

**Briefing from Together for Short Lives:**

**Lord Cotter to ask Her Majesty's Government what progress they have made in implementing the proposals for support for mental health provision for children and young people in schools, set out in the December 2017 Green Paper, Transforming children and young people's mental health provision**

**Wednesday 28 March 2018**

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1. Together for Short Lives is the UK charity for children's palliative care. We are here to support and empower families caring for seriously ill children, and to build a strong and sustainable children's palliative care sector - so that no family is left behind.
2. We welcome the green paper and mental health support teams which are proposed by the government. In particular, we welcome the focus they will have on supporting young people who have been bereaved. We call on the government to make sure that the work of these teams not to be restricted to schools, colleges and NHS services: we ask that they also work with voluntary sector children's palliative care providers, such as children's hospices, which care for children and young people who have been bereaved of siblings. This would make sure that these children are identified and offered the support they need.
3. We suggest a series of supplementary questions which we would be grateful if peers could ask the minister:

**Question 1: Will the minister make sure that the work of the proposed mental health support teams is not restricted to schools, colleges and NHS services - and that they also work with voluntary sector children's palliative care providers, such as children's hospices, which care for children and young people who have been bereaved of siblings?**

**Question 2: Will the minister consider measuring the extent to which children and young people and their parents or carers are satisfied with the information they are given about emotional and psychological support?**

4. As set out in the third quality statement of the National Institute for Health and Care Excellence (NICE) Quality Standard 160 'End of Life Care for Infants, Children and Young People'<sup>1</sup> we recommend that the level of satisfaction of infants, children and young people with a life-limiting condition, and their parents or carers, with information they are given about emotional and psychological support should be measured.

**Question 3: What steps can the minister take to make sure that the views of children and young people with complex, life-limiting conditions are taken into account as mental health support teams are developed?**

5. We call on the government to engage national and local organisations which work with or on behalf of children and young people, including children's hospices and charities such as Together for Short Lives. Such organisations provide fora for young people to express their views about the care and support that they and their families receive. For example, Together for Short Lives maintains our 'Young Avengers' forum, which provides an opportunity for young people with life-limiting condition to have their say about a range of

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<sup>1</sup> The National Institute for Health and Care Excellence. 2016. Transition from children's to adults' services – Quality standard [QS140]. Available to download from: <https://www.nice.org.uk/guidance/qs140>

issues which affect them. It is also important for the government to take account of the fact that many children with life-limiting conditions will be cognitively impaired and/or non-verbal. The government should make sure that parents and carers of these children are able to influence work to develop the new teams so that they are able to meet their mental health support needs.

**Question 4: What steps will the government take to sustainably fund non-mental health services which nonetheless have a positive impact on the mental health of children and young people? Children's hospices have been proven to have a positive impact on families' mental health, for example, yet receive patchy and unsustainable funding from the NHS and local authorities.**

6. There are 40,000 babies, children and young people in England with life-limiting and life-threatening conditions<sup>2</sup>; many need pre-bereavement support to help them come to terms with their condition, the likelihood that they are likely to die before they reach adulthood - and the impact that this is likely to have on their family. Many have siblings who also need bereavement care and support both before and following their death.
7. The pressure on parents of having a child with a life-limiting condition is immense. Most relationships will suffer, with 36% experiencing a breakdown of the family<sup>3</sup>. In turn, this can have a detrimental impact on siblings of children who have life-limiting conditions: many brothers and sisters will miss school or experience educational difficulties, and many will be bullied or feel isolated at school.
8. In addition to provide mental health care and support, Mental Health Support Teams could help these children by referring families to services which provide short breaks for respite for children with life-limiting conditions and their families. Many of these services are provided by children's hospices and other children's palliative care charities.
9. New UK-wide research conducted by Julia's House Children's Hospice and Bournemouth University<sup>4</sup> has examined the impact that caring for a child with a life-limiting or life threatening condition has had on parental relationships. 17 children's hospices from across England and Scotland took part. The research has found that:
  - 64% of divorced or separated parents cited having a child with complex needs as a reason for the breakdown of their relationship of those couples, 75% had no access to short breaks at that time.
  - Most parents (74%) rated short breaks provided by children's hospices as having a direct, positive effect on their relationship with a partner, giving them rare time together as a couple. Others used short breaks to spend time with their other children or just enjoyed time to themselves, regaining some balance in their lives, ultimately benefitting the whole family.
  - Couples whose relationships were identified as 'non-distressed' by the research were found to have received on average 43% more hours of short breaks from a children's hospice compared to those who were in distressed relationships.

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<sup>2</sup> 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/1yvEeHs>

<sup>3</sup> Steele R. (2000) Trajectory of certain death at an unknown time: children with neurodegenerative LTC illnesses. *Cancer Journal of Nursing Research* 32, 49-67

<sup>4</sup> Julia's House Children's Hospice and Bournemouth University. 2017. Campaigning for Children's Hospices. Available to download at: <https://www.juliashouse.org/services/campaigning>

10. Despite this evidence, Together for Short Lives is concerned that local authority short break funding is not keeping pace with need. New evidence gathered by the Local Government Association (LGA)<sup>5</sup> shows that, in 2015/16, local authorities in England overspent their children's social care budgets by a total of £605 million. The LGA predicts that councils will face a £2billion children's social care funding shortfall by 2020. As budgets come under increasing pressure, the demand for children's social care is rising: the government's own data<sup>6</sup> shows that the number of children in need increased to 394,400 on 31 March 2016 compared to 391,000 on the same day in 2015. This represents an increase of 0.9%.
11. We are deeply concerned by this new evidence, which indicates that children's social care in England is financial unsustainable. If it continues to be overlooked within Budget deliberations, the promised social care funding green paper and in the negotiation of local government finance, we are concerned that fewer and fewer children and families who need care and support will be able to access it. Ultimately, our children's social care system it will become unsafe.
12. In England, despite the government's commitment to short breaks<sup>7</sup> local authorities are failing to support them. A recent set of freedom of information (FOI) requests revealed that even though local authorities have a legal duty to provide short breaks for disabled children around 1 in 5 (21%) are failing to commission these services. And a staggering 3 in 5 (62%) councils are failing to plan and fund palliative care for children and young people<sup>8</sup>.
13. We want the UK's governments to hold local authorities to account to increase funding for short breaks for disabled children.
14. A government-commissioned review of funding arrangements for palliative care published in 2011 (Hughes-Hallett T, Craft A and Davies C. 2011. Palliative care funding review - creating a fair and transparent funding system; the final report of the palliative care funding review. Available to download from: [bit.ly/XQBIE7](http://bit.ly/XQBIE7)) recognises that "short breaks which provide respite for the carers and families of children requiring palliative care should be funded by local authorities and the NHS under their respective legal short breaks duties", including the short breaks duty on local authorities in England.
15. We ask the government to work with us to review the way in which children's social care is funded in England. We also ask the government to work with us to issue joint guidance from the secretaries of state for health and education to NHS clinical commissioning groups (CCGs), sustainability and transformation partnerships (STPs) and local authorities. This should remind them that they are all responsible for planning and funding short breaks for these children in their local areas.

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<sup>5</sup> Local Government Association. 2017. Children's social care at breaking point, council leaders warn. Available to download from: <https://www.local.gov.uk/about/news/childrens-social-care-breaking-point-council-leaders-warn>

<sup>6</sup> Department for Education. 2017. Characteristics of children in need: 2015 to 2016. Available to download from: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/564620/SFR52-2016\\_Main\\_Text.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/564620/SFR52-2016_Main_Text.pdf)

<sup>7</sup> Department for Education. 2010. Short breaks for carers of disabled children: departmental advice for local authorities. March 2011 <http://bit.ly/1EmRyvM>

<sup>8</sup> Together for Short Lives. 2017. Commissioning in England 2017. Available to download from: [www.togetherforshortlives.org.uk/commissioning2017](http://www.togetherforshortlives.org.uk/commissioning2017)

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