

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

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Briefing for MPs in Northern Ireland

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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).

## Briefing for MPs in Northern Ireland



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.

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*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 1,300 babies, children and young people in Northern Ireland with life-limiting and life-threatening conditions<sup>1</sup>, a number which is growing as a result of advances in medical technology and better care. In 2012, there were 184 deaths of children aged between 0 and 19 years in Northern Ireland<sup>2</sup>. A significant proportion were 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 Northern Ireland Department of Health's 'Providing High Quality Palliative Care for Our Children: A Strategy for Children's Palliative and end-of-life care 2016-26'<sup>3</sup>. This would mean that after their child had died, families would be able to say:

- professionals and other stakeholders recognised the uniqueness of children's palliative and end-of-life care.
- professionals and other stakeholders delivered the best possible quality of life for them and their child.
- they and their child were involved in making decisions, which were all in the child's best interests (physically, emotionally, psychologically, and spiritually).
- they and their child were at the centre of any model of care.
- their child had an individual care plan drawn up in partnership with them and their multi-disciplinary team; this was based on a holistic assessment of need and was subject to regular review.
- they were empowered to make informed and timely end-of-life care plans for their child.
- their care and support was planned; it took account of their wishes and needs, in addition to those of their child; it focussed on their child's best interests and their quality of life.
- their plans included preference for place of death and care after death.
- organ donation was considered as part of their child's end-of-life planning.

4. **The National Institute for Health and Care Excellence (NICE) quality standard 'End of Life Care for Infants, Children and Young People'<sup>4</sup> 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.

5. **NICE calculates that if the Northern Ireland Executive invested £476,769 in implementing the guideline on end of life care for children<sup>5</sup>, non-cash savings worth £1.3 million could be released back into the health and social care system.**

6. In 'Providing High Quality Palliative Care for Our Children: A Strategy for Children's Palliative and end-of-life care 2016-26', the Department of Health sets out 23 objectives to be met in order to achieve the outcomes described in paragraph three. These include:

- Objective 7: Each child should have access to 24/7 multi-disciplinary community services and direct access to 24/7 crisis and specialist palliative care advice and end-of-life services, including access to medicines for symptom relief.
- Objective 14: A new Regional Network for Children's Palliative Care should be established as a subgroup within the Paediatric Managed Clinical Network proposed in the Paediatric Community and Hospital Based Strategy. This subgroup should have a wide remit, including the delivery of standards of care (including routine and emergency stock levels), the development of care pathways, research, improved co-ordination of care, improved communication with families and carers, influencing commissioning, and governance.
- Objective 23: Pre-registration and post-registration courses for key professional groups should include children's palliative care. A range of initiatives to ensure the highest possible level of competency for all staff involved in the provision of palliative care services should be developed.