

The Neurological Alliance of Scotland

Assisted Dying for Terminally Ill Adults (Scotland) Bill: Detailed Consultation Response

Are you responding as an individual or on behalf of an organisation?

Organisation

Name of organisation

The Neurological Alliance of Scotland

Information about your organisation

The Neurological Alliance of Scotland (NAoS) is an umbrella body of over 50 organisations that represent people with a neurological condition and those who support them. We work to improve the care and support that people receive.

An estimated one million people in Scotland live with a neurological condition that has a significant impact on their lives.

Our vision is for everyone affected by neurological conditions in Scotland - including carers and those who support them - can access high-quality, timely, and holistic care and support at every stage of their life, regardless of where in Scotland they live.

In partnership with our members we inform policy, raise awareness and support improvements in services. We aim to make sure that the experiences of people with neurological conditions - and those around them - are recognised.

We do this by raising these issues directly with the Scottish Government, NHS bodies and other groups; and by contributing to publications and consultations, sharing information between members, and working with other bodies on common issues.

Neurological Conditions

Neurological conditions affect the brain, spinal cord, nerves and muscles. They are often the result of illness or injury.

There is a very wide range of neurological conditions, and they can affect people in very different ways. Some neurological conditions are present from birth (such as cerebral palsy), others develop at a later stage in life - from childhood to old age.

Some conditions are genetic (such as Huntington's disease) while others are caused by infections (such as meningitis). The cause of many conditions remains uncertain.

Some neurological conditions are very common but some are extremely rare.

Most neurological conditions affect people's quality of life and some will cause life-long impairments. While some conditions can be cured or managed as long-term conditions, some conditions are progressive or terminal.

It is important that people affected by a neurological condition receive the right care and treatment at the right time.

Question 1 - Overarching question

Which of the following best reflects your views on the Bill?

Please select one item

(Required)

Fully support

Partially support

Neutral/Don't know

Partially oppose

Strongly oppose

Space for further comment on your answer

The Neurological Alliance of Scotland recognises that there are a range of personal views around the legalisation of assisted dying. As in society as a whole, you will find strong supporters of a change in the law, people who are implacably opposed and every shade of opinion in between these positions amongst people with neurological conditions and those who support them.

As a membership organisation of 54 charities, we have sought to confine our response to the proposals laid out in the consultation, and how they could affect people living with neurological conditions. We do not propose to make any comments either for or against the central principle of legalising assisted dying.

The Neurological Alliance of Scotland believes that everyone living with a neurological

condition should be able to access safe and compassionate care that responds to their needs and preferences for support. This includes the provision of supportive care and care at the end of life.

Which of the following factors are most important to you when considering the issue of assisted dying? Please rank a maximum of three options.

Please rank these from 1 to 3

Impact on healthcare professionals and the doctor/patient relationship

Personal autonomy

Personal dignity

Reducing suffering

Risk of coercion of vulnerable people

Risk of devaluing lives of vulnerable groups

Sanctity of life

Risk of eligibility being broadened and safeguards reduced over time

Other – please provide further details in the text box (200 characters max)

If you selected Other, please provide your answer in the text box below

Neurological conditions are complex and no two people experience their condition the same. We therefore cannot select three factors but rather list our considerations listed below.

Space for further comment on your answer

Protecting vulnerable people- Some people with neurological conditions meet the criteria of being a protected person, and therefore we would wish to see explicit safeguards in the Bill to make sure that those who are vulnerable are properly protected so that any abuse, coercion or control to which the person is subjected is identified and managed.

Right to palliative care- There is a very high level of unmet need for specialist palliative and end of life care for people with neurological conditions with people facing the end of their lives without the support they need. There are concerns that individuals feel an assisted death is the only viable option for them. It is essential people with neurological conditions have timely and equitable access to palliative care services before being offered the option of an assisted death.

Specialist consultants- There are over 600 neurological conditions, and often there is little understanding or knowledge within the healthcare system of these conditions and how they affect individuals. We believe it is essential that a specialist clinician with specific knowledge of the condition of the person seeking assisted dying is required to be involved in the assessment of eligibility.

Mental health- Our Together for the One in Six report highlighted that in Scotland, 80% of adults and 95% of children and young people said their neurological condition negatively impacts their mental health. NAOs remains concerned that people with neurological conditions experiencing mental health issues choose an assisted death due to a lack of knowledge by professionals of their condition and the lack of access to appropriate services for mental health support.

Care crisis- Evidence from other jurisdictions illustrates how people choose assisted dying due to a fear of being a “burden”. Proper, equitable and securely funded support for carers and the care sector is essential in supporting people to make a free and informed choice.

Question 2 - Eligibility

Which of the following most closely matches your opinion on the terminal illness criterion for determining eligibility for assisted dying?

Please select one item

No-one should be eligible for assisted dying

Assisted dying should be available only to people who are terminally ill, and the definition of terminal illness should be narrower than in the Bill

Assisted dying should be available only to people who are terminally ill, and the definition of terminal illness in the Bill is about right

Assisted dying should be available only to people who are terminally ill, but the definition of terminal illness should be broader than in the Bill

Assisted dying should be available to people who are terminally ill, and to people in some other categories.

Other – please provide further details in the text box (200 characters max)

If you selected Other, please provide your answer in the text box below

Please see below for: 1. Issues defining ‘terminally ill’ for people with neurological conditions; 2. Future broadening of eligibility and 3. Equity and equality of access.

Space for further comment on your answer

1. The proposed definition of ‘terminal illness’ is ambiguous and could lead to inconsistencies in who is deemed eligible for assisted dying. There is no standardised definition of ‘progressive’ or ‘terminal’ and therefore eligibility is left to the clinician’s interpretation. NAOs believes there is a high risk that the definition could cover many people with neurological conditions who have may have many years of life left. Additional safeguards would be needed in any legislation to make it clear that the person’s condition must be sufficiently advanced for them to be considered to be reaching the end of their life.

Many of our members support people to live as well as they can with their condition and would be concerned if people came to see assisted dying as the only way in which people can exercise control over their condition.

It is important to note that the current definition was developed for the purposes of accessing disability assistance. It must be considered whether this definition is appropriate to be used in the assessment of assisted dying or if it should be revised.

We also recognise that the discussion of “dignity” and “independence” can be problematic for some disable people, including many people with neurological conditions. It is extremely important that any legislation includes explicit safeguards to make clear that a life where someone needs support with daily activities must not be viewed as inherently less valuable or dignified than a life without these.

2. It is reasonable to expect that over time eligibility for assisted dying will widen as societal attitudes change. In the future, the exclusion of people with ‘mental disorders’, including learning disabilities, may be challenged as discriminatory. As the Bill stands, much is left to the discretion of future Scottish Ministers on how they will interpret the definition of terminal illness and potential widening of eligibility.

Which of the following most closely matches your opinion on the minimum age at which people should be eligible for assisted dying?

Please select one item

No-one should be eligible for assisted dying.

The minimum age should be lower than 16

The minimum age should be 16

The minimum age should be 18

The minimum age should be higher than 18

Other – please provide further details in the text box (200 characters max)

If you selected Other, please provide your answer in the text box below

NAoS does not hold a position on a minimum age threshold for assisted dying. See below for considerations for children and young people with neurological conditions.

Space for further comment on your answer

In Scotland the definition of a child varies depending on the context.

Evidence shows that the brain is not fully developed until around the age of 25. Young people with neurological conditions tend to be complex to manage, their condition fluctuates and therefore prognosis is even more challenging to predict. Access to palliative care services for young people (aged 16-25) is poor, less than 25% of those who would benefit are able to access. Children's services for those living with a neurological condition are not good enough; they are disconnected and there is a lack of responsibility for those accountable to children, resulting in a lack of integration from child to adult services. Service providers often lack understanding of neurological conditions, and common features such as fluctuations. The Neurological Framework only applies to adult services, so there has been no systemic attempt to deliver much-needed improvements in care and support for children and young people.

Many young people with complex neurological conditions remain eligible and are managed by children's services until they reach the age of 26 years.

The period when a young person transitions from child to adult services can be incredibly challenging and too frequently causes disruption and stress, resulting in unmet needs. Often, young people and their families have to cope with this transition alone, as our Together for the One in Six report illustrates, 92% of children and young people told us they had no named transition worker. This period can be made even more challenging if there are no adult services to transition into (such as for cerebral palsy). This can have notable impact on a young person's mental health and wellbeing.

If the legislation were to be expanded to include children below the age of 16, further safeguards must be introduced to ensure they are supported in making this decision, including consultation of family members.

Question 3 - The Assisted Dying procedure and procedural safeguards

Which of the following most closely matches your opinion on the Assisted Dying procedure and the procedural safeguards set out in the Bill?

Please select one item

I do not agree with the procedure and procedural safeguards because I oppose assisted dying in principle

The procedure should be strengthened to protect against abuse
The procedure strikes an appropriate balance
The procedure should be simplified to minimise delay and distress to those seeking an assisted death

Other – please provide further details in the text box (200 characters max)

If you selected Other, please provide your answer in the text box below

The procedures should be strengthened. There should also be greater understanding of contextual safeguards and how neurological conditions can fluctuate, impacting a person's cognition and capacity.

Space for further comment on your answer

Recommendations:

The doctor who signs the declaration should have known the patient for a minimum of 6 months. This time period allows for the doctor to understand the patient's social and family circumstances and assess any risk of coercion.

We recognise that the above safeguard might give rise to a risk of individuals being unable to give effect to their wishes because their treating clinician wished to exercise their right to conscientious objection to the request. In that case, appropriate exceptions could apply.

As the bill currently stands, a person can request assisted dying and be assessed by two practitioners who have no prior relationship to the patient. This could mean that practitioners may miss nuances in the person's situation, including potential coercion. To ensure assessing practitioners are as informed as possible when they do not have a prior relationship to the patient, they should require a report from a clinician or practitioner who has known the patient for a minimum of 6 months.

Some members raise concern that many clinicians may not feel comfortable assessing coercion as this is outwith their expertise as a medical practitioner. Therefore, we recommend the assessment of coercion should be carried out in conjunction with a trained professional who has expertise in this area.

A further safeguard against coercion could be included in Section 7 of the Bill under 'Further Provision', stipulating clinicians can request and consider contextual evidence from a family member, friend, faith leader or social worker to aid their assessment of coercion.

The independent doctor should have professional knowledge and experience of treating the condition of the patient.

There is a range of views within our membership regarding the length of time for reflection (14 days) with some members feeling it should be longer to take into account the fluctuations in mental health in those with conditions, such as neurological conditions.

Question 4 – Method of dying

Which of the following most closely matches your opinion on this aspect of the Bill?

Please select one item

It should remain unlawful to supply people with a substance for the purpose of ending their own life.

It should become lawful to supply people with a substance for the purpose of ending their own life, as proposed in the Bill

It should become lawful to supply people with a substance for the purpose of ending their own life, as proposed in the Bill, and it should also be possible for someone else to administer the substance to the adult, where the adult is unable to self-administer.

Other – please provide further details in the text box (200 characters max)

If you selected Other, please provide your answer in the text box below

Issues around physical impairments.

Space for further comment on your answer

People with advanced neurological conditions, like Motor Neurone Disease, commonly have significant physical impairments, which could make it more difficult to meet some key criteria outlined in the proposal. Specifically, the requirement that the person must self-administer the medication. We believe that any legislation should consider whether these requirements have the unintended consequence of leaving people with some physical impairments unable to give effect to their wishes.

We would also like to echo the concerns the Scottish Partnership for Palliative Care raise in their response to this Bill:

- What if the medication doesn't have the expected effect?
- What if the illness trajectory doesn't follow a predicted path?
- Dealing with complex social and emotional situations

- Evidence base on drugs for assisted dying

Question 5 - Health professionals

Which of the following most closely matches your opinion on how the Bill may affect the medical profession? Tick all that apply.

Please select all that apply

Medical professionals should not be involved in assisted dying, as their duty is to preserve life, not end it.

The Bill strikes an appropriate balance by requiring that there are medical practitioners involved, but also allowing those with a conscientious objection to opt out.

Assisting people to have a “good death” should be recognised as a legitimate role for medical professionals

Legalising assisted dying risks undermining the doctor-patient relationship

Other – please provide further details in the text box (200 characters max)

If you selected Other, please provide your answer in the text box below

Trust is the foundation of the clinician-patient relationship. Any legislation must make clear that healthcare professionals’ primary responsibility is to avoid causing harm.

Space for further comment on your answer

In order to ensure that there is a trusted clinician-patient relationship, and in order to safeguard against “doctor-shopping” we would support the proposal the bill should be clear that the doctor signing the assisted dying declaration should have known and treated the patient for a minimum period of 6 months, unless, as stated above, the patient’s doctor is withdrawing consent as a conscientious objector.

It must also be considered that individuals with limited mobility, who live in remote areas, may have reduced access to assisted dying services. This may be further complicated if their primary clinician opts out due to conscientious objection and they struggle to find alternative practitioners.

It is essential that training and support for these health professionals to ensure they can deliver a consistent, coherent and sensitive response. There should also be

mechanisms in place to support the mental health and well being of the professionals involved.

Question 6 - Death certification

Which of the following most closely matches your opinion on recording the cause of death?

Please select one item

I do not support this approach because it is important that the cause of death information is recorded accurately

I support this approach because this will help to avoid potential stigma associated with assisted death

Other – please provide further details in the text box (200 characters max)

If you selected Other, please provide your answer in the text box below

The Neurological Alliance of Scotland believes that both assisted dying and the underlying terminal illness should be recorded in the death certification.

Space for further comment on your answer

We believe this is the only way we can assess a) if there is equitable access b) if some conditions more likely to lead to assisted death than others. This will help public health officials identify conditions where there may be higher levels of assisted dying and the reasons why. This could be hugely valuable in helping officials address issues made visible from this data, for example in service provision or care pathways for these conditions.

It is also worth noting that we do not believe omitting assisted dying as the cause of death is an appropriate way to tackle stigma. Hiding the cause of death from official records may lead people to think assisted dying should be kept secret, implying a degree of shame, rather than empowering patients to die with dignity, as the Bill seeks to enable.

Question 7 – Reporting and review requirements

Which of the following most closely matches your opinion on the reporting and review requirements set out in the Bill?

Please select one item

The reporting and review requirements should be extended to increase transparency

The reporting and review requirements set out in the Bill are broadly appropriate

The reporting and review requirements seem excessive and would place an undue burden on frontline services

Other – please provide further details in the text box (200 characters max)

If you selected Other, please provide your answer in the text box below

Given that the overseeing body is yet to be identified, our comments are confined to what we would wish the overseeing body to be responsible for.

Space for further comment on your answer

We would agree that it should be independent and would expect that it would be asked to report to the Scottish Parliament on an annual basis, along similar lines to other non-departmental public bodies.

The independent body should monitor the following:

- Reasons given by the patient for requesting assisted dying
- Number of people who died as a result of assisted dying
- Number of people who requested assisted dying and did not go through with it
- Medical condition of the patient
- How long between taking the lethal drugs/drugs being administered it took for the patient to die
- Interventions that were necessary in between taking the lethal drugs/drugs being administered and time of death
- A register of medical professionals who signed or countersigned assisted dying declarations
- Specialism of medical professionals who signed or countersigned assisted dying declarations
- A register of those present during death

We also support these elements identified by the Scottish Partnership for Palliative Care:

- Bill requires reporting on data which will not be available – it is unclear how Public Health Scotland will be able to report since there is no process in place for creating a data source.

- Limited data set does not support the proper understanding of the operation of the bill
- Lack of arrangement for scrutiny limits data on operation of the bill
- Lack of reporting and recording of untoward incidents and concerns
- Scope of 5 year review too narrow – it should be broadened to consider issues of wider public importance

Question 8 – Any other comments on the Bill

Do you have any other comments in relation to the Bill?

Please use this textbox to provide your answer

We will use this section to offer addition comments to questions 1, 2, 3 and 5. We will then present data collected by our members and offer some concluding statements.

Question 1: Overarching question

Protecting vulnerable people

We seek further clarity on how any new law would identify and protect people whose decision to end their lives derives mainly from the wish to avoid “being a burden” to family and friends, rather than their own experience.

People with neurological conditions, such as cerebral palsy, were amongst those who experienced the imposition of Do Not Resuscitate orders (Do Not Attempt CPR) without consultation or consent during the pandemic in Scotland, and this is a recent example of why we need to ensure that the safeguards referred to in the consultation to protect vulnerable people are fit for purpose. We believe that this area would require extensive additional consultation prior to any new law being put into place.

The Right to Palliative Care

Palliative care, which is the provision of physical, emotional, practical and psychological support, focusses on improving quality of life during the time someone has left. People receiving a life-changing terminal neurological diagnosis should be receiving all these forms of support from the get-go, irrespective of the amount of time someone is expected to have left to live or where they live. People diagnosed with a terminal neurological condition follow widely varying pathways and can live for many weeks, months, and even years post-diagnosis albeit with increasing levels of disability.

Generalist palliative care provision, which is simply good health and social care provided when someone’s health is deteriorating, is often not sufficient for terminally ill people with neurological conditions. Due to the complexity of fast progressing terminal

neurological conditions, people often require specialist palliative care provided by specially trained multi-disciplinary teams either in a hospice, NHS specialist palliative care unit, or an acute hospital setting. Unfortunately, evidence shows that many people with neurological conditions do not have access to specialist palliative care.

Barriers to specialist palliative care for people with progressive and terminal neurological conditions can include:

- a lack of referral pathways from people's long-term neurological care teams, care homes, GPs and home-based care to palliative care
- the complexity of care needs, including issues with mobility, continence, swallowing, breathing and communication which require intervention and ongoing support over the long term rather than in the last few days and hours of life – some hospices do not have the facilities to support people with end-stage neurological illness
- Issues with mental health and cognition in some progressive conditions are significant

There is a very high level of unmet need for specialist palliative and end of life care for people with neurological conditions. Factors such as poverty, geographical isolation, and the acute care needs of some people with neurological conditions prevents them for receiving specialist palliative care in the setting they desire (ie at home rather than in a hospital). For those who are receiving support from generalist teams, we know that hospital beds and suitable care packages are extremely scarce as the health and social care system in Scotland is still struggling to cope with the recovery from the Covid19 pandemic. As a result, people are facing the end of their lives without any of the support that they need. Given this backdrop, there are concerns that individuals may feel that assisted dying is the only viable option for them.

We also note that most hospices in Scotland are third sector organisations and their ongoing sustainability is dependent on their ability to raise funds including direct funding from the NHS. Not every area has a hospice.

Legislating for a right to palliative care would address some of these inequalities and inequities and would encourage data collection on the experiences of people in palliative and end-of-life care. This would inform ongoing service delivery including how to reach hard-to-reach groups and provide more choice to people about where they can receive palliative and end-of-life care.

Mental health

Within neurology there are some conditions where depression is a common co-morbidity, and some where depression is driven by the condition themselves. Suicide rates in the Parkinson's and epilepsy communities are higher than expected. These are not the only neurological conditions for which a risk of suicide exists.

For example, Our Together for the One in Six report³ highlighted that in Scotland, 4 out of 10 adults (40%) and 3.5 out of 10 children and young people (35%) reported that their mental health needs were not being met 'at all'. Furthermore, 80% of adults and 95% of children and young people said their neurological condition negatively impacts their mental health.

This is compounded by the fact that there is very little support for people experiencing mental health challenges, with 72% of children and young people and 49% of adults experiencing a delay accessing mental health services. This does not account for the proportion of people who did not seek help, nor those where there was no help available.

It is also important to consider the mental wellbeing of families and carers of people with neurological conditions, where the stress and exhaustion of their caring responsibilities may have a negative impact on their wellbeing and inadvertently influence a person's decision to choose an assisted death.

Care Crisis

In Oregon 59 per cent of those opting for an assisted suicide in 2019 cited the fear of being a burden on family, friends and caregivers as a consideration for end of life. We therefore think it is important to consider how the underfunding of care and lack of support for unpaid carers may affect someone's decision to choose an assisted death.

Our Together for the One in Six report highlighted how 83% of adults and 67% of children with neurological conditions had not been assessed for social care needs.

It is therefore possible to imagine a situation where a person witnessing the incredible strain placed on their care giver from providing 24/7 care feels pressure, directly or indirectly, to choose an assisted death.

Question 2: Eligibility

Issues defining 'terminally ill' for people with neurological conditions

The proposal defines terminally ill people as those who 'have 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.' The definition of terminal illness is problematic in relation to many neurological conditions – historically, conditions which have a rapid rate of progression such as Motor Neurone Disease (MND), Progressive Supranuclear Palsy (PSP) and Multiple System Atrophy (MSA) have been diagnosed as "terminal", while those which result in a longer period of illness such as Parkinson's, some forms of MS and Huntington's have been characterised as

“progressive”. More recently, Alzheimer’s and other dementias have been recognised as terminal conditions.

Members of NAOs supported the removal of the requirement for a clinician to certify that a person was in their last six months of life to enable them to claim disability benefits under special rules in Scotland. Charities working with people with neurological conditions recognised that prognostication is complex across all conditions, with estimates often based on survival statistics proving unreliable when applied to individuals. This is especially the case when clinicians are asked to estimate life expectancy over periods of months or years.

These issues are magnified for people with many progressive neurological conditions, where sudden deaths can occur and people can survive for a relatively long time with very advanced symptoms. Many clinicians simply felt unable to identify whether or not a person was in the last 6 months of life, reducing timely access to vital financial benefits when reaching the most advanced stages of their condition.

NAOs recognise that the definition provided in the proposal is consistent with this approach. However, it is important to note that the current definition was ‘developed for the purposes of accessing disability assistance’ for the Implementation of Benefits Assessment⁴. It is therefore important to consider whether this definition is appropriate to be used in the assessment of assisted dying, when its intention was to enable individuals to access disability support.

We also recognise that the discussion of “dignity” and “independence” can be problematic for some disabled people, including many people with neurological conditions. People with neurological conditions often require aids, adaptation and support from paid and unpaid carers to enable them to live with their condition. Bladder and bowel issues are very common, along with problems with movement, eating and drinking and communication. It is extremely important that any legislation includes explicit safeguards to make clear that a life where someone needs support with daily activities must not be viewed as inherently less valuable or dignified than a life without these.

Future broadening of eligibility and equity and equality of access

It is reasonable to expect that over time eligibility for assisted dying will widen as societal attitudes change. This can be seen in countries such as Canada where the eligibility has been significantly broadened since the law was passed in 2016.

Currently, people with ‘mental disorders’ are not eligible for assisted dying. The policy memorandum expands that ‘mental disorder’ includes ‘any mental illness, personality disorder, or learning disability, however caused or manifested’ (Explanatory Notes p.4 section 16).

1 in 2 people with cerebral palsy have a learning disability. This means, only half of those with cerebral palsy will be eligible for an assisted death. Under the Equalities Act 2010, 'it is unlawful to discriminate against someone because of certain 'protected characteristics' when you are for example: in the workplace; being provided with a public service (like social care, health care, or education); being provided with a service or good by a business.'⁵ Therefore, it is unlawful to discriminate against someone because of certain protected characteristics when they are being provided with health care. There is the potential that the eligibility criteria in the proposed Bill may be challenged as discriminatory of people with mental disorders, such as learning disabilities, as they should have the same equality of access to health care, including assisted death, as others.

The Human Rights Act has also been used in various court cases to challenge access to assisted death. For example, in 2014, stroke survivor Tony Nicklinson sought a declaration from the Supreme Court of England that the current law on assisted suicide was incompatible with his right to a private life under Article 8 (R (Nicklinson) v Ministry of Justice (2014)). While the court did not rule in Nicklinson's favour, 'four Justices considered that the compatibility of the law on assisted suicide with Article 8 was an "inherently legislative issue" that should be left to Parliament, and that the courts lacked the constitutional authority to make a declaration on this issue'⁶. Therefore, it is reasonable to believe that compatibility with the Human Rights Act is something Scottish ministers will have to consider in future legislation on eligibility criteria.

Definition of a child

In Scotland the definition of a child varies depending on the context. Police Scotland state: 'There are many different definitions of age in Scotland. It can make defining an individual as a young person or a child more complex. In the past we have generally defined a child as being under 16 years of age. However, we recognise that nationally and internationally children are defined as under 18 years of age. We also realise that young people are considered to be between 18 and 24 years of age.'

Question 3 The Assisted Dying procedure and procedural safeguards

It is important for people to be given time and support to come to terms with a diagnosis of a neurological condition, and as such safeguards must include a clinical assessment by a condition-specific specialist and include another clinical professional or GP that has known the person for a minimum of 6 months, unless the patient's doctor has withdrawn consent as a conscientious objector.

Capacity

The definition proposed for the bill makes clear that it applies only to a person who ‘has capacity to request lawfully provided assistance to end their own life’ (6.4.b) and outlines that two registered medical practitioners will have to confirm a person’s capacity for decision-making. This is an area which will require careful consideration for people with progressive neurological conditions.

For example, speech can be affected in many conditions, so communication support needs to be provided to allow an accurate assessment to take place. For complex neurological conditions including Multiple System Atrophy, people lose the ability to communicate verbally very early on, which means there’s a need to have this conversation much earlier than clinicians would consider as part of an acceptable timeline. There are also considerations to be taken into account when patients use augmentative and alternative communication. For example, some AAC users may not have the right vocabulary on their communication aid to adequately express the complexity of how they are feeling. There should be a wider inclusion of communication issues in the proposal such as requesting speech and language specialists to assist in conversations and allowing for conversations with professionals about assisted dying to happen earlier if there is a risk the patient will lose verbal communication.

Some progressive conditions have an impact on cognition – including the risk of developing dementia. It is essential that the people undertaking the diagnosis understand that dementia may not present with memory problems at first, that a diagnosis of dementia does not of itself mean that a person does not have capacity, and that in neurological conditions it is not unusual for capacity to fluctuate, meaning that the person may be competent at some times but not at others.

Some progressive conditions cause mental health symptoms that can lead to a lack of capacity, such as psychosis, impulse control issues and severe depression. It is particularly important that capacity is accurately assessed in people with severe mental health symptoms so that people who lack capacity are identified appropriately.

Some people may become depressed, and potentially consider ending their life, in response to their diagnosis and fear of the future.

The Bill does not adequately outline the level of specialism required by the practitioner to assess capacity of the individual. We believe that any legislation must include a requirement for people with neurological conditions to have their capacity assessed by a clinician who has particular expertise in assessing people with neurological conditions.

Contextual safeguards

It is insufficient to only consider procedural safeguards.

There are numerous contextual factors which must be taken into account when assessing risk for people with neurological conditions, such as a lack of access to high-quality, specialist support to help manage their condition or those effected by economic deprivation unable to cope with the rising cost of living with a neurological condition. Appropriate contextual safeguards must be in place to ensure individuals are exerting a free and informed choice without external pressure.

1. Access to high-quality, timely, and holistic care and support at every stage of life, regardless of where in Scotland as a contextual safeguard.

There is a lack of adequate treatment and support for people with neurological conditions in Scotland. Our Together for the 1 in 6 report showed:

- The pandemic has had a negative impact on waiting times across all areas
- GPs and non-neurology specialists do not know enough about neurology
- There is inequity of access to care across Scotland

69% of people with MS were not able to speak with a specialist when they needed to.

37% of adults and 38% of children and young people in Scotland waited more than 12 months to get a diagnosis. This is worse for young people than in the UK as a whole where only 30% waited for more than 12 months.

Support for conditions can vary hugely depending on where in the country a person lives with patients often feeling like they are in a 'post-code lottery' when accessing treatment, care and support. For example, Our Together for the 1 in 6 report showed that access to specialist nurses is very difficult in Scotland in line with the UK. Issues include long waiting times, conditions without specialist nurse provision and variability of provision between NHS Boards. This further widens health inequalities across Scotland.

These factors all contribute to how well a person can cope when receiving a diagnosis of a serious lifelong condition, with no available cure, and are able to manage their condition when their symptoms worsen. Early intervention and equitable access to timely, holistic care when the person needs, including the right to specialist palliative care at point of diagnosis, is a significant safeguard to ensuring people with neurological conditions can live and die well. The option of an assisted death should not be an alternative to receiving the care individuals need to lead a full and integrated life. Members of the Neurological Alliance of Scotland feel that an evaluation of a person's care and support should be included in the assessment process for an assisted death.

2. Proper resourcing of healthcare services as a contextual safeguard

The crisis in budget cuts to the NHS, Health and Social Care Partnerships and third sector funding has led to many not receiving access to adequate, life long care.

The Neurological Alliance remains committed to ensuring compassionate care and support for everyone in Scotland living with a neurological condition. We urge the Scottish Government to ensure that health and social care is adequately resourced and that the ideals of the Framework for Action for Neurological Care and Support and the Health Improvement Standards for Care for people with Neurological Conditions are delivered.

Any debate around proposals for assisted dying should not in any way be based on saving money for health and care services. At a time when NHS and social care budgets are severely stretched the Neurological Alliance is concerned that people with lifelong, complex care needs will be offered the option of “assisted dying” before their health and care needs are adequately resourced. The discrepancies in healthcare provision depending on geographic location also mean that patients in health boards with poorly funded services or inadequate integrated care may be at a higher risk of feeling an assisted death is their only option due to their circumstance.

In common with the debate about the impact of describing people who need a lot of health and care support as “High Resource Individuals”, and in the context of the recent issues around DNACPR orders outlined above, we are concerned that continued pressure on NHS resources could lead to individuals and clinicians making decisions not in the person’s best interests, but according to NHS and social care budgets.

Spending cuts for third sector providing clinical services and social support is also a pressing issue. Fair funding of third sector is essential to ensuring people with neurological conditions are receiving intervention and support early on, which in turn enables them to access appropriate treatment to manage their condition and social support such as information, peer groups, helplines, advocacy and advice.

3. Involvement of mental health professionals as a contextual safeguard

The policy memorandum cites the GMC guidance on consent and decision making but does not cite item 70 which states: ‘Patients may feel pressure to have particular treatment or care. Pressure can come from others – partners, relatives or carers, employers or insurers – or from patients’ beliefs about themselves and society’s expectations.’ This last point identifying pressure from ‘patients’ beliefs about themselves and society’s expectations’ is a difficult risk to assess but an important consideration not currently appropriately safeguarded against in the Bill.

There is no requirement in the assessment process to enquire about the patient’s reasoning and motivation for applying for assisted dying. It is important for both the patient and the clinician to have these conversations as they allow for a fuller assessment of the patient’s psychological and social situation. It may become apparent that a person is experiencing preventable stress or suffering which is significantly

impacting their decision and may be resolved through other pathways. For example, if a person has experienced significant trauma in their life, seeing a therapist may help alleviate their emotional suffering.

In order to have these complex conversations, there would need to be a qualified mental health professional involved in this process. In the instance where there is no concern identified in the patient's motivation or reasoning, having a mental health professional involved to help guide the patient and their family during the process would also be of great benefit. Therefore, rather than only seeking the advice of a mental health professional 'if either doctor is unsure about the person's illness and/or capacity to request an assisted death' (Policy memorandum, 'Further Safeguards', section 39), integrating mental health workers into the process will be a significant safeguard to ensure both the patient and their families are supported in the decision.

4. Cost of living as a contextual pressure

Many people with neurological conditions already face high living costs and low incomes due to their condition. Households with children with neurological conditions are similarly affected. Over 1 in 4 (27%) of our 'Together for the One in Six' survey respondents in Scotland said that they did not have enough money to manage well, and 1 in 5 (20%) said that they were struggling to cover their costs.

Despite free prescriptions in Scotland, open responses to our survey show that people who have the means are turning to the private sector to access healthcare to reduce their waiting time for treatment, creating a two-tier system. Those without financial means are left to wait.

This survey fieldwork took place before the recent fuel and other inflationary price increases. These findings suggest that the cost-of-living crisis will become an even greater issue across the neurological community in Scotland. Where people on low incomes are already struggling to meet their housing, heating and food costs, the increase in daily living costs will push even more households over the edge and into extreme poverty.

Households forced to make choices between heating and eating will already have sacrificed other activities involving transport and access costs, with only prescribed, access-supported activities remaining as available options. People with neurological conditions and their families risk being isolated in their homes, with reduced physical activity and no social contact beyond their household.

It is important to consider how economic factors contribute to a person with a neurological condition deciding to have an assisted death.

Question 5: Health Professionals

Cultural taboo around death and dying

It should be noted that there is still a taboo around the words 'death' and 'dying' which is part societal, part cultural. Our charity members note a general reluctance for healthcare and social care professionals to be open about the fact that someone will die from a certain neurological condition. People are told they will die 'with' the condition, i.e. from pneumonia or another infection. This absence of being upfront about death and dying, limits people's ability to connect with services that would support them physically, emotionally, socially and spiritually in the time that they have left to live. Part of the assisted dying bill needs to address the cultural taboo attached to death and dying, and to be more open and upfront about support that could be useful, to ensure people don't think an assisted death is the only option.

Data from members

We have received submissions from members regarding data they have collected on assisted dying via audience surveys. We have offered to share this data on behalf of members.

The MSA Trust

In the MSA Needs Survey (2019), the MSA Trust sought the views of people living with MSA and former carers about this complex issue. In the survey for people living with MSA they asked:

“Whether or not you would want the choice for yourself, do you feel the option of assisted dying should be made legal by Parliament?”

- Among the 77% of respondents who answered Yes or No, 85% were in favour of a change in the law and 15% were against

They then asked: “If assisted dying, alongside comprehensive end of life care, was legal in the UK, would you potentially consider it?”

- Among the 71.5% of respondents who answered Yes or No, 76% said they would potentially consider it, with 24% saying they would not.

In the survey for former carers of people who had died from MSA they asked:

“If assisted dying had been legal in the UK, how would the person you cared for have felt about having this choice available to them (if there were adequate safeguards) alongside comprehensive end of life care?”

- Among the 78.7% of respondents who answered Yes or No, 67.5% said they felt they would have wanted the choice, with 32.5% against.

These responses show that people with MSA and their families have a range of views on assisted dying.

The MS Trust

A survey of 117 people affected by MS, conducted by the MS Trust in March 2024, revealed 85% supported and 14.5% opposed assisted dying for someone with a terminal illness. This represents a 14% increase in support of assisted dying, since the last survey was taken in 2017. Almost all respondents either strongly agreed or strongly disagreed with assisted dying.

As an organisation the MS Trust maintains a neutral stance on assisted dying but believes it is vital people with MS have access to good palliative care. We need to address issues with access to care, social isolation, and lack of support for family carers so people are able to make an informed choice about end-of-life options. The MS Trust calls for further investment in palliative care services and a wider recognition amongst both people affected by MS and health professionals of what palliative care can offer.

Concluding comments

The needs of the neurological third sector

A steady year on year increase in the prevalence of neurological conditions, coupled with extended NHS waiting times and difficulty accessing neurology services, has led to an overwhelming demand on the neurological third sector.

Statutory services rely on social support being available through the neurological third sector. The Scottish Government, NHS clinical staff and websites and Local Authorities all routinely refer people to our services, many doing so because they know the importance of social support delivered by the neurological third sector. And yet, many charities do not receive anything from statutory services or Scottish Government for delivery of social support.

The third sector in the UK (along with many other countries) operates under a scarcity-based model of funding, which prioritises underpaid staff, the goodwill of volunteers giving up their time freely, and the lowest possible overheads. We have already started to see the closure of health charities, with others increasingly operating within the margins of their reserves. Most health charities cannot continue to provide social

support without meaningful funding from local authorities, the NHS or Scottish Government.

With the concerns raised by the neurological third sector remaining unaddressed, it is our worry that people with neurological conditions will fall through the gaps as charities are no longer able to provide services and there is no support from NHS or local authorities. This may cause individual's to feel their only option is an assisted death, as they can no longer receive the support they need.

Opportunities to support people to live and die well

Despite the welcome existence of the Neurological Care and Support Framework for Action and the progress made through its implementation, we are concerned that the Framework comes to an end in 2025 and there is still much to be achieved to ensure its vision that “everyone with a neurological condition will be able to access the care and support they need to live well, on their own terms”. There is no further funding allocated for this work and no plan to support further work post March 2025.

NAoS believes that enabling people to access the care and support they need to live well, on their own terms, must be addressed as a matter of urgency and supports the current proposal for the legal right to palliative care for terminally ill people in Scotland.

Equalities

The Neurological Alliance of Scotland is aware of the variety of personal views held by members of the neurological community. However, we would want to ensure that the rights of people with neurological conditions, and particularly those who are vulnerable, are suitably safeguarded. We believe that every person with a neurological condition has the right to adequate care and support, to supportive care through declining health and quality end of life care when it is needed. We know that too many people do not currently receive this. We believe that, whatever the outcome of this bill proposal, there is still a lot to do to improve the experiences of people dying with complex and advanced neurological conditions in Scotland.