

Tony Nicklinson Memorial Prize Winner 2021

In a society that wants legal assisted dying, who should be eligible for a right to die?

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In a society that wants to legalise some variation of assisted death, including euthanasia; assisted suicide – or even what is nominally referred to as ‘assisted dying’ which is itself its own ideological and value laden term for what otherwise is either some version of euthanasia or assisted suicide that is linguistically more palpable, the question remains who *should* be eligible for a right to die? This is a difficult question to answer since ordinarily, it is presumed that anyone in a free society should be able to make use of such a right. In other words, in a society where it is possible to choose an assisted death of some kind, anyone should be free to enjoy such a right – or at the very least should be free to make some claim as to their wish to have an assisted death. The problem however with this line of reasoning is that not everyone is free to make certain choices vis a vis their health care or medical treatment in the same way.

When we talk about choice in the context of health care, and specifically in the context of assisted death, it is the choice to have an assisted death and this choice is usually talked about in the context of some basic universal truth that is attributed to everyone. However, this is not the case. Take for example, the issue of mental competence – even Lord Joffe, arguably one of the most ardent supporters of a change in the law recognises that only those who are mentally competent should be able to exercise such right. Specifically, he argues that “only a competent patient can make a decision in relation to his or her own life. For people who are mentally incompetent there needs to be, perhaps, a different system, but it cannot be based...on personal autonomy”.¹ Thus, we see here that mental competence is one acknowledged constraint on the right to die even amongst those who would argue forcefully for a change in law and policy.

There exists a convention within the assisted death debate to talk about choice in the context of autonomy i.e. choice is the aperture through which autonomy may be expressed. In its most basic form, autonomy is understood as ‘self-governance’, what Tom Beauchamp and James Childress refer to as the ability to deliberate, choose and act on the basis of those deliberations “just as a truly independent

¹ Lord Joffe as cited in John Keown, *The Law and Ethics of Medicine* (Oxford University Press 2014) 272.

government is capable of controlling its territories and policies".² John Harris talks about autonomy in the context of freedom defining autonomy as "the ability to choose and the freedom to choose between competing conceptions of how to live"³ and presumably we might extend this logic to also having the ability and freedom to choose between competing ideas of how to die. Thus, we can see then that there is no autonomy without the parallel action or composition of choice. Going further, however, one might say there can be no choice i.e., the freedom to choose, that does not presume or institute at the same time the existence of autonomy. The latter constitutes the former and the former constitutes the latter. It is for this reason why it makes sense to talk about autonomy and choice as autonomy-choice, where the most important aspect is the hyphenation itself because the hyphenation serves an important function of linking the concepts of autonomy and choice together whilst simultaneously indicating their supposed intrinsic inextricability.

However, beyond this essentially bioethical vignette of choice-autonomy, some would argue that the hyphenation of choice-autonomy is wrong because there can exist no such thing as autonomous choice or autonomous decision making precisely because choice i.e. the freedom to choose, rather than being free and reflexive, is actually informed and constrained by socio-cultural and economic structures.⁴ Ultimately what a person may be 'free to choose' varies considerably depending on what class or race they belong to and we especially see this with respect to the healthcare delivery of people from minority backgrounds – it is a generally accepted reality that Black and other minority women, for example, do not have the same level of reflexivity or capacity of choice as White women when it comes to the delivery of their children and this lack of reflexivity and capacity to exercise choice no doubt contributes the disproportionate number of deaths in childbirth. Understood in this particular context, the freedom to choose an assisted death, and the capacity to act on that choice would similarly be a matter of privilege because choice in the context of health is often, always unequally, distributed. Thus, even if such a right were to exist the way in which it would be exercised would be differentiated because the way in which choice in a medical context is exercised is itself differentiated and historically, culturally and socio-economically contingent. The fact of which often ignored amongst the bioethical tradition as highlight by the likes of Renee C. Fox and Judith Swazey who argue that bioethics argumentation "generally manifests itself in the form of systematic inattention to the social and cultural sources and implications of its own thought".⁵

² Tom Beauchamp and James Childress, *Principles of biomedical ethics* (Oxford University Press 1999) 121

³ Professor John Harris as cited in Select Committee on the Assisted Dying for the Terminally Ill Bill 'Assisted Dying for the Terminally Ill Bill [HL] [Volume I: Report/HL Paper 86-I] (House of Lords 2004) 20

⁴ See for example, Matthew Adams, 'The Reflexive Self And Culture: A Critique' (2003) 54 *The British Journal of Sociology* 221–38. See also Zygmunt Bauman, *Consuming Life* (Polity 2007).

⁵ Renee Fox, and Swazey J, 'Medical Morality Is Not Bioethics—Medical Ethics In China And The United States' (1984) 27 *Perspectives in Biology and Medicine*, 337-338. See also, C. Rosenberg, 'Meanings, Policies, And Medicine: On The Bioethical Enterprise And History' (1999) 128 *Daedalus*.

Nevertheless, all things being equal, let us assume for a moment that none of this mattered. The question asks us to consider who should be eligible for a right to die. The true answer to this question is that in a society which wants some form of legal assisted death, no one would have the right to die in the same way that decriminalising suicide did not bestow on to every living person the 'right' to kill themselves. That the law on suicide has changed and it is no longer a criminal offence to attempt suicide, this does not in and of itself provide a right to kill oneself. Similarly, a change in the law and policy on assisted death would not extend to everyone the right to die – especially for example if that person lacks mental capacity. As with all medical procedure and medical options, assisted death if it were to be legalised would be subject to the same constraints that all medical treatments and options are – namely, the resource allocation and distribution; available expertise and above all else, professional will. Thus, maybe then the question asks us not to consider who should have the right to die, but rather who should have the option to die which are not necessarily the same things but nevertheless bring us back to the same difficulties and concerns regarding capacity and reflexivity mentioned earlier.

This is perhaps unsatisfying to those who want a change in the law, but it is nevertheless a reality of the problem that often goes overlooked. The real crux of this question, however, is no doubt whether there should be a time constraint on qualification; or whether only those with severe, terminal illness should qualify. Take for example the time limit which has been argued forcefully and passionately by Dignity in Dying for example. Calculating the available time someone has left to live is incredibly difficult and there is no ethical reasons as to why someone with six months left to live should qualify but someone with seven months left to live should not. These constraint and distinctions are not ethically or medically motivated but appear to be largely political driven -- a way to garner support in the first instance; an attempt to stave off accusations of a slippery slope initially, but nevertheless short and sweet enough that once support is garnered in the first instance they provide a back door to extend the six month time limit further -- in the future. Either, everyone who believes that death is the preferred option for themselves should qualify, or no one should. Anything to the contrary, is an attempt of appeasement and is wholly disingenuous because once the six-month limit is accepted into law this would not be the end of the matter but merely the beginning.

The view of those countries, like Belgium for example, who have some of the most permissive laws on euthanasia⁶, that believes that the 'right' to die should be extended to those who suffer mental illness is

⁶ Henry Samuel, 'Belgium Authorised Euthanasia Of A Terminally Ill Nine And 11-Year-Old In Youngest Cases Worldwide' (*The Telegraph*, 2018) <<https://www.telegraph.co.uk/news/2018/08/07/belgium-authorised-euthanasia-terminally-nine-11-year-old-youngest/>> accessed 14 April 2021.

not one that we should support. This is one constraint that is acceptable and one class of patients that ought not qualify for a state-sponsored assisted death program. This constraint is a logical one since mental health and mental illness although manifests through some medical pathology actually benefits from social solution and therefore once death becomes an available treatment option for mental illness then we have lost the battle on mental illness and mental health altogether. Another reason for why we must always reject the viability of death as a treatment option for people with significant mental health issues is because whilst it is true that those who believe death is better option for themselves, we can never be sure whether death would be the better option if the mental illness was not driving the desire to die.

Ergo, in a society that wants to legalise assisted death, the question asks us to consider who should, and indeed who should not be eligible for a right to die? As mentioned earlier this is a difficult question to answer because it presumes that everyone exercises 'rights' and enjoyments in the context of healthcare and medicine in the same way and this is not true. From a practical reason, it may well be necessary to impose certain constraints for political expediency, but these prove to be disingenuous once the plasticity of these constraints continue to be tested further down the line. Perhaps the more important question is not necessarily, who should (or should not) be eligible for a right to die, but rather by what means or mechanism that right, option, or claim should be provided for. Recent attempts and proposals have included the medical institution, specially those attached to the National Health Service, and have looked to the likes of Oregon for inspiration who charge between \$3000-\$5000 for lethal dose of secobarbital which is usually recovered against the deceased medical insurance or legal estate. This begs the question, who should pay for this in our context? And why should those who would not take up the option or who are wholly, and holy, against the option foot the Bill? The use of assisted dying in Oregon for example is a small minority of largely white, middle-class university educated people which tells us a lot about who would be eligible for a right to die.⁷

Nevertheless, to maintain pride in our current health system and to ensure that those who currently suffer harm irrespective of sufficient safeguards and ethical guidelines and practices would not fall victim to abuse, the most preferable option is a means or method that exists beyond the confines of the hospital wing it and one which operates outside the parameters of the National Health Service itself. In this way, to answer the question as to who *should* be eligible for a 'right' to die, the answer would simply be those mentally competent people who are able to opt *into* a privatised system, that is ultimately demedicalised⁸

⁷ See for example, Luai Al Rabadi and others, 'Trends In Medical Aid In Dying In Oregon And Washington' (2019) 2 JAMA Network Open.

⁸ See for example Suzanne Ost, 'THE DE-MEDICALISATION OF ASSISTED DYING: IS A LESS MEDICALISED MODEL THE WAY FORWARD?' (2010) 18 Medical Law Review.

and independent of the state -- where death is made available as part of the market of options for one's fate rather than forming part of the repertoire of public medical care.

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