The Scottish Parliament
Pàrlamaid na h-Alba

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1 April 2025

Committee Evidence on the Assisted Dying for Terminally Ill Adults (Scotland) Bill

Dear Ms Haughey,

I am writing to you in your capacity as Convenor of the Health, Social Care and Sport Committee regarding the Assisted Dying for Terminally Ill Adults (Scotland) Bill.

I understand that the committee recently took evidence as part of its Stage 1 scrutiny of the Bill and I hoped that you would add to your evidence a letter from me to the Committee, enclosed at Appendix 1, setting out concerns I have on the proposed legislation and consider further context on the evidence session on Tuesday 14 January, which I will set out below.

Open Letter on Assisted Dying

The letter in Appendix 1 is not something I have considered sending lightly, but as the only permanent wheelchair user in the Scottish Parliament, and a long-term advocate for disabled people's rights, I felt it important to make clear my views. I thank you and the committee for considering it.

Evidence Session on Tuesday 14 January

I recently hosted an event for the Cross-Party Group on Disability with Jeremy Balfour MSP. At the session, which all members were invited to, we heard from crossbench peer Tanni Grey-Thomson and actor Liz Carr. It was a powerful session and I hope to be able to offer further opportunities for members to hear from both Liz and Tanni.

In the Q&A that followed presentations, a number of disabled people highlighted some issues they had picked up from an evidence session, which I agreed to write to you about.

Representatives from Disabled People's Organisations (DPOs) were invited give evidence on the Bill on Tuesday 14 January. While this is an emotive issue for many disabled people, the DPOs in attendance were grateful for the opportunity to offer their views on the Bill.

During the session, it was put to the panel of witnesses that polling evidence suggests that support for assisted dying among the disabled community broadly maps the position of the population at large. A survey of Disability Scotland's membership was quoted to specifically state that there was strong support for assisted dying among 57% of its members, support for it among 20% of its members, with opposition at just over 10%.

This information was put to the panel, and they were asked to respond. The survey response was put forward as evidence of a representative sample of disabled people and so following the session, DPOs present felt it was important to set out to the committee that the views they were expressing were not their own, but from their members, with the DPOs in attendance being member-led organisations.

I think it might also be helpful for the Committee to understand that one of the DPOs present had decided previously not to take a position on assisted dying but were approached by the membership who asked the organisation to take a position against the proposals, on their behalf, particularly following the treatment of disabled people during COVID 19.

Lastly, during the session they were asked whether their views were motivated by religion. They have asked that I clarify that they are not, and that it is their belief that all lives should be valued regardless of whether a person is disabled or non-disabled, that drives their opposition to the bill.

As a serving member of a Committee in this Parliament, I understand the importance of robust evidence being presented to committees. It is my hope that in offering some context and clarification on behalf of the organisations present on Tuesday 14 January, Committee members can see that the organisations were coming from an informed, broad base of support for their views from their membership, and not simply putting forward a view of a minority of people.

I hope that the Committee find this helpful in their deliberations on the bill.

Yours sincerely

Pam Duncan-Glancy MSP
Member of the Scottish Parliament for Glasgow Region

APPENDIX 1

1 April 2025

Dear colleagues,

I don’t often do this, and I haven’t taken this decision to write to you lightly, but as the first permanent wheelchair user in the Scottish Parliament I am asking you to vote against the Assisted Dying for Terminally Ill Adults (Scotland) Bill at Stage 1 and to stand up for disabled people who, like me, are frightened about what it will mean for us.

I know that some MSPs support the principle of assisted dying/assisted suicide but have some doubts about what is in – and not in – this bill. You are right to have doubts: we are not simply voting on the principle of individual choice, but on a hugely consequential piece of legislation that I believe would put sick and disabled people in very real danger.

If this bill passes, there is a real risk that, for people like me, it will be easier to access help to die than to live.

Some supporters of the bill say that it is not for people like me, disabled people are not included. But by most definitions, including the Equality Act definition, someone who has ‘an advanced and progressive disease, illness or condition from which they are unable to recover and that can reasonably be expected to cause their premature death’, is a disabled person. It is worth noting that this is the case whether the person was disabled for all or only the end of their life. Disabled people *are* therefore included, both because we exist already as part of the population, and, because at the point at which the eligibility test for the bill is met, the person who was not previously considered disabled, would be considered disabled. To say that it excludes disabled people, is not therefore the situation, which is why simply saying disabled people are excluded is neither the case, nor enough to reassure us.

Some people also say that it doesn’t apply to *all* disabled people and so we shouldn’t worry, but the truth is, we only need to look at other countries where assisted suicide is legalised to see why we’re still worried. In almost all cases, the legislation has been extended to include people who are not at the end of their life, but that are experiencing pain and suffering. And, indeed, the bill before us doesn’t stipulate time to end of life. It is very open ended and is significant cause for concern.

While the bill’s title implies that it is aimed at those who are terminally ill, many people live with ‘conditions from which they are unable to recover and that in some cases can reasonably be expected to cause their premature death’. This broad criterion, as it stands, includes many people who can reasonably hope to live joyful lives for decades yet.

It includes me.

Without the support network I am lucky to have, someone with my condition could easily be vulnerable to coercion, covert or otherwise, or being made to feel like a burden.

Even were time limits to be included, as with the bill at Westminster, my deep concern still stands. The difficulty for doctors in accurately predicting terminal patients’ time remaining is well known.

Additionally, there is nothing in the bill to address any potential perverse incentives for the underestimation of someone’s likely lifespan, either for merciful reasons, like the patient having expressed a wish to die, or much more troubling reasons, such as a shortage of hospital beds – indeed, the Financial Memorandum to the bill notes savings to the NHS.

There are also issues with the relationship between the health professional and the patient, which I will turn to later. In short, no time limit is extremely dangerous, but adding a time limit does not address fears or concerns either.

Proponents of assisted dying point to intolerable pain and suffering as a reason for supporting this bill. What constitutes intolerability is of course subjective and, although it is true that many people experience what they would describe as intolerable pain and suffering, other things are also true: that someone's judgement of what is intolerable is affected by what support is available to them and what hope they have that the suffering may be alleviated, and that many people who at one point have wished to end their life have gone on to be very glad they did not. We all work hard to ensure a good life for our constituents, but I'm sure we would all recognize that there is much to do to support disabled people and people at the end of their lives to live and to prevent them from being in circumstances that could be considered intolerable to them in the first place. Unless and until we can say that our responsibility as legislators and representatives should be to support people to live their lives with less pain and more support, not simply make it easier for them to end their own lives.

Many of the organisations who support this legislation also support its extension. And indeed, when asked, supporters of the legislation want it to go further – they see this as just the first step. Lessons from other countries show that extensions are likely.

Supporters of the Terminally Ill Adults (End of Life) Bill in the House of Commons talk of solid safeguards against coercion but have not been able to set out details of how such safeguards could be achieved. Indeed, when the ability of the Courts to deal with any rise in cases that the bill would incur was highlighted, that safeguard was removed. An acceptance that protection and support from the state is reliant on structures and systems and that where that capacity is not there, the protection is removed. This is exactly the sort of thing that gives us cause for concern.

I've also been particularly worried to hear MPs explicitly state that someone feeling like a burden (including a financial burden) is a legitimate reason to assist them in ending their life. This is a brutal sentiment in itself, and in the context of overstretched health, justice, and social care systems it is impossible to see how there could ever be certainty that someone has not been pressured into feeling like this.

As a disabled person, I am lucky. I've been empowered in many ways. But even from a position of relative power I, like most disabled people, still experience negative attitudes and discrimination, firsthand. Most recently, I was asked in a radio interview whether I ever wanted to end my own life. The interviewer had no basis on which to ask me this question except for the fact that I am disabled. Societal attitudes are such that there is no one who 'this bill is not for'.

I know that this is a deeply personal issue for many of you, and it is for me too. I cannot do many of the things other people take for granted, my condition will not improve, and, for various reasons, I too have felt at times that life was incredibly painful, intolerable even.

Some of that is about physiological pain and suffering, yes, but the truth is, the moments that have caused me the most pain and suffering have come when I have been faced with structures, systems and attitudes that do not support me to participate in society or lead an ordinary life: when I've been told my care package could end, or when I had to defer entry to university for two years because I couldn't have my needs met, or when I've been fighting everyday ableism and got so tired of it that I've come to believe the low opinions people have. In those moments, it has felt intolerable.

I have been asked whether I'd wear incontinence pads, to reduce my need for care to help me to the toilet. I have been told there is no accessible examination bed for essential cancer checks. And I have spent an inordinate amount of my life navigating the endless bureaucracy that surrounds disabled people's access to their rights (it takes hours just to gather the evidence needed to apply for a Blue Badge). I share these to highlight the extent to which disabled people can be ground down by a society not yet ready for them. We must have a better answer to this than to make it easier to die.

The current bill speaks of affording people "dignity" at the end of life. The concept of "dignity in dying," as it's generally understood, implies that it is inherently undignified to suffer, or to need help. It is not, and – particularly as someone who has always suffered, always needed help, and always will – I find this idea extremely upsetting, and I am terrified of the potential consequences of it being enshrined in law, particularly when rights for disabled people to practical assistance and support to enjoy a dignified life are not. The overwhelming perception that where we to need significant care and support we would be *better off dead* is at best deeply damaging to the perception of disability, and at worse, has resulted in people having DNAR orders wrongly put on them, and is easily internalized when it is so pervasive to the extent that someone can come to believe they are of no worth.

During COVID-19, my husband and I wrote letters to say, "please do not put a DNAR on us". This was not paranoia. Such is the value placed on disabled people's lives, even by some medical professionals, that in the height of the pandemic, *hundreds* of DNAR orders were decided upon without any discussion with the patient or their family. No one should feel their existence is a burden on others and I honestly fear that this bill could make this already present feeling among citizens much, much worse.

In 2017, the UN Rapporteur accused the UK and devolved administrations of "grave and systematic violations" of disabled people's human rights. In 2024 the UN concluded that, not only have these issues not been tackled, but there have been further regressions, partly due to COVID-19 and the impact of the cost-of-living crisis on disabled people. Research shows disabled families are 62% more likely to fall into deep poverty, one in four disabled people don't get the palliative care they need and 10,000 people in Scotland are stuck in their own homes because they are not accessible.

Attitudes towards us are also worsening. Disabled people's lives are often portrayed as tragic and worthless in the media, on TV and in literature, and these illustrations promote and support the concept that people would be *better off dead* if they cannot walk, talk, eat, or go to the toilet without assistance. All of this shapes the context in which people decide if their lives are "tolerable" or not.

These factors lead to internalised ableism that no safeguard can counter. The feeling in your gut that you are not worthy. That you use services that mean public finances are tight. That you are a burden.

For these reasons, I'd ask you to ask yourself; are you sure that in today's world, there could ever be enough safeguards to protect disabled people, whose lives are undervalued, from being under pressure to end their lives?

I'd also ask you to consider our vulnerability to coercion. Abuse and coercion remain a reality across all areas of life – within families, regulated care settings such as care homes, schools, hospitals, and community support services – that occur despite multiple safeguards, regulatory bodies, inquiries, and prosecutions. Disabled people, and in particular disabled women, experience coercion and abuse more than others. Despite being among the most regulated group of people in the world, we are not immune from it. Nothing has protected us from it yet.

The rights of care home residents were disregarded as patients with COVID-19 were admitted to their homes, while limits were placed on who would receive vaccinations, boosters, and treatments.

Coercion is not always easily recognisable, and its interplay with everyday ableism cannot be underestimated. For that reason, I find it hard to imagine a circumstance in which coercion, especially covert coercion, is properly safeguarded. And in this instance, the price of that would be life.

Relying on a registered medical practitioner, as the bill does, to detect coercion is problematic too. Many people struggle to see a GP or other medical practitioner for ordinary healthcare issues, and many have not had a face-to-face appointment since the COVID-19 pandemic began. This means the relationship with their patients and extended family has changed, and that it could be more difficult for them to recognise incidences of abuse or coercion. This is particularly concerning given that much coercion is covert, rather than overt. It is also for these reasons that even having a time limit is not a safeguard.

It’s worth emphasising the issue of choice and capacity. In the context of our lived reality, I worry how it can be possible that disabled people can make a free and equal choice to allow the system that oppresses them, to also potentially help them to die. We would have to be very confident that none of these factors - coercion, feeling or being made to feel like a burden, the hospital needing the bed etc. etc. - will affect the individual’s decision making, before we could honestly say that this covert coercion and internalised ableism were safeguarded against. I believe anyone who is honest must acknowledge that we are very, very far from that point, and likely to remain so for the foreseeable future.

The bill says that a person has capacity to request lawfully provided assistance if they *are not suffering from any mental disorder which might affect the making of the request, and are capable of; understanding information and advice about making the request, making a decision to make the request, communicating the decision, understanding the decision, and retaining the memory of the decision*. It is entirely possible that someone meets all of these tests, but there is nothing to protect against the wider ablism, or coercion in this context.

I know that supporters of the bill say that this one is different from the ones people fear, as it has ‘the strongest ever safeguards’. The bill at Westminster made similar claims. Quite apart from the fact that both bills are markedly different and can’t both represent the ‘safest in the world’, the ‘safeguards’ to mitigate feelings of being a burden, coercion, fear of loss of function, can never be strong enough against a backdrop of a world of oppression for citizens – and have already, before it is even law, been watered down. The slippery slope is a reality.

I serve my constituents as you all do, and we work day and night to make life better for them. I am in this job because I believe against all odds, we can do that for everyone. And I know that you do too. I know that MSPs are considering the matter deeply, and I am writing to you today to ask that you consider the reality that disabled people face, and the consequences of an option you may open to them - making the choice not to live the easier one.

I promise you, that with the right support and the same freedoms, choice, dignity and control as others, life can, does and must go on.

Disabled people are under-represented in chambers making decisions like these. And we need you to keep fighting for our rights and levelling the playing field for us. Ultimately, the rights of disabled people are hugely compromised due to disabling barriers such as poverty, inequality, austerity, and the impact of the COVID-19 pandemic.

The answer to our pain and suffering is not to end our lives. The answer is to keep fighting, as you all do, to improve our lives and reduce pain and suffering by making our country better. For all to live well, including at the end of life.

Rather than legislate for assisted dying, legislate for assisted living. In my position as an MSP, I can represent and advocate on behalf of disabled people, and I hope you will keep them in your thoughts when you vote on (and I'd ask against) assisted dying.

Yours sincerely

Pam Duncan-Glancy MSP
Member of the Scottish Parliament for Glasgow Region