CHAS Consultation Response: Proposed Right to Palliative Care (Scotland) Bill

Question 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?

"It's hard knowing you're going to die young. It's difficult to live like that, you want to fit it all in, everything, and you want to do everything before it's too late. Can you image how difficult that is to deal with every day – knowing what's going to happen? It's devastating." **(Young person referred to CHAS)**

CHAS strongly supports the proposal for babies (including pre-natally), children and young people[1] - alongside adults - across Scotland to have an explicit legal right to palliative care.

Our policy vision is that all children with life-shortening conditions and their families should have timely access to high quality care, equally across Scotland, when and where they need it.

That support should be seamless, and extend from diagnosis through to either bereavement and beyond, or transition to adult services where needed. And that support needs to be sustainably resourced.

When time is precious, children with life-shortening conditions have a right to live their best possible lives.

The Scottish Government has made repeated commitments to ensuring it will ensure that everyone who needs it can access seamless, timely and high-quality palliative care – including high quality children's palliative care, regardless of location.[2]

Yet as this response will set out, that it not currently the case everywhere, or for everyone, across Scotland.

1.1 Defining the cohort

The cohort supported by paediatric palliative care is diverse – both in terms of developmental stage, and category of condition.

Paediatric palliative care extends from the point a condition is recognised or diagnosed – which can be pre-natally, neonatally, or at any age extending through to young adulthood.

There are a wide range of conditions affecting children and young people with palliative care needs, which can be categorised broadly into four groups. Diagnosis is only part of the process of identifying children who need support from palliative care services: the spectrum and

[1] In much of this document we use the term "children" as shorthand for babies, children and young people of all ages. CHAS supports young people up until the age of 21, although we appreciate that in some but not all legislative and policy contexts in Scotland, adulthood is defined as being aged 16 or 18 upwards.

[2] *A Fairer, Greener Scotland: Programme for Government 2021-22*, Scottish Government. September 2021. https://www.gov.scot/publications/fairer-greener-scotland-programme-government-2021-22/documents/

severity of the disease as well as the needs/wishes of and impact on the child and family also need to be taken into account.[3] The four categories can be defined as follows:

1. Life-threatening conditions for which curative treatment may be feasible but can fail

Access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services.

Examples: cancer, irreversible organ failures of heart, liver, kidney.

2. Conditions where premature death is inevitable

There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities.

Examples: cystic fibrosis, some forms of muscular dystrophy.

3. Progressive conditions without curative treatment options

Treatment is exclusively palliative and may commonly extend over many years.

Examples: batten disease, mucopolysaccharidoses.

4. Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death.

Children can have complex health care needs, a high risk of an unpredictable life-threatening event or episode, health complications and an increased likelihood of premature death.

Examples: severe cerebral palsy, multiple disabilities, such as following brain or spinal cord injury.[4]

It's important that any right to palliative care extends right across the diverse needs of these age ranges and condition categories.

1.2 The Scottish model of children's palliative care

Scotland has a unique model of children's palliative care, with CHAS as the single, national and specialist provider of hospice care to children working in close partnership with NHS and Local Authority colleagues.

CHAS' aim is to deliver integrated care across a variety of settings: in our two hospices, in hospital, at home.

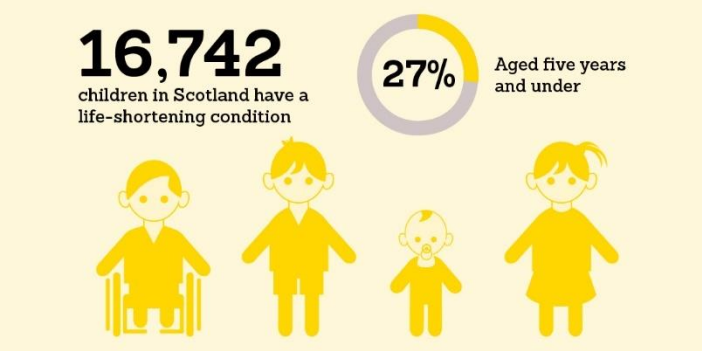
Much has been achieved over the course of the last decade or so, and everyone involved with children's palliative care in Scotland should rightly be proud of the progress made.

We've seen a recognition of children within the Scottish Government's Strategic Framework for Palliative and End of Life Care (2016); the commissioning of the national Paediatric End of Life Care Network (PELiCaN), which aims to improve access to high quality end of life care for children; and the creation of the first paediatric palliative medicine consultant posts in Glasgow

[3] *A Guide to Children's Palliative Care: Supporting babies, children and young people with life-limiting and life-threatening conditions and their families*; Together for Short Lives (2018)
[4] *A Guide to Children's Palliative Care: Supporting babies, children and young people with life-limiting and life-threatening conditions and their families*; Together for Short Lives (2018)

and Edinburgh. We have also seen SNP and Programme for Government commitments to "ensure[ing] provision of high quality child palliative care, regardless of location".[5]

1.3 Increasing need, and increasing complexity



The consultation document sets out how an ageing population is resulting in increased palliative care needs across Scotland, but it should also be noted that increasing numbers of children are living longer with life-shortening conditions.

The numbers of children in Scotland with palliative care needs is going up.

According to the latest available figures, there are there are more than 16,700 babies, children and young people1 (aged 0-21) across Scotland who may die from a life-shortening condition. Although many of these children are stable at present, and some may make a complete recovery from illness, nearly 6,000 will need hospital care in a given year. And about three children die from a life-shortening condition every week in Scotland.[6]

Because rising prevalence is in part due to children living longer, more children than ever before are living with significant medical complexity.

These children and their families need the integrated care and support of CHAS, the NHS, Local Authorities and others more intensively, and over a longer period of time. Instability and deterioration, leading to end of life care, may occur at any time. Sadly, three children a week die from a life-shortening condition in Scotland.

Anecdotally, CHAS is also seeing greater numbers of families in crisis and needing the holistic support of our Family Support Team.

Within our own service, we know we aren't reaching every child and family that could benefit from the support we offer. And we know that to be true within other setting supporting children with palliative care needs too.

In a survey conducted by CHAS in September 2020, over two-thirds of families told us there are gaps in their care – looking across all settings.[7]

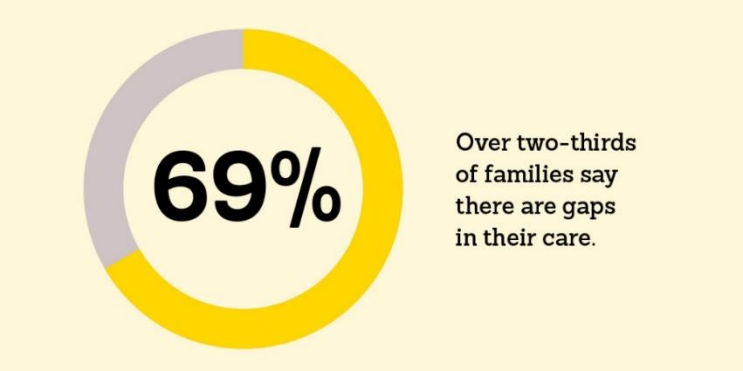
That is unacceptable, and we believe a right to palliative care could ensure that no-one faces the death of their child without the full range of support they need.

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[5] *SNP 2021 Manifest; Scotland's Future, Scotland's Choice*. https://www.snp.org/manifesto/ ; *A Fairer, Greener Scotland: Programme for Government 2021-22*, Scottish Government. September 2021. https://www.gov.scot/publications/fairer-greener-scotland-programme-government-2021-22/documents/

[6] *Children in Scotland requiring Palliative Care (ChiSP) 3*, Public Health Scotland (2020)

[7] *Time is Precious, Time to Act: CHAS manifesto priorities 2021-26*; Children's Hospices Across Scotland (2021)



1.4 Specific areas families where have told us they want more support

We recently published 'Unwavering Care: Our Strategic plan 2024–28, a plan that sets out our vision and how we will achieve it over the next four years.[8]

We created this plan by involving as many of our stakeholders as possible. Firstly, we listened to families. Over 135 of them shared what is important to them about CHAS.

We also heard directly from 77 children and young people through stories, art, and play. These babies, children and young people had used many different CHAS services, including hospices, care at home, family support, and joint CHAS / NHS teams in hospitals.

Through this work, we heard detailed views about what works well for those families, and how the support they get from many organisations could be different.

These insights are valuable when thinking about what a right to palliative care might include.

In particular, families told us that there are three critical stages on their journey where they need CHAS most. These are set out below.

Learning your child is seriously ill and may die young

Learning your child is seriously ill and may die young is heartbreaking. Families tell us they need more support at the beginning of their journey.

For most, this shocking news means entering a world they know nothing of, while feeling the loss of the life they were expecting with their child.

Families need more emotional, clinical, and practical help at this early stage, when their lives change enormously. This includes advice and support around financial wellbeing, fun activities, medical advice and social work.

Living well

[8] *Unwavering Care: Our Strategic Plan 2024-2028*; Children's Hospices Across Scotland, 2024. https://chas-assets.s3.eu-west-1.amazonaws.com/sites/59dde5b10f7d33796f8cd11b/assets/662f588f0f7d330a797df635/Unwavering-Care-Our-Strategic-Plan-2024-28.pdf

Caring for a seriously unwell child is exhausting for the whole family. The pressure of round-the-clock care puts a strain on family life.

Parents should be parents, not just carers, and children should be able to be children and have fun, no matter how short their life is. Siblings of seriously ill children often describe how hard their childhood is.

The whole family – including parents and siblings – need help to live well even in the face of complexity, worry and uncertainty.

This includes helping children be included and to have fun, creating precious memories that will last a lifetime.

Dying well and Bereavement

The death of a child is overwhelming, distressing and catastrophic. Just as every child is unique, so is every death.

Families told us that a meaningful goodbye is important and that choice in place of death and good planning can support families in their immediate grief, and beyond.

More families are choosing home as place of death, which often requires specialist care and support 24 hours a day from CHAS and a range of partners.

1.5 A rights-based approach to palliative care

Existing principles

We believe taking a rights-based approach to palliative care is not only desirable, but also to some extent a natural extension of other key human rights instruments.

The principle of the right to palliative care aligns well with the United Nations Convention on the Rights of the Child.[9] Under UNCRC, which is now incorporated into Scottish law, children under the age of 18 already have a range of rights that are, broadly speaking, pertinent to a right to palliative care. These include the right to: my best interests being considered (article 3); life (article 6); to be listened to (article 12); to join in (article 15); information (article 17); protection from harm (article 19); reach full potential as a disabled child (article 23); be as healthy as possible (article 24); an education (article 28); rest, relaxation and play (article 31).

It's pertinent too that that UNCRC is a "floor" and not a ceiling of rights compliance. It sets minimum standards beyond which duty bearers can and should strive. So too does the UNCRC Act set out the legislative "starting point" for rights compliance, but duty bearers can and should go beyond this insofar as that is possible[10] – and a right to palliative care could be seen as a natural extension to the clauses set out above, for some of Scotland's most vulnerable babies, children and young people.

Likewise another foundational instrument is the UN Convention on the Rights of Persons with Disabilities (UNCRPD).[11] Good quality palliative care is likely to support the realisation of rights such as to independent living and equal participation in society.

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[9] https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child

[10] uncrc_statutoryguidance_response_may2024.pdf (togetherscotland.org.uk)

[11] https://ec.europa.eu/social/main.jsp?langId=en&catId=1138

Finally, it is worth considering the International Covenant on Economic, Social and Cultural Rights (ICESCR).[12] Under ICESCR, as well as several other international health treaties, individuals have what's commonly known as a 'right to health' - the "right of everyone to the highest attainable standard of physical and mental health".[13]

That the right to health is defined as the "highest attainable standard" is directly relevant to the proposed Bill. Whilst people living with life shortening or terminal conditions may experience an unavoidably lower standard of health than people without such conditions, they still have the right to the best health possible under their individual circumstances.

Palliative care makes a significant and essential contribution to realising this right. For children, that includes symptom management and specialist nursing and medical care, but also access to play, to experiences and to making memories.

Building the right to palliative care around and on top of these existing rights would be a natural extension of existing rights-based approaches.

Ensuring a right is enforceable

Ensuring that any right to palliative care is enforceable will be key to ensuring that those who most need to benefit from potential legislation are able to do so.

The right should create a legal instrument by which a child or young person and their family can hold providers accountable, while providers can in turn use the right as leverage with the Scottish Government who have enshrined the Act in law, should the resources to realise the right be lacking.

Clearly, for a child who may die young and whose time is short, there may not be the time or ability for a family to challenge a right that is not being met.

The hope therefore is that any right is embedded in statutory guidance, aligned to the new national policy framework, and that implementation is embedded into a whole system infrastructure, and commissioned, funded, and resourced as part of core health and social care services.

1.6 Case study: Insights from England

In 2022, integrated care systems (ICSs) were introduced in England, with the aim of bringing together NHS organisations, local authorities, and others in the planning of services across geographical areas.[14]

Within this new structure came integrated care boards (ICBs). As statutory bodies, ICBs replaced clinical commissioning groups (CCGs) and assumed the responsibility of planning and funding most NHS services in the area.[15]

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[12] https://www.ohchr.org/en/instruments-mechanisms/instruments/international-covenant-economic-social-and-cultural-rights

[13] Article 12: https://www.ohchr.org/en/instruments-mechanisms/instruments/international-covenant-economic-social-and-cultural-rights

[14] The King's Fund. (2022). Integrated care systems explained. Available at: https://www.kingsfund.org.uk/insight-and-analysis/long-reads/integrated-care-systems-explained

[15] The King's Fund. (2022). Integrated care systems explained. Available at: https://www.kingsfund.org.uk/insight-and-analysis/long-reads/integrated-care-systems-explained

Since their formation, ICBs have been tasked with developing joint forward plans. These plans describe how the ICB, and its partner trusts intend to arrange and provide NHS services to meet their population's physical and mental needs.[16]

Later that year, the Health and Care Act 2022 placed a legal obligation on ICBs to commission palliative care as they consider appropriate for meeting the reasonable requirements of the people for whom they are responsible.

The experience from colleagues in the paediatric palliative care sector in England however is that this has not yet resulted in a seamless access to services.

Whilst a recent review of all 42 joint forward plans by the palliative and end of life care team at NHS England (NHSE) found 69% of these plans to directly mention palliative and end of life care, Together for Short Lives has cautioned that in practice there is still a postcode lottery when it comes to accessing high quality children's palliative care that meets national standards.[17]

Nevertheless, the statutory framing has provided a basis on which to hold ministers and officials to account. It has further provided an opportunity to raise awareness across the whole system – officials, professionals, public bodies and service providers - of the needs of children and people with regards to access to palliative and end of life care.

1.7 Potential legislative vehicles

Palliative care and the National Care Service (NCS) Bill

While we agree that the National Care Service Bill could reasonably be amended to create a right to palliative care, any legislative vehicle that involves the NCS needs to be mindful of the fact that it remains far from clear whether children's services will explicitly be included under the NCS. It's also worth noting that the timescales for the Bill's progress are slipping.

In a policy landscape in which there are already significant barriers between a transition from children's services to adult services for children with palliative care needs, relying on the NCS Bill to deliver a right to palliative care for people of all ages is a less favourable legislative route so long as the situation remains unclear, or in the circumstance that children's services are explicitly excluded from the NCS.

Palliative Care and the forthcoming Scottish Human Rights Bill

As set out elsewhere above, the International Covenant on Economic, Social and Cultural Rights (ICESCR) includes within Article 12 "*the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*."

The forthcoming Scottish Human Rights Bill will incorporate several international treaties into Scots law, including ICESCR, making it easier for people to access their rights (and to create clear duties for public bodies to realise those rights). We agree with the SPPC that bill's interpretative provisions could include clear and specific references to a right palliative care,

[16] NHS England. (2022). Guidance on developing the joint forward plan. Available at: https://www.england.nhs.uk/wp-content/uploads/2022/12/B1940-guidance-on-developing-the-jointforward-plan-december-2022.pdf.

[17] https://www.togetherforshortlives.org.uk/changing-lives/speaking-up-for-children/policy-advocacy/an-overview-of-childrens-palliative-care-in-the-uk-in-2024/

and that a right to palliative care could be included in the sections about 'Minimum Core Obligations'.

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 legal right to palliative care?

The WHO definition of palliative care is: "Palliative care is an approach that improves the quality of life of patients (people and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual".

2.1 Describing children's palliative care: philosophy and approach

At its simplest, paediatric palliative care "no longer means helping children die well; it means helping children and their families to live well and then, when the time is certain, to help them die gently."[18]

More expansively, children's palliative care is described as "an active and total approach to care, from the point of diagnosis or recognition throughout the child's life and death".[19]

It embraces physical, emotional, social, and spiritual elements, and focuses on enhancement of quality of life, as well as maximising opportunities in life, for the baby, child or young person and support for the family.

It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.

The philosophy of children's palliative care is to promote the best possible quality of life and care for every child with a life-shortening condition and their family.

Palliative care can be seen as a thread that runs through the lives of children, but it often runs alongside other treatments. This is why the concept of parallel planning is important, where palliative care is offered in parallel with and alongside curative treatment, or treatment aimed at significantly prolonging life.

The palliative care approach should be present from diagnosis or recognition that curative treatment is not an option, or may fail.

Palliative care needs to be dynamic and responsive to the changing needs of children and their families, who may dip in and out of using dedicated palliative care services as their condition fluctuates.

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[18] The description is from Mattie Stepanek, a young person who died from a life-shortening neuromuscular illness.

[19] *A Guide to Children's Palliative Care: Supporting babies, children and young people with life-limiting and life-threatening conditions and their families*; Together for Short Lives (2018)

As children become more vulnerable to complications, palliative care becomes a more active element of their support package.

This is particularly relevant for the growing number of technology-dependent children and those who are receiving experimental treatments for which there is a high risk of unknown complications.

Giving families real choice is key to this approach: choice of place of care; choice of place of death; choice of emotional and bereavement support; and putting the child and family at the centre of decision making to produce a plan for care that is right for them.

This philosophy extends beyond childhood and includes the support young people need as they prepare for adulthood and settle into adult services, often at times of significant deterioration in health.

Palliative care for children is different from adult palliative care in several important ways:

- The number of children dying is small, compared with the number of adults.
- Many of the individual conditions are extremely rare with diagnoses specific to childhood or young adulthood.
- Many of the illnesses are familial, so there may be more than one affected child in the family.
- Parents bear a heavy responsibility for personal and nursing care and siblings are especially vulnerable.
- A characteristic of childhood is continuing physiological, emotional and cognitive development. Children's palliative care providers need to understand and be responsive to the impact of a child's physiological development on handling of medications as well as each child's changing levels of communication and ability to comprehend their illness, treatments and prognosis.
- Provision of play for all children is essential and education is a legal entitlement.[20]

It is therefore extremely important that irrespective of the definition on the face of the Bill, statutory guidance should be created that specifies some of the particulars in relation to paediatric palliative care.

2.2 Perceptions of children's palliative care

"when [my child] was first diagnosed, I didn't want to have like CHAS…involved because then it actually meant that I had to actually face up to that [the child] was ill." ***(Parent of a child referred to CHAS)[21]***

[20] *A Guide to Children's Palliative Care: Supporting babies, children and young people with life-limiting and life-threatening conditions and their families*; Together for Short Lives (2018)

[21] Quote from a presentation given by Dr Sivers to CHAS in October 2023, following in her research titled *"Understanding the causes of local disputes in paediatrics to develop pathways to dispute resolution in North East Scotland".* This project was funded by NHS Grampian Charity and carried out by Dr S Sivers from The Law School, Robert Gordon University, with M Downie, Dr F Herd, Dr J Tai, Dr H Morgan and Prof S Turner.

As with adult palliative care, a lack of knowledge and / or understanding about the nature of palliative care can result in a reluctance to engage with or be referred into palliative care services.

One recent research study into the causes of disputes in paediatrics in north-east Scotland found, in the context of paediatric palliative care, that "Both parents and clinicians recognise that sometimes accessing support means facing a reality they are not yet ready for."[22]

Parents often need support to understand the choices that are available to them from the outset, and throughout their child's life.

More broadly, we also know that all too often, death and dying remain subject taboo subject matters.

Nearly three-quarters of families we have spoken to told us they do not think Scottish society is open enough when it comes to death and dying.[23] Yet grief and bereavement are natural parts of life. More can and should be done to help ease the pain of those who experience this.

"I want people to know that death is the norm for my family. That talking about it, planning for it, helps. This is a journey and planning makes the journey easier." ***(Parent of a child referred to CHAS)***

We hope the national conversation that a right to palliative care might generate will provide a platform for some of this open dialogue.

2.3 Use of the WHO definition

CHAS does not object to the use of the WHO definition, which has the benefit of being used elsewhere in the UK and of being an authoritative articulation of the scope of palliative care.

It has the benefit of:

- Focussing on quality of life, not on death
- Directly referencing children and their families
- Alluding to the concept of 'total pain'.

Nevertheless, it can't encompass everything we might wish to see in relation to children and young people, such as for example referencing that palliative care should begin from the point a condition is recognised or diagnosed.

We therefore have a few suggestions for how to ensure that this definition works as well as possible, without necessarily moving away from the WHO definition:

- That more detailed guidance should sit beneath the definition that sits on the face of the Bill. This would allow for an additional level of detail around what a right to palliative care entitles an individual to, and this should have differentiated sections for children

[22] *Understanding the causes of disputes in paediatrics to develop pathways to dispute resolution in North East Scotland*. Sivers, S. (2023). Aberdeen: Robert Gordon University.
[2323] *Time is Precious, Time to Act: CHAS manifesto priorities 2021-26*; Children's Hospices Across Scotland (2021)

and young people, versus adults, that take into account some of the more specific elements of palliative care for children.

- That some of the language could be simplified so that it is more accessible to the average person, yet still suitable for legislative drafting. We agree with the ALLIANCE that the word "psychosocial", for example, is not widely used and sounds jargonistic. This could be replaced with something along the lines of "physical, mental, social, environmental or spiritual".

- That a further simplified definition and a range of child-friendly communications materials should be produced to aid understanding (see more below). This could include the 'simple definition' created by Mattie Stepanek, cited at the beginning of this section.[24]

2.4 Communicating about a right to palliative care

Irrespective of the exact wording of the definition of palliative care on the face of the Bill, significant work will need to be done by to raise awareness that the right exists, and also to ensure that there is widespread understanding about what this means, how the right will be realised, and what to do if an individual suspects their right is being breached.

We also believe that as with rights-based legislation such as UNCRC, a wide range of supportive communications materials would need to be produced, including simplified child-friendly versions. These should be produced in collaboration with children and young people with life-shortening conditions and their families, as well as staff in the paediatric palliative care workforce.

Question 3: 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 terminal illness?

3.1 Impact on age and disability as protected characteristics

CHAS' policy vision is that all children with life-shortening conditions and their families should have timely access to high quality care, equally across Scotland, when and where they need it. That support should be seamless, and extend from diagnosis through to either bereavement and beyond, or transition to adult services where needed.

If enacted well, a right to palliative care would ensure that this was realised, and that children with life-shortening conditions were supported comprehensively to live their best possible lives in the time they have, and that their families are not constantly "fighting" to get access to the care and support that will enable them to do so.

"It is exhausting and demoralising fighting for your child's rights to an education, for equipment, for health, fighting ambulance services, lodging complaints in hospital to make people listen

[24] I.e. Paediatric palliative care "no longer means helping children die well; it means helping children and their families to live well and then, when the time is certain, to help them die gently." The description is from Mattie Stepanek, a young person who died from a life-shortening neuromuscular illness.

and change what is necessary. I should be enjoying the time I have left with my child not fighting for what everyone else receives when they aren't disabled and dying." (**Parent of child referred to CHAS)**

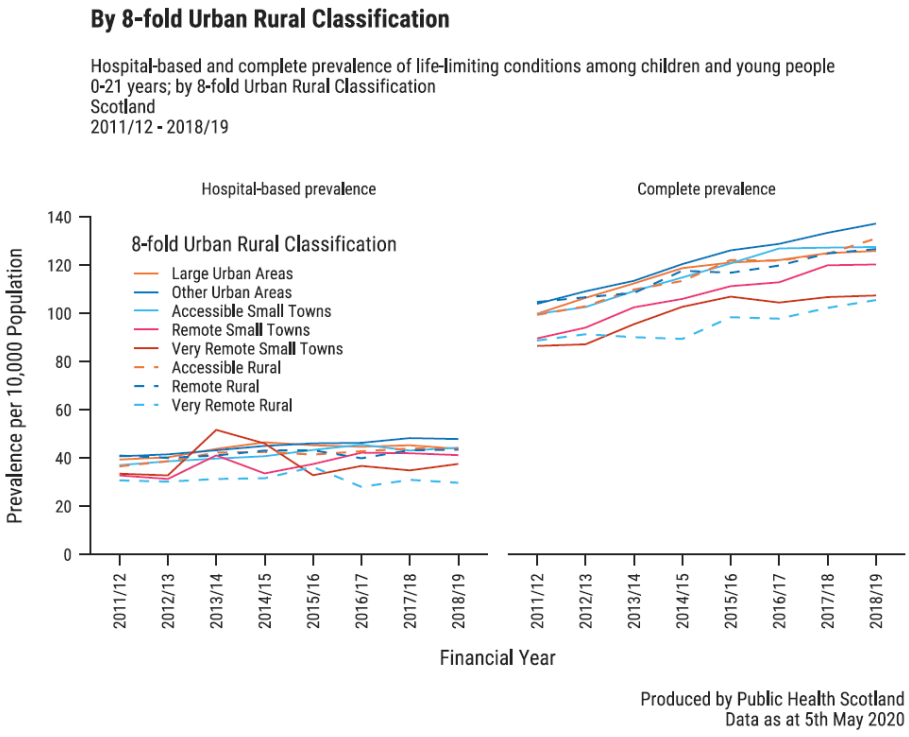
Given that most children with life-shortening conditions would generally be considered to have disabilities, an enforceable right to palliative care for people living with those conditions would naturally have a positive impact on disabled children too.

More generally, we could expect the national conversation around the role and function of palliative care that a legal right to palliative care might generate, if enacted, to have a positive effect on children.

As set out in question 2, palliative care can still be conflated with end-of-life care, and as a children's hospice service we are aware that there can sometimes be a reluctance within speciality medicine to refer onto palliative care, as some professionals may feel they are "giving up", as well as a reluctance on behalf of families to accept that palliative care is the right pathway for their child.

"It was down to the care and perseverance of one lovely nurse that I agreed to go and visit Robin House, and although it was the hardest decision we have ever had to make for [our child], it ultimately was the most perfect." **(Bereaved parent of child supported by CHAS)**

3.2 Impact on remote and rural communities



The majority of children with a life-shortening condition in Scotland live in an urban or accessible location, with the latest available figures showing that only 8% reside in a location classed as remote.[25] This is not due solely to the demographic make-up of the areas as it is also

[25] *Children in Scotland requiring Palliative Care (ChiSP) 3*, Public Health Scotland (2020)

reflected in the prevalence figures, which means families are less likely than the population as a whole to live in remote areas.

For its part, CHAS is committed to reaching every family that needs its support, irrespective of location. As well as our two hospices, in Kinross and Balloch, we bring all the services from our hospices into the community, and primarily to children's homes, across the whole of Scotland. This includes visits and respite care from highly skilled nurses, either as a one off or from time-to-time as needed, or for end of life care. It also includes specialist support from social workers and child and family workers, to help with difficult things in people's lives; help with money worries and benefits; and sibling support, to help brothers and sisters cope with what is happening in their family.

We also have a permanent presence in five hospitals in Scotland. We work closely with different teams across the NHS to deliver complex care to babies, children and young people through: palliative care teams, with medical and nursing specialists who are employed by or funded by CHAS, to support complex symptom management; activities sessions to bring some fun to a long hospital stay; support at end of life; access to all the other CHAS services available at home or in the hospice.

Nevertheless, for those children and their families who live in remote and rural locations, there is no question that they face more limited choices than those living in more densely populated areas.

It may be less practical or desirable, for example, for them to travel to respite stays in a hospice setting.

Or a child may have less direct access to the range specialist support from critical care specialisms in a hospital environment.

Outside the central belt and urban centres, teams supporting a child often may have to pull together the right care in an ad hoc way, upskilling colleagues such as district nurses, for example, whose expertise is in adult care.

A right to palliative care should explicitly seeks to redress this balance.

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?

4.1 The existing landscape

In comparison with adult palliative care, the numbers of children receiving both specialist and generalist palliative care support are extremely small. Nevertheless, as with the adult sector, the organisation and delivery of palliative care for children in Scotland is spread across numerous professional groups operating within both the public and third sectors. This includes consultants in paediatric palliative care working closely with disease-direct specialists and general and specialist paediatricians, including neonatologists; lead clinicians for paediatric palliative care in district general hospitals; specialist palliative care nurses based in hospitals, hospices and in the community; General Practitioners; Community Children's Nurses; District

Nurses; social work and allied health professionals. The role of social care – both in the form of paid carers and family carers – must also be acknowledged.

In recognition of the "fragmented" patchwork of professionals and services involved, an integrated model for the delivery of children's palliative care was developed in 2012 by the Scottish Children and Young People's Palliative Care Executive Group (SCYPPEx). The document, *A Framework for the Delivery of Palliative Care for Children and Young People in Scotland,* set out a range of outcomes and objectives for service providers including Health Boards, Social Work, Education, CHAS and other voluntary organisations - taking into consideration the age, geographical and social needs of their particular population of children and young people.[26] See Box 1 and Box 2 below.

BOX 1 – KEY OUTCOMES

The following outcomes and objectives should underpin any palliative care service for children and young people in Scotland, no matter where or how it is provided.

Outcome 1 Each Health Board should clearly identify lead professionals with overall responsibility for delivering children and young people's palliative care services.

Outcome 2 Children and young people's palliative care services should be planned and developed on the basis of incidence and prevalence in each Health Board area.

Outcome 3 All children and young people should have equitable access to palliative care which is flexible, planned and person-centred and takes account of their physical, emotional and spiritual needs.

Outcome 4 All children and young people with palliative care needs should be cared for and die in their preferred place.

Outcome 5 All children and young people with palliative care needs will receive safe, effective and person-centred care delivered efficiently and on time by a trained and competent workforce adopting a GIRFEC (Getting it Right for Every Child) approach.

BOX 2 – KEY OBJECTIVES

1. Lead doctor and nurse for children and young person's palliative care

Every Health Board should ensure that there is an identified lead doctor and nurse within their children's services for palliative care. These could be identified on a regional basis.

2. Identification of all children and young people with palliative care needs

All children and young people with palliative care needs should be identified as this will allow children's services in each Health Board to plan appropriate services and to analyse the gaps between the total resources required against those already committed to palliative care.

3. Breaking bad news

[26] www.gov.scot/binaries/content/documents/govscot/publications/advice-and-guidance/2012/11/framework-delivery-palliative-care-children-young-people-scotland/documents/framework-delivery-palliative-care-children-young-people-scotland/framework-delivery-palliative-care-children-young-people-scotland/govscot%3Adocument/00408254.pdf

Every family should receive the news of their child's diagnosis or deteriorating condition in a face-to-face discussion in privacy and should be treated with respect, honesty and sensitivity.

4. Lead paediatric consultant

Every child and young person should have an identified lead paediatric consultant who will have overall clinical responsibility for ensuring that care is co-ordinated in a holistic manner.

5. Assessment of care needs and multi-agency care plan

Every child and young person should receive a multi-agency assessment of their palliative care needs and have an anticipatory care plan agreed with them that identifies a lead professional/key worker for the family and provides co-ordinated care and support to meet these needs.

6. Planning discharge

Every child and young person diagnosed with palliative care needs in the hospital setting should have an agreed discharge plan. This plan should include tertiary and secondary hospital services, hospice services, community services and other voluntary services as required.

7. Recognition and planning for end of life care

Every child, young person and family should be supported to agree an end of life plan when the end of life stage is recognised. This should include choice of place of care, place of death and completion of an advanced care plan and CYPADM (Child and Young People's Acute Deterioration Management) form.

8. Care after death

Following the death of a child or young person every family should be allowed time and privacy with their child. Bereavement support should be offered for as long as the family requires this and should be appropriate for all family members.

9. Transition

Health Boards should develop local pathways for transition of young people with palliative care needs to appropriate adult services.

10. Education and training

All staff, caring for children and young people and their families with palliative care needs should be able to access education and training in order to achieve and maintain the requisite skills, knowledge and competencies to meet the specific palliative care needs of each child or young person.

4.2 Unmet need

While there has been no definitive research into the scale of unmet need in children's palliative care in Scotland, it is widely acknowledged that not all of the objectives set out in the 2012 Framework are being met. Take Objective 4, for example - All children and young people with palliative care needs should be cared for and die in their preferred place.

Case study: 24/7 end-of-life care at home

As set out above, provision of palliative and end of life (EOL) care in the preferred setting of children, young people and their families is a priority within palliative care policy and practice.[27]

Yet one area where there is clear unmet need in Scotland is in access to 24/7 end-of-life care at home.

CHAS already works closely with NHS colleagues to support children and families with step-down care from hospital should they want it – either to their home, or to one of our hospices. This enables care in a setting of the family's choice – with associated savings to the health service.

Yet in Scotland, not all families are equally able to access consistent 24/7 support for end of life care at home, if they choose it. And indeed, they may be deterred from choosing this option due to lack of dedicated services.

The choice of care at home may be particularly important for families who, for various reasons, cannot travel from home to hospice or hospital for end of life care, or indeed for families with babies in neonatal units who would otherwise never have the opportunity to take their baby home.

Some Health Boards in Scotland can consistently offer this service.

In NHS Ayrshire and Arran, the Paediatric Supportive Care Team was put in place specifically to address this issue. The team provides round the clock out of hours medical and nursing support to families in their chosen place of care and CHAS part-funds the doctor leading this team.

In NHS Lothian, CHAS has partnered with the Health Board to provide the Care 24 Lothian service, allowing children and their families access to specialist end of life care in their own home. In time, we hope to provide even more out of hours care across Scotland.

Elsewhere, however, the picture is mixed and may be reliant on ad hoc arrangements, supported by CHAS wherever possible, working alongside paediatric palliative medical teams, Community Children's Nursing (CCN) teams, specialist palliative care nurses, and district nurses. These professionals often work beyond their contracted hours and remits, out of good will, to support families in this way.

The gold standard is a 24/7 service in all Health Board areas, provided by nurses and supported by advice from consultant paediatricians who have completed sub-specialty training in paediatric palliative medicine (also known as GRID training).

Work is underway to develop a single national medical on-call MDT which will be able to provide telephone support from a specialist paediatric palliative medicine doctor to any setting in Scotland. This is an initiative developed by CHAS, in collaboration with NHS Greater Glasgow and Clyde, and NHS Lothian, and with support from NHS Grampian.

Medical staff on the rota will be GRID / SPIN trained[28] in paediatric palliative care, and all will be either CHAS employees or CHAS-funded posts. Other clinicians involved have significant experience in the fields of paediatrics, neurodisabilities and palliative care.

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[27] *A realist evaluation of the Care 24 Lothian service: summary report*, Edinburgh Napier University and Edge Hill University, 2020.

[28] GRID trained specialists are consultant paediatricians who have completed sub-specialty training in paediatric palliative medicine. SPIN training is 'special interest' training that a paediatrician with a particular interested in paediatric palliative care can undertake.

This national medical on-call provides the underpinnings of a potential 24/7 end of life at home service, but will need to be supplemented with nursing support on the ground – which in turn would need require more resource than is currently available. CHAS is happy to play its part in this.

This family story illustrates the powerful impact that choice in place of death can have on the whole family, though sadly not every family across Scotland who may want this type of support can currently be guaranteed access to it.

Fin's Story

Gillian Donald's son Finlay (Fin) died in May 2020 when he was just 11 years old. Fin was supported to die at home in Aberdeenshire by CHAS, working in partnership with staff from Royal Aberdeen Children's Hospital.

Fin was an active, fun-loving boy. At about the age of 5, however, he was diagnosed a very rare degenerative peroxisomal disorder, called D-Bifunctional Protein Deficiency, also known as pseudo-Zellweger.

Throughout Fin's life, his family did not want to travel to a hospice. Their priority was to make sure every day was fun for him, and Fin was homeschooled and provided with full-time care by his parents.

Towards the end of his life, Fin and his family were supported to plan for his death by CHAS' Diana Children's Nurse Louise Esson, and Dr Fiona Herd, a paediatric (oncology) consultant who is part-funded by CHAS, and leads the paediatric palliative care service in Aberdeen.

Gillian says: "There are no words to explain how hard it is as a parent to plan for your child's death. But [Diana Children's Nurse] Louise guided us through making these plans, supported us during Fin's deterioration, and did everything she could to ensure Fin had the right death for him."

"And in the end, Fin had the best death he could have, in his own bed at home. He passed away peacefully and comfortably in his mummy's cuddle with daddy holding his hands, and his precious dog Barney at his feet.

"Without CHAS's intervention and help, this would have been a very different story. We would have been in the place he hated the most - the hospital. I'd have been horrendously stressed with unnecessary medical people about. And with Covid restrictions, his Dad would likely not have been with us… never mind his best friend, the dog Barney!"

4.3 National Standards

A right to palliative care could help galvanise the resources needed to bridge the gap between ambition reality.

But in order to ensure the right delivers an enhanced experience for children with life-shortening conditions and their families, the right would need to be underpinned by specific, measurable standards, enshrined in secondary legislation.

These could be based on the some of the themes set out in the 2012 Framework, but these should be updated to reflect the current priorities of children with life-shortening conditions and their families – see section 4.4 below for some initial insights in this area.

Accountability is key, and therefore delivery against national standards should be monitored through data gathering, and reported against at regular intervals. They could be added to a HIS inspection framework. Clear and accessible complaints procedures should also be established.

4.4 What might 'good' look like?

Together for Short Lives has set out the key elements that comprise children's palliative care, based on considerable research into the needs of this cohort of children and their families.[29]

The things that matter the most to children and families are:

Pain and symptom management: this should extend throughout the child's illness as well as at end of life. Management includes both pharmacological and non-pharmacological approaches, including for example sensory play and hydrotherapy.

The provision of accurate and relevant information: All families should be signposted to relevant sources of local and national support. Interpretation services and translated materials should be provided to families whose first language is not English. Age and developmentally appropriate resources should be provided for children. Consideration should be given as to how to include children and families – e.g. including them in MDT meetings where appropriate.

Children being cared for in the place of their/ their family's choice wherever possible: For many, this is at home, but it may be in hospital (where they may feel safest and where the care team is familiar) or in a children's hospice. Regular open and honest communication is needed as families' choices may change over time and it is important to explain why it may not be possible or safe to provide care in their place of choice. This is especially significant at end of life, where families having agency over place of death can have a significant impact of a family's grief trajectory.

> *"The whole support at home was really amazing. I think it would have been so much more different for me and my grief if [child] died in hospital and we hadn't been given that choice, or in the hospice".* **(Family who used the CHAS and NHS Lothian Care 24 service, to enable their child to die at home)[30]**

Emotional, psychological and spiritual support being offered to the child and those close to them: Emotional and spiritual support should be provided to the child and their family throughout the course of their illness and should continue when the child has died. Support should be extended to include siblings, grandparents and wider family. Although grief is a normal process and most families do not need specialist help, some families will require more specialist bereavement counselling and access to this should be available as part of the service provision pre and post death.

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[29] *A Guide to Children's Palliative Care: Supporting babies, children and young people with life-limiting and life-threatening conditions and their families*; Together for Short Lives (2018)

[30] *A realist evaluation of the Care 24 Lothian service: summary report*, Edinburgh Napier University and Edge Hill University, 2020.

Practical and social support: Practical support is often a high priority for families who are caring round the clock for a sick child. For example, this may be support with accessing the right aids, equipment and adaptations for the home, moving to more suitable housing, help with transport or help with accessing benefits.

Opportunities to access education or employment that is right for the child or young person: Children with life-shortening conditions should have access to as wide a range of opportunities as possible.

The child and family's wishes concerning end of life care should be discussed and planned for well in advance: A key element of children's palliative care is supporting children, young people and their families to develop Anticipatory Care Plans (ACPs) which set out their wishes for current care and treatment in the future. ACPs should be regularly updated. A parallel planning approach is very helpful to enable children and families to plan for hopes and wishes for life as well as advance plans for their end-of-life care.

Short breaks/ respite: Short breaks have a hugely beneficial effect on children and their families. Short breaks not only give parents a break from their caring responsibilities – to allow parents to be just parents - but can also provide an opportunity for a child to have access to experiences that might not be available to them at home – for example, access to a hydrotherapy pool. In Scotland, CHAS' hospices provide much-needed respite for families, although it is recognised that more capacity would be welcome especially with the closure of other types of respite facilities in the aftermath of the pandemic.

Transition to adult services: Transition to adult services is often a stressful time, and particularly so for young people with life-shortening conditions and their families, as they navigate a range of transitions across healthcare, education, and social care. It's important that planning for transition starts early, from age 14 at the latest, and that provision is individual and personalised. Young people should be at the centre of planning for their care whilst also acknowledging the support and emotional needs of their families and the central role that they play, particularly when a young person has severe cognitive impairment. Health care must underpin the provision of all other services so that young people and their families feel confident that their medical and nursing needs will be met.[31]
While recognising that good practice exists in some areas across Scotland, high quality transitions support and suitable services are not consistently available across the country, and we believe there is significant room for improvement. Issues include (but are not limited to): the process not starting early enough; lack of age-appropriate services; inadequate budgets; lack of dedicated lead role; and lack of specialised support.

"Beyond awful. Eye-wateringly inefficient. Years and years and years of meetings discussing the same problem: that there was nowhere, and nothing to transition her to." **(Parent of a young adult referred to CHAS)**

Question 5: Are there any other comments on the proposed Bill, for example, on its financial implications, impact on equalities and sustainability?

[31] *A Guide to Children's Palliative Care: Supporting babies, children and young people with life-limiting and life-threatening conditions and their families*; Together for Short Lives (2018)

Some financial resource will certainly need to be allocated if a right to palliative care is to be fully realised, and if everyone who needs it can access seamless, timely and high quality palliative care – including high quality children's palliative care, regardless of location. We would emphasise that this outcome has already been committed to, in the SNP manifesto (2021), and subsequent Programme for Government – so it is now vital that the funding follows the policy commitment.

As outlined elsewhere above, the number of children with palliative care needs is going up, and their needs are becoming more complex – at a time public services are more stretched than ever before.

We recognise there is limited financial headroom in the current economic climate. Yet investment in palliative care would make sound fiscal sense. For example – for every £1 of statutory funding CHAS receives, it is able to generate £6.24 of public value in return.[32]

The care CHAS provides can stop children from going into hospital, allow earlier discharge from hospital, alleviate pressure on the most expensive NHS beds, and stop families from going into crisis. All of which has powerful preventative spend implications.

In that sense, we would agree with the SPPC that a right to palliative care may reduce or at least reprofile existing expenditure in the long term, rather than simply representing an additional and competing ask for investment.

At a roundtable convened by CHAS and attended by over 30 professionals involved in paediatric palliative care from across the public and third sectors, a number of cross-cutting thematic areas were identified that may help alleviate unmet need without significant additional resource. These are set out below, but it was highlighted that none of these solutions are a replacement for the "boots on the ground" personnel in place to deliver more equitable access to, for example, end-of-life care at home.

Better partnership and cross-organisational working

It was recognised that the pool of individuals involved in paediatric palliative care is relatively small, and that more could be done to come together across organisational and sectoral boundaries to develop virtual 'hubs' or 'networks' of individuals to share learning and skillsets, and improve working relationships.

Better informal training models, especially in rural areas

Because the absolute numbers of children with life-shortening conditions are so small – with generalist staff particularly in rural areas unlikely to see more than one of two children with the same set of symptoms over the course of their career - agile, targeted training is key. One participant from CHAS highlighted a 'pop-up' nursing training model that they informally delivered, to orient community or district nurses to paediatric palliative care specifically in relation to the child in their locality, as and when that child presented as having a life-shortening condition. These sessions help to guide nursing colleagues in some of the decision making around symptom management at end of life.

Individuals would need be to be authorised to allocate time to invest in such training.

[32] *Children's Hospices Across Scotland: An Economic Evaluation of Hospice Services*; York Health Economics Consortium (2021)

Another colleague talked about the importance of education and training to ensure that palliative care is more consciously embedded in more generalist roles – such as general paediatrics, community nursing, general practice, as well as within children's health services within hospitals. Project ECHO is one model for this.[33] CHAS and Highland Hospice have implemented regular on-line teaching and training programmes focussing on the educational need of different cadres of staff working with children with life-limiting conditions in NHS and third sector.

Honorary contracts

For key medical staff in remote or rural location such as in Islands communities, they could potentially be given honorary contracts in one of the major centres to enable them to maintain skills that they may only otherwise use rarely.

For more information, please contact:

Mona Vaghefian

Policy & Public Affairs Manager

Children's Hospices Across Scotland

monavaghefian@chas.org.uk

Information on how I process your personal data is set out in my **privacy notice**, which can be found here https://www.milesbriggs.scot/right-to-palliative-care-consultation. Please confirm that you have read the privacy notice by ticking the box below.

☒ I confirm that I have read and understood the **privacy notice** (referred to above) to this consultation which explains how my personal data will be used.

[33] Project ECHO is a worldwide movement providing an online learning and support methodology. It supports knowledge sharing between professionals from across health and social care, and facilitates the exchange of specialist knowledge and best practice.