforts of affected individuals and the clear common origin of their motivation in kindness and a wish to avert or avoid suffering in others, the available evidence indicates that the majority of doctors remain consistently opposed to changing the law on euthanasia and assisted suicide. Evidently, many view the arguments based on autonomy, dignity and suffering, as unconvincing.

There are a number of reasons for this. Regarding suffering, to include the deliberate and intentional killing of your patient on the list of things a doctor might reasonably do to circumvent suffering seems extraordinary. The point is not merely that this would both constitute and convey defeat and despair, and demean palliative care. It is, rather, an inappropriate response, and a fundamental distortion and betrayal of the relationship of one human to another. It has never been proposed that people around the globe suffering from the appalling consequences of poverty, or of hunger, or of thirst, could or should be relieved of their undoubted suffering through this response to the problem. Nor in the case of disease should it be an acceptable final solution.

At one level, the question of dignity is identical to that of suffering; a compassionate response to a perceived lack of dignity is surely not to dispatch the patient. But there is also a more fundamental point, relating to our understanding of the term ‘dignity’. There is an autobiographical sense of the word, closely related to personal pride, which is severely compromised by what may befall us during illness. Urinary and faecal incontinence are (amongst continent patients) the most feared examples: most of us would assume a dramatic ‘loss of dignity’, of self-value and self-worth. But for a doctor to do nothing more than collude with the incontinent patient’s reactive self-perception, and agree—if you think this renders you fit for nothing other than euthanasia, then who am I to disagree?—is surely, again, a monstrous betrayal. That function of the sphincters should determine while paying grand testament to the corrupting power of the first cranial nerve, must in the end be preposterous. The proper practice of medicine has always, and must always, involve the doctor or nurse remaining blindly indifferent to the accidents of the illness. The level of respect due to a sick patient, the perception of his or her personal dignity, remain absolutely equal regardless of whether the particular disease happens to have compromised bladder or bowel or, for that matter, cognitive function.

There is then another more profound usage of the term ‘dignity’ that has nothing to do with personal pride and emerges simply from a shared humanity. All human beings have inherent worth and dignity. Part of the basis of society and law, and of the concept of human rights, is that a certain minimal respect is due to all human beings purely by virtue of their being human. This safeguard protects the individual from abuse, from torture and from being disposed of if in some sense judged inconvenient. Or rather, since the safeguard fails, the acceptance of this form of dignity,
and its direct consequence, the inviolability of human life, at least guarantees that such abuses are, intrinsically, wrong. ‘Right’ and ‘wrong’ in this context are not subjective or relative terms, but absolute and constant. The dignity of being human requires this to be absolute and never conditional. The moment the law, or society, accepts that the rule of fundamental respect can be waived in certain individuals, whether of their choice or otherwise, the principle is lost. Mere anarchy is loosed.

But what of autonomy? To have others electing to override the inviolability of an individual’s life is obviously a bad thing. But if, as proposed, the principle of autonomy is overridingly important, then it is truly my choice, and I am competent, can I not have my inviolability waived?

Here, advocates assert that we all have a ‘right to die’, but it is hard to identify in the history of ideas and in the writings of the great philosophical, political and social thinkers of recent or more ancient history any basis for such a right. How can a right to something that inevitably happens to all of us suddenly arise? What seems to be meant is a right to die when and how we choose, and it is not at all clear that this is a reasonable or rationally defensible proposition. Certainly, the point illustrates how suicide and euthanasia are inextricably linked—it must surely be impossible to believe in such a right without overtly defending suicide.

But to many, the most important reason why belief in such a right is wrong-headed lies in a consideration of society. For both as a society, and for the sake of society, we in fact hold that self-determination, and patient choice, are not moral absolutes. We maintain legal and/or moral prohibitions, for example against, incest between consenting adults, competent adults abusing seriously toxic drugs, bizarre practices of consenting individuals gaining gratification by mutilating, killing and eating one another, and against the rather more prosaic ‘choice’ of not wearing a seat belt.

In every instance, there is one constant principle: that in attempting to waive our personal inviolability in some way, in choosing to abuse ourselves or be abused, the harm is not just to ourselves but, far more importantly, to others around us, to society as a whole. The impact of our choices and actions on society, on its health, on its vulnerable members, has always overridden autonomy in such instances. Paradoxically, given the broad support for assisted dying from the progressive media, perhaps only a cod-Thatcherite philosophy of autonomy—the individual is all, and there is ‘no such thing as society’—could justify the acceptability of any form of personal choice that tends towards self-destruction: ‘any effect this might have on others is not my problem’.

Moreover, to consider not merely what might be flawed in pro-euthanasia arguments, but some of the more positive reasons for opposing the practice, there is a broader need to move the focus away from the suffering individual and towards other people, vulnerable or otherwise.

Legalizing any form of euthanasia or assisted suicide sends out a powerful and clear message that, in terms of the inviolability of human life, we no longer have a single standard; some lives may be ranked differently to others. If assisted suicide becomes a legal option, part of the spectrum of available health-care choices, then who could doubt that the elderly, the sick, the disabled and others would at times perceive real or imagined pressure to take this option—for the sake of families, carers, offspring, medical over-spend or whatever incentives and pressures might fret the affected individual. There are unsettling data reporting that the legalization of assisted suicide is supported by <35% of frail elderly patients, but by >55% of their relatives. Patients more likely to oppose assisted suicide represent a particularly vulnerable element of society—the elderly, women, ethnic minorities and the poor, uneducated and demented (Koenig et al., 1996).

Then comes the ‘slippery slope’ argument—what might be voluntary assisted suicide now, will become someone else deciding my fate in the future. There is of course a logical, reasoned basis for this suspicion—if we accept a principle that some individuals are ‘better off’ dead, then is it reasonable to deprive people of this ‘benefit’ simply because they are incapable of being asked to be killed? And there is also evidence. In 1991, the Dutch Ministry of Justice commissioned the Remmelink Report (Remmelink, 1991), a statistical analysis of all 129,000 deaths in The Netherlands during the preceding year. It found there to have been over 3000 deaths from euthanasia, and just over 1000 where euthanasia appeared not voluntary (‘without explicit request’). Five years later, there were a total of 4500 deaths through euthanasia or assisted suicide, of which 900 were non-voluntary, with no explicit request (Jochenssen and Keown, 1999).

But perhaps the most transparent illustration of the ‘slippery slope’ in practice—the extension of voluntary euthanasia to voluntary—appeared in 2005 in the New England Journal of Medicine (Verhagen and Sauer, 2005). This report described the ‘Groningen Protocol’—an approach to euthanasia in infants, and how it applied to the 22 cases of euthanasia in newborns reported to district attorneys’ offices in The Netherlands from 1998–2005. Indeed, the authors point out that ‘each year there are 15–20 cases of euthanasia in newborn infants’, but evidently most are not reported. None of the doctors involved has been charged, though euthanasia for infants remains illegal in The Netherlands. Contributing factors such as ‘predicted lack of self-sufficiency’ or ‘predicted inability to communicate’ were considered reasonable grounds for euthanasia, and the authors appeared to see no awful irony in pointing out that ‘after the decision has been made and the child has died, an outside legal body should determine whether the decision was justified’.

Compared with this, considering the impact of legalizing assisted suicide on the practice of medicine is relatively parochial, and may appear merely protective, but how medicine would be undermined from the patient’s perspective is important. The practice of medicine surely depends on patients being able to trust doctors, and doctors cannot inspire that trust if patients know that doctors will ask themselves whether assisted suicide might be the appropriate option for this particular individual, or whether he or she is worth treating more conventionally. Of course, in addition, whole branches of medicine, such as palliative care, would be—as mentioned above—existentially threatened by such legalization.

To return to where we began, this consideration of the arguments for and against assisted dying may begin to illuminate why change in favour of legalization appears to be gaining traction. The three main arguments for the practice (notwithstanding the reasons to question each)—relieving suffering, protecting dignity
and respecting autonomy—could all be said to be centred on the affected individual. In contrast, the main arguments against all emerge from a consideration of society, its individuals and principles, other than or apart from those exclusive to the sufferer.

This shift of focus is not to say (as assisted dying proponents often appear to fear) that desperate patients are to be abandoned and condemned to their suffering—far from it. Paradoxically, never in history have there been fewer patients whom medicine is unable to help, either symptomatically or more fundamentally. Further advances in palliative care, a specialty virtually invented in the UK, will continue to shrink this number. Also, two important aspects of (particularly) end-of-life medicine still apply. First is the principle of consent; it has always been and must remain perfectly valid for competent patients to refuse medicines or other interventions if they may reasonably be deemed futile (unlikely to restore the patient to his or her former health) or excessively burdensome; and there is no duty of care for health professionals to provide such treatments. Second is the principle of ‘double effect’. There need be nothing illicit or immoral in using treatments to relieve symptoms, knowing that death may result as an unintended but predictable consequence (opiates for pain relief in the terminally ill would be the common example). ‘Intention is all.’ A primary intention to relieve pain (for example), knowing that a secondary consequence might be accelerated death, is consistent with good medical practice. Conversely, using any drug with the primary intention of causing death is not.

In weighing the pros and cons of this difficult area, the fact that many of the core arguments in support of euthanasia are in essence centred on the individual, while most of the opposing arguments are more general and societal, may help explain why support for changing the law seems to have grown in recent years. Human interest stories gain ever more prominence in the media; harrowing personal accounts rightly distress and move us all, while those who argue that we should shift our focus away from these individual stories to more abstract principles appear cold and callous. Of the two polar approaches to dealing with such complex issues, it is far easier and feels more human (and more humane) to be guided by direct human sympathy than by a dispassionate analysis of the broader implications and consequences. It has always been so, but the democratization of medicine in society, with a dramatic decline of patrician attitudes and of hierarchical paternalism, has surely and substantially altered the balance of influence of the two approaches.

Debbie Purdy has written her life story. Some is pure autobiography; with an uncompromising but remarkably unself-pitying account of the development and course of primary progressive multiple sclerosis. No small portion is of course devoted to end of life questions and to her arguments concerning the ‘right to die’ (she was a Member of the Board of the Voluntary Euthanasia Society), and of course her request to, legal battle with, and ultimately triumph over the Director of Public Prosecutions, forcing Mr Starmer to publish guidelines concerning the possible prosecution of accomplices to assisted suicide. Ms Purdy is still kicking and fighting, of course, but this is a tragically pyrrhic sort of victory if ever there was one.

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