

Support for children with life-limiting and life-threatening conditions and their families

Westminster Hall debate
Tuesday 29 January 2019, 9:30am

A briefing for MPs from Together for Short Lives

About us

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. We support all the professionals and children's palliative care services that deliver lifeline care. We have over 1,000 members, including children hospices, voluntary sector organisations and statutory service providers.
2. Together for Short Lives is the secretariat for the [All-Party Parliamentary Group \(APPG\) for Children Who Need Palliative Care](#).

Key points to convey during the debate

3. Together for Short Lives supports the recommendations of the APPG for Children Who Need Palliative Care, which published a report¹ of its inquiry into the government's end of life care choice commitment for babies, children and young people on 21 October 2018. More information about life-limiting and life-threatening conditions in children and the range of palliative care services they need, including children's hospices, is set out in the [appendix to this briefing](#). It is also available in the APPG report.
4. The APPG identified five barriers which explain why the government's choice commitment is at serious risk of not being met. It also identified where there are opportunities for government ministers and officials, working with partners including NHS England and Health Education England, to work to overcome. During this debate, we ask MPs to call upon the minister to take these actions, and set out what steps the government is taking to respond to the APPG's recommendations:

Leadership and accountability

5. The government's 2016 response² to a review of choice in end of life care in England states that to support high quality personalised care for children and young people, commissioners and providers of services **must** prioritise children's palliative care in their strategic planning; this is so that services can work together seamlessly and advance care planning can be shared and acted upon.
6. However, the way in which NHS CCGs and local authorities plan, fund and monitor (a process known as 'commissioning') children's palliative care in hospitals, children's

1 All-Party Parliamentary Group (APPG) for Children Who Need Palliative Care. 2018. End of life care: strengthening choice - an inquiry report by the All-Party Parliamentary Group (APPG) for Children Who Need Palliative Care. Available to download from:

www.togetherforshortlives.org.uk/appg

2 Department of Health. 2016. 'Our Commitment to you for end of life care: The Government Response to the Review of Choice'. Available to download from: <http://bit.ly/2oU5fj>

hospices and the community represents a postcode lottery³. Almost half (46%) of CCGs are failing to implement the government's end of life care choice commitment and have no plans to do so. Only a third (35%) of CCGs responded that they are implementing this guidance, while a further 19% stated that their plans to do so are in development.

7. **Will the government and NHS England consider appropriate mechanisms to bridge the children's palliative care accountability gap?**
8. **Will the government develop a system to monitor how sustainability and transformation partnerships (STPs), integrated care systems (ICSs), CCGs and local authorities are supporting children's palliative care in accordance with their legal duties?**
9. **Will the government develop outcome indicators which measure the extent to which children with life-limiting conditions and their families can make choices about the palliative care they receive? If so, will they reflect the outcomes set out in the NICE quality standard for end of life care for infants, children and young people⁴.**
10. In its written evidence to the APPG inquiry, NHS England⁵ states that work to deliver its end of life care programme is managed through a cross-system governance board, established October 2016. It says that the board brings together all partners and delivery plans in a cohesive and co-ordinated approach to gain greater impact for the limited resources available and assures the Department of Health and Social Care that the end of life care commitment will be achieved. Members of the board include NHS England directors, senior arm's length body (ALB) leads, the department, CCGs and representatives from the Ambitions Partnership who are all supporting work to deliver aims and objectives of the end of life programme. The board, however, does not include a representative of the children's palliative care sector.
11. **Will the minister call on NHS England to make sure that a representative of the children's palliative care sector is added to the cross-system governance board that delivers its end of life care programme.**
12. The West of England Child Death Overview Panel (CDOP)⁶ routinely reviews whether children who die as a result of a life-limiting condition have done so in the place they have chosen. We note that CDOPs across England are not obliged to collect this information; we have found little evidence of others doing so.
13. **Will the minister mandate CDOPs to collect data about where children die, and whether children who die as a result of a life-limiting condition have done so in the place they have chosen?**
14. We welcome the government's emphasis on making sure that the Care Quality Commission (CQC) focusses on end of life care in all settings where it is delivered. We note that the CQC has streamlined its assessment frameworks and placed children's

3 Together for Short Lives. 2017. Commissioning children's palliative care in England: 2017 edition. <http://bit.ly/2MbiE4O>

4 The National Institute for Health and Care Excellence. 2017. End of life care for infants, children and young people – NICE quality standard [QS160]. Available to download from: <http://bit.ly/2M6BHx3>

5 NHS England written evidence. Available to download from: <http://bit.ly/2M9fWwO>

6 The West of England Child Death Overview Panel. 2017. Annual Report April 2016 – March 2017.

hospices within the hospital framework. CQC has produced sector-specific guidance for those inspecting hospices for children and young people.

15. We also welcome the fact that the CQC's key lines of enquiry, prompts and ratings characteristics for healthcare services⁷ state that inspectors should assess the extent to which services are delivered and coordinated to ensure people who may be approaching the end of their life are identified, and that this information is shared.
16. **Will the minister set out the approach that the Care Quality Commission (CQC) is taking to make sure that its approach to regulation brings about a consistent system for inspecting children's palliative care services, regardless of the setting in which they are provided?**

Clarity

17. Poor commissioning is often caused by CCGs and local authorities being confused about the elements of children's palliative care they are responsible for commissioning. Most typically, CCGs and local authorities are confused about who commissions short breaks (respite) for children with life-limiting conditions and specialised children's palliative care.
18. Together for Short Lives welcomes NHS England's decision to recognise children's palliative care as an important priority in the NHS Long Term Plan. It is also a clear message to CCGs that planning and funding palliative care for children with life-limiting conditions in hospitals, hospices and the community is part of their core business.
19. **Will the minister assess the extent to which the NHS treats children's palliative care as a priority, as it commits to doing so in the Long Term Plan – and if so, how?**
20. **Will the minister work with her colleagues at the Department for Education and NHS England to write to STPs, ICSs, CCGs and local authorities to clarify which parts of the health and care system in England are responsible for commissioning palliative care for children and young people aged 0-25? This is vital to make clear who is responsible for commissioning short breaks and specialised children's palliative care, as described by NHS England²⁷.**

Funding

21. The children's palliative care provided by voluntary sector organisations, including children's hospices, helps ease pressure on the NHS. Children's hospices, for example, make a crucial contribution to local health economies. Without them, this clinical care would otherwise have to be provided and paid for in its entirety by the NHS. However, the statutory funding they receive from NHS England, CCGs and local authorities is patchy and unsustainable.
22. There is overwhelming public support to make sure that children with short lives are not short changed by the state: 81% of the public think that children's hospices receive too little funding from statutory sources. The public think that children's hospices receive 38% of their funding from statutory sources, when in reality they only receive 22%. The public also think that children's hospices should receive more statutory funding (73% of their total funding).

⁷ Care Quality Commission. Key lines of enquiry, prompts and ratings characteristics for healthcare services. Available to download from: <http://bit.ly/2KfMR12>

23. On average, the overall amount of statutory funding for charities providing children's palliative care continues on a downward trajectory, falling year on year (22% in 2015/16 compared to 23% in 2014/15 and 27% in 2013/14). Statutory funding remained at 22% in 2016/17⁸.
24. When taking the NHS children's hospice grant and funding from CCGs and local authorities into account, there was a wide range in the state's contributions to VCS children's palliative care providers' charitable costs in 2015/16. The maximum contribution received by a charity in 2015/16 was over half (53%). The lowest was 2%. 30% of charities received a contribution of between 21% and 30%. 30% of organisations received between 11% and 20%.
25. Together for Short Lives was delighted to welcome NHS England's decision to increase vital children's hospice funding from £11million to £25million, better enabling lifeline hospices to support some of England's most seriously ill children. As part of the NHS Long Term Plan, additional funding will be available each year over the next five years, increasing by up to £7m a year by 2023/24, if CCGs also provide additional match funding.
26. **Will the minister monitor the amount of money that NHS England, CCGs and local authorities are contributing to children's and adult hospice and palliative care charities? If so, will the minister make sure that they are bringing about parity in the state's percentage contribution to their charitable costs?** This would mean that children's organisations would receive at least a third of their charitable costs. We note that the Scottish Government has committed to bring about parity and fund 50% of the agreed charitable costs of Children's Hospices Across Scotland.
27. These challenges are being exacerbated by the government's decision not to provide financial support to help voluntary sector providers who do not apply Agenda for Change pay and conditions to mitigate the recent **pay rise for non-clinical NHS staff**.
28. **Will the minister provide financial support to help voluntary sector children's palliative care providers, including children's hospices, who do not apply Agenda for Change pay and conditions to mitigate the recent pay rise for non-clinical NHS staff?**
29. The government's proposal to increase the proportion that employers need to contribute to the **NHS Pension Scheme** from 14.9% to 20.9%⁹ will also incur significant costs for children's hospices. While the cost of the increases for NHS organisations will be met by the government through additional funding, currently the potential additional costs for charitable hospices will not. This means that children's hospices will be faced with only two options – either to increase their fundraising efforts from their local communities to meet the shortfall, or to cut services to absorb the additional costs. Neither of these options are palatable. Children's hospices are now faced with the puzzling situation where NHS England is giving them more money in one hand, yet through the pension scheme changes, the government is taking it away with the other.

8 Together for Short Lives. 2017. Statutory funding for voluntary sector children's hospice and palliative care providers in 2016/17: a briefing from Together for Short Lives. Available to download from: <http://bit.ly/2RTFZhF>

9 Department of Health and Social Care. 2018. NHS pension scheme: proposed changes to scheme regulations 2019. Available to download from: <http://bit.ly/2B0G6OX>

30. **Will the minister meet the significant costs that will be incurred by children's hospices as a result of the government's proposal to increase the employers' contribution in the NHS Pension Scheme?**
31. The government and NHS England should go further to make sure that children's palliative care provided by the statutory sector, in hospitals and in the community, is funded equitably and sustainably in England. NICE calculate that by investing £12.7million in implementing its guideline on children's palliative care²⁵, non-cash savings worth £34.7million would be released back into the NHS in England¹⁰.
32. **Will the minister undertake a review of the children's palliative care currently available to children with life-limiting conditions in England as a matter of urgency?**
33. **Will the minister develop a funded, cross-departmental children's palliative care strategy for achieving better outcomes for children and families across the statutory and voluntary sectors?**
34. **What steps is the minister taking to bring about greater access to funding for services providing emotional and practical support for families in the community?**
35. **Will the minister work with her colleagues at the Department for Education to review the way in which short breaks for disabled children, including those with life-limiting conditions, and families are funded?**
36. More personalised approaches to assessing children's needs and desired outcomes, as well as to planning and funding the care they need (including through more children having access to a personal budget) has potential to increase choice and control for families. However, we caution that personal budgets are not appropriate for all families.
37. **What steps is the minister taking to make sure that the government meets its end of life care choice commitment for children with life-limiting conditions and their families who decide not to use a personal budget?**
38. **What steps is the minister taking to make sure that families of children with life-limiting conditions, children's palliative care professionals and provider organisations can adapt to and use personal budgets?**

Workforce

39. There are too few professionals with the skills, knowledge and experience needed to provide children's palliative care in hospitals, children's hospices and in the community. Specific skills are needed when speaking to children and families about the choices available to them and developing advance care plans with them; shortages in children's nurses and children's palliative care consultants are particularly acute.
40. The Royal College of Paediatrics and Child Health states that there are currently 14 children's palliative care consultants in the UK and several paediatric consultants who

10 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.

practice with an interest in palliative care¹¹. There are many regions in the UK with no access to children's palliative medicine specialists. Many single-handed consultants have no cover for leave or sickness and 'reprieve' from service requirement can be very challenging.

41. RCPCH has made a conservative estimate that between 40-60 children's palliative care consultants are needed in the UK. This suggests a significant deficit of 26-46 consultants¹².
42. The Royal College of Nursing (RCN) states that hospital specialist nurses are often restricted to working only in hospitals. This limits what care and support the statutory sector can provide for children who are spending more of their time living with their condition outside of hospital. This can place a greater demand on voluntary sector organisations such as children's hospices to fill gaps in care and support.
43. The RCN recommends that for an average-sized district, with a child population of 50,000, a minimum of 20 WTE community children's nurses are required to provide a holistic community children's nursing service¹³. The Office of National Statistics estimates that there are 13,770,873 children aged 0-18 in England¹⁴. If the RCN recommendation were to be met, this would require approximately 5,508 community children's nurses. There were just 555 community children's nurses in England in September 2018¹⁵.
44. From a survey of children's hospice organisations in the UK which Together for Short Lives undertook in 2016¹⁶, we understand that:
 - the nurse vacancy rate among children's hospice organisations is equal to that of the NHS in England. The average vacancy rate was this year found to be over 11%, an increase on 2015's findings of 10%. This represents over 130 whole time equivalent (WTE) posts unfilled
 - there is an increasing shortage of experienced nurses in children's hospice organisations. In 2016, the number of vacancies was highest at a salary equivalent to Band 6 compared to salaries equivalent to Bands 5 and 7. In 2015, the highest number of average WTE vacancies were in Band 5
 - there is a lack of skilled nurses available to fill posts. More than half (61%) of children's hospice organisations cited a lack of available appropriately skilled nurses

11 All-Party Parliamentary Group (APPG) for Children Who Need Palliative Care. 2018. End of life care: strengthening choice - an inquiry report by the All-Party Parliamentary Group (APPG) for Children Who Need Palliative Care. Available to download from:

www.togetherforshortlives.org.uk/appg

12 All-Party Parliamentary Group (APPG) for Children Who Need Palliative Care. 2018. End of life care: strengthening choice - an inquiry report by the All-Party Parliamentary Group (APPG) for Children Who Need Palliative Care. Available to download from:

www.togetherforshortlives.org.uk/appg

13 RCN. 2014. The future for community children's nursing: challenges and opportunities. P.10. Available to download from: <http://bit.ly/1QgLhZb>.

14 Office for National Statistics. 2018. Population estimates analysis tool. Available to download from: <http://bit.ly/2KhPnE5>

15 NHS Digital. 2018. NHS Workforce Statistics – September 2018, Provisional statistics: Staff Group, Area and Level. Available to download from: <http://bit.ly/2FCijb7>

16 Together for Short Lives. 2017. The state of the UK children's hospice nursing workforce: a report on the demand and supply of nurses to children's hospices. Available to download from: <http://bit.ly/2kcovqb>

being available to fill posts – similar to the 65% which reported this in December 2015

- it is getting harder for children's hospice organisations to fill nursing posts. Nearly two thirds (65%) of vacancies are described as hard to fill (vacant for over three months). This is greater than the 57% reported in 2015.
45. These shortages are forcing children's hospice organisations to cut back the palliative care they can offer to children and families. A majority of organisations (58%) now state that vacancies are having a negative impact on care – including a reduced offer to families or reduced short breaks offer. This is greater than the 43% of children's hospice organisations which reported this in 2015. Nearly one fifth (17%) stated that they were being forced to close beds. Three (13%) services reported that vacancies affected their ability to provide 24/7 care, making 2016 the first year that this was specifically mentioned.
 46. **Will the minister make sure that the NHS workforce implementation plan, due to be published later in 2019, specifies the need for a healthcare workforce in England which can meet the end of life care choice commitment for babies, children and young people?**
 47. **Will the minister make sure that Health Education England assesses the demand for nurses from voluntary sector children's palliative care organisations and include it in their planning models?**
 48. **Will the minister make sure that a competency framework for providing children's palliative care is developed?**
 49. **Will the minister make sure that partners including Health Education England and the Council of Deans of Health work with the Royal College of Paediatrics and Child Health, the Royal College of General Practitioners, the Royal College of Nursing and Together for Short Lives to develop a children's palliative care training and education model?** This should help make sure that all professionals – both specialist and general – who provide care for children with life-limiting conditions have the necessary skills and knowledge.
 50. **Will the minister make sure that children's hospices are reimbursed for the placements they provide to undergraduate nurses in a consistent and transparent way across the UK. Will she give them access to the education and training tariffs determined annually by the Department of Health and Social Care?**
 51. **Will the minister ask Health Education England to focus specifically on outlining career pathways and providing guidance for delivering outcomes-led education for children's palliative care nurses?**

Integration

52. Single, joined-up education, health and care (EHC) assessments, plans and personal budgets for children and young people up to the age of 25 are only available to children and young people who have a special educational need. We are also unclear as to how the government's approach to personalising palliative care for children and young people, which is also underpinned by joint plans and budgets, correlates with the SEND system.

53. NICE recommends that children's palliative care services should be based on managed clinical networks (MCNs) should collaborate on planning and providing care. However, East of England is the only region in England which has a children's palliative care MCN.
54. **Will the government make disabled children, including those with life-limiting conditions, a priority by providing ministerial leadership to ensure a cross-departmental approach to improving outcomes for disabled children and their families?**
55. **Will the government make sure that all 40,000 babies, children and young people in England with life-limiting or life-threatening conditions have the right to an integrated assessment, plan and personal budget?**
56. **Will the minister commission a review of health and social care law, to strengthen and clarify rights and entitlements for disabled children and their families, including children with life-limiting conditions?** This would help to bring about more integrated assessments and plans.
57. **Will the minister invest in supporting work to develop of children's palliative care managed clinical networks across England?**
58. **How is the CQC making sure that it can assess the way in which networks of providers offer joined-up care to children and young people with life-limiting conditions, including managed clinical networks?**

Reducing the financial cost to families when a child dies

59. The prospect of losing a child is a parent's worst nightmare. Tragically, for the parents and carers of 5,000 babies, children and young people who die in the UK every year, this nightmare becomes a reality.
60. When the worst happens, parents forced to come to terms with the impact of losing their child must also contend with a number of other issues. If the child dies with a long-term disability, they may also have to endure significant short-term financial hardship caused by the immediate loss of their income. This could be due to the end of benefits such as carer's allowance, disability living allowance and child benefit. This can often compound the debt legacy which families of children with life-limiting or life-threatening conditions may have incurred as a result of the additional costs of caring for their child over a long period of time.
61. Contact's 2018 'Counting the Costs' survey¹⁷ found that families who provide long-term care for a disabled child face huge financial difficulties. This survey showed that in the past year, over a third of families have extra disability and care related costs of £300 or more per month. They also found that 7% of families had taken out more than five loans in the past year and that almost half (46%) the families had been threatened with court action for non-payment of bills. This is partly explained by the fact that 87% of families reported having caring responsibilities that mean they are unable to work as much as they would like. Additionally, the survey found that:
- 26% of parents said their child's condition has worsened due to going without basics
 - 33% have taken out a loan to pay for food

17 Contact. 2018. Counting the Costs. Available to download from: <http://bit.ly/2AOYmdZ>

- 26% of disabled children are going without essential therapies.
62. Research by Corden et al. shows that families caring for a child with a life-limiting or life-threatening condition face additional financial pressures as they are 'less likely to be in paid employment than other parents and may face financial hardship associated with lack of opportunity to work'.¹⁸ This is because parents may leave their employment, or not join the labour market so that they can care for their child – often 24/7. Because the trajectory of their child's condition is likely to be unstable, it is also difficult to plan time off work to attend medical appointments or to deal with long periods of acute illness. Corden et al. found that these factors, as well as difficulties finding appropriate substitute care to allow them to go to work, mean that 'during the period leading up to a child's death, both parents may therefore be depending on out-of-work income.'¹⁹
 63. In addition to the extra financial pressures of caring for a child with a life-limiting or life-threatening condition, parents must also pay for a funeral for their child. [Royal London](#)²⁰ **have found** that the average funeral in 2018 now costs £3,757. Across its five years of reporting, the average cost of a funeral has increased by 6%.
 64. Local councils still run most of the UK's crematoria and burial grounds. There have been very steep increases in the prices charged by local authorities and there are very large differences from one local authority to the next²¹.
 65. The UK government's [Social Fund Funeral Expenses Payments](#) was designed to cover the cost of a basic funeral for grieving families who would otherwise be unable to afford one. However, Royal London calculates that there is likely to be a gap of at least £1,500 on average between the costs incurred (assuming a funeral director is used) and the value of the SFFEP pay-out.
 66. **Will the minister work with her colleagues in government to increase the amount of money available for funeral expenses through the [funeral payment](#) in line with funeral cost inflation?**
 67. **Will the minister work with her colleagues in government taper benefits paid to families when their child dies, rather than ending them immediately?**
 68. [Together for Short Lives is delighted that the Prime Minister has intervened to establish a Funeral Fund for grieving parents who have lost their child.](#) Under the scheme, parents will no longer have to meet the costs of burials or cremations. Fees will be waived by all local authorities and met instead by government funding. The Welsh Government has also scrapped burial charges for children in Wales. The news was announced by [Welsh Government First Minister Carwyn Jones AM during his speech to the Welsh Labour conference in 2017.](#)
 69. Both reforms followed a determined, passionate campaign led by Carolyn Harris MP who lost her own young son and found that she was unable to afford to bury him. In May 2018, [the Scottish Government announced that bereaved parents will no longer be charged by local authorities to bury their children.](#) We were also delighted that [the UK](#)

18 <http://www.york.ac.uk/inst/spru/research/pdf/Financial.pdf>

19 <http://www.york.ac.uk/inst/spru/research/pdf/Financial.pdf>

20 Royal London. 2018. Buried In Debt: The price of a 'good send-off'. Available to download from: <http://bit.ly/2RRMgu1>

21 Fair Funerals. 2017. Influencing councils. Available to download from: <http://fairfuneralscampaign.org.uk/content/influencing-councils>

[Government decided not to charge a new medical examiner fee to parents bereaved of children up to the age of 18.](#)

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Appendix: further information

Life-limiting conditions in children – and the palliative care they need

1. 49,000 babies, children and young people are living in the UK with health conditions that are life-limiting or life-threatening and the number is rising: 40,000 live in England alone.
2. Hearing the news that your child has a life-limiting condition and is likely to die young is devastating. It is an incredibly distressing and confusing time. These children have very complex and unpredictable conditions and often need round the clock care, seven days a week.
3. Families have to cope with the knowledge that their child will die before them, and daily life for the whole family can become challenging. Although there are many excellent services helping them, many families still have difficulties accessing the care and support they need.
4. Children with life-limiting conditions need palliative care from the point at which their condition is diagnosed or recognised until the end of their lives. Families also need care and support throughout the trajectory of their child's illness, including bereavement care after they have died. Palliative care for children includes, but is not limited to, end of life care, and the two terms should not be used interchangeably.
5. These children and their families rely on palliative care provided in hospital, children's hospices and in the community, by the statutory and voluntary sectors. Children's palliative care providers offer a range of services, including supporting families to manage their children's pain and distressing symptoms, providing children and their families with life-line short breaks and offering bereavement support both before and after the child has died.
6. Families want to be able to choose where they receive the lifeline children's palliative care services that they rely on, when they need and want them. They also want to choose who cares for their child and which treatments they receive. However, the extent to which children and their families can access the palliative care they need – and make meaningful choices about how and where they receive it – varies considerably across England.

The current policy framework affecting children with life-limiting conditions, their families and the professionals and services who care for them

7. In July 2016, the government published its end of life care choice commitment for babies, children and young people. The commitment, entitled 'Our Commitment to You for End of Life Care: The Government Response to the Review of Choice in End of Life Care'²², states the following:

²² Department of Health. 2016. 'Our Commitment to you for end of life care: The Government Response to the Review of Choice'. Available to download from: <http://bit.ly/2oOUsfj>

Our commitment to you is that, as you approach the end of life, you should be given the opportunity and support to:

- have honest discussions about your needs and preferences for your physical, mental and spiritual wellbeing, so that you can live well until you die
- make informed choices about your care, supported by clear and accessible published information on quality and choice in end of life care; this includes listening to the voices of children and young people about their own needs in end of life care, and not just the voices of their carers, parents and families
- develop and document a personalised care plan, based on what matters to you and your needs and preferences, including any advance decisions and your views about where you want to be cared for and where you want to die, and to review and revise this plan throughout the duration of your illness
- share your personalised care plan with your care professionals, enabling them to take account of your wishes and choices in the care and support they provide, and be able to provide feedback to improve care
- involve, to the extent that you wish, your family, carers and those important to you in discussions about, and the delivery of, your care, and to give them the opportunity to provide feedback about your care
- know who to contact if you need help and advice at any time, helping to ensure that your personalised care is delivered in a seamless way.

‘Our Commitment to You for End of Life Care’: page 10

8. The government has stated that it believes there is scope for the commitment to be included as a pledge in the NHS Constitution by 2020. It has also said it is considering reflecting the commitment as a section in the NHS Choice Framework. The government is clear that the commitment applies to people of all ages who need palliative care:

“Our Commitment to end of life care is for people of all ages: children, young people and adults. Similarly, most of the measures we have set out to deliver the commitment apply equally to people of all ages needing end of life care. Children and young people with the most complex needs should be able to live their lives as they and their parents wish, and enjoy the same independence and choice which we all expect. As we have reflected in our Commitment, it is essential that the voices of children and young people are heard so that they are involved in their care, able to express their needs and preferences and make informed choices about their care.”

‘Our Commitment to You for End of Life Care’: page 36

9. The government is also clear that commissioners must actively plan and fund palliative care for children:

“To support high quality personalised care for children and young people, commissioners and providers of services **must** prioritise children’s palliative care in their strategic planning so that services can work together seamlessly and advance care planning can be shared and acted upon. Commissioners should also consider how they can structure services that offer accessible, high quality respite and bereavement support for children and their families.”

‘Our Commitment to You for End of Life Care’: page 36

10. To realise this commitment, on page 37 the government states:

- “We will explore with commissioners, NHS providers and the hospice sector how best to encourage a dialogue on commissioning well-coordinated palliative and respite care, and different approaches to funding locally commissioned services, using the palliative care currencies as ‘building blocks’.”
- “NHS England will explore the scope for Integrated Personal Commissioning (IPC) to include end of life care services. IPC is a new way to support both adults and children with complex needs by joining up health, social care and other services at the level of each individual. The approach focuses on person-centred care and support planning, facilitating an earlier, more personalised discussion of end of care for those with the most complex needs.”
- “NHS England will work with a small number of interested areas to assess rapidly the options for personalising services and improving choice and control for individuals at end of life, using the learning from the delivery of personal health budgets and integrated personal commissioning in end of life care, including for children.”

11. In September 2017, [the government’s ‘One Year On’ report](#)²³ gave an update on the progress achieved in meeting the end of life care choice commitment. It cites the National Institute for Health and Care Excellence’s (NICE) guideline ‘End of Life Care for Infants, Children and Young People: Planning and Management’²⁵, published in December 2016, as an important step forward. NICE has also recently published a quality standard on the same topic⁴, another important guide to help the NHS, voluntary and private sectors better plan, fund and provide children’s palliative care.

23 Department of Health. 2017. One year on: the government response to the review of choice in end of life care. Available to download from <http://bit.ly/2AOFadM>

The extent to which the end of life care choice commitment is being met for children in England

12. The All-Party Parliamentary Group (APPG) for Children Who Need Palliative Care recently published a report of an inquiry into the extent to which the government is meeting its end of life care choice commitment to these seriously ill children and their families²⁴.
13. Despite the end of life care commitment, the APPG has heard evidence from young people, families, services and professionals that the quality of palliative care children and families can access is patchy and depends on where in England they live. MPs and peers state that this is unfair and represents a wholly unjustified health inequality. The APPG highlights five areas of particular concern, where many children and their families have limited access to:

1. Access to children's palliative care out of hours and at weekends: The National Institute for Health and Care Excellence (NICE) states²⁵ that children with life-limiting conditions who are approaching the end of their lives and are being cared for at home should have access to advice from a children's palliative care consultant (for example by telephone) and children's nurses at any time (day and night). This is critical in making sure that children with life-limiting conditions and their families can choose to receive palliative care at home. However, professionals providing palliative care to children at home only sometimes:

- have 24/7 access to specialist medical advice on managing complex symptoms
- have 24-hour access to advice from a children's palliative care consultant
- are able to provide 24-hour multi-disciplinary children's palliative care at a child's home.

There is a major discrepancy between services planned and funded ('commissioned') between 8am and 6:30pm Monday-Friday and services commissioned to provide care out of hours. 93% of clinical commissioning groups (CCGs) commission community children's nursing (CCN) teams, but just 67% commission them to provide care out of hours. Although 64% of CCGs commission services to provide community paediatricians, only 29% commission them to provide out of hours care.

2. Access to short breaks (respite): Children with life-limiting conditions and their families rely on frequent short breaks for respite, provided by skilled people who can meet their often complex needs. This may be for only a few hours – or overnight for a few days at a time. The 24/7 pressure on parents of having a child with a life-limiting condition is immense, so social care is vitally important to relieve this stress, catch up on sleep, spend time as a family and do the things that other families do. NICE recognises the need for short breaks in its guidance²⁵. However, we have heard evidence from parents who have been unable to access short breaks when they needed them most. Too few CCGs and local authorities in England plan and fund

24 All-Party Parliamentary Group (APPG) for Children Who Need Palliative Care. 2018. End of life care: strengthening choice - an inquiry report by the All-Party Parliamentary Group (APPG) for Children Who Need Palliative Care. Available to download from: www.togetherforshortlives.org.uk/appg

25 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: <http://bit.ly/2ODg2hY>

short breaks for children who need palliative care and many argue about who is responsible:

- More than one in five (21%) local authorities are failing to meet their legal duty to commission short breaks for disabled children with life-limiting and life-threatening conditions
- Only 68% of CCGs reported that they commission services for children with life-limiting and life-threatening conditions jointly with their local authorities
- Fewer than half (49%) of local authorities reported that they jointly commission these services with CCGs.

Where CCGs and local authorities fail to plan and fund short break services for children with life-limiting conditions, families have little alternative other than admitting their children to hospital when they reach breaking point.

3. Access to age-appropriate palliative care and smooth transitions to adult services:

For young people with life-limiting conditions, making the transition from children's to adult services can feel like falling off a cliff edge. Medical advances mean there are now 55,000 young adults aged between 18 and 40 with life-limiting conditions and this figure continues to grow. However, the transition these young people have to undergo from the comprehensive care offered by children's palliative care to unfamiliar adult services can be daunting and is often not joined up. There are also too few palliative care services which meet the needs and wishes of young people in ways which are appropriate to their age and developmental stage. Only 50% of young people and their parents say that they had received support from a lead professional during the process leading up to transition to adult services. One in six (16%) CCGs are not commissioning age and developmentally appropriate services. Furthermore, a similar proportion (15%) of CCGs do not take steps to ensure that these young people experience smooth transitions from children's to adult palliative care services.

4. Access to specialist children's palliative care teams led by Level 4 consultants:

NICE states that children with life-limiting conditions should be cared for by defined multidisciplinary teams (MDT)²⁵ which include members of specialist children's palliative care teams. Children with life-limiting conditions usually receive coordinated care, provided by a MDT, which have access to medical advice provided by Level 3 children's palliative care consultants. These consultants are able to provide elements of specialised children's palliative care, including prescribing alternative opioids and managing complex symptoms²⁶. However, NHS England states²⁷ that specialist children's palliative care teams should be led by medical consultants working at Paediatric Palliative Care Competency Level 4²⁶. These consultants are vital because they:

- can manage uncommon symptoms
- are able to advise on medical support for which there is no evidence base

26 Association for Paediatric Palliative Medicine Education Subgroup and Paediatric Palliative Medicine College Specialty Advisory Committee, Royal College of Paediatrics and Child Health. 2015. Curriculum in paediatric palliative medicine. Available to download from: <http://bit.ly/2AvDzOJ>

27 NHS England. 2013. E03/S/h – 2013/14 NHS standard contract for paediatric medicine: palliative care particulars, schedule 2 – the services, A – service specifications. Available to download from: bit.ly/11yjtVS

- lead and develop services within and beyond a local children's hospice
- support and teach other professionals who are not trained in palliative medicine.

We have found that, across England, specialist children's palliative care teams are only sometimes led by Level 4 consultants.

- 5. Access to advance care planning:** NICE states²⁵ that professionals should develop and record an advance care plan (ACP) at an appropriate time for the current and future care of each child or young person with a life-limiting condition. ACPs help to set out the needs and wishes of children and their families and can help to make sure that their choices are realised. Despite this, only some areas are undertaking advance care planning.