#followthechild: Transforming end of life care for babies, children and young people

Briefing for Peers

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The Brain Tumour Charity registered in England and Wales (1150054) and Scotland (SC045081). Together for Short Lives registered in England and Wales (1144022) and Scotland (SC044139). Marie Curie registered in England and Wales (207994) and Scotland (SC038731). CLIC Sargent registered in England and Wales (1107328) and Scotland (SC039857). The Gold Standards Framework - a Community Interest Company 7231949. Teenage Cancer Trust registered in England and Wales (1062559) and Scotland (SC039757).

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1. Having to plan and prepare for a child's end of life care and death is the most heart-breaking thing that any parent can face. Driven by the experience of families and children, our collective ambition is for every single family facing the unimaginable to have the best possible end of life care for their child. This means achieving the best possible quality of life, however short that might be, and care and support for the whole family from experienced professionals, regardless of where they live.

> *It was down to luck that my son, DD, had a calm and peaceful death at home, as he wished, and yet I consider that good death the greatest achievement of my life and my biggest consolation in grief. That luck should dictate whether you are able to follow your child's wishes and manage a good death for them is outrageous."*
>
> **Parent, Sacha Langton-Gilks**

2. There are 49,000 babies, children and young people in the UK with life-limiting and life-threatening conditions[1], a number which is growing as a result of advances in medical technology and better care. 5,000 babies, children and young people in the UK under the age of 19 die every year[2]. A significant proportion are seriously ill children who need end of life care.

3. **Parliamentarians have a vital role to play in connecting seriously ill children with the end of life care services** that can make sure they have the best possible quality of death, consistent with the Ambitions for Palliative and End of Life Care[3]. This would mean that after their child had died, families would be able to say:
    - My child was seen as an individual.
    - My child had fair access to care.
    - My child's care was coordinated.
    - Staff were prepared to care for my child.
    - Each community was prepared to help my child.

4. **Crucially, families should be able to say that, together with their child, they were able to choose how and where they received end of life care, consistent with their child's needs, wishes and best interests.**

5. **The National Institute for Health and Care Excellence (NICE) quality standard 'End of Life Care for Infants, Children and Young People'[4] states that infants, children and young people with a life-limiting condition and/or their parents or carers should:**
    - Be involved in developing an advance care plan.
    - Have a named medical specialist who leads and coordinates their care.
    - Be given information about emotional and psychological support, including how to access it.
    - Be cared for by a multidisciplinary team that includes members of the specialist paediatric palliative care team.
    - Be offered support for grief and loss when their child is nearing the end of their life and after their death.
    - Have 24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care.

6. **NICE calculates that by investing £12.7 million in implementing its guideline on end of life care for children[5], non-cash savings worth £34.7million** would be released back into the NHS in England[6]. In its 2016 document 'Our Commitment to You for End of Life Care: The Government Response to the Review of Choice'[7], the government stated that to support high quality personalised care for children and young people, commissioners and providers of services must prioritise children's palliative care in their strategic planning; this is so that services can work together seamlessly and advance care planning can be shared and acted upon.

7. Despite NICE's clear quality statements, the government's commitment and the compelling health economic case, **there are five barriers preventing children from accessing the end of life care which they and their families should expect to receive:**
    - There are too few doctors and nurses with the skills, knowledge and experience needed to care for children at the end of their lives[8].
    - The number of children with life-limiting conditions is growing, yet never been closely or regularly monitored.
    - Too many children cannot choose where they receive end of life care. Just two thirds (67%) of NHS clinical commissioning groups (CCGs) in England plan and fund community children's nursing teams to provide care out of hours and at the weekend[9].
    - State funding for charities delivering vital children's palliative care in England, including children's hospices, is patchy and declining year on year.
    - NICE recommends that children's end of life care should be joined up by managed clinical networks (MCN). Yet only one region of England has an MCN.

8. **To address this, we would like the government to** commit to developing a national children's palliative care strategy for England:
    - It should be developed based on a national inquiry into the care and support offered to the 40,000 babies, children and young people in England with life-limiting and life-threatening conditions and their families.
    - Its scope should include the health, education, social care and financial support on offer to them.
    - It should bring about a system which is joined-up around the needs of seriously ill children and their families and which implements the National Institute for Health and Care Excellence (NICE) guidance on end of life care for children.
    - Funding should be made available to test new approaches to implementing the strategy in pilot areas across England.

9. Together for Short Lives, The Brain Tumour Charity, CLIC Sargent, Teenage Cancer Trust, Marie Curie and The Gold Standards Framework are working together with families to **ask parliamentarians to help these families at their time of greatest need. You can help by** pressing the government to initiate an inquiry into children's palliative care by **securing a debate, tabling parliamentary questions and by writing to ministers.** By doing so we can help thousands of families across England to get the care and support they are entitled to and desperately need. For further information and support please see contacts on back page.