

Key quotes from evidence sessions during the Committee stage of the Terminally Ill Adults (End of Life) Bill

Disability and Equality

“The Assisted Suicide bill highlights this arbitrary nonsense around a six-month perspective (what constitutes six months left to live) particularly if you are engaging with technological devices with medical assistance. I have a progressive condition which continuously gets weaker and have respiratory complications. If I remove my ventilator which I use at night and if I remove my medical devices and my engagement with therapeutic services- does that constitute then that I will have a terminal illness because my rapid acceleration towards death becomes more evident?”

Dr Miro Griffiths, disability studies scholar and researcher, Leeds University, Terminally ill adults (end of life) Bill, Committee Debate, 4th Sitting morning session, Wednesday 29th January 2025

“There should, in our view, be an advocate who is supporting the person and preparing them for that discussion. Under the principles of the Mental Capacity Act 2005, the person should have accessible information in advance of that discussion so that they are fully informed about all their rights in terms of treatment options at end of life. That discussion with a clinician should not be taking place until the person has been able to consider that information and have support from an advocate, so when the conversation does happen the person is fully informed and has had time to think about what their wishes might be. That would reduce the risk, which is absolutely there, that people could take the initiation of that discussion as a statement, “This is what you should do.” We absolutely do not want people to be in that position. We want strong safeguards and support in place if the Bill becomes law.”

Dan Scorer head of policy, information and advice at Mencap, Terminally ill adults (end of life) Bill Committee Debate, 7th Sitting afternoon session, Thursday 30th January 2025

“I think when it comes down to individuals, as I say, you are not going to be able to work out whether someone is disabled, terminally ill, black—people have so many identities. The issue for us, and the reason we are opposed to it, is not that we do not think that what is happening to people at the end of their lives is difficult—of course it is. But we took the view that we are trying to create a society where disabled people are equal and valued, and in that sense the Bill actually makes it harder for us to reach a disability-inclusive society. We come at it from that view. As parliamentarians, I know you want to look at the problems of individuals, but you also have a responsibility to think about the society we want to create. I and other disabled people feel that we already have an uphill struggle convincing people that our lives are of equal value, and this Bill hinders us in this.”

Fazilet Hadi Head of policy, Disability Rights UK, Terminally ill adults (end of life) Bill Publications, Committee Debate, 5th Sitting afternoon session, Wednesday 29th January 2025

“On coercive pressure, we have heard recently about social care provisions. Social care is an integral part of this story, because the data shows that it is older disabled people—disabled across a spectrum including mental health, dementia and so on—who are likely to be in care or to require social services. If we are not going to get the result of those reforms until 2028, we are told, with potentially no legislation in place for another couple of years after that—say, 2030 or 2031—then all of you in Parliament need to think about whether this is putting the cart before the horse. In deciding on these provisions, which are integrally linked to the other aspects of disability and access to care—I hope we will come on to the variable treatment of palliative care later—you need to think about whether this is the right order of things.”

Baroness Kishwer Falkner, chairwoman, Equality and Human Rights Commission, Terminally ill adults (end of life) Bill Committee Debate, 4th Sitting morning session, Wednesday 29th January 2025

“I work predominantly with an ethnically diverse population- I've gone into those communities, I've spoken to them about this Bill and what they say overwhelmingly to me is we're scared. We're really fearful that this is going to result in disproportionate impact on our community. We've seen that through covid, and we're really scared. We already don't access your services, we're all we're really worried that we're not going to want access to them anymore or to enter a hospital.”

Dr Jamilla Hussain, clinical academic and consultant in palliative medicine, Bradford Teaching Hospitals NHS Foundation Trust, senior research fellow, Bradford Institute for Health Research, and honorary senior research fellow, Wolfson Palliative Care Research Centre, Hull York Medical School, Terminally ill adults (end of life) Bill, Committee Debate 5th Sitting afternoon session, Wednesday 29th January 2025 Available at:

Eating disorders

“My area of research has historically been the treatments and prevention of eating disorders, but last year it took a turn and I, along with my co-author, Dr Catherine Cook-Cottone, completed a systematic review of assisted death in eating disorders. Our findings really shocked me. We found that at least 60 people around the world have been euthanised or assisted in suicide—I am using jurisdiction-specific terminology there; I will use “assisted death” and “assisted dying” today including in three jurisdictions in the United States, where I am from: Colorado, California and Oregon. That is important for the Committee because those are jurisdictions where assisted death is legally restricted to terminal conditions. We saw anorexia nervosa listed by name as a terminal condition. Most alarmingly to me, in two of the states we could find no mention of documented cases in the annual state reports. Had a physician and her colleagues not written a paper and told the world about it, we would not know that those young women had died. In 100% of the cases we reviewed, the people were women, a third were between the ages of 18 and 30, and two thirds were under the age of 40. I have to emphasise that these were young women who did not have failing organs and did not have comorbid terminal conditions; in none—zero—of the cases we reviewed was there organ failure or comorbid conditions, and they had decades of life ahead of them.”

Chelsea Roff, Founder of Eat Breathe Thrive, Terminally ill adults (end of life) Bill, Committee Debate 4th Sitting morning session, Wednesday 29th January 2025 Available at:

Palliative care

“People pointing out problems with palliative care in the UK is not a pro or anti position in this debate. It is a statement of fact. Clearly, extrapolating that through, an outcome in which someone chose an assisted death because of a real or imagined fear that they could not get pain relief or other symptom alleviation, or because their family would not get support through their illness, would clearly be a moral and practical disgrace for any country. I think that is why people who are passionate about palliative care would obviously be concerned, but I think they also would be very encouraged by the fact that everybody who spoke at the debate in November, without exception, expressed commitment for improved palliative care, irrespective of what they felt about the rights and wrongs of the motion that they were considering.”

Toby Porter, chief executive officer Hospice UK, Terminally ill adults (end of life) Bill Publications Committee Debate, 5th Sitting afternoon session, Wednesday 29th January 2025

“That more recent evidence shows that although palliative care services have improved in those countries where assisted dying has been implemented, they have improved three times more in countries where assisted dying has not been implemented. The evidence from that study shows that the implementation of assisted dying is impeding the development of palliative care services.

The other thing we are really concerned about is the impact on funding. It is unclear how this is going to be funded. It looks as if it is going to be within healthcare, and if so, there will inevitably be competition with other aspects of healthcare, including palliative care, for those limited resources. There are finite numbers of doctors, nurses and side rooms in hospitals. If palliative care and assisted dying were funded from the same pot, I think there would be a massive detrimental effect on palliative care because we would be in competition for a limited resource.

I am also concerned about our palliative care workforce, which we know is already in crisis. Eighty-three per cent. of our members told the Royal College of Physicians in 2023 that they had staffing gaps, and more than 50% were unable to take leave because of those staffing gaps. Forty-three per cent. said that if assisted dying were implemented within their organisation, they would have to leave. This has a massive impact on palliative care, in terms of its potential to develop both our funding and our workforce, who are really concerned about this.”

...

“The first thing to say is that palliative care is currently inadequate. Not only do we need to ensure that it does not decline, but we need to massively improve it so that this Bill offers patients a real choice. We know that effective palliative care can change a terminally ill person’s point of view from wanting to die to wanting to live.

We also know that 25% of people who die in this country do not have the palliative care they need. That is more than 100,000 people a year. Providing palliative care, which might make their lives better, reduce their suffering and even change their perspective on whether they would want assisted dying, should be our priority in reducing suffering in this group.”

...

“Of course we do not want people to have to make that choice. I will refer to everything I have said before: are they are making a real choice, and have they had access to really excellent palliative care?”

I also make a brief point about the impact of the discussion around what dying looks like that the Bill has raised, and the fact that the stories that have been told have suggested to many members of the public that death is inevitably ugly, horrific and dramatic. Actually, that has made many people fearful, and they have been emailing me and saying, “I am now afraid of dying, and I wasn’t before.” They may then choose assisted dying before they need to because they have had a fear instilled in them that death is inevitably horrible and dramatic.”

Dr Sarah Cox, president, Association for Palliative Medicine, Terminally ill adults (end of life) Bill Publications Committee Debate, 3rd Sitting afternoon session, Tuesday 28 January 2025.

Elder abuse

“I think there is a fundamental misunderstanding around what the abuse of older people is, and that has been borne out by a number of research papers that we have written, some working with YouGov, for example. Likewise, as I said, it is also a question of understanding what coercion is and getting the older person to open up, to help them to understand and to trust the person they are talking to. We fully believe that there is nowhere near enough training and understanding across the medical profession and the judiciary around understanding the signs of abuse or coercion. Even though we completely welcome the new law on coercive control in the Domestic Abuse Act 2021, we have not seen a significant change. If anything, we as a charity believe that there is an epidemic of abuse against older people at the moment. Some of it is due to the economic climate that we are in, with people just wanting to have their inheritance now, and some of it is due to the fact that older people feel like a burden. You mentioned Oregon: of course, there is also the statistic that 48% of people who went down the assisted dying route in Oregon cited being a burden as part of their decision-making process. I think that the abuse of older people in this country is vastly underplayed. I have mentioned the 75,000 impacts that we see and the 2.6 million people affected by it, but we have to fight for headlines and for understanding in every sector of society. It is seen as a minority issue, and it is really not. It is not a niche issue, and it is growing.”

Richard Robinson chief- executive officer, Hourglass, Terminally ill adults (end of life) Bill, Committee Debate, 5th Sitting afternoon session, Wednesday 29th January 2025

All evidence transcripts can be accessed at: <https://bills.parliament.uk/bills/3774/publications>