



Department of Health

Consultation on the Children and Young People's Continuing Care Framework

Please note that responses can also be made at:

<http://consultations.dh.gov.uk/children2019s-health-and-well-being/children-and-young-peoples-continuing-care>

Introduction

1. What is your name? (please provide a name, even if you are responding on behalf of an organisation - the organisation name can be given under Question 3).

Patrick McKenna

2. What is your email address or other contact details?

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3. If you are responding on behalf of an organisation, what is its name and role?

Together for Short Lives. We are the leading UK charity for all children 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 hospices.

Views on the framework

4. Does the framework adequately define the scope of children and young people's continuing care?

Mostly. We welcome the inclusion of children with life-limiting conditions are included in 'factors which result in a child having a need for continuing care' (paragraph 4). We ask that the list also includes children with a life-threatening condition, i.e. those for which curative may be feasible but can fail.

We support Anna Gill's submission to this consultation, particularly around the importance of aspirations for the child or young person and their family. The framework should set out that outcomes should be agreed which are designed need to meet *their* aspirations, which cannot be decided *for* them.

We also support David Widdas' contribution to this consultation, particularly his preference to retain the term 'continuing care'. This term is strongly supported by children's services and families as it enables funding directly from commissioners to provide services for children.

In Annex A, we ask that the document clarifies this by including the four categories of life-limiting and life-threatening conditions in children and young people as defined in Together for Short Lives in 'A Core Care Pathway for Children with Life-Limiting and Life-threatening Conditions'¹. Our suggested text would be:

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

Life-limiting and life-threatening conditions in children and young people can be defined by the following four categories

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,

¹ 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.

leading to susceptibility to health complications and likelihood of premature death – such as severe brain injury.”

We ask that the following passage is included in Annex A:

“Babies, children and young people with life-limiting and life-threatening conditions need palliative care from the point of diagnosis or recognition, throughout their life, death and beyond. Children’s palliative care is an active and total approach to care. It embraces physical, emotional, social and spiritual elements and focuses on the enhancing quality of life for the child or young person and support for the family. It includes managing distressing symptoms, providing of short breaks and care through death and bereavement.

In Annex A, we ask that the final paragraph is amended to:

“End-of-life and palliative care

Where a child or young person has needs that require the input of end-of life and/or palliative care services, they should be referred to the specialist palliative services for an assessment. Children and young people with a rapidly deteriorating condition and expected short-term life expectancy should be able to receive continuing care immediately. Strict time limits are not relevant for end-of life cases, and should not be imposed; the nominated children and young people’s health assessor should identify such cases.”

This is on the basis that we do not wish those reading the document to consider end of life care and palliative care as interchangeable terms. Children’s palliative care is an active and total approach to care, from the point of diagnosis or recognition, throughout the child’s life, death and beyond. While end of life care is an important element of palliative care, the latter term encompasses a much wider model of care.

5. Does the framework set out a clear process?

Yes. However, as children, young people and families are at the centre of the process, it is crucial that this step-by-step process is translated in to a resource that is accessible for them. This should include timescales, ‘what to expect’ for each stage, and signposting to services that can provide further support.

6. Does the framework provide clear guidance on the process for assessing needs and agreeing a package of care? Is there sufficient detail on

practice?

The 'areas of evidence that should be considered in the assessment' (para.16, 76) should include a child or young person's aspirations. This is so that any care agreed in the 'decision-making phase' can support their wishes and individual preferences.

We welcome the inclusion of a requirement to announce decisions 'verbally to the child or young person and their family or their representative' (para. 22). Given that families, especially those of children who need palliative care, often have numerous consultations and appointments, the guidelines should also specify that those arranging this meeting should take into account the families' preferred location and time.

7. Are the domains of the Decision Support Tool appropriate? :

Yes

8. Is there sufficient information on the role of the Assessor?

Broadly yes; we ask that listening skills are included in the 'minimum expertise' list (para. 73) rather than the 'ideal expertise' (para. 74) list. We believe that this would further help ensure that the assessment process firmly puts the views of children, young people and families at the centre of the process.

We ask for greater clarity to be provided over how the multiple assessors outlined in para. 72 should work collaboratively. We also ask for clarity about who would take the lead on any decisions.

We support David Widdas' contribution to this consultation, that 'for a children's process the assessor should be a registered practitioner qualified in children's health assessment'.

9. Does the framework provide enough support to professionals leading on, or participating in, continuing care assessments?

Yes. We welcome the fact that the government recognises that it is unlikely that a single individual will have all the necessary skills or knowledge to assess all of a child or young person's needs - and that several assessors will be needed (para 72). Furthermore, we believe that the emphasis on information sharing (para. 60) will support professionals to make their decisions in a timely and accurate manner.

10. Does the framework explain how the Education, Health and Care plan process relates to the continuing care process?

Yes. We ask the government to recognise that families may find the links between continuing care and the new SEND system confusing. As we set out in our response to question four, we suggest that a guide for families would help to clearly explain these links.

11. Does the framework support an effective transition to adulthood and the NHS Continuing Care framework?

We welcome the requirement that conversations around transition to adult services should start at the age of 14. This is line with our recommendations for all transitions from children's to adults' palliative care services and allows sufficient time for the young person and their family to adequately plan for their care needs and the needs of those caring for them.

Similarly, we welcome the requirement to make any changes to the services provided 'in a planned manner, in full consultation with the young person' (para. 117).

We ask that the document refers to the legal duty in the Children and Families Act 2014 which states that for children in or beyond year 9 with EHC plans, local authorities have a legal duty to include provision to assist in preparing for adulthood in the EHC plan review. We also ask that the document refers to the duties in the Care Act 2014 on local authorities to undertake child's needs assessments and child's carer's needs assessments of social care needs before young people reach adulthood. We ask that in this document, the government recommends as best practice that transition planning for future continuing care, education and social care needs all take place at the age of 14.

12. Do you have any other comments you would like to make on the draft framework? Is there something missing, or something which needs to be changed?

We suggest that a definition of children's palliative care is included in the glossary of key terms as follows:

Children's palliative care

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 the enhancement of quality of life for the 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.

Responses to the consultation must be submitted before 23th October 2015

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or by post to:

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