Right to Palliative Care Bill (Scotland) Neurological Alliance of Scotland response

About the Neurological Alliance of Scotland

Neurological conditions are those which impact any part of the nervous system; both the central and peripheral nervous system as well as the brain and spine.

Neurological conditions are one of the most frequent, disabling, and costly of all non-communicable diseases in the UK and are one of the leading causes of ill health worldwide. From migraine to stroke, an estimated 600 neurological conditions impact 1 in 6 people in Scotland, which is about 1 million people. The neurological landscape is complex and the challenges that people live with can vary considerably between, and within, conditions.

Established in 2004, the Neurological Alliance of Scotland is an umbrella body of nearly 60 organisations operating in Scotland, representing people with a neurological condition and those who support them. We work to improve the care and support that people receive.

Find out more about us here: https://www.scottishneurological.org.uk/

1. **Do you agree that terminally ill adults and children and young people with life shortening conditions residing in Scotland should have a legal right to palliative care?**

Strongly Agree

NAoS strongly agrees that there should be a legal right to palliative care for terminally ill people in Scotland. There are no national standards of care for people approaching the end of life and no systemic data gathered on people's outcomes and experiences of end-of-life care in Scotland. Making it a legal right would enforce local authorities to prioritise palliative and end-of-life care in the same way that other services such as maternity care are prioritised.

The level to which palliative care is included in Health and Social Care Partnerships varies widely with many H&SCPs not having palliative care strategies at all. Part of the purpose of this bill would be to equalise the postcode lottery of palliative care provision across Scotland.

Providing good palliative care for people with neurological conditions is challenging. Terminal neurological conditions are multi-faceted and complex, making prognostication difficult and presenting with widely varied symptoms often impacting breathing and swallow; memory, emotions and cognition; balance, movement and co-ordination and bladder and bowel incontinence.

There is evidence from Marie Curie that people over 85 with a terminal condition are less likely to be referred to palliative care than those under 65, perhaps due to a misconception that older people's needs are already being met. However, older people with neurological conditions often fall between the gaps, particularly if they are admitted to hospital for a fall or a reason related to increased frailty, rather than due to their neurological condition. There is also a higher risk of their neurological condition not being considered or managed during their hospital stay, and with increased risk of infection due to older age, older people with neurological conditions have a higher risk of dying in hospital.

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. A point we would like to make is that unfortunately, evidence shows that many people with neurological conditions do not have access to specialist palliative care.

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 right to palliative care needs to address the cultural taboo attached to death and dying, and to be more open and upfront about support that could be useful.

Question 2: What is your view on the World Health Organisation definition of palliative care, that is the basis of statutory guidance in England on palliative care provision, being the basis for a right to palliative care?

Partly Agree

The WHO defines palliative care as 'an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual'.

NAoS believes this is a useful articulation of the general aims of palliative care, but that its focus on 'life-threatening illness' places the onus on crisis and end of life, rather than at the point by which clinical and treatment decisions are impacted by the patient's trajectory towards death, which as we know, can be a period of months or years. Palliative care is about providing the best possible quality of life during the time someone has remaining, rather than simply preparing for death.

The WHO definition also fails to guide people as to what they can expect from palliative care, and NAoS believes that efforts should be made to better understand people's experience of palliative care across rural and urban settings, across different socio economic groups and amongst people with protected characteristics in order to manage expectations of provision of health and social care in a palliative care period.

A sensible place for legislation for the right to palliative care would be through the National Care Service Bill.

Question 3: Any new law can have an impact on different individuals in society, for example as a result of their age, disability, gender re-assignment, marriage and civil partnership status, pregnancy and maternity, race, religion or belief, sex or sexual orientation, caring responsibility, or location (urban or rural and island community settings).
What is your view on the different impacts that a right to palliative care would have and the different considerations there would be in implementing that right for different groups and people in Scotland living with a terminal illness?

Everybody, irrespective of who they are and where they live, should have fair and equal access to palliative care. Unfortunately, it is recognised that people with protected characteristics may have worse experiences of healthcare, and outcomes at the end of life.

Neurological conditions are estimated to impact 1 in 6 people, which translates as one million people in Scotland. They impact both men and women, with some conditions being more prevalent in men, and other conditions are more common in women. However, women often have informal caring roles as well, and so the impact of neurological conditions is more likely to have an impact on the health (particularly the mental health) and wellbeing of women, irrespective of whether they have a neurological condition themselves or not.

It is recognised that people in lower socio-economic groups are less likely to be able to access healthcare and that co-morbidities are more common partly as a result of this, resulting in more complex care needs. People living in poverty are also less likely to engage with palliative care or ask for help.

Furthermore, people with progressive and terminal neurological conditions often have complex palliative care needs, requiring specialist palliative care in the form of multi-disciplinary teams which normally operate in hospital or specialist hospice settings. The choice of where to receive palliative and end of life care is often unavailable to people – whether it is due to poverty and being unable to opt to die at home, due to housing issues (e.g. living in a flat without access to a lift, or in a property without an accessible bathroom, living rurally without anyone to care for you) or due to complexity of condition (e.g. any

condition impacting mobility, movement, breathing and swallow) and yet place of care and death is one of the most important measures in the experience of palliative and end of life care.

People with neurological conditions in acute care settings should be considered when it comes to disadvantage as some people who have been admitted to acute care for another reason (e.g. an accident or due to another long-term condition), sometimes do not have their neurological condition well managed whilst in hospital. This could be someone with cerebral palsy who doesn't have access to their communications device even though that's the only way they can communicate, or someone with Parkinson's who isn't able to access their Parkinson's medications at the right time.

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.

Question 4: What is your view on how a right to palliative care should be implemented? For example, you may wish to consider which bodies would be responsible for delivering palliative care and what their duties may be, and what data would need to be collected to assess how the right is being implemented

Legislative responsibility for delivering palliative care currently falls to the Integration Authorities and NAoS believes that they should retain that responsibility. The actual delivery of palliative care falls to a variety of different bodies and organisations – primary care, acute and community hospitals, hospices, third sector, care homes, NHS specialist palliative care units, Scottish Ambulance Service, the independent sector and local authorities. The issue of multiple delivery agents coupled with the absence or presence of palliative care strategies across H&SCPs and a lack of Scotland-wide palliative care standards, contributes to the huge variety in experience and satisfaction with palliative care services across Scotland.

NAoS supports the idea of introducing minimum palliative care standards that should be adopted as soon as possible, including the right to early intervention and planning which are key to delivering person-centred care.

Question 5: Are there any other comments you wish to make on the proposed Bill, for example, on its financial implications, impact on equalities and sustainability? Please explain the reasons for your response.

No answer.