

A briefing for Peers

Oral question on implementing the National Institute for Health and Care Excellence (NICE) guideline on end of life care for babies, children and young people



Tuesday 5 September

1. During oral questions on Tuesday 5 September, Baroness Walmsley will ask:

“How Her Majesty’s Government intends to implement the NICE guideline End of life care for infants, children and young people with life-limiting conditions: planning and management”

2. Together for Short Lives welcomes this important oral question: if implemented, the NICE guideline has the potential to significantly improve the way in which children’s palliative care is planned, managed and provided in England, Northern Ireland and Wales (it does not apply in Scotland). It could help to remove the postcode lottery of support for the 49,000 babies, children and young people in the UK with life-limiting and life-threatening conditions - and their families.
3. It is vital that children with life-limiting conditions can access high quality palliative care when and where they need it. Many of these children will need palliative care from the point at which their condition is diagnosed or recognised until they die. Beyond this, their families will need access to bereavement support.

About us

4. Together for Short Lives is the UK charity that, together with our members, speaks out for babies, children and young people who are expected to have short lives. Together with everyone who provides care and support to these children and families, we are here to help them have as fulfilling lives as possible and the very best care at the end of life.
5. We are a membership organisation and represent professionals and organisations spanning the statutory, voluntary and private sector who provide palliative care to babies, children and young people.

Suggested supplementary questions

6. We would be grateful if the following points could be made. Background information relating to each of these questions is provided under the corresponding letter in the appendix to this briefing:
 - A. Together for Short Lives’ commissioning maps of children’s palliative care illustrate the wide variance in children’s palliative care across NHS clinical commissioning groups (CCGs) in England. For example, they have found that over a quarter of CCGs do not commission out of hours community children’s nursing teams, which means that many families across England are not receiving the support that they need in their own home. What steps will the government take to reduce this inequality and will the minister meet with Together for Short Lives and me later this year to discuss the results of their 2017 commissioning maps and the steps the government can take to make sure that all children can receive high quality palliative care?
 - B. In response to a recent written question from Lord Carlile of Berriew (see paragraph 13 in the appendix), health minister Lord O’Shaughnessy responded that NHS England expects all CCGs to implement the guidance. How will the government monitor the implementation

of this guidance, to ensure that children receive the high quality palliative care stipulated by NICE?

- C. For the NICE guidance to be implemented in full, it requires the right number of health and care professionals with the right skills to deliver it. However, evidence from Together for Short Lives shows that there is an 11% nurse vacancy rate at children's hospices, limiting the care that each can offer. One hospice told the charity that "We have recently stopped providing 24/7 care, even for those at end of life". What steps will the government take to make sure that there are enough doctors, nurses and other health professionals working in children's palliative care to deliver this guidance?
- D. The NICE guidance states that bereavement support should be discussed and offered to the family of a child with a life-limiting and life-threatening condition before they have died, However, research from Together for Short Lives shows that one in six CCGs do not commission bereavement support for families and nearly 40% do not commission this support out of hours or at weekends, so cannot offer families the flexibility they may need. What steps will the government make to ensure that CCGs recognise the importance of bereavement services and their responsibility to commission them for families?
- E. Children's hospices provide essential children's palliative care services to children and their families. The NICE guidance rightly recognises this, stating that they should be involved at every stage of a child's care planning. However, children's hospices are woefully underfunded - receiving just 22% of their funding from the state. And this proportion is decreasing year on year. Will the Minister follow the lead of the Scottish Government and agree to fund 50% of children's hospices charitable costs?

Appendix

A. Postcode lottery of children's palliative care

7. Together for Short Lives submitted a series of freedom of Information requests to clinical commissioning groups (CCGs) in April 2016 to understand how children's palliative care is being commissioned in England.
8. This research found a wide variance in children's palliative care commissioning across England.¹ For example:
9. More than a quarter (27%) of CCGs do not commission out of hours community children's nurses to support children in their own home.
10. Over a third (36%) of CCGs failed to achieve a 4-star or 5-star rating in Together for Short Lives children's palliative care commissioning survey.
11. Together for Short Lives submitted a new series of FOI requests to CCGs in May 2017 to update these findings and to request further information from CCGs across England. The findings of this research will be published in Autumn 2017.

B. Monitoring the implementation of the guidelines

12. In March 2017, Lord Carlile of Berriew submitted a written question:

*"To ask Her Majesty's Government what steps they will take to ensure that Clinical Commissioning Groups are accountable to NHS England for delivering a consistent level of children's palliative care across England."*²

13. The minister's response to this was that:

"NHS England expects clinical commissioning groups to commission services in accordance with National Institute for Health and Care Excellence guideline End of life care for infants, children and young people with life-limiting conditions"

C. Nursing workforce

14. The NICE guidance stipulates that all children with a life-limiting or life-threatening condition should be cared for by a specialist paediatric palliative care team, which should include a nurse with expertise in paediatric palliative care.
15. However, there is currently an 11% nurse vacancy rate at children's hospices across the UK. In a 2017 survey by Together for Short Lives, 58% of services stated that vacancies are having an impact on the care that they can offer (up from 43% in 2015).³
16. In their response to the survey, one hospice stated that:

¹ Together for Short Lives (2016). Commissioning children's palliative care in England. Available at: http://www.togetherforshortlives.org.uk/assets/0001/5669/Commissioning_children_s_palliative_care_in_England_FINAL.pdf

² Oral Question HL6151 from Lord Carlile of Berriew. Asked on 16 March 2017. Available at: <http://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Lords/2017-03-16/HL6151/>

³ Together for Short Lives (2017). The state of the UK children's hospice nursing workforce. Available at: http://www.togetherforshortlives.org.uk/assets/0001/9508/Together_for_Short_Lives_-_The_state_of_children_s_palliative_care_nursing_in_2017.pdf

“We have recently stopped providing 24/7 care, even for those at end of life, which is very difficult for staff and families as this should be our 'core business'”

17. This challenge is not only limited to children’s hospice organisations. Evidence published by the Royal College of Paediatric and Child Health (RCPCH) shows that in the year to September 2015, shortages of nurses and/or doctors led to periods of closure to new admissions by 31% of paediatric inpatient units and 41% of neonatal units across the UK.⁴ The evidence also highlights substantial vacancies at both consultant and trainee levels, the low number of academic consultants and the fact that General Practitioners and Practice Nurses have limited training in child health.

D. Bereavement support

18. The NICE guidance states that when a child is approaching the end of their life, professionals should speak to their parents or carers about available bereavement support. Bereavement support for the whole family, including siblings, is an essential part of holistic children’s palliative care.
19. However, research from Together for Short Lives shows that one in six (17%) CCGs do not commission bereavement support and only 61% of CCGs can offer this support out of hours or at weekends.⁵

E. Support for children’s hospices

20. Children’s hospices provide lifeline support for children with life-limiting and life-threatening conditions - and their families. The NICE guidance refers repeatedly to the role that children’s hospices play and the importance of involving them at all stages of a child’s care planning.
21. However, children’s palliative care is woefully underfunded and resourced. For example, on average, adult hospices in England receive 33% of their funding from statutory sources and children’s hospices receive an average of 22%.⁶ Unless this funding gap is addressed, then we, as a country, are making a judgement that we place greater value on the life of an adult than that of a child. This is neither moral nor fair.
22. In England, local authorities’ contribution to the cost of providing children’s palliative care in the voluntary sector fell significantly by 61% between 2014/15 and 2015/16 when the cost of providing complex care increased (up 10% this year).⁷ It is simply unsustainable for local authorities to contribute just 1% to the costs incurred by children’s palliative care charities.
23. Together for Short Lives is calling on the government to follow the example of the Scottish Government, who have allocated £30million over 5 years for children’s hospices so there is parity with funding for adult hospices. Children and young people with life-limiting and life-threatening conditions in England, Northern Ireland and Wales deserve the same recognition, opportunity and support as those in Scotland.

⁴ RCPCH (2017). State of Child Health Short Report Series: The Paediatric Workforce. Available at: http://www.rcpch.ac.uk/sites/default/files/user31401/2015%20RCPCH%20State%20of%20Child%20Health%20The%20Paediatric%20Workforce%20v1.1_1.pdf

⁵ Together for Short Lives (2016). Commissioning children’s palliative care in England. Available at: http://www.togetherforshortlives.org.uk/assets/0001/5669/Commissioning_children_s_palliative_care_in_England_FINAL.pdf

⁶ Together for Short Lives (2016). On the brink: a crisis in children’s palliative care funding in England. Available at: http://www.togetherforshortlives.org.uk/assets/0001/7464/Together_for_Short_Lives_Commissioning_and_Funding_Survey_Report.pdf

⁷ Ibid.

F. Cost savings of implementing the NICE guidelines

24. NICE published a resource impact template alongside the new guidelines. This tool allows local areas to input their population data and it calculates the overall cost and savings of implementing the new guidelines.
25. Using the total population of children in England, NICE calculate that by investing £12.7million in implementing the guidance, non-cash savings worth £34.7million would be released back into the NHS in England.⁸

G. Managed clinical networks

26. The new NICE guidance recommends that children's palliative care services should be based on managed clinical networks, which coordinate the way in which they are planned and provided in local areas.⁹
27. Managed clinical networks help to build a strategic and joined up approach to children's palliative care across health and social care services. They bring together statutory and charitable providers. They can analyse services over an entire network area and assess where there are gaps and how they can be filled. This enables network areas to plan the 24/7 children's palliative care which NICE states that children who need it should have access to.
28. This approach has already been adopted in Wales, where the All Wales Managed Clinical Network supports children with life-limiting conditions and their families by facilitating appropriate specialist care in whatever clinical environment the child is located.
29. Managed clinical networks should build on the 10 established children's palliative care networks in England (East Midlands; East of England; London; North East; North West; South Central; South East Coast; South West; West Midlands). If these networks are to be transformed into managed clinical networks, they require funding for regional network coordinators. They must also be given the authority to implement their local children's palliative care strategy. This would provide a coordinated and collaborative approach to providing children's palliative care in each of the regional areas.

For more information, please contact:

Shaun Walsh
Director of External Relations
07506 211 765
shaun.walsh@togetherforshortlives.org.uk

James Cooper
Public Affairs and Policy Manager
07415 227 731
James.cooper@togetherforshortlives.org.uk

Patrick McKenna
Public Affairs and Policy Officer
0117 989 7861
Patrick.mckenna@togetherforshortlives.org.uk

⁸ NICE (2016). End of life care for infants, children and young people with life-limiting conditions: planning and management 'Resource Template'. Available at: <http://bit.ly/2k4V2jZ>. This figure for the whole of England was calculated using the 'Population & resource summary' tab.

⁹ NICE (2016). End of life care for infants, children and young people with life-limiting conditions: planning and management. P 32. Available at: <http://bit.ly/2g9nIWA>