



The All-Party Parliamentary Group for Children Who Need Palliative Care

Inquiry into how the government is meeting its commitment to choice for babies, children and young people who need palliative care

Terms of reference

What do we want to achieve?

1. A select committee-style inquiry into the extent to which the government's commitment to choice in palliative care in England is being met for babies, children and young people aged from birth to 25.
2. We would like to obtain answers to the following questions:
 - What choices can children and young people in England with life-limiting and life-threatening conditions - and their families - reasonably expect to make? Do these vary in relation to different conditions?
 - Can children and young people in England with life-limiting and life-threatening conditions make these choices? To what extent is this the case? Is this being measured - and, if not, can it be? Do these vary in relation to different conditions?
 - What are the barriers preventing children and young people from making these choices? Do these vary in relation to different conditions? Are there barriers which are preventing services from offering choices?
 - What are the opportunities for improving the extent to which children and families can make these choices? What policies do the government, NHS England and others have in place to improve choice for children? Are there examples of where children and families have been offered choices that others can learn from, including from Northern Ireland, Scotland and Wales?
 - What actions can the following individuals and organisations take to improve the extent to which children and families can make these choices?
 - Children and young people with life-limiting or life-threatening conditions
 - Families
 - Providers of children's palliative care in the statutory, private and voluntary sectors
 - Government
 - NHS England
 - NHS commissioners
 - Local authorities
 - Workforce planners
 - Educators
 - Charities including Together for Short Lives.

3. We would like all of the above individuals, organisations and groups to submit written evidence to the inquiry.

What we are seeking

4. Written evidence which answers the above questions from:
 - the public
 - MPs and peers
 - relevant select committees
 - other relevant APPGs
 - think tanks
 - UK-wide charities including those working in the palliative care and disabled children's sectors
 - the National Institute for Health and Care Excellence (NICE).
5. Oral evidence provided across four two-hour sessions in February and March 2018 to APPG members and an expert advisory committee.
 - **Session one:** young people and families:
 - **Session two:** children's palliative care providers: individuals and organisations (including children's hospice services and other charities)
 - **Session three:** commissioners (statutory planners and funders) of children's palliative care
 - **Session four:** government departments, NHS England and NICE.
 - **Session five:** the children's palliative care workforce.

The outputs we will produce

6. A report of the inquiry which includes:
 - The findings from the inquiry
 - A series of recommendations for the individuals, groups and organisations listed in paragraph 2.
 - The written evidence we receive as part of the inquiry.
 - Transcriptions of the oral evidence received.
7. We will conduct a short audit of the extent to which the inquiry's recommendations have been implemented one year after they are published.

Terms of reference for our expert advisory group

8. The inquiry will be supported by a group of individuals which will provide expert advice to the APPG and Together for Short Lives.
9. The group will ideally comprise the following:
 - I. A young person with a life-limiting condition
 - II. A parent carer of a child or young people with a life-limiting or life-threatening condition
 - III. A medic
 - IV. A children's palliative care nurse working in the statutory sector
 - V. A children's palliative care nurse working in the voluntary sector

- VI. A professional providing social care to children and young people with life-limiting or life-threatening conditions
- VII. A representative of a children's hospice
- VIII. A representative of a non-hospice children's palliative care charity
- IX. A CCG commissioner
- X. A local authority commissioner
- XI. An academic.

For more information please contact:

James Cooper
Public Affairs and Policy Manager
Together for Short Lives
0117 989 7863
0741 522 7731
james.cooper@togetherforshortlives.org.uk