

Written evidence submitted by Nuffield Council on Bioethics (ADY0494)

Key points

- Ethical debates on assisted dying are often presented as ethical tensions within the *status quo*. This arises from consideration of the act/omission distinction and the doctrine of double effect, as well as apparent clashes between individual autonomy and legal prohibitions on assisted dying.
- These matters are exacerbated by questions about the ethical integrity of institutions, and a reluctance in Parliament to implement change (in any direction).
- In analysing ethics and assisted dying, it is important to consider basic moral questions: to ask whether, there is or may be a ‘right to die’. Such an exercise invites a consideration of fundamental moral principles, such as the sanctity of life and individual autonomy. It also requires consideration of questions regarding differential treatment of persons, for example on the grounds of disability.
- When considering potential changes in policy and medical practice in relation to assisted dying, it is important to take account of practical questions around safeguards and potential future developments, both in relation to the law and medical practice.

Introduction

1. The Nuffield Council on Bioethics is a leading independent policy and research centre, and the foremost bioethics body in the UK. We identify, analyse, and advise on ethical issues in biomedicine and health so that decisions in these areas benefit people and society.
2. Our submission is focused on the ethical considerations involved in allowing physicians to assist someone to end their life. We do not have an organisational position on assisted dying. We use the term ‘assisted dying’ in a broad sense; our aim is to provide an overview of ethical considerations relevant to cases in which the Suicide Act 1961 and the common law crime of murder are relevant.¹
3. We wish to draw to the Committee’s attention the fact that we are about to begin a major project exploring public views on the ethics of assisted dying. This work will include a Citizen’s Jury engagement exercise, the first of its kind in the UK.

Challenges for ethical analysis in the assisted dying debate

¹ We take these to be the provisions most germane to discussion of law and policy in England and Wales. We refer to the definitions adopted by the Committee, which uses assisted dying as an umbrella term and draws a distinction between “assisted suicide” (where the individual self-administers the lethal medication) and “euthanasia” (where it is administered by a third party, such as a doctor).

4. The question of legalised assisted dying engages a range of complex and challenging ethical considerations. These may be seen as applying at various levels and in relation to distinct practical matters:
 - a. Ethical critique of the *status quo*: arguments are made regarding apparent ethical incoherence in the rules governing end-of-life decision-making in a medical context. Such arguments do not, of themselves, tend in favour of permitting assisted dying, though they invite critique of leaving things as they are;
 - b. Moral arguments about the permissibility, in principle, of (physician) assisted dying;
 - c. Ethical considerations regarding the viability of a legally regulated system in which (some form of) assisted dying is permitted. Here, it is accepted, for the sake of argument, that assisted dying is morally permissible, to allow the analysis to focus on whether a system may be ethically developed and administered to allow its practice.

5. Ethical debates regarding assisted dying can be challenging because opposing views often appeal to apparently similar grounds. We find arguments both that assisted dying should be seen as inconsistent with principles of basic care, and that it follows logically from the principles of basic care. To improve the clarity of these debates it useful to distinguish:
 - a. Conceptual clarity: what do key terms such as ‘autonomy’ and ‘sanctity’, mean in the context within which they are being used?
 - b. Evaluative clarity: where an argument is based on a value, such as the importance of respecting autonomy or sanctity, how is that value established and how (if it all) could it be balanced against other values?
 - c. Empirical clarity: where a practical reality is described, on what basis is it assumed and evidenced?

6. There are also many different kinds of ethical question that arise. There are questions of moral autonomy, including a person’s basic moral entitlements. At the heart of these is the question of whether there may be any sort of moral right to die. There are questions of professional ethics, for example: where assisted dying involves physicians, how would a system that permits it accord with the ethical norms that govern medical practice? There are questions of political morality: in a liberal political system, where people hold plural and contradictory moral positions, what can and should the law permit or prohibit? And, relatedly, there are questions of institutional ethics and integrity: what are the ethical consequences of what the law might permit and what should (not) fall within the remit of medicine?

Ethical challenges surrounding end-of-life care

7. End-of-life care in England and Wales is governed according to general norms of medical law. This means that there is a burden of justification before any intervention is provided. Such justification rests on two bases: first, that the intervention is clinically indicated (i.e. that there should be a good medical reason to provide it); secondly, that a mandate is provided to authorise the intervention (i.e. through the consent of a patient, someone empowered to

consent on the patient's behalf or, where no-one is authorised to consent, with the intervention being in the person's overall best interests). These norms encompass all interventions outside rare, exceptional contexts recognised in mental health law and public health law. From a legal perspective, a medical practitioner is never asked, for instance, to determine whether it is in a person's best interests not to receive a life-sustaining treatment; rather, they must consider whether providing treatment is medically justified.

8. A person has no legal right simply to demand and receive an intervention. However, the requirement for consent described above means that it is legally obligatory to refrain from providing medical interventions—including ones necessary to sustain a person's life—if consent is withheld (or, where consent cannot be given, where the intervention is not in the person's overall, as opposed simply to their medical, best interests).
9. This leads to a position where there is a right to make life-ending decisions to refuse a medical intervention where death is the result of non-intervention ('being allowed to die'). That moral and legal right to bodily integrity is not mirrored, however, by a right to request lethal interventions. Within ethical analyses, this is often discussed in terms of a distinction between act and omission. For some, the distinction leads to claims of arbitrariness: if a person can make life-ending choices by refusing an intervention, it is argued that there is an incoherence if that same person is not able to make life-ending choices by demanding an intervention. For others, the distinction rests on the responsibility that a physician undertakes when intervening in a way that breaches another's bodily integrity (even with their consent) rather than the permissibility of life-ending decisions *per se*.
10. A second alleged inconsistency arises from the doctrine of double effect. This doctrine provides that an intervention that may have a life-shortening effect can be permissible where it is a consequence of treatment provided to secure a medically indicated effect in the patient's interest, such as the alleviation of pain. In an end-of-life care context, this may be seen as providing justification for the provision of palliative treatments to relieve unbearable suffering, even where such treatment may have a side effect of shortening life (although there are arguments from within palliative medicine that with proper pain control this matter should not arise). Supporters of the doctrine of double effect argue that it is ethically sound to distinguish the aims in support of a medical intervention rather than simply to make a judgement based on all its direct and indirect consequences. Others argue that it cannot make sense to claim that physicians only will some of the foreseeable consequences of their actions. Thus, if it is acceptable to provide drugs that the physician knows may shorten a patient's life, this cannot be reconciled with laws that also prohibit assisted dying.
11. A final point regarding ethics and the *status quo* concerns the roles and decisions of institutions. From a political perspective, it is notable that views regarding assisted dying do not fall out along party political lines. As such, it is not a question that has been addressed through the introduction of legislation. This raises ethical questions for those—whatever their moral view—who find the *status quo* ethically incoherent and/or problematic. If the Government will not legislate, and if the law is unsatisfactory, what ethical obligations arise

for other institutions? We have seen a series of legal challenges, but the courts tend against the view that they are the appropriate forum to provide for radical reform in this area. Similarly, where the institution of medicine might provide leadership (in whichever direction), beyond lobbying there is limited scope to promote change. Consequently, there are questions about the role of Parliament and the ethics of leaving things as they are.

Ethical arguments against assisted dying

12. When considering ethical arguments against assisted dying, it should be recognised that such a position is not necessarily one that accepts the *status quo*. The Committee invites consideration of the quality and reach of provision of palliative care in England and Wales. This implicitly suggests that there may be a need for improvements in such care. There are also views that claim support from considerations we set out below, that suggest the law should be more restrictive.²
13. A central moral argument against legislating to permit assisted dying is that a regime that would allow intentional killing, or assistance in killing—however kind or compassionate the motive—breaches the fundamental principle of the sanctity of life (sometimes described as the ‘inviolability of life’ principle). The sanctity of life principle is held by its advocates to be fundamental to the moral integrity of a society and its laws. Yet its critics claim that if the sanctity principle entails an absolutist commitment to preserving life at any cost, this is morally problematic. For instance, a person may, consistently with the principle, refuse to accept or continue to receive a life-preserving treatment that causes unavoidable and intolerable suffering. Yet, whilst a treatment may be considered excessively burdensome, life itself should not be considered a burden, or killing a means of relieving suffering.
14. The sanctity of life position does not just relate to the acts of third parties: it is not only concerned with *assisted* dying, but also condemns unassisted suicide. In England and Wales, death by suicide ceased to be a crime with the passing of the Suicide Act 1961. Advocates for the sanctity of life position often stress that a change in the law is defensible for affording a more compassionate system of support in instances where a person might try to die by suicide. They do so whilst also holding that that legal position does not represent a legal endorsement of some sort of ‘right’ to die by suicide.
15. As well as general moral arguments concerning the wrongness of killing, significant moral opposition to assisted dying is grounded in arguments that it wrongly de- or disvalues particular *sorts of* lives. Perhaps most notably, these may be found to apply to persons who are older, ill, and/or disabled. The arguments here may relate to explicit criteria (‘qualifying conditions’) within proposed assisted dying laws: for instance, if assisted dying laws are designed to help (and thereby exceptionalise) people with physical disabilities, it is suggested that this could imply that the life of a disabled person is of less value and that

² An example of a legislative proposal in such a direction is found in the Medical Treatment (Prevention of Euthanasia) Bill 2000. Note might be taken as well of the debates leading up to the enactment of the Mental Capacity Act 2005 and the inclusion within it of section 4(5), which states that a best interests decision-maker “must not, in considering whether [life-sustaining] treatment is in the best interests of the person concerned, be motivated by a desire to bring about his death.”

such a law risks creating a tiered system in which some lives are presented as inherently more or less valuable than others.

16. We note that the Committee's inquiry is focused on questions concerning physician-assisted dying. Some opponents argue that *even if* assisted dying were permissible, it is not something that is compatible with the professional ethics of medicine. This may be a direct claim about activities in which doctors should not engage: that the physician's role is to cure and care, and killing cannot form a part of this. It may, alternatively, be a claim that the consequences for trust in professional medical ethics will be eroded if physicians assume a role in assisted dying.

Ethical arguments for assisted dying

17. In moral arguments in favour of assisted dying, the two principles of respect for personal autonomy and the avoidance of suffering, usually in combination, are offered as moral bases for the permissibility of assisted dying.
18. Supporters of legislation for assisted dying argue that rights to choose autonomously are of profound moral importance. When and how one dies is a matter of such significance that individuals ought, they claim, to have the freedom to define the timing and manner of their deaths. This claim draws support from the fact that people have a recognised freedom to make certain life-ending decisions. This includes death by suicide, but it also includes life-ending decisions in clinical contexts, for example, the right to refuse life-saving treatments.
19. As such arguments are based in liberal concepts of autonomy, there is a clear focus on the idea that—if it is to be honoured—a wish to die should be made voluntarily, that is, by a person who has decision-making capacity and who is not suffering coercion or undue influence. Where that is so, the principle of autonomy is said to offer a basis for a 'right to die'.
20. As noted in above, it is often the case that even where autonomy is given as a *necessary* condition for morally permissible assisted dying, it may not be considered a *sufficient* condition and requires the addition of a further principle, such as the principle of the avoidance of suffering. Debates may limit this in various ways: it may mean avoidance of suffering that cannot otherwise be treated (i.e. through methods of palliative care); it may mean suffering that surpasses a particular threshold (e.g. contrasting acutely unbearable suffering with (say) weariness of living). In any case, a suffering criterion generally invites some sort of expert assessment or diagnosis.
21. We noted that there are also arguments in favour of assisted dying that relate to disability and infirmity. Such arguments concern cases in which a person wishes to end their own life but cannot do so, for instance because of a physical disability. Here, it is argued that equal respect requires that provision be made to allow a person to end their life, or have their life ended, because such a choice, which is available to others, is denied to them as a result of their physical condition and the legal prohibitions therefore create an inequality.

22. Finally, arguments against assisted dying that apply specifically to *physician*-assisted dying, are opposed by arguments that good medical practice includes within it support for assisted dying. Some of these arguments turn on the special place that regulated medicine holds in England and Wales, both in relation to the sorts of decisions that physicians are expected to make, including end-of-life decisions, and their role, within carefully regulated contexts, to prescribe and control the use of lethal substances. The arguments here tend in favour of the view that if assisted dying is permissible, it should be provided within the domain of good medical practice or a similarly regulated context.

Ethical questions regarding a regulated system that permits assisted dying

23. The previous two sections have noted ethical arguments in relation to assisted dying. A further set of ethical concerns arises when we consider the implications of a *system* that permits and regulates assisted dying. A first consideration relates to the application of a system that allows and provides assisted dying. Issues include:
- a. Adequate drafting of defensible inclusion criteria: is it possible adequately to define who may be beneficiary of such a system? Risks here include under-inclusion; for instance, a criterion that says a person must have a terminal illness with fewer than six months' life expectancy would exclude some people with chronic conditions that cause enormous and unwelcome suffering. Having such a criterion may be presented as necessary in order to avoid unduly broad criteria or may be criticised as problematically narrow.
 - b. Risks concerning inclusion criteria also will operate under real-world constraints, such as the potential inaccuracy of a prediction, for instance, of life expectancy. What level of tolerance for that sort of uncertainty may be ethically justified is again a question that must expressly be addressed.
 - c. Overall, an ethical system of regulated assisted dying will need to provide safeguards; it would need to assure respect for the rights of those who would wish to avail themselves of it, whilst also respecting the rights of others.
24. A second consideration may be more future-oriented. Rather than looking to the question of whether abuse would occur under a particular assisted dying system, it could be asked whether that system would simply be a precursor to a future system that would be morally repugnant. This 'slippery slope' argument suggests that we might find ourselves on an irresistible path to sanctioning what should be unacceptable killings, and the only way to avoid this is not to take the first step.
25. A third consideration looks to the *systematised* effects of a practice of permitting assisted dying. Such matters relate to points raised earlier, concerning the (effective) differential value assigned, for example, to the lives of disabled people. When looking to these sorts of factors, we look not simply to the moral questions raised. We also invite consideration of whether particular characteristics will come to define groups who seek and receive assisted dying. Ethical questions arise that must be addressed regarding the risks of changing social *mores*, or creating social pressures, in ways unintended in the development of a regime that permits assisted dying.

26. Finally, and again having regard to the medical context of the Committee's inquiry, we note that there is a question of conscience for professionals who would be involved in the system. Whilst physicians must routinely make life and death decisions, there are doctors who are concerned by the idea that they may be forced to participate in assisted dying. In such a morally-controversial area, a professional right to conscientious objection should be considered—and has been in proposed legislation—as a means of avoiding the ethical bind to which this might otherwise give rise.

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