

John Kleinsman

Euthanasia and Assisted Suicide good or bad public policy?

Laws, like nation states, are more secure when their boundaries rest on natural frontiers.

The law that we have rests on just such a frontier – it rests on the principle that involving ourselves in deliberately bringing about the deaths of others, for whatever reason, is unacceptable behaviour.

To create exceptions, based on arbitrary criteria such as terminal illness or mental capacity, is to create lines in the sand, easily crossed and hard to defend.

Elizabeth Butler-Sloss, quoted in Bingham, 2013

This quote from Baroness Butler-Sloss, a former president of the Family Division of the High Court in the United Kingdom, provides a useful description of what is involved in the debate about whether or not to legalise euthanasia and/or assisted suicide. It is a debate about the merits of staying with a long-established boundary which provides a bright line and that is 'natural', versus the merits of exchanging that boundary for one that is 'arbitrary ... easily crossed and hard to defend'.

Even a cursory analysis of what has happened in the Benelux countries shows the arbitrariness of the boundaries that were set up around euthanasia and assisted suicide. In these countries the debates that preceded the law change focused on 'difficult cases' involving mostly elderly persons, with terminal illnesses, near the end of life and able to give consent.

John Kleinsman is a member of the Care Alliance and director of The Nathaniel Centre, the New Zealand Catholic Bioethics Centre.

The arguments employed at the time were very much focused on the need to help such people avoid unnecessary physical pain. However, the current situation in Belgium and the Netherlands is that euthanasia is available to people who are not dying, persons with dementia and persons with mental illnesses such as depression.

Along with an increase in the scope of those who qualify (bracket creep), there is also a troubling increase in demand. In Belgium the total annual number of euthanasia cases increased from 1,432 in 2012 to 1,807 in 2013, an increase in one year of more than 25%. Going back to 2008 when there were 708 cases, the 2013 figure represents an increase of more than 150% in just five years. There is undoubtedly a significant change that has occurred at a deep cultural level: what we are witnessing in Belgium, as well as the Netherlands, where there is a similar rate of increase, is the normalisation of euthanasia. The sharp increase in demand belies the argument that changing the law is about allowing the small number of high-profile cases that attract media attention to proceed without threat of prosecution. As Robert Preston, former director of the UK think tank Living and Dying Well, notes:

The point is that legalisation doesn't just reproduce the status quo in legal form ... The reality is not like this. Experience shows that enabling laws have a tendency to encourage the acts they enable – because they change the law's underlying social message. (Preston, 2015)

The more recent concerted push in both Belgium and the Netherlands for euthanasia to be available for persons 'tired of life' is further evidence of the arbitrariness of the boundaries set up around euthanasia and assisted suicide. From an ethical perspective it is well described as a re-writing of the narrative about what constitutes a 'good life' and about whose lives are worth living and whose lives are not.

In New Zealand, Maryan Street, author of the 2012 End of Life Choice Bill, has refused to rule out euthanasia

for children, stating publicly when asked: 'Application for children with a terminal illness was a bridge too far in my view at this time. That might be something that may happen in the future, but not now' (quoted in Fleming, 2013). Street's view is an honest one and highlights an important point. If we introduce a law allowing voluntary euthanasia or assisted suicide for a prescribed group, then we are effectively opening the door to non-voluntary euthanasia of non-competent persons, including neonates, very young children and persons with dementia. It is a small step but, critically, a logical step. If the purpose in legalising euthanasia is to

Netherlands that euthanasia occurs in circumstances where the legal requirements are not met, including the failure to report to the appropriate authorities.¹ These developments illustrate the ineffectiveness of legal safeguards. Why would we think such flagrant abuses would not happen in New Zealand?

Proponents of a law change are aware of the potential dangers but insist that effective protections can be put in place to ensure that people will not feel coerced into euthanasia and/or assisted suicide. So why do I and many others hold a contrary view? Firstly, while legalising euthanasia was supposed to allow the

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prevent or end unbearable suffering, then why should some people be excluded? There is no rational basis for restricting the choice to certain groups only, such as those who are adults or competent or suffering from terminal illnesses. What starts out, genuinely, as a voluntary choice for competent adults will soon become a choice exercised on behalf of others unable to make that choice for themselves.

In other words, a law change around euthanasia and/or assisted suicide would take us into the territory of judging the worth of human lives – both our own lives and the lives of those most vulnerable, those unable to articulate their own needs and desires. This is dangerous territory, especially in the current social environment (characterised by ageism and growing levels of elder abuse) and economic environment (characterised by increasing financial constraints on our health-care and elder-care systems).

Furthermore, it has repeatedly been shown in both Belgium and the

undercover practices that were already happening to be brought into the open and monitored in a more regulated way, thereby making them safer, the evidence (noted above) shows that in Belgium and the Netherlands there continue to be high levels of non-compliance.

Secondly, the main reasons people favour euthanasia or assisted suicide are not related to extreme physical pain (an experienced palliative-care physician reassures me that these days no one need die in physical pain) but to such things as loss of autonomy (see, for example, Oregon Public Health Division, 2013), feelings of being a burden and dependency on others (see, for example, Malpas, Mitchell and Johnson, 2012), decreasing ability to participate in activities that made life enjoyable, fear of losing control, and social isolation (Steck et al., 2014). Euthanasia and assisted suicide are, in other words, overwhelmingly linked to 'existential suffering', and, critically, existential suffering is inextricably linked to attitudes deeply embedded in our

ableist culture, which is now becoming increasingly ageist, evidenced by growing rates of social isolation and associated poorer mental health among the elderly (La Grow and Neville, 2012).

This is not contentious and cannot be simply dismissed as 'scaremongering'. Pro-euthanasia doctors such as Rob Jonquiere openly recognise that many concerned elderly people will choose euthanasia or assisted suicide for such reasons. Jonquiere has noted:

The elderly have feelings of detachment ... The elderly have feelings of isolation and loss of meaning. The elderly are tired of life ... Their days are experienced as

to question or otherwise interfere in such a person's decision (ibid.).

Looked at through a lens of social justice and inclusion, Jonquiere's analysis and conclusion is deeply disturbing. The intolerable situation that increasing numbers of elderly people are in might be a direct result of neglect, ageism, abuse, ignorance, lack of funding for services, poor public policies or, worst of all, a lack of societal will to care. Jonquiere's conclusion means that the state, which governs over the society in which these persons live, the very same society that will in many cases be complicit in their intolerable condition, can assuage its conscience by sanctioning their deaths.

This raises the spectre of a society

Do they realise this reduces the second patient's will-to-live request to a mere personal whim – perhaps, ultimately, one that society will see as selfish and too costly?' (Valco, 2014)

It is not possible to create laws that will protect persons against this sort of coercion. This is why, when debating the merits and risks of a law change, it is not enough to simply focus on the particular plight of individuals. The 'hard cases' which appear in the media, and which most people fall back on when pressed about their reasons for supporting euthanasia and/or assisted suicide, tell only a part of the story. When contemplating a law change the challenge is to consider its impact on our society, including the unintended consequences. This is what robust social policy thinking does. We are fortunate that we can learn from Belgium and the Netherlands. While they might not have been able to envisage the direction in which the acceptance of euthanasia and assisted suicide would take them, we in New Zealand cannot say the same. To ignore the profound shift in social attitudes and behaviour that we are seeing in such countries is to walk into this with our eyes wide shut.

We must consider the future generations who will inherit the legacy of our policy choices. Personal dignity and a commitment to equality and social justice call for a wholehearted dedication to holistic care and unconditional inclusion for those who are suffering, elderly or disabled. It will require a determined effort to ensure that what makes us distinctively human – our ability to show and receive care – is reflected in familial, social, political and cultural structures. I am in no doubt that the legalisation of euthanasia and/or assisted suicide will undermine our ability and willingness to show such care and practice such inclusion. It is undoubtedly a harder way forward, but also, arguably, a more authentically human response.

All of which explains why many people who are supportive in principle of euthanasia or assisted suicide for the so-called 'hard cases' ultimately oppose their legalisation.

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useless repetitions. The elderly have become largely dependent on the help of others, they have no control over their personal situation and the direction of their lives. Loss of personal dignity appears in many instances to be the deciding factor for the conclusion that their lives are complete.

Jonquiere has further stated that 'the problem is not so much physical, but social and emotional' (Jonquiere, 2013).

Jonquiere's response to this is to advocate for these people to have the right to die. 'The conclusion that life is completed is reserved exclusively for the concerned persons themselves ... They alone can reach the consideration whether or not the quality and value of their lives are diminished to such an extent that they prefer death over life.' This leads him to the brutal conclusion that it is 'never for the state, society or any social system'

in which the needs of the elderly and disabled to overcome isolation, neglect and the ignominy of feeling a burden will be ignored in favour of making it easy for them to 'dispose' of themselves, their real needs for inclusion and care papered over by appeals to the principles of autonomy and compassion which are morally vacuous because the choice to die would, for such people, be a choice made out of desperation, a choice made because of a lack of real choices. Looked at like this, granting 'the right to die' in our current societal context is aptly described as an abandonment of the foundational principles of an ethical and caring society. As an experienced nurse wrote:

Do assisted-suicide supporters really expect doctors and nurses to assist in the suicide of one patient, then go care for a similar patient who wants to live, without this having an effect on our ethics or empathy?

Upholding the status quo will mean denying a small, vocal and strong-minded group of people access to something they see as a 'right'. Is this discriminatory? Arguably yes. But this does not make the current law wrong, because the status quo, imperfect as it is, represents 'the lesser of two evils'. There are many areas in society where the interests of the common good justify placing constraints on the autonomy of individuals. Euthanasia and assisted suicide, with its

myriad of complexities and unintended consequences, is one of those areas. There would be a huge price to pay for legalising these practices counted in the additional anxieties and burdens for large numbers of our most vulnerable citizens and, most importantly, lives prematurely ended on the basis of a sad perception by many that their lives were not worth living because they had become a dispensable 'burden' for society.

¹ Reporting is mandatory in both countries. In Belgium nearly half of all cases are not reported (Smets et al., 2010) and in the Netherlands at least 20% of cases are unreported (Onwuteaka-Philipsen et al., 2012). In unreported cases there is a higher likelihood that legal requirements are not met, such as the need for a written request (involuntary euthanasia), for consultation with palliative care physicians, and a requirement that only physicians perform euthanasia. In Flanders, Belgium, it was reported that 32% of physician-assisted deaths in 2007 were without explicit patient request (Chambaere et al., 2010). Meanwhile, Smets et al. (2010) also note drugs were administered by a nurse in 41% of unreported cases (none for reported cases).

References

- Bingham, J. (2013) 'We tinker with assisted suicide laws at our peril', *Telegraph*, 15 December, <http://www.telegraph.co.uk/news/uknews/law-and-order/10517189/We-tinker-with-assisted-suicide-laws-at-our-peril-warns-Baroness-Butler-Sloss.html>, accessed 14 July 2015
- Chambaere, K., J. Bilsen, J. Cohen, B.D. Onwuteaka-Philipsen, F. Mortier and L. Deliens (2010) 'Physician-assisted deaths under the euthanasia law in Belgium: a population-based survey', *CMAJ*, 182, pp.895-901
- Fleming, H. (2013) 'Euthanasia bill close to MP's heart', *Taranaki Daily News*, 12 August, <http://www.stuff.co.nz/taranaki-daily-news/news/9029192/Euthanasia-bill-close-to-MPs-heart>, accessed 14 August 2015
- Jonquiere, R. (2013) 'Dying assistance for the elderly in the Netherlands – an historical and ideological analysis', fourth annual lecture to the Society for Old Age Rational Suicide, London, 20 September, <http://www.soars.org.uk/index.php/pages>
- La Grow, S. and S. Neville (2012) 'Loneliness and self-reported health among older persons in New Zealand', *Australasian Journal on Ageing*, 31 (2), pp.121-3
- Malpas, P., K. Mitchell and M. Johnson (2010) "'I wouldn't want to become a nuisance under any circumstances": a qualitative study of the reasons some healthy older individuals support medical practices that hasten death', *New Zealand Medical Journal*, 125 (1358), pp.9-19
- Onwuteaka-Philipsen, B.D., A. Brinkman-Stoppelenburg, C. Penning, G.J.K. de Jong-Krul, J.J.M. van Delden and A. van der Heide (2012) 'Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: a repeated cross-sectional survey', *Lancet*, 380, pp.908-15
- Preston, R. (2015) Personal communication with the author
- Oregon Public Health Division (2013) *Death with Dignity Act – 2013*, <https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year16.pdf>, accessed 14 July 2015
- Smets, T., J. Bilsen, J. Cohen, M.L. Rurup, F. Mortier and L. Deliens (2010) 'Reporting of euthanasia in medical practice in Flanders, Belgium: cross sectional analysis of reported and unreported cases', *British Medical Journal*, 341, <http://www.bmj.com/content/341/bmj.c5174>
- Steck, N., C. Junker, M. Maessen, T. Reisch, M. Zwahlen and M. Egger (2014) 'Suicide assisted by right-to-die associations: a population based cohort study', *International Journal of Epidemiology*, 43 (2), pp.614-22
- Valco, N. (2014) 'I lost my daughter to suicide: a nurse's response to Brittany Maynard's campaign for assisted suicide', <http://www.thepublicdiscourse.com/2014/10/13979/>, accessed 14 July 2015