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

Briefing for MPs in Wales

Cameron Miller,
The Brain Tumour Charity
cameron.miller@thebraintumourcharity.org
01252 749047

James Cooper,
Together for Short Lives
james.cooper@togetherforshortlives.org.uk
0117 989 7863

Scott Sinclair,
Marie Curie
scott.sinclair@mariecurie.org.uk
020 7599 7116

Clare Laxton,
CLIC Sargent
clare.laxton@clicsargent.org.uk
07730 537 003

Tom Tanner,
Gold Standards Framework
tom.tanner@gsfcentre.co.uk
020 3903 2773

Sasha Daly,
Teenage Cancer Trust
sasha.daly@teenagecancertrust.org
07508 359 252

References:

1. Fraser LK, Parslow RC, McKinney PA, Miller M, Aldridge JM, Hain R, Norman P (2012). Life-limiting and life-threatening conditions in children and young people in the United Kingdom; final report for Together for Short Lives. Available to download from: http://bit.ly/1z24ZQw
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. Welsh Government. 2017. Palliative and end of life care delivery plan - March 2017. Available to download from: http://bit.ly/2pW2Kjs
4. The National Institute for Health and Care Excellence (NICE) quality standard 'End of Life Care for Infants, Children and Young People' - NICE quality standard [QS160]. Available to download from: https://www.nice.org.uk/guidance/qs160
5. The National Institute for Health and Care Excellence. 2016. End of life care for infants, children and young people with life-limiting conditions: planning and management - NICE guideline [NG61]. Available to download from: https://www.nice.org.uk/guidance/ng61

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).

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

---

Briefing for MPs in Wales

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 1,000 babies, children and young people in Wales with life-limiting and life-threatening conditions[1], a number which is growing as a result of advances in medical technology and better care. In 2011, there were 222 registered child deaths in Wales[2]. 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 Welsh Government’s ‘Palliative and End of Life Care Delivery Plan - March 2017’[3]. This would mean that after their child had died, families would be able to say:
   - Conversations about their child’s serious illnesses were appropriate and empowered them and their child to take informed decisions.
   - Their child’s illness - and the fact that they needed palliative care - was identified early.
   - They and their child experienced care that met their needs and preferences.
   - They and their child felt supported at all stages and by all staff.
   - They and their child had the information they needed to make decisions.
   - Professionals caring for them and their child were equipped in all health care settings to support them.

4. **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.

5. **NICE calculates that if the Welsh Government invested £690,000 in implementing its guideline on end of life care for children[5], non-cash savings worth £1.9 million would be released back into the NHS in Wales.**

6. In the ‘Palliative and End of Life Care Delivery Plan - March 2017’3, the Welsh Government states that to plan effectively for their populations, local health boards must build and lead coalitions with NHS Trusts, locality networks, GPs, nursing homes, pharmacists, dentists, opticians, social services, prison services and the third sector voluntary bodies. An all-Wales Paediatric Palliative Care Network and Implementation Group, chaired by Dr Richard Hain, enables a one Wales approach, providing peer support and acting as an effective information sharing platform.

7. Despite NICE’s clear quality statements, the Welsh Government’s plan and the compelling health economic case, there are barriers preventing children from accessing the end of life care which they and their families should expect to receive:
   - No dedicated children’s palliative medical and nursing care time is funded in Powys.
   - There is limited funding for specialist paediatric palliative care in north Wales.
   - There is a lack of inpatient children’s hospice care in west Wales.
   - Too many children with life-limiting conditions are referred to palliative care services too late - particularly in neuromuscular, cardiac and renal services.
   - It is unclear how local health boards are funding and providing children’s palliative care.
   - Children’s community nursing is not available out of hours and at weekends in some areas of Wales.

   To address this, we would like the Welsh Government to:
   - allocate the funding recommended by NICE in paragraph four.
   - put children’s palliative care on an equal footing with the adult specialty, strengthening representation of children’s needs on the End of Life Board by establishing the authority of the Paediatric Palliative Care Implementation Group through effective resourcing and a mandate by the Cabinet Secretary for Health and Sport.
   - measure the extent to which outcomes improve for children and young people with life-limiting and life-threatening conditions as well as those for older adults.
   - make sure that there is a sustainable children’s palliative care workforce in Wales, including further support for North Wales.
   - make sure that local health boards and local authorities fund children’s palliative care fairly and sustainably - including the time of a children’s palliative care consultant in Powys University Health Board to make sure that children with life-limiting conditions are able to choose where they receive care throughout their life.
   - promote collaboration and improved communication within children’s palliative care.