



About us

Together for Short Lives is the leading UK charity for all babies, children and young people with life-threatening and life-limiting conditions and all those who support, love and care for them. We support families, professionals and services, including Children's Hospice Association Scotland (CHAS). Our work helps to ensure that children can get the best possible care, wherever and whenever they need it.

1. Do you think that the new National Care Standards should be grounded in human rights?

Together for Short Lives agrees with this approach and welcomes the Scottish Government's recognition of the UN Convention on the Rights of the Child (UNCRC) and the UN Convention on the Rights of Persons with Disabilities.

We also believe that the standards should reflect the World Health Organisation's resolution to strengthen palliative care as a component of comprehensive care. The resolution was made by the World health Assembly in May 2014 (<http://bit.ly/1s6vAgo>).

2. (a) Do you agree that overarching quality standards should be developed for all health and social care in Scotland?

Yes

(b) Do you agree that the overarching quality standards should set out essential requirements based on human rights?

Yes

(c) Do you agree that the current National Care Standards should be streamlined and a set of general standards developed that would sit below the overarching standards and apply to all services?

Yes

(d) Do you think general standards should set out essential requirements and aspirational elements?

Yes

(e) Do you agree that a suite of specific standards are developed for particular aspects of care, circumstances or need?

Yes. We welcome the proposal to develop a specific standard for palliative care. We ask that this standard applies across all health and social care services in Scotland which provide palliative care to babies, children and young people - in acute, community, home, hospice and tertiary settings, for example.

We call on the Scottish Government to be clear about the terminology of this standard. For example, there are differences between the palliative care needed by adults and children.

Palliative care for children with life-limiting or life-threatening conditions is an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on enhancing quality of life for the child/young person and supporting the family. It includes managing distressing symptoms, providing short breaks and care through death and bereavement¹.

Life-limiting conditions are those for which there is no reasonable hope of cure and from which children are expected to die. Life-threatening conditions or events are those for which curative treatment may be feasible but can fail.

Children's palliative care differs from adult's palliative care. Whereas the majority of adults only need palliative care at the end of their lives, children with life-limiting and life-threatening conditions require palliative care over a much longer period, often from birth. It is common for their conditions to fluctuate and, as such, it is often much more difficult to identify when a child is moving into their end of life phase. Children with life-threatening and life-limiting conditions often have complex disabilities, while the range of health conditions which results in children requiring palliative care is more diverse.

Children's palliative care is an approach to care which can be used exclusively or in conjunction with curative treatments. It can be defined by the following four categories²:

1. Life-threatening conditions for which curative treatment may be feasible but can fail - such as cancer or congenital heart disease.
2. Conditions where premature death is inevitable but where there may be prolonged periods where the child is well – such as Duchenne muscular dystrophy.
3. Progressive conditions without curative treatment options, such as Batten disease.
4. Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death – such as severe brain injury.

A comprehensive local children's palliative care service spans health, social care and education. It is a whole-family approach and has the following characteristics:

- It is flexible and focussed on children, their parents and their siblings.
- It is accessible 24 hours a day, seven days a week, 365 days a year – from diagnosis or recognition to bereavement.
- 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 diagnosis³.
- It is multi-disciplinary and multi-agency.

¹ Together for Short Lives (2013). Definitions. Available to download at: bit.ly/Z34i5s (Accessed on 15 March 2013).

² Together for Short Lives (2013). A Core Care Pathway for Children with Life-limiting and Life-threatening Conditions. Available to download from: bit.ly/18Vd3JV (Accessed on 20 June 2013).

³ NHS England (2013). E03/S/h - 2013/14 NHS standard contract for paediatric medicine: palliative care particulars, schedule 2 – the services, A - service specifications. Available to download from: bit.ly/11yitVS (Accessed on 20 June 2013).

- 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.

Together for Short Lives also calls on the Scottish Government to ensure that any standard on palliative care reflects the *Framework for the Delivery of Palliative Care for Children and Young People in Scotland*⁴.

We ask that cross-cutting issues, such as the importance of ensuring that young people experience smooth and well-planned transitions from children's to adult's health and care services, are included in the standards. Age-appropriate services for young adults should also be reflected in this work.

3. (a) What are your views on how standards should be written?

Together for Short Lives supports the GIRFEC principles and would welcome them being extended to all age groups.

(b) What are your views on the example of how the rights and entitlements of people using services and the responsibilities of service providers could be set out?

We support this approach.

4. (a) Do you think the Care Inspectorate and Healthcare Improvement Scotland should hold services they regulate to account for meeting the proposed overarching standards, the general standards and the suite of specific standards?

Yes

(b) How should we ensure that services not regulated by the Care Inspectorate and Health Improvement Scotland comply with the new standards?

Together for Short Lives believes that all providers of health and social care services should be regulated by Healthcare Improvement Scotland and/or Care Inspectorate Scotland. The regulators should assess the extent to which these standards are being applied and whether care provided is consistent with them. In addition, health and social care commissioners should also ensure that they hold services to account for applying the standards.

(c) We suggest that the Care Inspectorate and Healthcare Improvement Scotland, consulting with others, should develop the suite of specific standards. Do you agree with this?

We think it would be sensible for both regulators to develop the standards on the basis that they should be responsible for assessing the extent to which they are applied. We call for

⁴ Scottish Children and Young People's Palliative Care Executive Group (SCYPPEX). 2012. A Framework for the Delivery of Palliative Care for Children and Young People in Scotland. Available to download from: <http://www.scotland.gov.uk/resource/0040/00408254.pdf> (accessed on 16 September 2014)

the process of developing the standards to be open. Opportunities should be offered to patients, service users, the public and provider organisations to shape the standards.

5. **(a) Please tell us about any potential impacts, either positive or negative, you feel any of the proposals set out in this consultation paper may have on particular groups of people, with reference to the ‘protected characteristics’ listed above.**

(b) Please tell us about any potential costs or savings that may occur as a result of the proposals set out in this consultation paper and any increase or reduction in the burden of regulation for any sector. Please be as specific as possible.

If developed appropriately, Together for Short Lives believes that all providers of children’s palliative care in Scotland could be asked to adhere to a common standard. We call on the Scottish Government to work with us to ensure that the regulatory burdens on providers, particularly in the voluntary sector, are fair and proportionate.

For more information

For more information about this response, please contact James Cooper, Public Affairs and Policy Manager at Together for Short Lives, by email james.cooper@togetherforshortlives.org.uk or telephone (01179 897 863).