

Briefing from Together for Short Lives:

Opposition day debate on cuts to local government funding

Wednesday 28 March 2018

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. Children with life-limiting conditions - and their families - rely on social care which is planned and funded by local authorities. This includes frequent short breaks for respite. The pressure on parents of having a child with a life-limiting condition is immense, so social care is vitally important to relieve this stress, spend time as a family and do the things that other families do.
3. However, too few local authorities in England plan and fund short breaks for children who need palliative care¹. More than one in five (21%) local authorities do not commission short breaks for children with life-limiting and life-threatening conditions, despite having a legal duty to do so. This figure has declined since 2016, when one in seven (14%) reported that they do not provide these short breaks.
4. Local authority funding for children's palliative care charities fell by 61% between 2014/15 and 2015/16, only contributing 1% of children's hospices' charitable costs².
5. Together for Short Lives welcomes the forthcoming green paper on adult social care. However, we ask that the government also addresses the crucial and pressing issue of funding for children's social care in England too. As a matter of urgency, we believe that the government must put children's social care on a sustainable financial footing. If it fails to do so, it risks leaving families caring for our children with complex, life-limiting conditions at breaking point. These families will have no option but to turn to already overstretched NHS services when their physical and/or mental health fails.
6. We call on the government to make it clearer to councils that they are responsible for commissioning short breaks for children with life-limiting conditions and their families. We suggest a series of questions which we would be grateful if MPs could ask ministers during the debate:

Questions for the minister

1. **As the government is doing for adult social care, will the minister commit to reviewing the way in which local authority-commissioned children's social care is funded in England?**
2. **Will the government work with charities such as Together for Short Lives to issue guidance to local authorities to remind them that they are all responsible for planning and funding short breaks for respite for children with life-limiting conditions?**

¹ Together for Short Lives. 2017. Commissioning in England 2017. Available to download from: www.togetherforshortlives.org.uk/commissioning2017

² Together for Short Lives. 2016. On the brink: a crisis in children's palliative care funding in England. The results of Together for Short Lives and Hospice UK's survey on children's palliative care funding and commissioning in England 2015/16. Available to download from: <http://bit.ly/2f7HowK>

- 3. Will the government review the way in which short breaks for respite for are provided for disabled children and their families to identify and address national, regional and local funding gaps?**

Annex: background information

Why social care is important for children with life-limiting conditions and their families

1. 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 family³.
2. Many mothers and fathers will need to give up work and this, combined with the extra costs of caring for a seriously ill child, means that many families may live in poverty.
3. Many brothers and sisters will miss school or experience educational difficulties, and many will be bullied or feel isolated at school.
4. Children with life-limiting conditions - and their families - rely on frequent short breaks for respite to enable them to relieve this stress, spend time as a family and do the things that other families do. Every family's needs are different: some need overnight, residential short breaks either with or without their child; some need short breaks for only a few hours at a time, provided at home or in hospital. Some will need a mix of both.
5. Too many local authorities in England are failing to support short breaks⁴. More than one in five (21%) local authorities do not commission short breaks for children with life-limiting and life-threatening conditions, despite having a legal duty to do so. This figure has declined since 2016, when one in seven (14%) reported that they do not provide these short breaks.
6. Local authority funding for children's palliative care charities fell by 61% between 2014/15 and 2015/16, only contributing 1% of children's hospices' charitable costs⁵.
7. UK-wide research conducted by [Julia's House Children's Hospice and Bournemouth University](#)⁶ 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

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

⁴ Together for Short Lives. 2017. Commissioning in England 2017. Available to download from: www.togetherforshortlives.org.uk/commissioning2017

⁵ Together for Short Lives. 2016. On the brink: a crisis in children's palliative care funding in England. The results of Together for Short Lives and Hospice UK's survey on children's palliative care funding and commissioning in England 2015/16. Available to download from: <http://bit.ly/2f7HowK>

⁶ 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>

- 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.
8. [New evidence gathered by the Local Government Association \(LGA\)](#)⁷ 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](#)⁸ 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%.
 9. 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.

What are the UK’s governments doing to make sure children and families can access short breaks for respite?

10. A government-commissioned review of funding arrangements for palliative care published in 2011⁹ 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](#).¹⁰

What would Together for Short Lives like to happen?

1. We ask the government to work with us to review the way in which children’s social care is funded in England.
2. We 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.
3. Together for Short Lives is a member of [The Disabled Children’s Partnership \(DCP\)](#), a growing coalition of more than 50 charities who have joined forces, working in partnership with parents, to campaign for better health and social care for disabled children, young people and their families in England. DCP is calling on the government

⁷ 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>

⁸ 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

⁹ 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.

¹⁰ Department for Education. 2010. Short breaks for carers of disabled children: departmental advice for local authorities. March 2011 <http://bit.ly/1EmRyvM>

to review the way in which short breaks are provided for disabled children and their families to identify and address national, regional and local funding gaps.

For more information please contact

James Cooper
Public Affairs and Policy Manager
james.cooper@togetherforshortlives.org.uk
@james_cooper_
@Tog4Policy
0117 989 7863
0741 552 7731