Right to Palliative Care (Scotland) Bill Consultation Response

Cerebral Palsy Scotland

Cerebral Palsy Scotland is the only organisation dedicated to helping people with cerebral palsy of any age throughout Scotland. Our mission is to help people with cerebral palsy (CP) build skills, knowledge, confidence and relationships. We advocate for the CP community to have life-long access to knowledgeable, compassionate services and support.

The charity, previously known as Bobath Scotland, was founded in 1995 by families in Scotland who had grown frustrated at travelling to London to get specialist therapy for their children who were living with cerebral palsy. In 2012 we expanded our provision with the launch of our therapy service for adults with cerebral palsy. The charity is a Scottish Charitable Incorporated Organisation, registered with the Office of the Scottish Charity Regulator (OSCR).

Our services have continued to grow and develop, guided by what's best for the CP community. These have included the launch of our annual Cerebral Palsy Scotland conference and exhibition in 2013, the provision of group therapy for babies, after school primary school children and teenagers (funding permitting), including mental health and wellbeing within our therapy offer and the development of a CP Support service

We treat anyone of any age with cerebral palsy from across Scotland, we support families and carers to better understand the needs of people with CP and we work collaboratively with professionals who support people with CP within statutory services through partnership working and training. In the policy sphere, we advocate for the CP community to have life-long access to knowledgeable, compassionate services and support.

Cerebral Palsy

Cerebral Palsy (CP) is the most common cause of physical disability in childhood. It is an umbrella condition that affects everyone differently and to a greater or lesser extent. It will always affect movement and physical development. As well as affecting movement, CP can affect other areas of function:

- 1 in 3 are unable to walk
- 1 in 4 are unable to talk and will use alternative methods of communication
- 3 in 4 experience pain
- 1 in 4 has epilepsy
- 1 in 2 has a learning disability

- 1 in 4 has bladder control issues
- 1 in 5 has a sleep disorder
- 1 in 5 has saliva control problems

There is no cure for cerebral palsy and although the damage to the brain does not worsen, the effects of the condition become more debilitating with age. As a person with CP grows, they can develop secondary muscular skeletal problems, such as increased tightness in muscles and joints and dislocations. This can change a person's physical abilities over time. People can also experience increased issues with pain and fatigue. Often these symptoms can mask other issues that prevent people with cerebral palsy gaining access to services and lead to lives being shortened due to lack of access to care for a condition unrelated to their cerebral palsy.

Children with CP in Scotland are seen through specialist children's services in their local communities and some will have regular reviews with consultant paediatricians. There are no specialist statutory services for adults with CP in Scotland, a situation recognised throughout the UK. Many people with CP are able to lead long and fulfilled lives, however, others require access to a range of services. Many adults have social care needs and rely on carers and PAs (personal assistants) in order to live their lives. Most adults access this support through general adult disability services. There is limited or no access to specialist input. Staying well, with regular access to specialist multidisciplinary therapy, is key to maintaining good health for people with cerebral palsy.

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?**

Since the passing of the 2022 Health and Care Act, Integrated Care Boards (ICBs) in England have a legal responsibility to commission health services that meet their population needs. Neither the NHS, Health and Social Care Boards or Local Authorities in Scotland have this statutory duty. Cerebral Palsy Scotland would strongly support HSCPs in Scotland being subject to the same statutory responsibilities to ensure that people with palliative and end of life care needs can access and receive high quality personalised care and support and there is a duty for HSCPs to commission palliative care services throughout Scotland.

Around 18% of children with cerebral palsy die in childhood. Acceptance criteria for children's hospices usually require the child to be likely to be life limited by the age of 25 years. This means that it is likely that only around a quarter of all children with cerebral

palsy will be accepted. Selecting the children most in need of specialist palliative care poses a challenge, in view of the unpredictability and uncertainty in the natural history of the condition. Most children succumb to respiratory illness, severe epilepsy or gastrointestinal problems.

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?**

Cerebral Palsy Scotland believe that a definition of palliative care that is clear and easily understood is essential for any statutory guidance. We accept that the WHO definition is the one most widely used and we welcome a definition that focusses on an approach that improves the quality of life of patients and their families as they navigate life-long and life-limiting conditions. However, we note the term 'life-threatening' rather than 'life-limiting', which we are concerned would mean people with cerebral palsy who would benefit from access to palliative care due but would be denied access until a point of crisis.

Palliative care includes, but is not exclusively about, end of life care. We agree with the Scottish Partnership for Palliative Care that *"End of life care is part of palliative care which should follow from the diagnosis of a patient entering the process of dying, whether or not he or she is already in receipt of palliative care. This phase could vary between months, weeks, days or hours in the context of different disease trajectories. There can be uncertainty involved in identifying when someone might be expected to die – illness can be unpredictable, and changes can occur suddenly and unexpectedly"*.

We also have reservations in that the WHO definition does not distinguish between 'generalist' and 'specialist' palliative care. Children and adults with cerebral palsy are more likely to require specialist palliative care with input from a trained multi-disciplinary team.

We believe palliative care is about providing the best possible quality of life for a person and should be available to all those whose health is in irreversible decline, regardless of their age and condition, or in what setting they are receiving care.

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?

People with cerebral palsy often have additional needs in palliative and end of life care. Understanding and considering these needs when providing care, can improve people's quality of life. It can also make sure they're getting the person-centred care they need. Research has identified that this population face barriers to access to palliative care because of limited knowledge and experience of their condition by health professionals. Ageing with cerebral palsy is little understood. This should be acknowledged in any statutory guidance so that people with cerebral palsy are not further ignored and discriminated against because of their condition.

Recognising distress or discomfort in someone with cerebral palsy can be challenging, particularly if communication is difficult. It is important that it is recognised that people with disabilities might communicate in different ways, which might change depending on their symptoms at that time. It is essential that each individual's wishes are taken into account. Parents, carers and family members should also be involved in decision making. If health professionals have not had experience of managing people with cerebral palsy then they should be required to seek out condition-specific input.

Cerebral Palsy Scotland would be concerned if a person's condition were not being considered or managed whilst receiving palliative care. We know of cases where people with cerebral palsy have not been able to access their communication aides or devices during a hospital stay, or a person's physical and functional abilities are not taken into account.

The current situation demonstrates variations in access to palliative care by diagnosis, with cancer patients more likely to access any level of palliative care. We are also aware that

inequities overall adversely affect the provision of services for those of Black, Asian or minority ethnic backgrounds. Older people, despite multiple comorbidities, often have less access to palliative care. Those in more deprived areas are more likely to die in hospital and less likely to die in a hospice, even though the national trend is for more people to die at home, in a care home or a hospice. We would hope these inequality issues are recognised and addressed.

Cerebral Palsy Scotland are continually frustrated by the lack of data on the population of people in Scotland living with cerebral palsy. We believe that people with cerebral palsy are invisible to service providers because there is no means to collect robust data on this population. We understand Scottish Government recognises digital transformation in health as a priority. We hope that this will lead to better identification of conditions like cerebral palsy across all services and in primary, secondary and community care settings. Without this we are concerned that this population's access to palliative care services would not be monitored.

We urge departments to work closely on the collection of data, and particularly on the prevalence of conditions like cerebral palsy, across the UK. Improvements in the collection of data by all relevant bodies (primary and secondary care and social care services) must be a key priority in the development of palliative care services and therefore this Bill. We would also urge Scottish Government to consider how data is shared between services and with individuals themselves in order to ensure that people with life-long conditions such as cerebral palsy become more visible to service providers.

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.**

In the same way we could not countenance having areas in Scotland with no maternity services or only rudimentary midwifery, without access to NHS specialist obstetric care in the event of a complication, we believe palliative care should be provided as a specialist clinical approach by the NHS. A palliative care service should provide personalised care and it is essential that it is available 24/7, including nights and weekends when people are in distress. About three quarters of people will not have a sudden death and these people, of all ages need care with a palliative approach. This should be approached the same as with

other disciplines, for example, a GP will manage a person with diabetes, but if it is complex or difficult to control that person will see a specialist, a diabetologist. Provision of palliative care should work in the same way.

Routine palliative care should be within the competencies of clinicians generally, provided they have had training in the fundamentals of such care. For some people, a palliative approach is needed from diagnosis, which is not the case for people with cerebral palsy. Some people with cerebral palsy will have complex problems, crises suddenly arise, emergencies occur. These people require more than a general clinical team can offer. Specialist palliative care involving doctors, nurses and allied health professionals with specialist training should be available for these people. Specialist services also drive up standards by teaching, being involved in research and providing advice to other clinicians.

Palliative care addresses distress, pain and suffering and should run alongside management of a person's condition. It is not either treatment or palliative care; it is balanced decision-making with patients. With early palliative care patients live better, and they live longer, at no additional cost overall.

We would point towards the development of palliative care services in Wales, which has set a national strategy for fair access to specialist palliative care. We recognise that the aim for 24/7 services may not be affordable. Wales therefore settled for 7-day specialist services with 24/7 advice available to any health or social care professional.

The Welsh Government policy intention for children, young people and adult Palliative and End of Life Care is supported by the NHS Executive and implemented through a series of health board enabling plans.

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?**

Cerebral Palsy Scotland note the existence of the Scottish Government's Palliative and end of life care Strategy Steering Group to oversee the development and delivery of a new palliative and end of life care strategy and associated work programmes. We welcome and support the overarching aims of this group, however, we note that, to date we have had no engagement with the group. We are not aware that this group has had any interaction with the National Advisory Committee for Neurological Conditions or what the input of disabled children's groups has been.

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Cerebral Palsy Scotland do not want to see just another government strategy and would hope that a statutory right to palliative care, as proposed in this Bill, would ensure that the aims and principles of providing equitable and timely access to general palliative care and specialist palliative care services as needed by each person of any age living with any illnesses in all places is finally achieved.

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