Adjournment debate:
Funding for Helen and Douglas House Hospice in Oxford

Friday 11 May 2018

A briefing from Together for Short Lives

Families of children with life-limiting conditions rely on the palliative care provided by the voluntary sector, including children's hospices. Despite their amazing work - and the pressure they take off the NHS - these lifeline services do not receive enough money from the state. The demand on them is increasing, yet the funding they receive is patchy and unsustainable. We are calling on the government and NHS England to increase the Children's Hospice Grant to £25million per year, bring about funding parity between children's and adult hospice services - and make it clear to the NHS and local authorities that they are responsible for funding children's palliative care.

The government's 2016 response[1] to a review of choice in end of life care 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. The government's commitment also sets out the range of services which children and young people with life-shortening conditions rely on from diagnosis until the end of their lives. It highlights the role of a range of services, including children's hospices.

Worryingly, this commitment is not being fulfilled in almost half of local areas in England. Evidence gathered by Together for Short Lives[2] has found that 46% of NHS clinical commissioning groups (CCGs) are failing to implement the commitment and have no plans to do so.

Key questions to ask the minister responding on behalf of the government:

1. **Will the government commit to bringing about parity of funding between children's and adult hospices, as the Scottish Government has done?** Together for Short Lives is calling on the government to follow the example of the Scottish Government, who have allocated £30million over five years for children's hospices[3] 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.

2. **Will the Department of Health and Social Care work with the Department of Education and NHS England to write to CCGs and local authorities to clarify that they are both responsible for commissioning children's palliative care services?** We would like the government and NHS England to urgently write to CCGs and local authorities to make clear 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 communication should set out the difference between specialised and general

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[1] 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

[2] Together for Short Lives. 2018. Commissioning in England 2017. Available to download from: http://www.togetherforshortlives.org.uk/changing-lives/speaking-up-for-children/policy-advocacy/commissioning-england-2017/

[3] Scottish Government. 2016. Children's palliative care boost. Available to download from: https://beta.gov.scot/news/childrens-palliative-care-boost/

children's palliative care and also promote our joint commissioning guidance[4]. NHS England and the local government sector should work with us to help guide CCGs and local authorities on how to use the currency and other new funding models.

3. **Will the minister hold CCGs and local authorities to greater account in meeting their commissioning responsibilities - including meeting the end of life choice commitment for children?** This is clear that commissioners and providers of services must prioritise children's palliative care in their strategic planning.

4. **Will the minister commit to providing NHS England with the funding it needs to increase the Children's Hospice Grant to £25million per year?** This would recognise the greater number of children with life-limiting conditions that children's hospices are caring for compared to when the grant was first introduced[5]. It would also reflect the additional costs in developing reporting mechanisms which children's hospices are incurring.

5. **Will the minister commit to developing a national children's palliative care strategy for England?** We believe that this should be developed based on a national inquiry into the care and support offered to the 40,000 babies, children and young people in England with life-limiting and life-limiting conditions and their families. Its scope should include the health, education, social care and financial support on offer to them. It should bring about a system which is joined-up around the needs of seriously ill children and their families and which implements the National Institute for Health and Care Excellence (NICE) guidance on end of life care for children. Funding should be made available to test new approaches to implementing the strategy in pilot areas across England.

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[4] Together for Short Lives. 2015. Jointly Commissioning Children's Palliative Care. Available to download from: www.togetherforshortlives.org.uk/jointcommissioning

[5] Together for Short Lives. 2017. Children's Hospice Grant consultation: Analysis of responses and Together for Short Lives' recommendations Report back to NHS England. Available to download from: http://www.togetherforshortlives.org.uk/wp-content/uploads/2018/03/PolRes_Childrens_Hospice_Grant_Consultation_report_to_PUBLISH_FINAL.pdf

Annex: background information

Why is statutory funding important in children's palliative care?

1. Together for Short Lives estimates that the cost of providing palliative care to children and young people amounts to hundreds of millions of pounds a year across the UK. The majority of children's palliative care is funded by organisations spanning the voluntary sector, the NHS and local government.

2. While the state funds the vast majority of the children's palliative care directly provided by the NHS, we believe it is right that it also contributes to the costs incurred by voluntary providers, including children's hospices. The children's palliative care provided by these organisations helps ease pressure on the NHS. Children's hospices, for example, make a crucial contribution to local health economies[6]:

   - 92% of children's hospice charities provided end of life care to children and young people in 2015/16

   - 89% provided care which helped children manage their complex symptoms

   - 75% provided step down care.

3. Without children's hospices, this clinical care would otherwise have to be provided and paid for in its entirety by the NHS.

4. Voluntary sector providers bring social value to communities. When local NHS organisations remunerate these charities for the children's palliative care they provide, the funding is matched and exceeded by charitable donations which also contribute to running services. Local volunteers also help to provide children's palliative care which are part-funded from statutory sources, further adding value.

5. We know that the demand for children's hospice care is increasing[7]; between 2006/07 and 2015/16, the average number of children supported by children's hospice organisations in England increased by 28%: 31 (86%) of children's hospice charities told us that they provided clinical palliative care to 8,735 children in 2015/16 (6,203 in-patient and 2,532 at home and in the community). This was an average of 323 children per children's hospice charity. 21 (68%) of the 31 children's hospice charities who were providing care in 2006/07 told us that they provided clinical palliative care to 3,679 children in 2006/07 (2,609 in-patient and 1,070 at home and in the community). This was an average of 252 children per children's hospice.

6. There is overwhelming public support to make sure that children with short lives are not shortchanged 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).

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[6] Together for Short Lives. 2017. Children's Hospice Grant consultation: Analysis of responses and Together for Short Lives' recommendations Report back to NHS England. Available to download from: http://www.togetherforshortlives.org.uk/wp-content/uploads/2018/03/PolRes_Childrens_Hospice_Grant_Consultation_report_to_PUBLISH_FINAL.pdf

[7] Ibid.

7. The National Institute of Health and Care Excellence (NICE) published a resource impact template alongside the guideline on end of life care for infants, children and young people. This tool allows local areas to input their population data and it calculates the overall cost and savings of implementing the new guidelines. 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].

What do we know about the way in which the state funds children's palliative care?

8. Worryingly, state funding for charities delivering vital children's palliative care in England is patchy and declining year on year. It is vital that children with short lives are not short changed by the state.

9. Every year, Together for Short Lives, together with Hospice UK, asks charities providing hospice and palliative care in England to tell us how much money they received from the state. In doing so, we have found that children's palliative care charities are on the brink of state funding crisis. Our main findings from 2015/16, which you can read in detail in our report[9] were:

   - Cuts and freezes in statutory funding for children's hospice and palliative care charities means a bleak outlook for seriously ill children and families in England. This is despite the cost of delivering this care increasing by 10% due to additional demand.

   - 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).

   - Charities say they will be forced to cut essential services if state funding continues to decline. Funding cuts and freezes across England mean that children's palliative care services are not able to expand to meet the needs of the growing number of children and young people with life limiting or life-threatening conditions. Without the support of children's palliative care charities, it is likely that more families are being plunged into crisis, putting ever more pressure on already stretched emergency services. It's make or break.

   - Children's palliative care funding represents a postcode lottery: the amount of money given by the state to children's palliative care charities varies considerably. There's a gulf in funding, depending on where a charity is based. When taking the NHS Children's Hospice Grant and funding from clinical commissioning groups and local authorities into account, the range of statutory contributions to charities is huge: one charity receives 53% of the money it needs to deliver children's palliative care from the state, while one receives as little as 2%.

10. On average, adult hospices in England receive 33% of their funding from statutory sources. 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

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[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] 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

neither moral nor fair. The Scottish Government recently committed £30million over five years to Children's Hospice Association Scotland[10]; this amounts to approximately 50% of their charitable costs.

The Children's Hospice Grant

11. Between November 2016 and January 2017, Together for Short Lives consulted children's hospice charities in England on a potential new future formula for allocating the Children's Hospice Grant. This is allocated annually to all children's hospices in England. The total grant amount has increased incrementally from £8,829,180 in 2006/07 (part of £27million awarded over three years) to £11,000,000 in 2015/16. We consulted all current recipients of the grant on behalf of NHS England, which is responsible for administering the grant.

12. From the evidence we received[11], the total amount of funding available through the Children's Hospice Grant is valued greatly but is also inadequate:

    - While this increase in the Children's Hospice Grant has been welcome, it has not kept pace with the growing cost of providing clinical palliative care incurred by children's hospice charities. In 2006/07, the grant contributed an average of 14% towards the cost of providing clinical care in children's hospices. In 2015/16, when it had risen to £11,000,000, it contributed an average of just 8%.

    - In 2006/07, the grant contributed an average of £1,129 per child cared for by a children's hospice charity. In 2015/16, that had fallen to £947 per child. This was a fall of £182.65 (16%) per child.

What do we know about the way in which CCGs and local authorities commission children's palliative care?

13. Children's palliative care embraces physical, emotional, social and spiritual elements and focuses on enhancing of quality of life and quality of death for children and young people. CCGs have a crucial role in planning this care and support. However, because social care is commissioned by England's 152 upper-tier local authorities, they also have a crucial part to play in making sure children and young people with life-shortening conditions and their families get the lifeline care they need. Our research shows that families face a postcode lottery of support across England[12]:

    a. Most CCGs have not implemented the new clinical guidance for children who need palliative care. Fewer than a third (31%) of CCGs stated that they are currently implementing the new NICE guideline on 'End of life care for infants, children and young people with life-limiting conditions: planning and management'. A further 27% stated that their plans to implement this guidance are 'in development'.

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[10] Scottish Government. 2016. Children's palliative care boost. Available to download from: https://beta.gov.scot/news/childrens-palliative-care-boost/

[11] Together for Short Lives. 2017. Children's Hospice Grant consultation: Analysis of responses and Together for Short Lives' recommendations Report back to NHS England. Available to download from: http://www.togetherforshortlives.org.uk/wp-content/uploads/2018/03/PolRes_Childrens_Hospice_Grant_Consultation_report_to_PUBLISH_FINAL.pdf

[12] Together for Short Lives. 2018. Commissioning in England 2017. Available to download from: http://www.togetherforshortlives.org.uk/changing-lives/speaking-up-for-children/policy-advocacy/commissioning-england-2017/

b. The government's end of life care choice commitment is not being fulfilled in almost half of local areas in England. Almost half (46%) of CCGs are failing to implement the commitment and have no plans to do so.

What is the UK Government and NHS England doing to improve the way in which children's palliative care is funded by the state?

14. In addition to providing the Children's Hospice Grant, NHS England has developed and published a children's palliative care funding currency[13] [14]. In simple terms, this a formula which describes for CCGs how the cost of providing children's palliative care varies depending on a number of factors. The currency provides official recognition that the NHS has a role in funding children's palliative care in England. It and could help CCGs to better understand their responsibilities for supporting these vital services. The guide also usefully sets out:

    - details of the currency formula model and how it helps commissioners to pay for local children's palliative care services
    - the data needed to use the currency formulas
    - an Excel template to help collect data
    - tools to support providers to collect and validate data
    - advice on sharing information with commissioners.

15. The guide also recommends that while bereavement counselling does not form part of the currency model, commissioners should think about the excellent value that these services provide when they commission services.

16. We welcome the guide. However, we are concerned that CCGs are not be forced to implement the new currency or the guide. There are also a number of important omissions from the guide, including:

    - how progress on achieving the objectives of the currency will be measured
    - how non-clinical elements of children's palliative care, such as short breaks for respite, will be funded
    - how voluntary sector providers can be supported to implement the systems they will need to collect data to make the new approach work.

What are UK Government departments and NHS England doing to improve the way in which children's palliative care is commissioned?

17. In England, CCGs, comprising GPs, doctors, nurses and other professionals, are responsible for commissioning local health services. CCGs are accountable to NHS England. Local authorities are responsible for commissioning local social care services for children and young people. The Children and Families Act 2014 places a duty on the

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[13] NHS England. 2017. Guidance for using the Children's Palliative Care Currency. Available to download from: http://bit.ly/CPCcurrency

[14] NHS England. 2017. Developing a new approach to Palliative Care Funding- Final Report 2015/16 Testing. Available to download from: http://bit.ly/currtest1516

NHS and local authorities to jointly commission care for children and young people with special educational needs and disabilities (SEND) between the ages of 0 - 25.

18. The government's 2016 response to a review of choice in end of life care 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.

19. The government's commitment also sets out the range of services which children and young people with life-shortening conditions rely on from diagnosis until the end of their lives. It highlights the role of a range of services, including children's hospices; community children's nursing services; paediatric inpatient services, specialist palliative care consultant teams; GPs; and the wider network of supporting services such as school services.

What would Together for Short Lives like to happen?

1. **Provide parity of funding between children's and adult hospices:** 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.

2. **Provide clarity over responsibilities and guide commissioners on how to apply new models of funding:** We would like the government and NHS England to urgently write to CCGs and local authorities to make clear 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 communication should set out the difference between specialised and general children's palliative care and also promote our joint commissioning guidance. NHS England and the local government sector should work with us to help guide CCGs and local authorities on how to use the currency and other new funding models.

3. **Increase the children's hospice grant:** We consider it pressing and urgent that the overall amount of funding available through the children's hospice grant reflects the increase in demand, costs and complexity of care needed by children and young people with life-limiting and life-threatening conditions. We recommend that the grant is increased in value to £25million per year. We base this on a 14% contribution to the current cost of the clinical care provided by children's hospices, which is equal to the contribution originally made by the Department of Health when the grant was first awarded in 2006/07. The uplift also recognises any additional costs in developing reporting mechanisms and new services to meet growing demand.

4. **Hold CCGs and local authorities to greater account in meeting their commissioning responsibilities - including meeting the end of life choice commitment for children:** This is clear that commissioners and providers of services must prioritise children's palliative care in their strategic planning.

5. **Commit to developing a national children's palliative care strategy for England:**

- It should be developed based on a national inquiry into the care and support offered to the 40,000 babies, children and young people in England with life-limiting and life-limiting conditions and their families.
- Its scope should include the health, education, social care and financial support on offer to them.
- It should bring about a system which is joined-up around the needs of seriously ill children and their families and which implements the National Institute for Health and Care Excellence (NICE) guidance on end of life care for children.
- Funding should be made available to test new approaches to implementing the strategy in pilot areas across England.

For more information

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