

Assisted Dying for Terminally Ill Adults (Scotland) Bill

Response from Glasgow Disability Alliance

22nd December 2021

We are happy for our response to be published and attributed to Glasgow Disability Alliance (GDA).

I confirm that I have read and understood the Privacy Notice, which explains how my personal data will be used.

Glasgow Disability Alliance (GDA) is a vibrant disabled people's organisation (DPO) controlled by 5500+ disabled members, who elect our Board of Directors.

Our mission is to build the confidence, connections and contributions of disabled people, recognising and building on talents and strengths.

Our vision is that disabled people participate and lead their own lives, connecting with each other, with opportunities and contributing to families, communities and wider society.

Community Development and Human Rights principles underpin GDA's work. We firmly believe that those experiencing inequality, should lead the changes and decisions that address such inequality. To achieve this GDA works collaboratively with others through partnerships & coproduction: working together, working differently, being leaders and demonstrating innovation and a culture of learning which we share with others, collaborating to make the most of our combined energy and resources.

GDA supports disabled people of all ages with any type of impairment, including those with long-term conditions and terminal illness.

We deliver free, inclusive and accessible activities and supports, including learning, digital inclusion, wellbeing, welfare rights, support to build voice and participation opportunities. We provide free transport, personal assistance, communication support, accessible information provided to enable participation. Thus, we are able to support those traditionally labelled 'hard to reach' who we feel should be more appropriately described as 'easy to ignore' as highlighted by What Works Scotland. At present, due to pandemic restrictions, all support is being delivered online.

Aim and approach

1. Which of the following best expresses your view of the proposed Bill?

· Fully opposed

Please explain the reasons for your response.

Glasgow Disability is fully opposed to any legislation that legalised Assisted Dying.

We have arrived at this decision based on our current consultation with 240 disabled people, over a series of large and small events, via phone and emails and discussion groups. Our response is further informed by previous and ongoing work with disabled people over a number of years. Like all other DPOs in the UK, we do not believe that this type of legislation is appropriate while disabled people remain unable to access their human rights on a basis equal to non-disabled citizens.

We have also considered evidence and research from other countries, states and provinces where assistance to die is legally permitted and are very concerned over these findings.

We wish to clarify the wording of the terminology used in our response. Although the Bill proposal uses the term 'Assisted Dying' we will use the term 'Assisted Suicide'. The medical profession is very clear that if a doctor prescribes medication for the purpose of ending a life and this is self-administered, this equates to assisting a suicide; if the medical professional administers life ending medication, this equals euthanasia. It is our view that the definition of the wording of the proposal amounts to Assisted Suicide. Other language is often used to make the subject more palatable, but we feel strongly that we need to be clear that this is what we are seeking doctors and other medical professionals to do.

We consider the timing of this Bill to be highly inappropriate, coming during a global pandemic, which has disproportionately affected disabled people. Our own research with 6000+ disabled people provided clear evidence of "[Supercharged Inequalities](#)"

- 60% faced digital exclusion, with no access to devices, WIFI and/or lacked confidence to use it.
- 80% were unaware of any local support services they needed and/or were unable to access them.
- 41% were unable to get information in the formats they needed.
- 82% worried about social isolation and loneliness.
- 62% were concerned about their mental health, with many people suddenly losing statutory and community based mental health support services.

- 90% were worried about both physical and mental health.
- 57% were worried about money and hardship.
- 47% were worried about access to food due to poverty, food shortages, lack of support to get food, digital exclusion and many were rapidly running out of food supplies.
- 47% were worried about social care – there were huge issues, including social care being withdrawn from around 1800 people with little or no notice. Others lost the regular informal support they relied on.

This lived experience is further evidenced by the [Disability Microbriefing](#): The disproportionate impact of COVID-19 on disabled people, produced by GDA, Policy Scotland and the Glasgow Centre for Population Health in Jan 2021.

COVID's impacts and the inequalities it has exposed and heightened have been dire. Disabled people are by far amongst the worst impacted and in fact, [National Records of Scotland](#) report a conservative estimate that 58% of deaths –were of disabled people, even though they make up only 20% of the overall population. The Report shows clearly that even adjusting for age and the conditions and impairments that we have- disabled women with higher support needs were 3.2 times as likely to die with COVID-19 compared to non-disabled women. Disabled men with higher support needs were 3.0 times as likely to die with COVID-19 compared to non-disabled men. And for those with some support needs there was still a significant increased risk of death - 1.8 times higher for both disabled women and men compared with non-disabled peers. (Deaths involving coronavirus (COVID-19) in Scotland, Week 11, 24th March 2021).

The Scottish Government report "[Covid19 and Disabled People in Scotland: health, social and economic harms](#)" published in March 2021, outlines how the pandemic has impacted more widely on disabled people and cites GDA's Supercharged report, as well as evidence from Inclusion Scotland.

Taking all of this into account, it is clear why many disabled people feel their lives are of less value, and this is the climate in which some people may make life-ending decisions which would be catastrophic. Indeed, over the past two years many more disabled people reported feeling suicidal and at breaking point due to feelings of hopelessness, physical pain, mental distress and lack of dignity, for example, losing social care support to wash, go to the toilet or deal with effects of incontinence.

Many people cited their experiences of the pandemic as the 'tipping point' that cemented their fears in relation to this legislation. "I can no longer trust that the state will look after me and make the best decisions for me as my health and wellbeing worsens. Everything I need to survive was taken away from me over the past 18 months. If it hadn't been for GDA, I just would not be here now."

Considering evidence from other countries, we are very concerned over widening of legislation, in Canada for example, where in only 5 years of being legalised, Medical

Assistance in Dying (MAiD) has been expanded from those whose death was 'reasonably foreseeable' in 2016 to now include those who are disabled people with impairments and chronic illness who have no terminal diagnosis, and by 2023 will include mental illness as a 'sole diagnosis'. It was [reported](#) that an elderly woman, who was not chronically ill or dying was euthanized in November 2020 to avoid living through another COVID-19 lockdown. Mrs Russell was described by her family as exceptionally social and spry. They said she chose a medically assisted death (MAiD) after she declined so sharply during lockdown that she did not want to go through more isolation this winter.

As Inclusion Scotland and Scottish Human Rights Consortium have described in their responses, we are highly concerned that legislation could easily be widened almost immediately as has been the case in other countries.

Care Not Killing and Not Dead Yet UK both have considerable evidence from other countries that clearly shows the 'legislative creep' that places disabled, older and ill people at extreme risk from any legislation that enables assisted suicide to become lawful. Inclusion Scotland have summarised this very helpfully in their response.

Our consultations with 240+ disabled people demonstrate our members clearly fear the impact of the proposed Bill and potential expansion of legislation:

- I'm really worried about this bill because I think the media are promoting that it's acceptable to be pro assisted suicide. Even if you put together a nuanced argument people don't listen. I wrote a letter to [national newspaper] and I spent a lot of time carefully putting it together. The responses were dreadful. One person said they were sick of hearing about disabled people. In a capitalist society where care costs money we are at disadvantage. People assume my life must be bad because of multiple conditions, but my life is great!
- I have had to fight continuously for the dignity of being considered an equal person, because people assume that my obvious impairments mean I am not an equally competent person. The association of dignity with physical competence means that I have far fewer dignity points to start with than any non-disabled person. I want the dignity of being alive, not the nothingness of being dead. To say that death is a more dignified position than disability is a position of such awesome non-disabled privilege that it frankly disgusts and terrifies me.
- How can we trust the right decisions will be made for us? Look at what happened with DNRs in the past year. It is terrifying that this would make it easier for judgements to be made about our lives.
- What about people who are not connected into organisations like GDA? When I first joined, I'd been planning my suicide, but to shut up my friend, I reluctantly agreed to come along to a GDA event. Four years later, I'm still here and loving life – it could have been so, so different.

- Shocked people could be killed because they're depressed – nothing could justify this being approved. Many of us feel very depressed and even suicidal at times, but when you get help it's easier to cope. What could happen if there's no help if just terrifying.
- I am concerned at how decision-making power is already often taken away from people with mental health impairments and learning difficulties. I feels that there is potential for non-voluntary euthanasia. It is particularly hard for many with mental health impairments to advocate for themselves, particularly in a crisis.
- I was recently on a University course on end of life and shocked I had to defend I had autonomy as a disabled person with a complex impairment. I might not be able to stand or walk, or go to the loo myself, but I have autonomy. No one thought I would feel I had autonomy and I was really shocked by their attitude to disabled people. Was for assisted dying in past but being on that course changed my views totally.

In conclusion we firmly believe this proposed Bill is unethical. Disabled people are vulnerable to society's lack of support, lack of services and ongoing discrimination. We do not believe that there can ever be any level of safeguarding to prevent coercion, abuse and ensure that all other alternative options have been explored.

We promote the visibility and value of disabled people's lives and therefore simply cannot support legislation that promotes the notion that their suicides are not worth preventing. We fear that such legislation is not only bad for disabled people, but bad for society, and in particular it undermines all our trust in the medical profession: "How could I ever put my trust and my life in the hands of doctors, knowing that they have the power to assist someone like me to end their life? I already face their judgement about my quality of life every time I go into hospital. I've been terrified for years they'd just 'let me go' if something happened to me. This just makes me even more terrified."

2. Do you think legislation is required, or are there other ways in which the Bill's aims could be achieved more effectively? Please explain the reasons for your response.

GDA does not believe this legislation is required. For years we have produced [Manifestos](#) which set out what disabled people need in order to participate, to remove discrimination and to ensure equality of opportunity.

We feel strongly that this potential legislation has huge negative implications for disabled people. The disabled people's movement is often criticised for suggesting that Assisted Suicide legislation will impact on disabled people and told by campaigners for this Bill that the legislation only applies to 'terminally ill people'. However, those who are the subject of the proposed Bill, are disabled people as defined in the Equality Act.

Moreover, the campaigns calling for "Assisted Dying" and media articles on this topic, most often feature disabled people as subjects, and not those who are actually 'terminally ill'. Margot MacDonald had Parkinson's Disease, Debbie Purdy had MS, Tony Nicklinson lived with locked-in syndrome, Diane Pretty and Noel Conway had MDN. Most recently we heard of Dawn Voice-Cooper who ended her life in Switzerland due to having severe arthritis and epilepsy. All of these prominent campaigners were disabled people, with conditions many of our members are living with. This is why disabled people are "terrified" of this legislation in Scotland.

- Since the BMA has changed stance from against to neutral, I've told my GP surgery I don't want to be treated by any doctor who is pro assisted suicide.
- When I was expressing my intolerable pain with a consultant, I was pushing for better care, however I later discovered that the consultant had put a 'DNR' note on my file which was not what I wanted. I feel messages can get misconstrued when proper care isn't in place and this could be extremely dangerous and very worrying if this bill passed.
- As a disabled person I will never support this, because a world in which assisted suicide is legal is a world in which I am much less safe.

We feel the aims of this Bill could be achieved more effectively by government prioritising the Actions contained in a Fairer Scotland for Disabled People strategy. Doing this would ensure disabled and ill people would have access to their rights to financial assistance, healthcare, social care, housing, education, employment and so on, like any other citizen. Further, we call on government to prioritise Independent Living for disabled people, as outlined in the UNCRPD.

- We get put in houses that aren't fit for animals. You would be allowed to have a service or rescue dog in this accommodation, so why is it ok for me. The way I am forced to live badly affects my mental health; some days it's a real struggle just to carry on.
- I read that 90% of DP who join GDA said they're lonely or extremely lonely when they joined. I can relate to that so much. It's shocking that in other countries that's a reason people choose assisted suicide. That's so wrong. Why not support people so they are not lonely.
- I'm worried about the time it's taking for proper social care to be put in place for those who need it. This could be extremely detrimental for vulnerable people if this bill is passed. It could mean they give up and opt for assistance to die.
- I've been in intolerable pain and had to wait for 3 years before proper care was put into place. I considered ending it many times.
- I am concerned that the reduction of pain medication can impact on how people feel towards their life. It is very dangerous territory that could lead to people wanting to end their life, when, in reality, proper care should be the focus.

We do not feel that Dignity in Dying's assertion that "17 people per day suffer when they die" considers the wider issues around dying, such as what constitutes 'suffering', who defines 'suffering' or how long that suffering lasts. What one person defines as 'suffering' may not be the experience of another. DiD do not give any context e.g. these 17 deaths are a UK figure and with a pre-pandemic average of 1900 per day, this means that over 99% of people do not 'suffer'.

This being said, we entirely support the call that we must do better for those who are dying, and those who are terminally ill. However, we do not believe this legislation is the way to ensure people do not suffer at the end of their life with a terminal illness. Instead we call for increased investment in palliative care, pain management and end of life care. Along with Inclusion Scotland, we support Scottish Partnership for Palliative Care's recommendation for "the explicit inclusion of a human right to palliative care within the forthcoming Scottish Human Rights Act" and along with many other organisations, we call for fast-track decision making around financial and practical support for terminally ill people and their families.

3. Which of the following best expresses your view of the proposed process for assisted dying as set out at section 3.1 in the consultation document (Step 1 - Declaration, Step 2 - Reflection period, Step 3 - Prescribing/delivering)?

GDA fully opposes the proposed process as set out in the consultation document.

It is our view that the proposals do not take into account the additional time and support that many people require in order to make informed decisions. There is generally a lack of independent advocacy, inaccessible information, lack of communication support, which many disabled people rely on in order to make informed decisions. Many people with learning difficulties, and those with mental health conditions are often subject to the Adults with Incapacity Act, which is often criticised by learning difficulty and mental health organisations. In particular, it is our view that until supported decision making is fully implemented, many people will be unable to fully understand and participate in the processes set out in this proposal.

Many people's decision making ability depends on so many factors beyond their control - e.g. health and social care services, medical treatments, poverty, etc and people cannot make informed decisions when their basic needs are not being met. We believe that until this is addressed, this proposal is not fair or safe.

4. Which of the following best expresses your views of the safeguards proposed in section 1.1 of the consultation document?

GDA is fully opposed to the safeguards proposed.

It is our view that there is a key danger in that the classification of 'terminally ill' is very much open to question, with several definitions across a range of policy areas in place at present. Our fear is that this can never be defined in a way that will not be open to legal challenge and inevitable widening of guidelines.

We firmly believe that it is impossible to safeguard such legislation, and as such the potential for some people to face coercion, exploitation, abuse and pressure remains. There is much evidence of such abuse taking place across health and social care despite supposedly stringent safeguards – e.g. in hospitals, care homes, nursing homes, psychiatric hospitals and within family homes. Disabled people face increasing hate crime and disabled women and girls are more likely to experience sexual and physical abuse than their non-disabled peers.

As noted in the previous question, those who are subject to Guardianship often report that their wishes are not taken into consideration.

Disabled people are not safeguarded by existing legislation and remain unable to access their basic human rights, despite legislation being in place to secure these – e.g. the Self-Directed Support Act; BSL Act; Social Security; Equality Act; and so on.

Clear evidence from other countries has shown that once Assisted Dying / Suicide / Euthanasia legislation is enacted, it is very quickly widened and thus safeguards lessen. For example, in Canada and Oregon where psychological assessment and 'cooling off' periods have been reduced further and further. In the past few weeks, the [New Zealand Ministry of Health have confirmed](#) that "Eligibility is determined on a case-by-case basis; therefore, the Ministry cannot make definitive statements about who is eligible. In some circumstances a person with COVID-19 may be eligible for assisted dying."

An example of legislative creep here in Scotland is that of Civil Partnership (Scotland) Act 2020, which has widened Civil Partnership to now include mixed sex couples.

A key highlight in terms of lack of trust in safeguarding has arisen due to the treatment of disabled people during the pandemic, particularly in terms of NDACPR / DNR, but also in relation to the sudden withdrawal of social care with little or no notice, meaning thousands of disabled people were left without support for basic needs, many people had no access to food, money, or other key essentials.

- I am really worried about the lack of awareness and information provided regarding DNR'S being put onto medical records. I lost my partner 4 years ago and was informed that a DNR had been put onto their records, which I know was against their wishes as we spoke about this. I was shocked angry that nothing was explained to me prior to their death. As two disabled people, it felt like the doctors considered us not worthy of a discussion and assumptions were made about quality of life that were not the doctors to make.

- Pervasive negative stereotypes about disability make me doubt that any legislative safeguards would be adequate. Assisted suicide would make me and others like me so unsafe.

GDA supports many people who have expressed feelings of suicide due to their simply awful living circumstances and complete lack of dignity. Some members have regularly been left sitting in their own urine and/or faeces for hours at a time, others have not been able to wash properly for years, others are experiencing severe uncontrolled pain. Members such as these fear they could be at risk if this proposed Bill was successful. Many people tell us their lives were completely unbearable before they connected with GDA and started to receive support.

5. Which of the following best expresses your view of a body being responsible for reporting and collecting data?

GDA is fully opposed to this Bill and therefore opposes the proposed data collection processes.

We do not feel that any potential body would be independent enough to collect, analyse and monitor data and ensure all safeguards were being followed. Our members were worried about who such a body would be and especially fear private consultants, they also talked of potentially there being little or no public accountability or transparency on who would be appointed.

We find it particularly disingenuous to suggest that death certificates do not mention assisted suicide / assisted dying and thus would not present an accurate picture of the effect on enacting such legislation.

[Evidence from other countries](#) outlines that information and data collection is not always as accurate as it should be and as legislation widens and safeguards slip, data failures are likely to increase.

Ultimately, data would be collected and reported on retrospectively, by which time it would be too late should anything untoward have taken place.

6. Please provide comment on how a conscientious objection (or other avenue to ensure voluntary participation by healthcare professionals) might best be facilitated.

GDA members are concerned that this legislation has the potential to put doctors in highly unethical positions. They are already fearful of losing trust in the medical profession and having to question every medic they interact with in terms of their position on this legislation.

Our view is that doctors and other medical professionals may be pressurised into supporting the implementation of something which is fundamentally opposite to their medical training.

We have seen evidence from Canada, Oregon and other countries that people are now 'shopping around' to find doctors who agree to what they want, regardless of their medical or personal circumstances and that doctors are leaving the profession due to such practice. We are particularly concerned that in some countries there is now little or no requirement for someone to have a relationship with the doctor(s) who makes the decision to allow MAiD.

Evidence from Canada illustrates that investment in hospice and palliative care services has fallen as a result of assisted dying legislation. Furthermore, many residential care establishments and hospices are being forced to offer MAiD as an option and losing funding if they refuse to do so.

Disabled people are already extremely vulnerable within establishments where their autonomy is reduced or diminished and we know levels of personal confidence fall quickly in these circumstances.

- I was put into a care home to get me out of hospital more quickly. Within a few days, I felt like I'd completely lost all sense of myself and kept my head down just to fit in and not upset the staff. I felt trapped and it was the scariest time of my life.

7. Taking into account all those likely to be affected (including public sector bodies, businesses and individuals etc), is the proposed Bill likely to lead to:

• a significant reduction in costs

We are majorly concerned that it will become less expensive to assist people to die rather than support them to live. It is our view that this proposal is unethical and places power further away from disabled, older and ill people who are already fairly powerless.

Older and disabled people frequently regard themselves as a burden on the state and society. The media delivers a rhetoric to wider society that disabled people are 'burdens', 'scroungers' and 'a drain on society'. It follows that many people who regard themselves in this way, will consider it their duty to save the state the money for their care / treatment by ending their lives prematurely.

[Canada reports shocking statistics around 'savings'](#) following the implementation of MAiD and also the reduction in funding allocated to hospices that refused to offer MAiD. They show that an increase in MAiD eligibility during 2021 will increase healthcare 'savings' from \$86.9m to \$149m (almost £87m) which represents 10 times the annual value of funding withdrawn from the Delta Hospice Society after it refused to offer MAiD.

Our view is that already overstretched health and social care services may not be prioritised when we are increasingly experiencing circumstances where decision making is based on costs, rather than human rights based outcomes.

8. What overall impact is the proposed Bill likely to have on equality, taking account of the following protected characteristics (under the Equality Act 2010): age, disability, gender re-assignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, sexual orientation?

• Negative

GDA firmly believes this proposed Bill will have a negative outcome in terms of Equalities.

Our own research, and that of Inclusion Scotland, Disability Equality Scotland, other DPOs and ally organisations underlines that disabled people are already experiencing 'Supercharged Inequalities' during an ongoing global pandemic. Pre-pandemic it should be remembered that the UN had declared disabled people's experiences as a 'Human Catastrophe'.

Discrimination, abuse, poverty and hostility have become part of daily life for disabled people. Increased pressure to opt for Assisted Suicide is a real and present fear for many disabled people: "I'm only just hanging on as it is. I can't believe I may soon have to justify my life to medical professionals just to get the support I need. We already have to jump through so many hoops. It's exhausting."

Until we address the Supercharged barriers and inequality disabled people face, bringing forward such legislation is entirely against everything the Scottish Government stands for. We do not feel the proposed Bill is compatible with A Fairer Scotland for Disabled People and the incorporation of the UNCRPD.

Disabled people's right to life is set out in the UNCRPD Article 10 – Right to life:

"States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others."

Our view is that until disabled people have equal access to their rights, it unjust to bring forward this proposed legislation. Scotland must learn from the negative impacts from every other country, state and province that has enacted similar legislation.

- When a healthy young man's suicide is regarded a tragedy and a disabled person's suicide seen as a blessing there's something wrong. Why does a disabled person wishing to end their life not have everyone rallying round trying to prevent this? Why is my life not as worthy as everyone else's?

9. In terms of assessing the proposed Bill's potential impact on sustainable development, you may wish to consider how it relates to the following principles:

- **living within environmental limits**
- **ensuring a strong, healthy and just society**
- **achieving a sustainable economy**
- **promoting effective, participative systems of governance**
- **ensuring policy is developed on the basis of strong scientific evidence.**

With these principles in mind, do you consider that the Bill can be delivered sustainably?

GDA does not consider this Bill to be sustainable.

There is nothing remotely just or fair of bringing forward legislation that will impact on people who right now are not supported to live with dignity. Disabled, older and ill people are unable to cope due to cuts to services they rely on to meet their basic human needs - support to wash, dress, go to the toilet, to eat, sleep, meet friend, keep their house clean. Our members have numerous examples of being denied services, or finding services inaccessible – this is why GDA had to step up and deliver accessible welfare rights, wellbeing, digital and even food provision support.

Disabled people's lives are blighted by inaccessibility and inequality. That is not sustainable for us as a society. We must do better to address these inequalities before even beginning to consider proposals as set out in this Bill.

10. Do you have any other additional comments or suggestions on the proposed Bill (which have not already been covered in any of your responses to earlier questions)?

GDA calls for disabled people's voices to be amplified in this debate – without fear of backlash and negative consequences. Many people told us they are terrified of this proposal, but also terrified to speak up as they are exhausted dealing with their day to day lives, compounded by the pandemic and its ongoing impacts.

We call for safe spaces and time to put forward our concerns as individuals and as organisations, along with our DPOs colleagues across Scotland.

Ends.