

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

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Briefing for MPs in Scotland

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2. Royal College of Paediatrics and Child Health. 2014. Why children die: death in infants, children and young people in the UK. Available to download from: <http://bit.ly/2kljcmu>
3. Scottish Government. 2015. Strategic Framework for Action on Palliative and End of Life Care. Available to download from: <http://www.gov.scot/Topics/Health/Quality-Improvement-Performance/peolc/SFA>

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.

2. There are 15,000 babies, children and young people in Scotland with life-limiting and life-threatening conditions¹, a number which is growing as a result of advances in medical technology and better care. Each year approximately 350 to 450 children die in Scotland². 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 Scottish Government's 'Strategic Framework for Action for Palliative and End of Life Care'³. This would mean that after their child had died, families would be able to say:

- their child received health and social care that supported their wellbeing, irrespective of their diagnosis, age, socio-economic background, care setting or proximity to death.
- they and their child had opportunities to discuss and plan for a future possible decline in health, preferably before a crisis occurred, and were supported to retain their independence for as long as possible
- people knew how to help and support each other at times of increased health need and in bereavement, recognising the importance of families and communities working alongside formal services.
- the staff who care for them were empowered to exercise their skills and provide high quality person-centred care.

4. In the Scottish Government's 'Strategic Framework for Action for Palliative and End of Life Care', it commits to working with stakeholders to:

- Support Healthcare Improvement Scotland in providing Health and Social Care Partnerships with expertise on testing and implementing improvements in the

identification and care co-ordination of those who can benefit from palliative and end of life care.

- Provide strategic commissioning guidance on palliative and end of life care to Health and Social Care Partnerships.
- Support the development of a new palliative and end of life care educational framework.
- Support and promote the further development of holistic palliative care for the 0-25 years age group.
- Support the establishment of the Scottish Research Forum for Palliative and End of Life Care.
- Support greater public and personal discussion of bereavement, death, dying and care at the end of life, partly through commissioning work to facilitate this.
- Seek to ensure that future requirements of e-Health systems support the effective sharing of individual end of life/Anticipatory Care Planning conversations.
- Support clinical and health economic evaluations of palliative and end of life care models.
- Support improvements in the collection, analysis, interpretation and dissemination of data and evidence relating to needs, provision, activity, indicators and outcomes in respect of palliative and end of life care.
- Establish a new National Implementation Support Group to support the implementation of improvement actions.

number of babies, children and young people with life- shortening conditions in Scotland. This research showed that the 15,000 babies, children and young people in Scotland with palliative care needs was a much higher number than previously thought¹. The study also showed that two thirds of babies, children and young people who die each year in Scotland do so without access to specialist palliative support.

6. The increased statutory funding will help CHAS to reach its goal of reaching every family in Scotland who needs its care, as set out in the CHAS Plan. CHAS will continue to work in partnership with the Scottish Government, health and social care colleagues and other key stakeholders across Scotland to support and promote the further development of holistic palliative care for the 0 – 25 years age group.

5. In 2016 the Scottish Government committed approximately £30 million of statutory funding to children's palliative care over the next five years. This followed the publication, in 2015, of research funded by the Scottish Government and commissioned by Children's Hospices Across Scotland (CHAS) which identified the



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