

**Written evidence submitted by Baroness Murphy MD PhD FRCPsych, (crossbench) (ADY0099)**

I have spoken in the House of Lords many times in support of restricted legislation to enable physician assisted dying at the end of life and will not therefore repeat here what is accessible in Hansard.

I worked as a gerontologist and psychiatrist in hospital and community services for most of my working life. I served on the Falconer Commission on Assisted Dying. I welcome wholeheartedly the Commons Select Committee and urge members, in drawing their conclusions, to concentrate on national and international evidence from peer reviewed research and not to be overly influenced by organisations, both professional and religious, which have an interest in preventing any change in the current law but which represent a minority of the general public.

I will address the specific Terms of Reference for the Committee as listed numerically in the Call for Evidence.

**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?**

A recent review by Finkelstein et al (*Journal of Pain and Symptom Management* vol 63 April 2022 E419-429) found that the UK, perhaps surprisingly, scored highest of 81 countries in its provision of palliative care services on 13 parameters of efficacy. (The US was placed at 43). Higher income, universal health coverage, and wide availability of opioids for pain relief were generally associated with better scores. The Lancet Commission on Palliative Care and Pain Relief (2017) suggested however that overall, the level of care is patchy, that pain relief in particular is often inadequate and described the widespread lack of access to inexpensive and effective interventions as a 'travesty of justice'. And these are not the best of times. As health systems become strained in recession, providing safe and effective palliative care, including end-of-life care, becomes especially vital and especially difficult.

Access to palliative care in the UK is too often focused solely on cancer patients and restricted to the last 6 months of life. Patients with other life limiting disorders are rarely referred and certainly rarely included in health plans locally. We all have personal stories of the difficulties in accessing palliative care for the very aged, those who are not dying 'fast enough' to qualify for hospice care or have mental disorders alongside the terminal illness.

There is therefore a temptation to think that if palliative care were in better shape with more general coverage, that the need for assisted dying would go away. This is however unlikely to be the case. Firstly, people who seek assisted dying rarely request it because of unbearable pain or other uncontrollable symptoms. Rather they seek greater autonomy to die on their own terms, feeling in control, to choose a departure date that precludes the frightening end stages of dependence on others.

The international evidence shows the development of palliative care often runs a parallel course with the greater awareness of death and the dying process stimulated by debates surrounding assisted dying legislation. But the picture is complicated by the difficulties in access to palliative care in many areas of the UK and the committed opposition of many palliative care physicians, although not all, to incorporating assisted dying into their spectrum of care.

A review of the international literature of the impact of Assisted Dying on palliative care developments by Gershon in 2020 was inconclusive, whereas a review of the situation in Benelux countries by Chambaere and colleagues showed a marked improvement of palliative care services after the introduction of Assisted Dying. But palliative care physicians' professional organisations across Europe have remained resolutely against any change, meaning that sadly they do not engage to shape the way services develop except on their own terms. In the UK we saw a similar impact of obstetricians and nurses opposed to termination of pregnancy on the implementation of abortion legislation in the early days...and indeed we still see that today in Northern Ireland today. This is a tragedy because far more people are in need of palliative care than would ever wish to end their lives early, indeed the majority of people whose death can be predicted within a finite period should be offered palliative care, whatever their diagnosis. But only a minute proportion of those at the end of life would wish to access assisted dying. It is crucial not to confuse the two streams of policy development nor to think that provision of palliative care would obviate the need for assisted dying.

It is also the case that palliative care research has shown that while the majority of patients will have symptoms relieved by specialist palliative care, there remain many whose symptoms are intractable. We should not abandon them if they seek to end their suffering when all palliative care expertise has been exhausted.

Why are palliative care physicians so opposed to assisted dying? One reason is the very high religious affiliation among palliative care specialists found in surveys of specialties. The hospice movement was originally overtly Christian in its ethos and this has had a huge influence on the development of the specialty. (Seale, C *Journal of Medical Ethics* <http://dx.doi.org/10.1136/jme.2010.036194>.) Furthermore, both palliative care physicians and geriatric medicine and psychiatry specialists are far more likely to be paternalistic in their approach to care than other specialists, which undoubtedly influences their approach to patients making their own decisions. They are more likely to think that they know better than the patient what is in their best interests. (Lynøe, N., Engström, I. & Juth, N. *How to reveal disguised paternalism: version 2.0. BMC Med Ethics* **22**, 170 (2021). <https://doi.org/10.1186/s12910-021-00739-8>)

While of course there are many palliative care physicians who hold no personal religious affiliations, they are I believe heavily influenced by the corporate attitudes of their professional organisations. This is gradually changing as younger people join the specialty. Palliative care physicians quite rightly press for universally better access to care but this does not need to preclude assisted dying provisions.

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

It is important to distinguish between those jurisdictions that support physician assisted dying only in those who are competent to make a personal choice and those jurisdictions which permit euthanasia without the patient making an explicit personal choice. The States in the USA that have followed the Oregon model have broadly adopted physician assisted dying and rejected euthanasia under all circumstances. So it is unsurprising that research from across the US report similar findings to research on Oregon's legislation. Hedberg reviewed all the literature on the Oregon legislation in the *Annals of Internal Medicine* 29 September 2017.

Overall, the numbers remained small over the 20 years of experience and while there was an increase in cases, the increase was not a statistically significant change in the population of terminally ill people who opt for an assisted death. Only two thirds of those prescribed a lethal medication actually took it, one third kept it as 'an insurance policy'. The median age at death was 72, younger than the population average age at death. These patients are more likely to be white, college educated and with a diagnosis of cancer (76%) or (7%) ALS (amyotrophic lateral sclerosis). Eighty eight percent of recipients in receipt of a prescription were receiving hospice care and were supported by a palliative care programme.

The review authors were however concerned that in the second decade fewer patients had received a psychological evaluation and since 2017 there has been a policy rethink in the States to improve the percentage who do get evaluated fully.

There has been relatively small participation by physicians in the work, only 6% of Oregon physicians participate, and this means that access is still difficult and the process is not incorporated into mainstream care as the policy developers had hoped.

There has been no 'slippery slope' to include disadvantaged people in any jurisdiction that supports physician assisted dying. The slippery slope is a convenient myth for the opposers to peg their arguments on without any evidence. The Netherlands is oft cited by the opposers of the policy to show how the Dutch have extended their policy but they have always supported euthanasia in addition to patient directed assisted dying and when their practice is examined in depth it emerges that extensions are few and regularly reviewed. Recently the Dutch court has reiterated that monitoring of unusual cases is crucial and that physicians must not extend the policy beyond what the law allows.

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

A physician's primary duty is to relieve suffering, not to prolong life. Of course, those physicians and nurses who have a religious belief that hastening death under any circumstances is wrong then have to suspend their ethical commitment to the relief of suffering under some circumstances. I am not sympathetic to this approach and I don't think I should comment further except to say that the current UK legislation is cruel, counterproductive, drives people to suicide and is ethically reprehensible.

We know that many doctors currently prescribe large doses of opiates to hasten death by hours when the dying process appears to be distressing, over and above what would be necessary for pain relief. This practice is condoned in many countries including the UK but is insufficiently talked about. If it is ethical to consider doing this in the final stages of an illness, why is it not ethical to do this at the patients' request some days or weeks earlier?

Much is made of the difference between enabling patients to withdraw from life saving treatment and physician assisted dying. In reality of course the end point is the same. The only difference very often is that in the first instance a cannula is pulled out and in the second a cannula is put in! It is beyond my understanding why, if both actions are at the request of a competent patient, one action might be considered a legal requirement and the other an unethical intervention.

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

The criteria should surely be that a person with mental capacity sufficient to make the decision is likely to be within a few months or so of death from an untreatable terminal illness and has expressed a wish to die which is sustained and rational, in the absence of a treatable mental disorder. It would be a mistake to include any reference to suffering or other subjective criteria since only the individual is in a position to decide whether suffering is bearable or not. Setting an arbitrary time limit on the date of expected death is not ideal, but one has to start somewhere and six months or a year seems right. What is crucial is not to get obsessed about specific time limits. It is rarely possible to predict accurately when death will occur

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

We must differentiate between coercion and undue influence. Coercion occurs when an overt threat of harm is intentionally presented by one person to another in order to obtain compliance. (eg. "If you do not kill yourself, Mother, you will not be able to come home to live with us again but will have to go into a home.") Undue influence by contrast occurs through an offer of an excessive unwarranted inappropriate or improper reward (eg. "Think how much better off your children will be if they do not have to be burdened with your care".) In a recent review the American Bar Association research review found that undue influence, while often cited, was rarely supported in testamentary capacity cases or other cases by the court judgement. Undue influence was found only in those with cognitive impairments and mental disorders of the kind that would preclude the individual from being eligible for assisted dying. There are some very rare cases of severe dependence of one family member on another, usually in an isolated eccentric two person household but these are easy to identify because of the interference of the dominant person.

It is crucial that any 'protections' to prevent coercion or undue influence should take a common-sense approach and not be so burdensome that a decision cannot be made quickly. In most jurisdictions two doctors, independent of each other have to interview the patient separately and agree that the illness is terminal, that the patient has the necessary decision-making capacity, that there is a cooling off period in which a patient has time to reflect. All doctors are trained to assess capacity (for testamentary capacity and consent to medical interventions etc).

Evidence from other jurisdictions is that the poor, the dependent and the very frail do not seek an assisted death but it is very important for doctors to be alert to 'hovering' relatives (memorably referred to as 'vultures' by Lord Tebbit) and the possibility of coercion. Battin et al, 2007 found that where assisted dying is already legal, there is no current evidence for the claim that legalised PAS or euthanasia will have disproportionate impact on patients in vulnerable groups. Those who received physician-assisted dying in the jurisdictions studied appeared to enjoy comparative social, economic, educational, professional and other privileges.

<http://dx.doi.org/10.1136/jme.2007.022335>

Baroness Finlay and Dr R George have criticised the methodology of Battin's paper, pointing out the lack of psychological assessments and indeed most papers about this topic can be similarly criticised. But these two vociferous and well known opponents of assisted dying have produced no evidence to the contrary of their own.

**Perhaps most importantly there should be a monitoring process for the review of individual cases and a reporting system that enables research data to be compiled.**

It has been suggested by the House of Lords and others that a judge should oversee the process and make the final decision. I am against putting this kind of barrier in the patient's way, however swift the judicial process, it will merely add to the bureaucracy and insert an extra hurdle to a process which should be part of care.

There will never be enough 'safeguards' for those opposed to assisted dying, and the search for the holy grail of total safeguards is a red herring designed to distract legislators away from what is possible and humane.

**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?**

Above all patients need honest conversations with their doctors, nurses and relatives about their illness, their hopes and fears and have an opportunity to have palliative care advice and support. This requires not one isolated discussion but several over the course of days or weeks. It is almost never a good idea for professionals themselves to raise the idea of assisted dying and unnecessary because patients raise the matter themselves, often in a very roundabout way, to 'suss out' their doctors' and nurses' views. But medical teams should be alert to what patients are saying and asking. Patients need time and open conversation above all. I cannot envisage any literature being a substitute for that. An independent advocate could be helpful in supporting a patient through the process but I would prefer as few extraneous people involved as possible.

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

The mental capacity to make the decision in the absence of mental disorder.

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

First and foremost, the Government should promote discussion in parliament and consult widely. This means allocating parliamentary time. Governments so far have been unwilling to do that with the consequence that we are falling behind many other countries.

**Final remarks.**

As a psychiatrist who has worked with old and dying patients, I know that the vast majority of older people who are expressing a wish to die are suffering from a treatable depressive disorder and one's sole duty as a clinician is to work tirelessly to help the patient survive through those suicidal feelings and support them through the depressive episode. Furthermore, some patients with a diagnosis of terminal illness go through periods of hopelessness after diagnosis or after a particularly gruelling course of treatment but with support come out of it again and face the terminal course of illness if not with equanimity, then with acceptance. It is important to sort out one group from the other and be there for all these differing phases of illness.

Patients with a terminal illness who know they are approaching death are often quite clear headed. As has already been said, dying people who seek an assisted death are usually distinctive personalities and sometimes not very easy patients. They hate above all the prospect of total dependence on others, detest losing control and are unwilling to sacrifice their individuality to institutional norms. They want to be in charge of their fate and it is the uncertainty about the end that is distressing to an unbearable degree. It is scarcely ever a matter of pain control, or release from other symptoms although, as we know, there is insufficient expertise in the palliation of pain and the expansion of palliative care services to the very old and those with longer term terminal conditions is long overdue. No, it is not that. What causes their unbearable suffering is not remediable by medicine nor psychological supports but by respecting their wishes and supporting them to choose their own time of death. I can think of no greater privilege, as a doctor, than being trusted to help make happen a person's final wish.

I would be very willing to attend the Committee in person if the members would find that helpful.

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