

Written evidence submitted by Baroness Barbara Young of Old Scone (Member at the House of Lords (ADY0310))

I sat on the Commission on Assisted Dying between 2010 and 2012, during which we heard endlessly and quite heartrendingly from medical professionals, patients and relatives of those who had already passed away about the inadequacies of the current choices that exist at the end of life. Years later, and the Parliamentary process has failed to give dying people in the UK the same choices as those now available to people in 26 jurisdictions across the world.

In the submission below, I wish to draw the Committee's attention to the experiences of dying people in the UK and the urgent need for Parliamentary time to be allocated for an evidence-based debate and a free vote on the issue of assisted dying.

Summary responses to terms of reference

- Palliative care and assisted dying can and must work together to offer dying people meaningful choice at the end of life
- I support the eligibility criteria proven to work in the legislative models adopted in the US, Australia and New Zealand - i.e. that which allows a terminally ill adult with mental capacity to make the decision to seek assistance to end their life via life-ending medication, following the approval of two doctors.
- Clinicians already assess life-expectancy and decision-making capacity and detect coercion. Assisted dying legislation and related reporting requirements will bring much needed transparency to end-of-life care. If all six states in Australia, New Zealand and nearly a dozen states in the US are able to develop, implement and monitor assisted dying laws which balance protection and autonomy, we can too.
- The role of the Government is to grant Parliamentary time for a full and proper debate so that all the necessary stages of a Private Members' Bill on assisted dying can be completed. Governments have in the past, facilitated similar liberal reforms which we now take for granted, such as the decriminalisation of homosexuality, the legislation of abortion and the abolition of the death penalty, and should do so again.

It has been over 10 years since I listened to evidence from individuals and family members and clinicians about the devastating impact of the current blanket ban on assisted dying. Parliament's failure to act means that what I heard during my time at the Commission on Assisted Dying, mirrors the correspondence I continue to receive from the public today.

These are the voices that matter and why I seek draw the Committee's attention to them.

Individual autonomy and a compassionate response to suffering should be at the heart of this debate

On the Commission, we heard testimony from terminally ill people or those who might well die prematurely from terminal conditions due to a family predisposition that the dread they were feeling of what might lie ahead would be considerably tempered by knowing that when it all got too

much, they had some way of being released at a time and in a manner of their choosing and in a familiar setting with family and friends around.

Debbie Purdy's evidence to the Commission addressed the principle of autonomy from a particularly personal perspective, emphasising the huge value of individual autonomy to her own life:

"I want to be in control of my life, and that means I want to be able to live it as long as I can, but I want to be able to choose what quality of life is liveable; I don't want somebody else to tell me that 'the quality of your life's ok, what are you complaining about?' I want to be able to make those choices myself. I want the help and support to make it."

Ms Purdy posed the question:

"As a civilised society, are we really saying that you have to live out your time however much pain you're in and however much the people you love have got to see you suffering...Rather than ending it earlier?"

Debbie Purdy argued that the risk of harm to vulnerable people posed by assisted dying legislation could be minimised by the inclusion of robust safeguards in law:

"I think it's not beyond our wit and wisdom to come up with solutions that provide support for people like me, and protection for people who would otherwise be pressured."

Debbie Purdy was right. Terminally ill citizens of 26 jurisdictions including eleven American States; six Australian states and nationwide in New Zealand have been afforded the ability to die as they have lived – on their own terms – while protecting those who may potentially be vulnerable. Over 200 million people around the world live in a place where some form of assisted dying is legal. In contrast, dying Britons are faced with an archaic set of choices.

The current law treats caring, traumatised relatives as criminals and forces terminally ill people to die alone

Chris Broad gave evidence to the Commission about his very difficult personal experience when his wife Michelle Broad, who was terminally ill, ended her own life and his family was subsequently investigated by the police under suspicion of having assisted her suicide. He explained that Michelle had been diagnosed with motor neurone disease and had made the decision 'that she was not going to see this disease out, because it is a horrible disease'. However, the fear of his prosecution meant that she felt she had to go through this alone. While Chris was very positive about the respectful manner in which the police handled their investigation it was a stressful and upsetting experience at one of the saddest times of his life:

"Michelle had organised the end of her life remarkably well — left little gifts for her tennis club members and notes for me and the children, and what have you. And they just swooped up all of those things and took them away."

Alan Cutkelvin Rees, who accompanied his terminally ill partner Raymond to Dignitas, told the Commission that while the police treated him with the utmost respect he felt unfairly stigmatised by the process. Moreover, as far as I am aware, despite his requests to remove them, Alan's fingerprints and DNA profile are still retained by the police. While Raymond thankfully did not have to travel alone, the experience was clearly very difficult.

“Mentally it would have been far better for Raymond, knowing that it could have been done in the country of his birth and he was just totally disgusted that it wasn’t. We did loads of research on assisted suicide or assisted dying, whatever you want to call it. And it was his choice; it was what he wanted to do. It was his choice, his body; he was the one suffering, no one else... If countries like Switzerland, for example, can have an assisted suicide procedure, done totally and utterly professionally and with lots and lots of compassion towards the people, then I can’t see why the UK can’t do that as well.”

That these investigations must continue to take place is no fault of the police, it is the fault of a law that is outdated, unpopular and lacking in compassion. Police officers will often feel distressed at having to investigate these cases, and it is a waste of police time and resources, not to mention the damage it does to public confidence in the police. It is clear the current law is not working well.

The current laws also make it difficult for those who choose to travel abroad for an assisted death. They are anxious about involving family or friends and often make the decision to travel while they are still able to do so unaided rather than implicate them.

Assisted dying should be just one of the many options at the end of life... it should be part of very good palliative care. (Dr Ann McPherson)

The late Dr Ann McPherson, chair of the campaigning organisation [Healthcare Professionals for Assisted Dying \(HPAD\)](#), gave evidence to the Commission in the knowledge that the pancreatic cancer she was suffering from would soon cause her death. Dr McPherson explained:

“The fact that doctors cannot even discuss patients’ desires for an assisted death under present guidelines seems to work against doctor–patient trust and the general principles of the End of Life Care Strategy of open discussion of death and fears related to death and dying. In effect, the law interferes with the doctor–patient relationship and as such a doctor cannot help or comply with patients’ choices when they might most want help. Indeed, when they are at their most vulnerable, patients are not protected.”

She felt she was *“letting patients down by not being able to talk about these things when they were at their most vulnerable and actually wanted to talk to me about them.”*

We need to ensure that it is seen as a normal part of medical care to have a relaxed and full discussion of all the options for a good death, including assisted dying. With the current state of the law, health care professionals shy away from such discussions as they fear being seen as culpable by the law.

Dr Ann McPherson argued that for some palliative care specialists, a patient’s desire for an assisted death is wrongly perceived as a failure on the part of the palliative care service:

“A very eminent palliative care specialist said to me that when I had patients who still wanted assisted dying, she said, ‘well they couldn’t have been having very good palliative care’, absolutely not true, they were having superb palliative care. I certainly challenged her to come and see the people in Oxford who run a very good service, at the hospice there and with outreach. It wasn’t that they were not getting very good palliative care, they were terminally ill and they had had enough of being paralysed and they wanted to die.”

Dr McPherson was also of the view that ‘good quality end of life palliative care can alleviate much, but not all, the suffering that the dying process can cause’.

Dr McPherson's observations remain true today. In the UK, there is a small but significant group of people who, [despite receiving the highest quality end-of-life](#) care, die without dignity, without pain relief and without full control of their symptoms. This is unacceptable.

Conclusion

It must be made absolutely clear that each jurisdiction crafts legislation to suit their society and citizens. But with the evidence of the devastating impact the ban on assisted dying has in the UK surely it is time to agree that doing nothing is not an option.

While we do lag behind other liberal democracies, it does mean we have the benefit of lessons learned in terms of clinical training, medical protocols, monitoring and reporting. There is an extensive quantity and quality of detailed evidence and it is imperative that we move away from speculation and utilise this robust data to inform our debates and decision-making.

This is the role of Government – to seek and gather evidence and devote time for a full and fair debate.

Moreover, it has been a decade since the Commission on Assisted Dying reported that the law on assisted dying was “inadequate and incoherent”. If anything, this situation has worsened in the intervening years, as we repeatedly face a ‘Grand Old Duke of York’ scenario in Parliament: laws are brought forward, approved at Second Reading, given inadequate time for further consideration, and fall at the end of the session. This is not how we as a Parliament should consider such important issues.

I would urge the Government to ensure that a bill on assisted dying should, if it is supported by Parliament, be given the time it needs to make real progress, so that we can properly debate the principle and the details of assisted dying, bringing us more into line with the public's views, with the laws of other liberal democracies, and with the wishes of dying people.

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