

Written evidence submitted by Professor Emily Jackson (ADY0290)

1. To what extent do people in England and Wales have access to good palliative care? a) How can palliative care be improved, and would such improvements negate some of the arguments for assisted dying/assisted suicide?

Palliative care can be excellent, but access to it is unacceptably patchy. Death is one experience that no one can avoid, and doctors from every medical speciality will encounter dying patients. Care of people who are dying should be regarded as core NHS business, and should be a core element of the medical curriculum. It should not be outsourced to charities and dependent on charitable fund-raising

Palliative care services need more funding, including for 'palliative care at home', where people are enabled to die at home, with the support they and their families need.

Improvements in palliative care will not negate the arguments for assisted dying because the reason why people express an interest in assisted dying, or seek access to it, is *not* that palliative care is inadequate. On the contrary, the three most frequently reported end-of-life concerns among people who received approval for assisted dying in Oregon in 2021 were: loss of autonomy (93%), decreasing ability to participate in activities that made life enjoyable (92%), and loss of dignity (68%). Patients' interest in assisted dying stems not from objectively inadequate symptom control, which might be alleviated through access to better palliative care, but from their *subjective* perception of what makes *their* life tolerable.

2. What can be learnt from the evidence in countries where assisted dying/assisted suicide is legal?

There are three key lessons, in my opinion.

First, the evidence is that, in addition to helping the small number of patients who actually access an assisted death, the availability of assisted dying helps a much wider group of patients who may never use it, but for whom it serves as a 'hypothetical exit plan'. The possible future availability of assisted dying serves as a 'comfort blanket', reassuring patients who are fearful of what lies ahead that they would be able to end everything, if it were to become unbearable.

Fear of the dying process is common, and knowing that they have the power to stop it provides this wider group of patients with reassurance, and in practice appears to make it easier for them to bear the burdens of their current situation. There is evidence from psychological research that our capacity to endure pain is higher when we have an 'off switch'.

Some patients are so fearful of a protracted and distressing death that they take their own lives prematurely, while they are still able to do so. For such patients, the availability of assisted dying might, in fact, prolong their lives.

Second, there is considerable evidence that the people who seek access to assisted dying around the world are more likely to be middle class, well-educated, comparatively well-off and irreligious. They are people who are used to being able to exercise control over their

lives. They are typically *not* from patient cohorts that we would ordinarily think of as vulnerable. The principal predictor of the desire to access an assisted death thus appears to be the patient's beliefs, characteristics, and priorities, rather than their illness or symptoms.

Third, the UK is now an outlier on assisted dying. If countries like Australia, New Zealand, eleven states in the US, Spain, Portugal and Canada are able to come up with adequate systems of regulation, which command public support and public confidence, it seems improbable that this is uniquely beyond the capability of the UK parliament.

3. What are the professional and ethical considerations involved in allowing physicians to assist someone to end their life?

It is important to acknowledge that a majority of deaths in the UK are preceded by a medical decision, whether that is to withdraw life-prolonging treatment, or to provide palliative care that might hasten the dying process. Both of these practices are lawful. If we allow doctors to take *some* decisions which result in patients' deaths, but not others, we need to be able to explain why assisted dying is different from withdrawing medical treatment that is keeping someone alive.

Where the withdrawal of life-prolonging treatment is at the request of a patient with capacity, as was the case in *Re B (Adult: Refusal of Treatment)* [2002] EWHC 429 (Fam), it is, from the point of view of the patient, functionally equivalent to euthanasia. From the point of view of the patient, the doctor does a positive act, in the certain knowledge that it will cause her death (ie they have the same *actus reus* and *mens rea*). The law is only able to draw a distinction between these two courses of conduct by describing pulling out the tubes that are keeping someone alive as an 'omission'.

The House of Lords decision in *Airedale NHS Trust v Bland* [1993] AC 789, that clinically assisted nutrition and hydration could be withdrawn from a patient in a permanent vegetative state, depended upon characterising the withdrawal of treatment as an omission. But it is worth noting that some members of the House of Lords were nevertheless sharply critical of the acts/omissions distinction. Lord Mustill, for example, said:

The acute unease which I feel about adopting this way through the legal and ethical maze is I believe due in an important part to the sensation that however much the terminologies may differ the ethical status of the two courses of action is for all relevant purposes indistinguishable. By dismissing this appeal I fear that your Lordships' House may only emphasise the distortions of a legal structure which is already both morally and intellectually misshapen.

Patients can insist that their doctors take steps to end their life, if their life can be ended by treatment withdrawal. We therefore must believe that we can be sufficiently certain that the patient's decision in treatment withdrawal cases represents their own wish, and is not the result of coercion. If we can be sufficiently certain of this when the patient's life is ended by pulling out a tube, why could we not be sufficiently certain of this in cases of assisted dying?

4. What, if any, are the physical and mental health criteria which would make an individual eligible to access assisted dying/assisted suicide services?

In my view, the criteria should be that the patient's suffering is both unbearable and cannot be relieved, and that their wish to die is a settled wish, and not a transient impulse, or a symptom of untreated depression.

5. What protections could be put in place to protect people from coercion and how effective would these be?

It would be a good idea to have a second opinion from an independent doctor, not already involved in the patient's care, and to ask him or her to judge whether the decision the patient wishes to take has been taken voluntarily, and represents their settled wish, rather than being a transient preference or symptom of a depressive disorder.

When someone makes the claim that the only way to protect the vulnerable is to have a blanket ban on assisted dying, for non-vulnerable patients as well, it is important to acknowledge that we do not do this in other contexts. For example, we do not prevent adult patients with capacity from refusing blood transfusions because we are worried about vulnerable patients being pressurised into making similar decisions against their wishes. Instead, we have a system in place in which a patient's capacity can be assessed, and if there is any doubt about their capacity, or whether their apparent decision reflects their wishes, applications can be made to the courts to resolve the matter.

A blanket ban on assisted dying in order to protect the vulnerable involves disregarding the rights and interests of non-vulnerable patients. If we think we can protect the vulnerable – while also respecting the autonomy of non-vulnerable patients – in the context of refusals of life-prolonging treatment, it seems implausible to claim that it would be impossible to protect the vulnerable when it comes to assisted dying.

6. What information, advice and guidance would people need in order to be able to make an informed decision about whether to access assisted dying/assisted suicide services?

People would need to know about their prognosis and what is likely to happen to them during the dying process. They would need to know how far palliative care would be able to control aspects of the dying process that they might find frightening. They would also need to know what an assisted death would involve for them and those they care about.

It is also important that patients who express a wish to die have the opportunity to discuss their feelings with a healthcare professional in a non-judgemental and open way. Not everyone who expresses a desire to die actually wishes to access an assisted death, and there would be huge benefits to facilitating conversations about the wish to die, in order to explore what it means for the individual patient. They may be seeking reassurance from others, or they may want to let their loved ones know that they realise they are dying and have reconciled themselves to it. Only a minority of people who express a wish to die will actually want to end their lives, but at the moment, these sorts of open discussions are hampered by the illegality of assisted dying. Rather than responding openly, a healthcare professional might feel obliged to say: 'I can't help you with that'.

There is a wealth of evidence that talking frankly about dying with a person before they die is good for dying patients, but that it also makes an overwhelmingly positive contribution to their loved ones' grieving processes. Anything that we can do to promote openness in talking about death is a good thing.

7. What capabilities would a person need to be able to consent to assisted dying /assisted suicide?

It would be simplest to say that they would need to have mental capacity, using the test for capacity in the Mental Capacity Act 2005.

The downside to using this as the test is that people who fear that their medical condition means that they are likely to lose capacity in the future might access an assisted death before they would ideally like to do so, in case they become incapacitated and hence lose their eligibility.

This unintended consequence would mirror current experience with people travelling to Dignitas in Switzerland, who may access an assisted death at Dignitas prematurely, out of fear that they will become unable to travel, and lose the opportunity. If assisted dying had been available in the UK, they could have waited until their condition became unbearable, and in practice, many of them might never have accessed an assisted death. It is therefore likely that some UK citizens who have died at Dignitas would have had longer lives, and died natural deaths, if assisted dying was lawful in the UK.

There isn't an easy solution to this problem. The obvious one would be to facilitate advance decisions for euthanasia, so that someone could be reassured that their wishes will be followed after they lose capacity, but that brings with it lots of further potential issues. We know from experience in the Netherlands and Belgium that even where advance decisions are lawful, compliance with them is vanishingly rare because doctors find it difficult to be sufficiently certain that the patient might not have changed her mind in the interim, or that now is the moment at which she would want her advance decision carried out.

8. What should the Government's role be in relation to the debate?

Ideally, the Government would – after proper deliberation and expert advice – decide to back a proposal for assisted dying, which would then be drafted properly by parliamentary counsel, and its implementation would be properly thought through by the civil service. Using Private Members' Bills for this sort of legislation has lots of disadvantages.

If the Government did not wish to 'nail its colours to the mast', it could offer a free vote on a number of options for reform.

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