

Written evidence submitted by Dr Robert Twycross (ADY0328)

I am one of the pioneers of hospice and palliative care in the UK. I worked with Cicely Saunders in the early 1970s as her Research Fellow in Therapeutics at St Christopher's Hospice in London. From 1976-2001, I worked at Sir Michael Sobell House – one of the first NHS hospices – in the grounds of the Churchill Hospital, Oxford, initially as its Medical Director and subsequently as Clinical Reader. My career embraced research, patient care and teaching. Since retiring from clinical responsibilities, I have continued to teach and write, though much less since I turned 80. I have taught in over 40 countries, and written several highly acclaimed textbooks and numerous papers. Palliative care has a lot to teach other areas of medicine, not only in relation to pain and symptom management but about the need for holistic care. From my observations, I believe that ultimately it will be a disaster to decriminalize Assisted Dying (AD) given that many (possibly the majority of) doctors seem unable to cope adequately with dying patients. Please read on...

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?

In the world rankings for palliative care, the UK has so far always come out top. But how well do the rankings represent reality 'at ground level'? Many of the distressing stories publicized by those in campaigning for AD are clear examples of woefully inadequate or non-existent palliative care.

With the demise and fragmentation of traditional General Practice with its guarantee of a named doctor who provided personal continuity of care both in the surgery and at home, high quality palliative care delivered at home by the GP and community nurses is now largely a thing of the past. Hence the emergence of 'Hospice at Home' services, generally funded by charities.

However, even in palliative care, truly integrated continuity of care can be more an aspiration than a reality – as my family discovered last year when my brother-in-law (Canada) and a niece (England) were dying. In neither instance was it clear who was coordinating care, and several different agencies seemed to be involved. Many gaps exist, and 'horror stories' of poor/non-existent palliative care will continue, and almost certainly increase.

From the Government's point of view, it would be cheaper to fund an AD service than to optimize palliative care services. In October 2020, a cost estimate produced by the Office of the Parliamentary Budget Officer in Canada indicated that a saving of around \$150 million per year could be expected when the amended Medical Assistance in Dying (MAID) Bill was fully enacted.⁽¹⁾ Although this is less than 1% of the Federal Health budget, it still a significant amount – though perhaps only if MAID itself continues to be underfunded (see 8. below).

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

That the criteria for AD tend to broaden over time – in Canada, in just a few years. This is probably because AD activists see a law limited to assisted suicide as only the first step. As

someone observed: 'Once the AD genie is out of the bottle, you must be careful what you wish for.'

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

'Death cannot be denied but its dignity can be – by thoughtless, underfeeling and overscientific care. Everything that is done for the dying patient should be based on the constant awareness that, although death may be postponed – sometimes dramatically – the master plan cannot be altered.'(2)

It is important that doctors, particularly oncologists, are more realistic about a patient's likely prognosis, and avoid 'therapeutic obstinacy' – a major cause of suffering – and include palliative care as a positive option which enhances quality of life:

'We have witnessed multiple patients with serious illness "saved" from imminent death by aggressive treatment who then turn around and request MAID. To decrease unnecessary suffering, [doctors] must shift attitudes towards natural death by using tools to clarify advance directives and re-shape medical culture and law concerning futile treatment.' (Scott J, personal communication)

All too often patients are referred far too late, despite the well-documented evidence of the benefits of early referral – and of 'shared care' when, for example, a patient with end-stage renal failure forgoes dialysis and opts for 'maximum supportive care' provided by a palliative care specialist working in the Renal Department (as in Oxford).

However, some people decline referral, particularly to a hospice, because they believe patients are drugged to death with morphine. I have no doubt that legalizing AD, particularly if incorporated into palliative care, will lead to more patients dying in pain and distress than at present.

Further, once AD is included in the range of therapeutic options, everything changes. A Canadian palliative care specialist recently told me:

'The MAID (Medical Assistance in Dying) situation in Canada is disastrous.... At the bedside level, we deal with the resulting chaos on a daily basis as patients agonize over how they should choose to die, and families are furious when incapacity rules out MAID since families have come to believe from media that the only good death is a MAID death.' (Scott J, personal communication)

This will become an even bigger problem if the professional expectation shifts towards routinely informing potentially eligible patients about AD as an option for consideration – as mooted recently by the College of Physicians and Surgeons of Ontario.

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

Depression greatly influences requests for hastened death in terminally ill patients,(3) but is often not recognized or is dismissed by doctors. Requests for AD are often based on exaggerated fears of what the future holds or a sense of hopelessness. However, *in most*

patients, the desire for to hasten death is unstable and generally responsive to psychosocial interventions.(4) As stated in the Position Statement of the Canadian Association for Psychosocial Oncology, patients who express a desire for AD, and their family members, should have access to psychosocial oncology and palliative care services.(5)

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

For many supporters of AD, individual autonomy has become the ethical trump card. However, given that a healthy society should act in the interest of the common good and protect the vulnerable, the essential questions for me would seem to be:

Can a law be devised with adequate safeguards which would:

- a. protect those considering AD because of psychological and social vulnerabilities or because of inadequate palliative care, mental healthcare and/or social support?
- b. prevent endangering those who do not desire AD by undermining cultural attitudes of compassion for the disabled, elderly or dying, and by weakening governmental support and funding for palliative care?
- c. prevent the unwitting abuse of AD by doctors linked to unconscious bias associated with transference and countertransference stimulated by their own fear of death.(6)

I doubt if it is possible to devise such a law. Indeed, *in many ways, doctors are the main problem* (point c above). Because doctors' psychological profiles include controlling characteristics, fear of death and a sense of failure and inadequacy when confronted with suffering, there should be concern that the rapid escalation of AD as seen over the last six years in Canada, could represent doctors' need for control and not simply patients' desire for autonomy.(7)

It is noteworthy that in the BMA Survey on Physician-Assisted Dying conducted in 2020 that, in answer to the question 'The BMA should actively oppose attempts to change the law', the three specialties with the highest scores were Palliative Medicine (70%), Geriatric Medicine (44%) and General Practice (39%), suggesting that *the more a doctor is involved in caring for dying patients, the greater the likelihood that they will oppose a change in the law.*(8)

In the past, the role of doctors was seen as threefold: *to cure sometimes, to relieve often, and to comfort always*. In other words, doctors were aware of their limitations and were 'balanced' practitioners. However, as the ability to cure has increased, medical training has become more 'biomedical' (cure-oriented) and less 'holistic' (comfort-oriented). The modern standard medical paradigm – *examine, diagnose, and fix* – has its limitations. Some problems cannot be repaired. The inability to relinquish the goal to fix can lead to feelings of failure, and an inclination to withdraw – with death seen as the only way to deal with the suffering.(Chochinov HM, personal communication) Thus, doctors who, when it is appropriate, cannot switch from a cure to a comfort *modus operandi* may well unconsciously coerce patients towards AD. There are numerous anecdotes supporting this contention. In fact, probably the only way to avoid medical abuse of AD is to dissociate AD entirely from the medical profession (see point 8 below).

In contrast in palliative care, there is a commitment to *non-abandonment*: 'Whatever happens, we will stay beside you every step of the way. Together we will get through this'.

Compassionate presence and compassionate listening together demonstrate that *the patient still matters and is still a person of worth*.⁽⁹⁾ This is the fundamental component of palliative care. It lightens the patient's load of cares by, *inter alia*, decreasing their isolation and sense of worthlessness. In such an environment most patients lose their wish to hasten death.

Further, there is a lack of awareness among doctors that a request to hasten death may be a subtle way for the patient to find out whether they are still regarded as someone worthy of respect and support:

A woman in her mid-60's with a slowly progressive incurable cancer was referred to my clinic. All she wanted was to be 'put down'. I pointed out that that was not an available option. I reviewed her symptom management and arranged for a Macmillan nurse to visit her regularly at home. I saw her every three weeks for over two years. Each time she would repeat her request to be 'put down'. Eventually, because of a chest infection, her GP requested inpatient admission. After examining her, I said, 'we have two options: one is to give you antibiotics, the other is to let Nature take its course and concentrate just on comfort.' She exploded: 'Are you suggesting you just let me die!?' I was amazed by her response because, over 30 years, she was one of only maybe three or four patients who seemed to have a fixed desire to hasten death. However, when push came to shove, that was not the case. I prescribed antibiotics. She improved and was discharged home in due course, dying peacefully some months later.

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?

Exercising personal autonomy implies making a choice. Choice requires reliable information. Without informed choice, autonomy is not valid. Anecdotes and published research confirm that the wish for AD is often linked to a lack of knowledge about palliative care. Also, because AD is often described as 'dying with dignity' in the media and by those actively campaigning for a change in the law, many people now imagine that anything else will be extremely distressing and undignified.

In a report from three jurisdictions where physician-assisted suicide and/or euthanasia have been decriminalized, doctors stressed the importance of finding out *what the patient really wants*; and what people most often want is *not to suffer*:

'I always say "What is the reason you're asking for this?" They tell me and then I ask, "Do you know what other choices you have?" They always say, "No. Do I have other choices?" I explain the other choices, and it happens frequently that a person changes their mind and tells me "Maybe I would prefer to just sleep a few days and then die, it's going to be maybe more natural and my family is going to be more comfortable with this idea, and maybe me too".'⁽¹⁰⁾

Some years ago, a Dutch doctor said:

'In the past, I offered patients euthanasia. Now when I tell them about palliative care, nine out of ten opt for that.'

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

Mental capacity.

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

First, to ensure that misinformation is exposed. For example, as noted above in (point 6), because AD is often described as 'dying with dignity' in the media and by its advocates, many people now imagine that anything else is likely to be extremely distressing and undignified. Thus, any Bill must *not* be named (or nicknamed) the 'Dying with Dignity Act' (as in Oregon) because it is misleading and fuels people's fears about 'natural' death.

Remarkably, the results of an online survey completed in 2021 by Survation on behalf of the APPG for Dying Well demonstrated that only 43% of respondents knew what the term 'assisted dying' means. (Ten percent thought it means providing hospice-type care to people who are dying, and 42% that it means giving people who are dying the right to stop life-prolonging treatment.) This suggests that claims about the level of support for AD by the public should be interpreted with caution.

Second, conscientious objection by doctors and other healthcare workers must be fully guaranteed. Lord Joffe once commented that, if doctors objected to AD, they should be forced to comply, thereby revealing a total misunderstanding of the doctor's professional role. If Lord Joffe's suggestion was adopted, it would turn doctors into technicians – simply doing what a patient demands as 'my legal right'. This would convert the traditional 'covenantal' relationship (based on partnership with the patient) into a transactional one (that of supplier and purchaser).

Third, be aware that AD has cost implications. Doctors registered to administer AD in Victoria, Australia, have pointed that the implementation of the Voluntary Assisted Dying (VAD) Act requires time, money, institutional supports, and peer networks. Because the necessary supports are not readily available, they must make do with the resources they can divert from other areas of their medical practice. *Co-ordinating a VAD application through to the patient's death takes about 60 hours of working time.*⁽¹¹⁾ As a result, because of inevitable time constraints, some doctors report undertaking less than ideal VAD assessments. Others report not being able to see their other patients because of their VAD workload. At present, much of the work they do around VAD is unremunerated. The situation is similar in Canada.

Fourth, it must be emphasized that, *if AD is permitted, it does not mean that it should be part of palliative care*, or of medical practice generally. Data indicate that the primary reason for a persistent desire for AD is to relieve distress over a perceived loss of autonomy and to experience a sense of personal control over the circumstances of their dying. *These are not medical reasons.* Thus, for patients fulfilling the legal criteria, a separate AD service should be established. Indeed, this would be the best way to prevent a corrosive effect on medical practice generally.

Finally, it is perfectly consistent to argue that, ethically speaking, AD may be permissible in rare cases but that it would be unwise to change the law. Not only is the law a blunt instrument for dealing with ethical complexities, but it may be better to continue with the *status quo* rather than introduce legislation with a considerable likelihood that it will become too permissive, and undermine the ethos and practice of palliative care in

particular. The Canadian experience strongly suggests that AD (almost entirely euthanasia) will lead to more harm than good, particularly since the so-called 'foreseeable death requirement' was scrapped.(12, 13)

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