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What matters to you about the future of palliative and end of life care in Scotland?



A written submission from Together for Short Lives

About us

Together for Short Lives is the leading UK charity for all children with life-threatening and life-limiting conditions and all those who support, love and care for them - families, professionals and services, including children's hospices. We work closely with other organisations and networks in Scotland and members of the Scottish Children and Young People's Palliative Care Executive (SCYPPEX) and the Scottish Children and Young People's Palliative Care Network (SCYPPCN).

Together for Short Lives is an active member of SCYPPEX. This is a strategic planning group which draws together individuals and organisations who can influence how children's palliative care is planned and provided in Scotland. Its members include:

- the Scottish Partnership for Palliative Care
- Children's Hospice Association Scotland (CHAS)
- managed clinical and service networks
- Scottish Government departments.

Life-limiting and life-threatening conditions in babies, children and young people

Life-limiting conditions are those for which there is no reasonable hope of cure and from which babies, children and young people are expected to die. Life-threatening conditions or events are those for which curative treatment may be feasible but can fail. Children and young people with life-limiting conditions need continuing palliative care throughout the trajectory of their illness.

Together for Short Lives' work helps to ensure that children can get the best possible care, wherever and whenever they need it. When children are unlikely to reach adulthood, we aim to make a lifetime of difference to them and their families.

There may be as many as 4,500 babies, children and young people in Scotland with life-limiting and life-threatening conditions. We welcome the work funded by Scottish Government and being led by CHAS to further develop the extent to which we understand the numbers and needs of babies, children and young people with life-limiting conditions.

Children's palliative care

Holistic children's palliative care spans health, social care, education and other services. It is a whole-family approach and has the following characteristics:

- It is flexible and focussed on children, their parents and their siblings.
- It spans the three stages of life-limiting and life-threatening conditions in children and young people: diagnosis or recognition; ongoing care; and end of life.
- Supports and enables children and families to choose the type, location and the provider of the care they receive and allows them to change their mind.
- It is not age, time or diagnosis specific – 15% of children who need children's palliative care have no definitive underlying diagnosis.
- It is multi-disciplinary and multi-agency.
- It is accessible to people of different faiths, culture, ethnicity and locations.
- It includes pre and post-bereavement support for families.

- It is able to manage symptoms.
- It supports parents in caring for their children according to their needs and wishes.
- It supports and enables smooth transitions for young people with life-limiting and life-threatening conditions who move from children's to adult's services.

Children with life-threatening and life-limiting conditions - and their families - need to be able to access a range of children's palliative care services, 24 hours a day, seven days a week, when and where they want and need it. This must be provided by professionals with the appropriate skills, knowledge and competencies. It is common for the condition of children and young people with life-limiting conditions to fluctuate, deteriorate, then recover and, as such, it is sometimes more difficult to identify when they are moving into their end of life phase. Often children are described as "dying many times" as they deteriorate, then recover, before further deteriorating. This uncertainty can be difficult for families and professionals to deal with and this is why access to expertise is imperative. Due to the variety and complexity of conditions, each child's prognosis, treatment and support needs will be unique.

Care is delivered in hospitals, family homes, community settings, schools, nurseries and children's hospices, or another chosen place. Providing out-of-hospital care is a more cost-effective approach for the NHS. Unfortunately, many children are unable to access the 24/7 palliative care they need - often because round the clock community children's palliative care services are not funded - or because there are insufficient numbers of professionals with the right skills, knowledge and competencies to care for children with life-limiting conditions.

Providing holistic children's palliative care requires support for parents, siblings and extended family after the death of a child. However, instead of services growing to meet the increasing demand for bereavement care, the opposite is happening as evidenced by services being suspended from The Royal Hospital for Children, Glasgow.

Scottish Government children's palliative care policy

SCYPPEX developed [A Framework for the Delivery of Palliative Care for Children and Young People in Scotland](#). This was published in November 2012 by the Scottish Government with [CEL 37 \(2012\)](#), a directive to NHS Boards in Scotland. Implementing the framework would lead to a better, more integrated and responsive experience for children with life-threatening and life-limiting conditions and their families.

The framework specifies that:

- "children and families should have their needs assessed as soon as possible after diagnosis or recognition"
- a "holistic and multi-agency approach should be used to avoid the need for multiple assessments"
- "every family should have a lead professional/key worker to co-ordinate the plan and information should be available for the child and family"
- "the child and family's needs should be regularly reviewed and a new care plan agreed to take account of the changes"
- when reaching end of life – "professionals working with these children and families should be honest and open about the probability that the child's life is nearing an end. Families should not be given false hope and should be allowed to plan for death".

The framework recognises that:

- discussions should involve the child or young person, as well as trusted and familiar practitioners; the conversations should take place in familiar environments, which are chosen by the family

- where young adults are capable of making important decisions about their end of their life care, it is important that professionals take account of their preferences over whether parent carers are involved in the process
- whereas the majority of adults will only require palliative time towards the end of their lives, children and young people may require palliative care over a much longer period
- anticipatory care plans can ensure that a child or young person can receive end of life care in a place of their choosing.
- there is also sometimes reluctance on the part of professionals to talk to parents and their child about the possibility their child will die and to introduce the support of palliative care; improved training and support for professionals would help increase the number of children and young people with ACPs.

In March 2015, the Scottish Government announced that a new integrated **Strategic Framework for Action for Palliative and End of Life Care** will be approved at the end of 2015. The framework will link clearly to the [2020 vision for health and social care](#); ministers state that it will reflect the Scottish Government's commitment to measuring and improving quality. **We call on ministers to ensure that it addresses the distinct issues affecting infants, children and young people with life-limiting conditions and their families.**

Until the integrated Strategic Framework for Action for Palliative and End of Life Care is published, we call on NHS Boards to continue to work to implement the Framework for the Delivery of Palliative Care for Children and Young People in Scotland directive - and to allocate funding to deliver this.

1. What have been the key achievements in the delivery of palliative and end of life care in Scotland since the publication of Living and Dying Well in 2008?

Together for Short Lives welcomes the Scottish Government's announcement in March 2015 that a new integrated Strategic Framework for Action for Palliative and End of Life Care will be approved at the end of 2015. This provides an opportunity to ensure that children and young people who have palliative care needs are able to access high-quality care where and when they need it.

We support the Children and Young Peoples Acute Deterioration Management CYPADM process which helps to share the family's wishes for the care of their child and supports communication between professionals.

We also support Arran and Ayrshire Health Board's decision to enable to complete the post graduate medical Diploma in Palliative medicine (Paediatric Option) from the University of Cardiff, in order to medically lead children's palliative medicine within this area. We call on the Scottish Government to ensure that every child has access to a children's palliative care specialist.

The Framework for the Delivery of Palliative Care for Children and Young People in Scotland directive (CEL 37 (2012)) recommends that individual "Health Boards should develop local pathways for transition of young people with palliative care needs to appropriate adult health services." We have highlighted the difficulties that young people face when transitioning to adult services through the Transition Taskforce, which is led by Together for Short Lives and therefore welcome this directive.

In addition to this, we support the inclusion of the Getting it Right for Every Child (GIRFEC) approach in the Children and Young People Act 2014. When developing statutory guidance on how to implement the act, we call on the Scottish Government to set out how the GIRFEC approach can be used to join up services for children and young people who need palliative care.

We applaud the appointment of Dr Edile Murdoch to work with CHAS and NHS Lothian to improve the palliative care of babies, children and young people. The appointment of Diana nurses to work across Scotland has also brought closer partnership working which contributes to improving care in Scotland.

2. What do you see as being the main priorities and objectives to improve palliative and end of life care in Scotland over the next 5 years (2015 – 2020) and beyond?

24/7 children's palliative care

There is a shortage of skilled professionals able to support children who need palliative care, particularly outside core hours, especially in terms of specialised medical support and community nursing services. Careful consideration must be given to the appropriate medical workforce required to ensure the delivery of 24/7 children's palliative care.

The lack of availability of community children's nursing (CCN) teams has a detrimental impact on 24/7 children's palliative care support. The Royal College of Nursing (RCN) recommends that for an average-sized district with a child population of 50,000, a minimum of 20 whole time equivalent (WTE) community children's nurses are required to provide a holistic CCN service. This is in addition to any individual child-specific continuing care investment. However, only 17 community children's nurses were due to qualify in 2014/15 in the UK. A holistic children's palliative care service has to be able to provide children's palliative care to children and young people in remote and rural areas. To do so, it is vital that health boards fund CCN teams for their local area.

The lack of trained CCNs is restricting the choice which children have over the place in which they receive care and in which they die. A failure to train enough CCNs to provide care in the home results in more acute hospital visits for children and young people and is not cost-efficient for the NHS. There is currently no education provision for CCNs in Scotland and therefore this shortage is worsening.

Together for Short Lives surveyed vacancies for nursing posts in voluntary sector children's palliative care provider organisations across the UK in December 2014. We found that:

- the average vacancy was 10% for posts equivalent to bands 5 to 8
- across the sector, more than 60% of vacancies in the sector are defined as hard to fill (unfilled for over three months)
- that a quarter of voluntary sector children's palliative care nurses are over 50 years of age; the age profile of the nursing workforce in the sector is a significant planning challenge in terms of the number who are likely to retire in the short to medium term.

Fair and sustainable statutory funding

Every child with a life-limiting or life-threatening condition, and their family, should have access to palliative care services, including children's hospices, which are fairly and sustainably funded. Children's palliative care services can reduce unplanned, unnecessary and costly hospital admissions. By consistently investing in this vital care, the NHS and local authorities can help ensure the best outcomes for the increasing number of children and young people with life-limiting conditions.

Short breaks (respite care)

Every child - and their family - should get a short break if they need one.

Children with life-limiting or life-threatening conditions - and their families - rely on short breaks to enable them to spend some time as a family. This enables them to do the things that other families do - recharging batteries, making memories with the child and spending

quality time with their siblings. Short breaks are provided by a range of organisations, including children's hospices.

However, not all families can access them as they are not fairly or sustainably funded. Short breaks should also be provided for carers and families of young people who require palliative care.

Ensuring smooth transitions to adult services - and access to age and developmentally appropriate palliative care

It is vital that young people undergo smooth and well-planned transitions from children's to adult's services when they reach adulthood and that the transition plan recognises what is most important to them. It is therefore essential that transition discussions and planning begins as early as possible. The discussions should be initiated by the age of 14, so that there is sufficient time to plan for the young person's care needs and the needs of those caring for them

Transition plans should support clinical, social and education needs and should taper services so that transition is less of a 'cliff-edge' - this includes intentions to:

- enter further education
- enter the workplace,
- move to independent or assisted living.

Ensuring integrated care for children who need palliative care

Many families of children and young people who require palliative care will routinely deal with over 30 professionals from health, social care, education and other services that they require. It is often the responsibility of parents to navigate their way through an uncoordinated system where communication between agencies is often poor. For families with children whose lives are likely to be short, this is particularly distressing as parents waste time through avoidable bureaucracy at the expense of spending time together as a family.

3. What are the most significant challenges to delivering improvements in (a) access to; and (b) quality of palliative and end of life care in Scotland in the future?

The engagement document acknowledges that 'more children with life shortening conditions are living into adulthood and many have complex care needs throughout their childhood that can be met in part from palliative care'. Due to advancements in medical science, more children are living longer through their childhood and into adulthood.

A palliative care strategy for children and young adults must recognise that this is a growing population and services should be funded accordingly in a fair and sustainable way.

The shortage of skilled professionals able to support children who need palliative care, as outlined in section two, poses a major obstacle to improving palliative care for children and young people. Furthermore, this is a problem which is likely to get worse as over a quarter of community children's nurses are over the age of 50 and are approaching retirement. This shortage also poses an obstacle to ensuring equitable access to palliative care as there are not enough community children's nurses to reach all children across Scotland.

As discussed in section two, many families will have to co-ordinate over 30 professionals from health, social care, education and other services that their child requires to ensure they receive the best possible support package. Parents spend a great deal of time as care co-

ordinators rather than parents and limits the amount of time that they can spend together as family. In order to prevent this, a strategic approach is required to ensure that agencies work together and integrate services to limit the burden on the parent or carer.

4. How can we support these improvements? (a) in access (b) in quality of care

The following recommendations correlate to the priorities set out in section two.

Until the integrated Strategic Framework for Action for Palliative and End of Life Care is published, we call on NHS Boards to continue to work to implement the Framework for the Delivery of Palliative Care for Children and Young People in Scotland directive - and to allocate funding to deliver this.

To ensure that all children across Scotland have access to appropriate services, we call on the Scottish Government to follow the example of the Arran and Ayrshire Health Board in appointing a medical lead on children's palliative care, with the aim of ensuring that all children in Scotland have access to a children's palliative care specialist. To ensure that the long-term workforce requirements are addressed, we also call on NHS Education for Scotland to:

- understand how prevalent life-limiting conditions are among children and young people in Scotland - and what the demand for children's palliative care is
- understand how the numbers and needs of CYP with life-limiting conditions in Scotland and the demand for children's palliative care impacts on the workforce
- assess the size, location and skill mix of the local children's palliative care workforce
- develop, publish and oversee the implementation of a local strategy for filling the gaps in the children's palliative care workforce in Scotland
- co-ordinate education, training and workforce development for the children and young people's workforce; maintain national standards and reduce the extent to which they vary across Scotland
- commission training to ensure that the workforce which cares for children and young people is properly trained to deliver age-appropriate care - and is able to assist children and young people in identifying where to go for care and when.
- consider pathways of care for children with life-limiting conditions
- consider the workforce required to provide care at different stages of these pathways
- produce materials, tools and resources to inform national and local planning policy decisions relating to the children's palliative care workforce.
- commission sufficient training places to meet the gaps in the children's palliative care workforce.

As outlined in section two, fair and sustainable statutory funding is vital to ensure high quality palliative care. Together for Short Lives calls on:

- NHS Scotland and local authorities to fund children's palliative care in a way that is fair and sustainable.
- NHS boards to fund children's palliative care - which includes 24/7 access to CCN teams across Scotland for children with life-limiting conditions.
- NHS boards and local authorities to fund 50% of the costs incurred by Children's Hospice Association Scotland, in line with the existing funding arrangements for adult hospices set out in CEL 12 (2012).

We also call on the Scottish Government to ensure that:

- short breaks are sustainably and fairly funded from ring-fenced funds
- children and families' preferences are taken into account when deciding who should provide short breaks

- information about local need for short breaks is collected and used to inform what services are offered and to whom.

To ensure that young people can make a smooth transition to adult services, we call on the Scottish Government to fund and stimulate age-appropriate palliative care services for young adults with life-limiting conditions.

To better integrate services, we call on the Scottish Government to set out - when developing statutory guidance on how to implement the Children and Young People Act 2014 - how important it is for the GIRFEC approach to be used in joining up services for children and young people who need palliative care.

5. What matters to you if time were to become short? What would you want Scotland's future approach to palliative and end of life care to provide you as a result of this?

Palliative care for children with LLCs or LTCs is an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond. It should meet their physical, emotional, social and spiritual needs. It should focus on enhancing their quality of life and providing support for their family. It should include managing distressing symptoms, providing short breaks and care through death and bereavement. Palliative care for children and young people should be provided in age and developmentally appropriate settings by professionals who are skilled in working with their age-group. This means that, rather than solely addressing the medical needs of a child or young person, they should be supported to fulfil their ambitions – whether forming new relationships, gaining employment or pursuing further education.

Outcomes required for a total approach to care for children and young people include:

- Better quality of life of the child or young person and their family members or carers
- Satisfaction of the child or young person with their care
- Satisfaction with care of the family members, carers (as appropriate) to the child or young person
- Mental wellbeing - for example resilience, depression or anxiety in the child or young person and their family members or carers (as appropriate)
- Prevention or management of pain and other distressing symptoms such as restlessness or agitation
- Access to care which is appropriate to the child or young person's age
- Access to education or training
- Starting or maintaining a job
- Starting or maintaining a hobby
- Independent living
- Building and maintaining a social life and social networks
- Forming relationships
- Access to regular short breaks
- Access to the treatments and equipment they need
- Awareness of the children's palliative care services available to them
- Access to information in a language which they can understand
- Minimising the number of times that families have to tell their story to professionals and agencies across health, social care and education in order to secure the care and support they need
- Access to a key worker
- Access to generalist professionals who understand how to support and care for children with life-limiting and life-threatening conditions
- Experiencing a smooth and well-planned transition to adult services

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