

Response from the Neurological Alliance of Scotland to the Consultation on the Proposal for an Assisted Dying for Terminally Ill Adults (Scotland) Bill lodged by Liam McArthur MSP

The Neurological Alliance of Scotland

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

The Neurological Alliance of Scotland is an umbrella body of about 50 third sector organisations that represent people with a neurological condition and those who support them in Scotland. We work to improve the care and support that people receive.

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.

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.

Our response to the Aim and Approach of the Bill

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, 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.

Palliative care provision

We note that the consultation document makes references to Scotland's excellent palliative care facilities. However, this section relates largely to specialist palliative care services, provided by hospices and specialist NHS teams. Unfortunately, access to specialist palliative care is often not available for people dying with neurological conditions. Although there has been some progress, most people dying with terminal or progressive neurological conditions die under the care of generalist health and social care teams in hospitals, care homes or at home. Recent research by Marie Curie has shown that about 1 in 4 people who could benefit from specialist palliative care in Scotland die without receiving it – and that people dying with neurological conditions are over-represented among those who miss out.¹

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

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.

There is a very high level of unmet need for specialist palliative and end of life care for people with neurological conditions. And 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 struggling to cope with the Covid-19 pandemic and stage a recovery. As a result, people are facing the end of their lives without any of the support that they need. Given this backdrop, we are very concerned that individuals may feel that assisted dying is the only viable option for them.

Definition of Terminal Illness

The proposal defines terminally ill people as those who “a registered medical practitioner has diagnosed ... as having a progressive disease, which can reasonably be expected to cause their 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 the Neurological Alliance of Scotland 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.

The Neurological Alliance of Scotland recognises that the definition provided in the proposal is consistent with this approach – but we think that 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. Without this safeguard, anyone with a progressive neurological condition could fall under the umbrella of this legislation at any time from diagnosis, without reference to symptoms, quality of life, or life expectancy.

The Neurological Alliance of Scotland believes that there is a high risk that the definition of people who are 'unable to recover, irrespective of how much time they have left to live' could cover many people with neurological conditions who - even though they have a terminal or progressive condition - may have many years of life left. Reference should be made in any proposed legislation to the CMO guidance on terminal illness.

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.

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.

Capacity issues and mental health

The definition proposed for the bill makes clear that it applies only to “competent adults” and outlines that two doctors 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. There should be a wider inclusion of communication issues in the proposal to clarify that declarations and consent might be given in ways that fit an individual’s communication needs.
- 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.

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.

Protecting vulnerable people

We recognise that 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.

We would also 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 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 very 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.

Additional safeguards

The safeguards we would want to see also include:

- The doctor who signs the declaration should have known the patient for a minimum of 6 months
- 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.
- 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.

Issues around physical impairments

People with advanced neurological conditions commonly have significant physical impairments, which could make it more difficult to meet some key criteria outlined in the proposal. Specifically, the requirement to sign a written declaration, which may not be possible for people whose condition means that they can no longer write, and 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. Failing to consider these issues could mean that people may choose to die at an earlier point than they otherwise would, rather than empowering them to die at a time of their choosing.

Monitoring and Evaluation

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. 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 (Are these to be NHS professionals?)

Role of healthcare professionals

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

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.

The proposed bill highlights geographical challenges faced by people in remote areas. Several people with terminal illnesses will also face mobility challenges and so it is necessary to take individual needs into account when stipulating assessment criteria.

Financial Implications

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, and we are concerned that the consultation document notes that an estimate made in 2017 of reductions in healthcare expenditure in Canada of between \$34.7m and \$138.8m. The consultation document does not make clear how these savings were made, and we believe that this risks dehumanising patients by treating the end of their lives as an economic and medical benefit to others.

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.

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 advanced neurological conditions in Scotland.

¹ Marie Curie: Triggers for Palliative Care: Implications for Scotland

<https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/june-2015/triggers-for-palliative-care-scotland-summary.pdf>