

The Neurological Alliance of Scotland

Palliative Care Matters for All: strategy consultation

Consultation opened: 18 October 2025

Consultation closes: 10 January 2025

Question 1a. *Do you agree with the aims for this strategy?*

The aims of the strategy are that, by 2030:

- *adults and children in Scotland have more equitable access to well-coordinated, timely and high-quality palliative care, care around dying and bereavement support based on what matters to them, including support for families and carers.*
- *Scotland is a place where people, families and communities can support each other, take action and talk more openly about planning ahead, serious illnesses or health conditions, dying and bereavement.*
- *adults and children have opportunities to plan for future changes in their life, health and care with their families and carers.*

[Agree]

Question 1b. Please add any comments you have about the strategy aims here.

NAoS members agree with these three strategic aims. People with neurological conditions almost certainly will require palliative care to support them and yet currently people with neurological conditions are less likely to access hospice care than those with cancer. (National Health Executive July / August 2024 Page 66)

Providing good palliative care for people with neurological conditions is challenging and people with neurological conditions are currently poorly served by palliative care. 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.

Provision of palliative care for people with neurological conditions is harder and more expensive than for cancer or cardiology, due to the fast progressing, or fluctuating and unpredictable nature of neurological conditions. Palliative care for people with neurological conditions often requires a multi systems approach and a workforce with specialist knowledge.

This quote from a report by Kluger et al (2023) explains:

“Unfortunately, most people with neurological diseases do not get the support that they need for their palliative care under current standards of healthcare. Improving this situation requires the deployment of routine screening to identify individual palliative care needs, the integration of palliative care approaches into routine neurological care, and collaboration between neurologists and palliative care specialists. Research, education, and advocacy are also needed to raise standards of care.”

The need for good palliative care for people dying with a neurological condition has never been more important. The Scottish Burden of Disease puts neurological conditions in the top three of conditions we are likely to die of by 2043. Our ageing population will lead to greater numbers of people developing dementia including Alzheimers, neurodegenerative diseases like MND, and movement disorders including Parkinson’s.

There are no national standards of care for people approaching end of life and no systemic data gathered on people’s outcomes and experiences of palliative 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 maternity services are currently prioritised.

Children and young people affected by life-threatening and/or life-limiting neurological conditions and their families require consistency in signposting and access to palliative care as early as reasonably practicable rather than towards end of life. The current reliance on Children’s Hospices Across Scotland (CHAS) to provide paediatric palliative and end of life care limits access for the ‘lucky’ ones and excludes others.

The Government’s strategic aims include the issue of limited public understanding and awareness of palliative care, raising public expectation of what can be expected and how to access it. Education around this element of the strategy is needed within the general public as well as within wider community services and amongst support providers.

The postcode lottery of availability of resources, provision of services and funding must be addressed to meet the basic needs of people dying well let alone to reach the gold standard that this strategy aims to achieve. A key challenge will be in the funding required to enable these three strategic aims to be achieved as well as realising a cultural shift required to de-stigmatise conversations about death.

Question 2a. *Do you agree with the strategy cornerstones, which form the basis for the strategy and delivery plans?*

- *We used four ‘cornerstones’ as the foundations for change and improvements in palliative care policy, service delivery and public involvement. These are:*
- *Working together to provide the care that’s right for each adult or child, their family and carers.*
- *Taking a whole-system population health approach using data and people’s experiences*
- *Ensuring equity and equality of access to palliative care for anyone who needs it*
- *Leadership across health and social care systems and with wider delivery partners, including third sector organisations (charities)*

[Agree]

Question 2b: Please add any comments you have about the four strategy cornerstones here.

This appears to be a holistic approach, taking into account the need to base services on data and evidence, which is currently lacking. The needs of children and young people with life-threatening and life-limiting neurological conditions must be considered from the outset of strategy and delivery planning if they are to be met effectively.

The cornerstones also address the importance of workforce and educating both members of the public and health professionals about the strategy. However, we would like to know where the workforce is coming from that will deliver the interventions given the proportion of unfilled vacancies in neurology and across community rehabilitation and care services too. Asking existing health professionals to provide specialist palliative care would likely result in other services being dropped.

At the heart of these cornerstones is the challenging question of funding. At present, the majority of palliative care is provided by the third sector, not only must they be “involved” they must be supported and funded to lead.

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.

This is also true of care homes, as highlighted in this Strategy’s supporting paper on population data, where the main causes of death of people in care homes are from cognitive and behavioural disorders, including dementia (21.2%), and other diseases of the nervous system (20.9%), i.e. neurological conditions.

For some people, health professionals often assume health issues are related to an existing neurological condition, rather than having a different cause. This leads to people being sent away from primary or secondary care without being offered adequate diagnostic tests (blood, urine, temperature etc) or appropriate healthcare advice. For conditions like Huntington's Disease, we know that people in hospital are often left bed-bound, catheterised and with their food left on a tray. This means that when discharged, they have lost their ability to mobilise, swallow, speak and they have become incontinent. Huntington's is a terminal disease and so people with Huntington's should be treated with a palliative care approach from the point of diagnosis, and yet too often they are being neglected with their basic needs unmet.

Long-term and consistent investment is required to deliver these four strategic cornerstones. Accountability and clear lines of responsibility will also make a difference to the success of this palliative care strategy.

Question 3a. *Do you agree with strategy outcome 1 and the proposed actions being developed to deliver this outcome?*

Outcome 1: People have the understanding, information, skills and confidence to support themselves and others to live well with serious illnesses or health conditions; to plan for the future; and to support each other through dying and bereavement.

Proposed actions:

- *Take forward work across relevant policy areas to improve the wider experiences of people receiving palliative care and care around dying; remove barriers to access; and maximise support, including areas related to children and young people, equalities, justice, fair work, housing and tackling poverty.*
- *Explore ways to promote access to financial benefits for adults or children with serious illnesses or health conditions and increasing health and care needs under the Benefits Assessment for Special Rules in Scotland (BASRiS) application process through improved public information and professional education and guidance.*
- *Work with agencies, statutory and third sector organisations responsible for housing and services for people who are homeless or vulnerably housed to develop and promote ways to enable adults and children living with serious illnesses or health conditions to access the social, practical and financial assessments and support they need.*
- *Collaborate with NHS 24 and wider partners to make sure the NHS inform website provides relevant, up to date and accessible public information about future care planning, palliative care and care around dying for adults and*

children, families and carers, including links to support organisations and resources for people from diverse groups and communities.

- *Support the Scottish Partnership for Palliative Care (SPPC) to provide a sustainable, national infrastructure that enables statutory and third sector organisations, palliative care providers, staff, community groups and individuals to work together to promote understanding and awareness of living and dying with serious or life-threatening illnesses and serious health conditions; and to contribute towards empowering people to be more informed and equipped to plan ahead and support each other through serious illness, dying, death and bereavement.*
- *In partnership with the third sector, widen access to community-led public education opportunities which provide knowledge, skills, resources and training to help more people be comfortable and confident in supporting family, friends and people in their local community when someone is dying, caring or bereaved.*
- *Work with Integrated Joint Boards (IJBs) and Health and Social Care Partnerships (HSCPs) to explore options for their strategic plans for palliative care to recognise and work collaboratively with local community groups, networks and projects that offer support for adults with serious illnesses; children and young people with serious health conditions; and their families and carers.*

[Unsure/ Don't know]

Question 3b: Please add any comments you have about outcome 1 and its actions here.

NAoS believes that much more needs to be done to improve public understanding and awareness of palliative care –a term which is often misunderstood to mean provision of care at the 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.

However, the current definition of palliative care as coined by the WHO is not expansive enough to meet this strategy outcome. Unless a broader, clearer definition is brought into play, it will be challenging to shift public perception using only the proposed actions listed above.

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

Fundamentally, long term investment is urgently required in palliative care. This needs to include education for the workforce, raising awareness of and demystifying palliative care in the community, boosting the existing workforce and funding third sector to continue to lead on and deliver core palliative care services.

The action points mention updating NHS inform and community led education initiatives. These do not go far enough to create sustainable, long-term change. Members suggest that education on palliative care and dying well must be improved in health and social care settings such as on the core curriculum for health and social care qualifications and revalidation, in induction programmes for all Health and Social Care staff in public, private and third sector organisations, and affordable training opportunities on palliative care developed for all health and social care, community based and formal education organisations.

Furthermore, community education must include: public initiatives to improve confidence and conversations about death and dying across age groups and socio-economic groups; easy access to information for the public of what is available locally; information packs for all community based organisations; marketing campaigns to promote conversation and the benefits of talking about peoples wishes and planning for something as part of a KIS (Key Information Summary). Planning for death need not just be for the dying rather, a natural part of our conversation and Getting it Right for Everyone (GIRFE).

Community education must also work to shift the narrative around palliative care to make people feel comfortable to seek and receive symptom management and support for their condition.

Going back to funding, without long-term ringfenced palliative care funding, none of the strategic outcomes in the Palliative Care Matters for All plan are realistic or achievable. The plan calls for a complete cultural shift in perceptions and understanding of palliative care - this requires a generational shift in thinking and is not something that an action plan will achieve without significant funding of services, and education in the community as well as in the workforce.

There must be security and sustainability in funding to be able to see real changes embedded over time in societal and health care attitudes toward palliative care.

Question 4a. *Do you agree with strategy outcome 2 and the proposed actions being developed to deliver this outcome?*

Outcome 2: Leaders, stakeholders and delivery partners will work together in partnership, with clear roles and responsibilities, to make sure there is reliable and

effective planning, delivery, accountability and improvement of palliative care services and wider support.

Proposed actions:

- *Develop guidance with IJBs and Health Boards to support the identification of a clinical and a managerial / executive lead, and to establish a Managed Care Network (MCN), updating previous guidance for Health Boards on MCNs.*
- *Work with Health Boards to establish new requirements for inclusion of integrated specialist palliative care services within annual delivery plans and performance monitoring.*
- *Work with HSCPs and adult independent hospice organisations to develop a national guidance framework to support and improve consistency of local planning and commissioning of independent hospice services.*
- *Work with the Scottish Partnership for Palliative Care to establish a national Palliative Care Innovation Network, where people and teams involved in palliative care delivery; community-led initiatives; improvement and research; or education can come together to share learning and ideas for improvement and innovation.*
- *Continue to engage with palliative care delivery partners on how the proposed National Care Service Board and the reformed Integration Authorities will improve national and local governance, roles, responsibility, commissioning, monitoring and reporting of specialist palliative care services and general palliative care*

[Unsure / Don't know]

Question 4b: Please add any comments you have about outcome 2 and its actions here.

NAoS agrees with this outcome. 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.

Outcome 2 would mean that effective delivery of appropriate palliative care services could be managed for everyone, which would include the provision of additional specialist palliative care services accessible to people in every health board in Scotland.

However, we are not convinced that the actions listed above will by themselves achieve this outcome.

Cross sectoral integration and partnership is critical and requires sustainable and fair funding. Third sector cannot act as an equal partner without sustainable and planned multi-year funding. Funding cannot be limited to 'new and innovative' projects, but to allow third sector to continue to deliver critical grass roots and community services.

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 strategy needs to equalise the postcode lottery of palliative care provision across Scotland.

Palliative care requires a whole-system approach, integrated from top down and from bottom up, with the whole of the health and social care sectors involved.

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.

Again, the needs of children and young people with life-threatening or life-limiting neurological conditions must be included in all decisions regarding provision of palliative and end of life care.

Question 5a. Do you agree with strategy outcome 3 and the proposed actions being developed to deliver this outcome?

Outcome 3: National and local leaders will have access to relevant data to inform planning and delivery of services; and will put in place improved ways to monitor and evaluate the outcomes and experiences of children and adults receiving palliative care, as well as their families and carers.

Proposed actions:

- Work with Public Health Scotland, Health Boards, HSCPs, and other key partners, including paediatric palliative care planners and service providers, across all sectors to improve the quality and range of palliative care data collected, analysed and reported. Such data can be used to inform improvement, experiences, and delivery of palliative care for adults and children, families and carers, and includes:
- updating and improving the existing adult palliative care population data reporting systems; and providing access for service planners and health and care staff.
- developing a national approach to data collection on paediatric palliative care services for babies, children and young people (0 -18 years) and developing a

new dashboard that can be accessed by paediatric palliative care service planners, and health and care staff.

- working with HSCPs and Health Boards to develop a data template that supports them to collect, analyse and report high quality data on general palliative care and specialist palliative care services delivered to adults, children and young people for service planning and improvement, which includes user experiences in all places of care.
- development of a Scottish minimum data set for all adult specialist palliative care services.
- development of a Scottish minimum data set for all paediatric and neonatal specialist palliative care services and transitions.
- Explore evidence based and emerging co-design approaches to hearing and measuring people's experiences of palliative care, care around dying and bereavement support in palliative care for all places of care, and establish a consistent national approach to help improve these experiences.

[Unsure / Don't know]

Question 5b: Please add any comments you have about outcome 3 and its actions here.

Again, we agree with the aims of the outcome, however we disagree that the actions listed will necessarily produce the desired results.

Lack of prevalence data and research on neurological conditions means there is huge gap in knowledge regarding how neurological conditions affect people and who is affected (this was identified in the 2022 Scottish Government report 'Neurological Conditions: estimating the prevalence in Scotland of selected conditions using General Practice and Hospital Admissions datasets' - p.3: "The Neurological Framework discussed the challenge in obtaining basic epidemiological data. It highlighted the need for more accurate population-level prevalence estimates to inform service planning and development."

Only 72.7% of registered patients were accounted for in GP data. The report outlined: 'The general practice data presented in this report does not include data for the whole of Scotland. Two out of the 14 NHS Boards did not participate in the data extract, and data from 21 general practices from the other 12 NHS Boards were removed following a PHS quality assurance process.' It recommended that 'The accuracy of future data extracts would be improved by the participation of all 14 NHS Boards, and by improving consistency in recording of general practice patient lists to avoid exclusion of data.'

Moreover, people with more than one neurological condition were also not accurately represented and the report highlighted the "potential of hospital records to underestimate the prevalence of disease". All of this evidence shows how attempts to collect basic information on prevalence has been limited by lack of participation across health

boards, invalid data and poor data collection methods which reduce complexity and nuance, meaning people's experiences are not accurately represented.

It is hugely important to improve the data we have to understand our communities and how we can improve services and support. We must make sure that engagement with data collection is consistent across all Health Boards and Health and Social Care Partnerships, that staff are aware and understand the importance of data collection and there are a variety of standardised data collection methods and analysis to ensure all experiences are captured.

In neurology, we have seen a lack of meaningful self-evaluations of neurological standards. Not all health boards participated in the evaluation of neurological standards 1,2 and 7 in April 2024 and of those that did, only four Health Boards provided mechanisms for patients to share their experiences. Feedback highlighted challenges including overwhelmed staff lacking time, capacity or resource to properly evaluate services and the patient experience. This is a major consideration when planning to ask more from frontline staff to report data and / or evaluate their services. There must be appropriate resource and capacity freed up for meaningful reporting and evaluating.

We'd like to see the development of a live neurology dashboard in Scotland, similar to the adult neurology ICB NHSE version which includes monitoring on key metrics and enables integrated commissioning. Data collection which is notoriously difficult at health board level might be done more easily centrally via AI.

Provision of data would inform ongoing service delivery including how to reach under-represented groups and provide more choice to people about where they can receive palliative and end-of-life care.

Would need to ensure assisted communications tech is available for those who need it to be able to speak up about their experiences.

Question 6a. *Do you agree with strategy outcome 4 and the proposed actions being developed to deliver this outcome?*

Outcome 4: Adults with serious or life-threatening illnesses will be identified earlier and be able to access general palliative care and specialist palliative care services, whenever and wherever needed.

Proposed actions:

- *Work with Healthcare Improvement Scotland (HIS) to improve guidance and promote improvements in use of evidence-based tools to support proactive identification and review of adults with unmet palliative care needs, their families*

and carers, by staff and teams working across health and social care in all HSCPs and Health Boards.

- *Work with NHS National Services Scotland (NSS) and HIS and digital science experts to explore further development and implementation of national health records screening tools to improve identification of adults with serious or life-threatening illnesses for earlier palliative care and future care planning.*
- *Explore viable options with NHS 24 and other delivery partners to provide a 24/7 national palliative care advice line (via the 111 system) for patients, families and carers that reduces delays in access to urgent primary care and social care and connects with locally delivered palliative care telephone helplines and services.*
- *Support collaborative working to promote inclusion of palliative care and care around dying in service planning and delivery for people with one or more long term health conditions.*
- *Support innovative models of care and consider options for service developments and partnership working to increase equity of access to adult specialist palliative care both in-hours and out-of-hours in all Health Boards and HSCPs, including a specific focus on people who have more barriers to accessing the specialist palliative care they need.*
- *Explore options with Health Boards and HSCPs to make sure there is consistent access at all times (24/7) to specialist clinical care from a consultant in palliative medicine and from senior nurse specialists whenever a person is receiving inpatient hospital or community hospital specialist palliative care, including contractual arrangements to support rural and island Health Boards.*
- *Work with Health Boards, HSCPs and third sector organisations to improve access to urgent palliative care services in the community that can reduce avoidable hospital admissions and shorten inpatient stays, and provide more effective, timely admission processes for those needing hospital care. This includes improving access to specialist palliative care advice in hospital and at home within wider national and local work on unscheduled care and early hospital discharge.*
- *Work with Health Boards, HSCPs and third sector organisations to support improved provision of professional-to-professional specialist palliative care clinical advice lines, ensuring these are available 24/7 in all parts of Scotland, so that other health and care staff providing palliative care, including the Scottish Ambulance Service, can access specialist palliative care advice at all times.*
- *Work with Health Boards, HSCPs, third sector organisations, other delivery partners, and community groups to improve palliative care, care around dying and bereavement support for people from minority communities and other groups who face barriers to accessing palliative care or who need flexible approaches tailored to their health conditions, situation, personal circumstances, values and preferences.*

[Unsure / Don't know]

Question 6b: Please add any comments you have about outcome 4 and its actions here.

We believe that clarity over how, when and where to access palliative support needs to be made from the point of diagnosis in order to fully support someone and their family. In the case of someone suffering from an undiagnosed condition, access to palliative care should be made available at the point that it is clear that recovery is unlikely.

Some neurological conditions are fast progressing impacting communication and / or cognition. However, as the End of Life Care for People with Neurological Conditions (2011) report says, whilst it may be necessary to have palliative and end of life care discussions sooner rather than later, this can be hard for the person involved, their family and clinicians. People cope better if given information at a rate they can handle mentally and emotionally.

Neurological conditions can be quite complex, with different conditions leading to different challenges at end of life. For instance, people with MS may suffer from mobility problems, bladder and bowel issues, spasms and swallow difficulties; those with MND are likely to have respiratory failure or increased breathlessness and difficulty swallowing. People with Parkinson's Disease will suffer from muscular rigidity, pain and neuropsychiatric decline. People with complex neurological conditions cannot be managed under generalist palliative care and require a more expensive specialist service which is often not available to them.

Systemic lack of knowledge, understanding and awareness of neurological conditions can undermine the best attempts at palliative care strategies. Until there is investment in neurology, there cannot be appropriate palliative care for people with neurological conditions. Therefore, part of this strategy must be to invest in more specialist nurses, clinicians and social care providers for the more complex neurological conditions.

Furthermore, many adults live with conditions that are not easily or quickly diagnosable, instead are diagnosed through a process of elimination. Conditions like MSA, CBD, MND and ME have no conclusive diagnostic test, and waiting lists to see a neurologist are nearly year and a half long in some parts of Scotland in addition to the consequent waiting lists for a specialist scan to aid diagnosis. Furthermore, many neurodegenerative conditions progress slowly to start with and may require multiple visits to a neurologist over many months before a diagnosis is possible. Quick identification of these patients is not always possible.

Neurological conditions account for between 10% and 20% of acute medical admissions, and 10% of the overall burden of disease in Scotland. Given the specific complexities of neurological conditions, it may be more appropriate to embed palliative approaches in neurological care.

Finally, if the third sector is to be an integral partner in the delivery of professional-to-professional specialist palliative care clinical advice lines, to improve access to urgent palliative care services in the community that can reduce avoidable hospital

admissions and shorten inpatient stays, to provide more effective, timely admission processes for those needing hospital care, and to improve palliative care, care around dying and bereavement support for people from minority communities and other groups who face barriers to accessing palliative care, the sector needs to be properly and sustainably funded.

Question 7a. *Do you agree with strategy outcome 5 and the proposed actions being developed to deliver this outcome?*

Outcome 5: Adults living with serious or life-threatening illnesses and children with serious health conditions will be offered person-centred future care planning involving their families and carers, and care plans will be recorded and shared using national digital systems

Proposed actions:

- *Support a national partnership programme for future care planning, overseen by the National Future Care Planning Working Group, that is person-centred, inclusive and takes a 'Once for Scotland' and 'digital' approach to development and delivery for children, young people and adults whose life, health or care may change, and which is suitable for all places of care.*
- *Continue to work with NHS Education for Scotland (NES) Digital, other national organisations and partners to develop and implement a national electronic urgent and emergency care plan for health and social care accessible to staff working in the community, NHS unscheduled care services and hospitals in all Health Boards, starting with health care staff and extending to social care staff, care homes and independent hospices.*
- *Continue to work with NES Digital, other national organisations and partners to develop and implement a national electronic hospital urgent care plan to improve treatment and care during a single hospital admission that connects digitally with community urgent and emergency care plans.*
- *Continue to work with NHS Education for Scotland, other national organisations and partners to develop and deliver national education and implementation resources on future care planning for use across Scotland.*
- *Promote future care planning across all sectors and involve a wide range of stakeholders in development and delivery including members of the public, adults, young people, families, parents and carers, minority groups, patient support groups and third sector organisations, and to develop accessible and inclusive resources and information about future care planning with them.*

[Unsure / Don't know]

Question 7b: Please add any comments you have about outcome 5 and its actions here.

We are supportive of the incorporation of education and digital system that all sectors can link in to. This is very much needed to ensure that access to shared information across departments and partner organisations is accessible. However, there is a real risk that not all health boards will have resources or capacity to enable access to their digital platforms and that the solution will be to develop a new platform which will in turn create duplication of reporting.

Question 8a. *Do you agree with strategy outcome 6 and the proposed actions being developed to deliver this outcome?*

Outcome 6: Quality and experiences of care around dying and bereavement support are improved for adults, their families and carers, in all places of care.

Proposed actions:

- *Oversee an update to the national guidance on Care around Death and work with Health Boards and HSCPs to make sure it is implemented as best practice in all places of care in Scotland.*
- *Work with Health Boards , HSCPs, primary care teams and pharmacy services to promote timely provision and use of ‘just in case medicines’ for adults dying at home and residents in care homes and improve staff education and public information.*
- *Work with HSCPs and Health Boards to promote and develop effective models of urgent palliative care able to provide rapid access to coordinated health and social care support for adults dying at home, their families and carers.*
- *Work with Scottish Ambulance Service and NHS Education for Scotland to ensure palliative care continues to be part of core training and professional development for ambulance clinicians.*
- *Oversee an update the public information leaflet “When someone has died – information for you” with NHS Education for Scotland and other partners, and promote its use along with additional local information through Health Board Bereavement Leads, HSCPs, and other organisations, including NHS Inform.*
- *Continue to champion, co-ordinate and work in partnership with key stakeholders to ensure compassionate advice, resources and support are available for people experiencing bereavement, following the death of an adult with a serious or life-threatening illnesses, or with a child who has a serious health condition, and explore improvements to bereavement care.*
- *Work with NHS Education for Scotland and other partners to develop a new education and training resource on bereavement care for staff across health and social care that includes staff support and spiritual care as part of the Support Around Death resources.*

[Unsure / Don't know]

Question 8b: Please add any comments you have about outcome 6 and its actions here.

NAoS strongly agrees that the quality and experience of care around dying and bereavement support needs to improve in Scotland, particularly for people affected by neurological conditions. We also believe 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.

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.

Whilst we agree with the strategy outcome, it is unclear how the actions will address workforce limitations, funding for this additional bereavement support, or how it will address the uncertainty faced by carers at end of life. Supporting someone who is dying from a neurological condition, by nature of the medical interventions needed, creates intensely challenging situations. How will these strategy actions address the trauma carried by carers who witness distressing and difficult end of life experiences?

Research has suggested that those spouses/partners who had difficulties accepting that their partner's condition was terminal were more likely to subsequently have prolonged and complex grief reactions. Those people who were isolated in their caring role may be more at risk of feeling abandoned or unsupported in bereavement. Overall, access to bereavement support is patchy and has been identified as a priority area of need, especially for carers of people with conditions which have tended to be overlooked in the bereavement literature (for example, Parkinson's Disease).

Paperwork for administering 'just in case' medications is different in each health board, which sees practitioners in one health board being given the autonomy to use their own clinical judgement as to whether an individual should be given a second just in case medication. An inexperienced practitioner does not and should not have this responsibility.

Research from 'End of life care for long-term neurological conditions: A meta-ethnographic review of the experiences of informal carers' (2020) shows that carers flagged various challenges including uncertainty over prognosis and timing, poor access to services, difficulty knowing who to talk to and end of life care decisions not being respected. These could be addressed by improving palliative pathways and protocols and improving access to bereavement services.

Question 9a. *Do you agree with strategy outcome 7 and the proposed actions being developed to deliver this outcome?*

Outcome 7: Babies, children and young people living with serious health conditions, and their families and carers, will experience improved support as their distinctive needs are recognised and addressed by paediatric palliative care, including care around dying or as they transition into adult services.

Proposed actions:

- *Work with key partners to develop a national approach to service planning for all paediatric palliative care, through a multi-agency steering group, to ensure children and families across Scotland have access to the services they need, wherever and whenever these are required, and to ensure that these services are equitable.*
- *Work with CHAS and Health Boards to review current models and develop a national specialist paediatric palliative care service available at all times (24/7) to meet the needs of children, families and staff across Scotland in all places of care.*
- *Support and develop improved transitions for young people with serious health conditions based on Getting It Right For Everyone (GIRFE) practice model, and the co-designed GIRFE 'team around the person' toolkit for young people in transition from GIRFEC (Getting it Right for Every Child) to GIRFE.*
- *Draw on best practice models to develop and agree paediatric palliative care standards to children and families across Scotland have equitable access to high quality general and specialist paediatric palliative care services wherever and whenever these are required.*
- *Explore options for a national approach to providing ethical clinical review of decision making in paediatric palliative care.*

[Unsure / Don't know]

Question 9b: Please add any comments you have about outcome 7 and its actions here.

How will the actions address the basic barriers such as servicing rural areas, financial constraints, access to suitable and timely transport and environmental factors which

must be considered and affect families' participation in health and social care services on a day to day basis?

According to the 'Make Every Child Count' report by Together for Short Lives, 'The prevalence of life limiting conditions was highest for congenital abnormalities followed by neurological disorders. Prevalence of life limiting conditions was highest amongst children of Pakistani origin (103.9 per 10,000). This is important in terms of flexibility of service to meet the needs of all children. More children than expected with a life limiting conditions lived in areas of higher deprivation (13% most deprived versus 8% in least deprived).'

There are unique challenges in palliative care for children and young people with neurological conditions. Children's neurological conditions can be life-threatening and/ or life-limiting, therefore access to palliative care may be required over extended periods rather than time-limited end of life care.

Young people with terminal neurological conditions can be complex to manage, as 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 particularly at transition with a lack of integration between children and adult services.

Therefore, we welcome the actions to address the challenges of transitions and consistency in care and support for young people with neurological conditions. The period when a young person transitions from child to adult services (i.e. between the ages of 16-25) 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 worker (someone to help them transition to adult services).

Question 10a. *Do you agree with strategy outcome 8 and the proposed actions being developed to deliver this outcome?*

Outcome 8: Employers, professional bodies and education providers will make sure that staff who deliver palliative care are trained, skilled and supported.

Proposed actions:

- *Work with Healthcare Improvement Scotland (HIS) to ensure there is sustainable management, updating and extension of the Scottish Palliative Care Guidelines as recommended best practice for symptom management across Scotland on*

the Right Decision Service; and explore options to develop and include Scottish paediatric palliative care guidelines.

- *Work with NHS Education Scotland (NES) to develop a designated online learning space readily available to all health and social care staff who deliver palliative care to adults, children and young people that provides a single point of access to relevant training and education resources on palliative care, care around dying and bereavement support.*
- *Work with NHS Education for Scotland (NES), statutory and third sector organisations, and education providers to support and enable local and national education and training for health and care staff to equip them to have sensitive and effective person-centred conversations with adults or children, families and carers, that are central to future care planning, palliative care, and care around dying, including NES Having Realistic Conversations resources.*
- *Work with NHS Education for Scotland (NES) and third sector palliative care education providers to promote and develop online learning opportunities and networks for health and social care staff across Scotland such as Project ECHO.*
- *Work with universities and further education colleges that provide pre-registration courses and undergraduate education programmes to enable all health and social care staff (including doctors, nurses, pharmacists, allied health care professionals and social workers) and to receive a level of adult or paediatric palliative care education appropriate to their roles.*
- *Encourage HSCPs and Health Boards to employ palliative care practice educators to support the sustainable delivery of palliative care education and training in line with the NES/SSSC Palliative Care Education Framework and work collaboratively with adult and paediatric palliative care specialists offering education and training.*

[Disagree]

Question 10b: Please add any comments you have about outcome 8 and its actions here.

As there is no standardised approach to palliative care across Scotland, the challenge of different approaches to palliative care across health boards means this outcome and actions alone will not improve people's experiences of palliative care. On top of this, complex conditions including neurological conditions need specialist resourcing or for neurologists to be invested in and embedded in palliative care teams. Furthermore, these actions alone do not address how a highly trained specialist workforce either in the NHS or in the third sector will be sustainably funded.

Before these actions can improve the delivery of a skilled, trained and supported palliative care workforce, some level of education and training needs to be provided to explain the nuances of neurological conditions to address the lack of awareness and education about neurological conditions in the workforce and by health care professionals. Feedback from the community suggests that people often feel

unsupported by health and social care professionals and that social care staff do not know of, or understand, their condition enough to support them adequately.

More needs to be done to upskill staff to the level that is required to deliver palliative care. Having designated online learning spaces will not make much of a difference. Has consideration been given to specialist palliative practitioners and trainers?

Finally, palliative care training needs to be included in paediatric training.

Question 11. *Please add any further comments you have about the draft strategy outcomes and actions here*

The strategy is welcome as the lack of investment in palliative care services in Scotland has led to a broken system where people and their families face real suffering and often have to make agonising decisions without real choice.

While we broadly agree with the outcomes of this strategy, we do not feel the actions sufficiently consider how to develop a functional, accessible and sustainable specialist palliative care service to cater for the needs of those with more complex neurological conditions.

Developing a culture of talking about death and dying isn't necessarily something that a government strategy alone can achieve. Conversations about what to expect when given a terminal diagnosis will only be effective when the person is in a position of being ready to listen and have this discussion. The readiness of family members and carers is critical too. Sometimes it is not effective or beneficial to discuss the certainty of death, and this includes discussions with people whose condition makes it difficult to understand how ill they are as well as people who are very frightened of death.

Discussions over what is likely to happen at the end of life may reduce fears, but only if the person is able to remain comfortable, e.g. they don't require medical apparatus, and they are very unlikely to have a positive impact once someone has been admitted to an acute hospital setting.

Question 12a. *Community action and support - Do you think this strategy explains why it is important to encourage people, families and communities to come together, support each other, take action and talk more openly?*

Living well with serious illnesses and health conditions, dying and loss are universal experiences affecting everyone.

[No]

Question 12b: Please add any comments you have about how to do this better in Scotland.

It is evident that the strategy explains the importance of communication between sectors to deliver best evidence-based practice, and highlights the importance of education, but it does not look at or target external support and resources for individuals and their families.

Normalising conversations about death and dying require a multitude of resources to ensure the most marginalised groups are not left out or unable to access what is available.

Question 13a. *Earlier access to palliative care - Do you think this strategy explains why getting palliative care long before someone is dying can help adults, children, their families and carers?*

Many people don't understand that palliative care helps adults with serious illnesses or children with serious health conditions to live as well as possible. Some people think they can only get palliative care in the last weeks or days of life. In fact, some adults and children can benefit from palliative care over many years.

[Yes]

Question 13b: Please add any comments you have about earlier access to palliative care here.

The strategy explains the importance and benefits of getting palliative care early, but it also must tackle the common misunderstanding that palliative care is what is left once all treatment options have been exhausted. The words 'palliative care' are often only mentioned at the later stages of someone's illness which reinforces the perception that it is only used towards the end of someone's life. There must be an acknowledgement that if you have a life-limiting condition, palliative care can be something someone accesses intermittently, upon demand, throughout their life. This can help to challenge the notion that palliative care is just for end of life.

If good palliative care should be made available to everyone with a life-threatening, terminal or serious illness, this would include everyone living with these illnesses

straight away. How will this be funded? It is not clear how palliative care resources will be made available to a much larger group of people. It is also difficult to palliate neurological conditions which impact balance, co-ordination, muscle strength, speech, swallow, cognition and memory.

Whilst this strategy explains the importance of early access to palliative care, it's not going to make any difference if it is not followed up with significant investment across health boards, IJBs, NES and the third sector to deliver it.

There also has to be more interaction between the H&SC sector and communities in order for it to reach the individual. The strategy must consider how to reach out and include the most marginalised in society. Nearly half of everyone in poverty is either disabled or lives with someone with disabilities. Digital poverty and social/community exclusion are not covered by this strategy.

Education, communication and resources to enable the strategy are required not just between sectors, but also between individuals and the wider community. If the information is not accessible, if the communication is not accurate and if the resources are not there, then the care cannot be person-centred and cannot be delivered in line with this strategy.

Question 14a. *Improving access to palliative care and support - Do you think that the actions in this strategy can improve the experiences of people with different personal characteristics and circumstances?*

How adults and children, their families and carers experience living and dying with different illnesses; access health and care services; and use their own community support networks is affected by their health conditions, situation, location, culture and personal circumstances. These include:

- *age*
- *disability*
- *race or ethnic group*
- *religion or belief*
- *gender*
- *sex*
- *sexual orientation*
- *rural or island areas*
- *socio-economic deprivation (poverty)*
- *illnesses or health conditions*

[Unsure / Don't know]

Question 14b: Please add any comments you have about impacts of the strategy on these or other groups of people here.

This strategy will only improve the experience of palliative care across different characteristics if it leads to investment into specialist palliative care services for people with complex conditions including neurological conditions.

The strategy has not looked at or identified the barriers that could prevent improvement for individuals. As evidenced in their Service Mapping Survey: 'Few NHS Boards (2) and HSCPs (5) reported using any specific ways to identify, assess and address the palliative care needs of people from minority ethnic groups or those with protected characteristics. Some noted they are developing these resources.' There is a lack of insight into the true barriers faced by those in the protected characteristics populations or how they can be reached or engaged. How do we engage these populations early and meaningfully when they are marginalised currently?

Question 15a. *Language and terms used in the strategy - Do you think the strategy explains what is meant by the terms palliative care for adults; palliative care for children; care around dying; and future care planning?*

It is important to use consistent terms and language that everyone can understand.

Care around dying - care around dying means whole person care for an adult or child who is dying and in the last hours, days or weeks of their life, care after their death, and support with loss and grief for families and carers throughout this time and when they are bereaved.

Future care planning - future care planning means supporting adults and children, their families and carers, to think and plan ahead for changes in their life, care or health.

Palliative care for adults - palliative care is holistic care that prevents and relieves suffering through the early identification, assessment and management of pain and other problems – whether physical, mental health, social or spiritual

Palliative care for children and young people - palliative care for children and young people is an active and total approach to care, from the point of diagnosis or recognition throughout the child's life. It includes physical, emotional, social, and spiritual elements, and focuses on enhanced quality of life for the child or young person and support for their family.

[Unsure / Don't know]

Question 15b: Please add any further comments you have about any of the terms that are used in the draft strategy.

Why is 'from point of diagnosis' listed under palliative care for children and young people and not adults?

Question 16. *Please add any other comments or suggestions you have about the draft Palliative Care Strategy here*

We welcome the development of this strategy and believe it is a useful and much needed positive step towards widening access to palliative care in Scotland. In the Service Mapping Report, 'Financial and human resourcing challenges were identified by adult and paediatric specialist palliative care service respondents. Concerns were raised that services are not sustainable, they cannot extend or develop their services to meet population needs, or have limited staff succession planning. There were also concerns raised of being unable to meet demands for education and training provision for other services and for the public.'

Better partnership working, workforce education and community resources are a good initial step forward. However, financial and human resource challenges need to be addressed before this strategy can have any impact.

Neurological conditions are complex and require additional resources to enable genuine choice including the option to spend your last months at home, surrounded by loved ones and creature comforts. We would like to see commitments to increasing access to specialist palliative care. We would also like to see sustainable long-term funding commitments outlined, to ensure the success of this strategy.