



DEBATE PACK

Number CDP 2016-0110 , 2 June 2016

Support for children and young people with life-shortening conditions

Summary

A Westminster Hall debate on Support for children and young people with life-shortening conditions has been scheduled for Tuesday 7 June 2016 at 9.30 am. It will be led by Stuart Andrew.

This debate pack contains a Library summary of the issues, relevant reports, press and parliamentary coverage, and links to further reading.

The House of Commons Library prepares a briefing in hard copy and/or online for most non-legislative debates in the Chamber and Westminster Hall other than half-hour debates. Debate Packs are produced quickly after the announcement of parliamentary business. They are intended to provide a summary or overview of the issue being debated and identify relevant briefings and useful documents, including press and parliamentary material. More detailed briefing can be prepared for Members on request to the Library.

Alex Adcock
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1. Summary

Palliative care for children and young people

In addition to the care provided by families and unpaid carers, palliative care¹ for children and young people is delivered by a range of providers in the statutory and voluntary sectors.

A significant proportion of care is delivered by the voluntary sector, including children's hospices. NHS funded services include medical consultants with expertise in the child's condition, with access to secondary and tertiary hospital care, and community children's nursing teams and paediatrics. In addition to social care services, local authority children's services include the provision of equipment to disabled children and breaks for respite. Children with significant special educational needs may also be entitled to a joint Education, Health and Care Plans.

It is estimated that more than 40,000 children (0–19 years) in England have a life-limiting or life-threatening condition.² The charity [Together for Short Lives](http://www.togetherforshortlives.org.uk) has called for a more integrated commissioning approach from CCGs, NHS England and local authorities. Because hospices generally receive funding from a variety of sources, including charitable donations, provision can vary. In 2015, a survey carried out by Together for Short Lives and Hospice UK found that statutory funding for children's and adult hospices was patchy and inconsistent.

Funding for children and young peoples' palliative care in England

CCG expenditure on end of life care (for children and adult services in hospices, and in hospitals and the community) was collected for the first time in 2013/14, with CCG total expenditure in 2013/14 reported as £473 million.³ Data for 2014/15 is currently being collected and is not yet available. A survey of hospices (for children and adults) carried out by Together for Short Lives reported that for 2014/15 NHS funding:

- remained the same for 52% of hospices surveyed.
- increased for 29% of hospices; and
- reduced for 17% of hospices;
- the remaining 2% responded "do not know" or "not applicable".⁴

¹ Palliative care includes management of physical symptoms such as pain, as well as social, psychological and spiritual support to the patient and their family and friends, including bereavement support.

² Information on the prevalence of life-limiting conditions in children and young people for every local authority district in England can be found in a study in 2011: https://www.togetherforshortlives.org.uk/assets/0000/1100/Leeds_University_Childrens_Hospices_UK_-_Ethnicity_Report.pdf

³ Programme Budgeting Collection, NHS England

⁴ Together for Short Lives, [Commissioning and statutory funding arrangements for hospices in England Survey results](#) (2015)

NHS England has maintained its £11 million annual funding for children's palliative care providers (through the annual Children's Hospice and Hospice-at-Home Grant). The Department of Health has also provided grant funding to Together for Short Lives to support improved approaches to providing care and support to young people with life-limiting or life-threatening conditions.

NHS England has led work on behalf of the Government in developing a draft funding tariff for palliative care (for all ages) which are now being tested with provider organisations. The aim is to put funding for children and adult hospices on a more equitable and sustainable footing, by clearly identifying the costs of care, so that it can be commissioned locally by clinical commissioning groups.

The *Finance Act 2015* introduced a new VAT refund scheme for palliative care charities. It took effect from 1 April 2015.⁵

In March 2015, the House of Commons Health Select Committee published a report of its inquiry into palliative and end of life. The Committee called on the Government to ensure that future funding proposals fully recognise the importance of the voluntary sector - and specifically set out how it intends to ensure sustainable, long term funding for the hospice sector. The Government's response providing the following on the development of a new funding tariff:

63. The recent publication by NHS England of the 2015/16 palliative care development currency represents an initial attempt to group specialist palliative care into packages of care. The currency is not mandatory and will be further tested and refined during 2015/16. The aim is that it will provide a meaningful tool to support service planning and commissioning of services. The currency was developed following a significant piloting exercise which actively involved the voluntary sector.

64. The currency will be further tested during 2015/16. This testing will involve a detailed data collection from providers of care and a qualitative study of commissioners and providers beginning to use the currency as part of the commissioning process. Organisations in the voluntary sector are taking part in this testing work, and the sector is also represented on the project's advisory board.⁶

Further information on funding children's palliative care services can be found on the [Together for Short Lives website](#). The charity has concerns that the new per-patient funding currency for children's palliative care will be limited to the medical elements of care and omit non-clinical elements such as short breaks and bereavement support.

Disability Living Allowance higher rate mobility component for young children

The charity Together for Short Lives has called for a change to the eligibility criteria for the mobility component of Disability Living

⁵ <https://www.gov.uk/government/publications/vat-refunds-for-palliative-care-charities>
<http://www.hospiceuk.org/what-we-offer/hospice-finance/vat-refund-scheme-for-hospices>

⁶ [Government response to the Health Select Committee's report on End of Life Care](#), October 2015.

Allowance so that 0-3-year-old children with life-shortening conditions dependent of heavy or bulky medical equipment can access adapted vehicles.

Disability Living Allowance has two components: a **mobility component**, for those who need help getting around; and a **care component**, for those with care needs. An award can consist of a mobility component, a care component, or both components. The mobility component is payable at two rates, and the care component has three rates.

Three is the youngest age at which the higher rate mobility component of DLA may be paid for a child. This means that parents of a disabled child cannot access the [Motability scheme](#). The lower rate DLA mobility component may be paid from age five. There is no lower age limit for the DLA care component. However, for both components, the child will normally have to have satisfied the disability conditions for three months before the award begins, and be expected to satisfy the conditions for at months (unless the child is terminally ill – for these purposes this means they are suffering from a progressive disease where death can be reasonably be expected within six months. If this is the case the three month qualifying period does not apply).

Further information on why there are lower age limits for the DLA mobility components is given below.

Why are there lower age limits for the DLA mobility components?

The higher rate mobility component of Disability Living Allowance can only be claimed for children who are aged three or over. The lower age limit used to be five, but was lowered to three as a result of section 67(3) in the *Welfare Reform and Pensions Act 1999*.

The higher rate mobility component of DLA can be paid for a child who, because of a physical disability:

- cannot walk at all; or
- can walk, but their ability to walk outdoors without severe discomfort is so limited they can be considered virtually unable to walk; or
- can walk but the effort needed could seriously affect their health.

A child aged three or over may also get the higher rate if they:

- have had both legs amputated above the ankle or through the ankle, or were born without legs or feet; or
- are certified as severely sight impaired or blind and meet other conditions relating to their sight loss; or
- are deaf and blind and they need someone with them when they are outdoors; or
- are severely mentally impaired with severe behavioural problems and qualify for the highest rate DLA care component.

Further information can be found in Disability Rights UK's factsheet F23, [Disability living allowance \(DLA\)](#), updated April 2016.

The original justification for limiting the mobility component to children aged five or over was that children under five were not independently mobile and needed constant supervision. The age limit of the higher rate mobility component was lowered from five to three in April 2001, as a result of section 67(3) in the *Welfare Reform and Pensions Act 1999*. The age limit for lower rate mobility remains five however. Background to the change is given in pp 80-81 of Commons Library [Research Paper 99/19](#).

In the Standing Committee debates on the *Welfare Reform and Pensions Bill 1998/99*, the then DSS Minister Hugh Bayley gave the Government's reasons for lowering the age threshold for the higher rate mobility component to three (and for leaving the age limit at five for the lower rate mobility component):

The higher rate mobility component is payable to people who cannot walk or who can barely walk. We took advice from a number of sources on the age at which children usually begin to walk a reasonable distance, rather than simply toddling from one end of a room to the other. Clinicians, the DLA advisory board and others suggested an age range of two-and-a-half to four. Therefore, we felt it appropriate to include three and four-year old children by extending the availability of the higher rate mobility component downwards from age five. The age of 36 months is rather closer to the lower estimate of 30 months than to the higher estimate of 48 months.

As with all such matters, one can argue about the needs of a child one month before the provision takes effect. However, I hope that Committee members will agree that the Government were right to reduce substantially the age at which the higher rate can be claimed. The change will provide children who have severe walking difficulties with an extra £35.85 a week. That will benefit approximately 8,000 children a year at a cost of about £15 million. We decided that it would be wrong to extend the provision beyond the age of three, not for reasons of cost but because it would be inconsistent with the advice that we received.

The lower rate mobility component is paid not to people who cannot walk, but to people who need guidance when they walk along unfamiliar routes. In the Government's view, it is inconceivable that parents would allow children aged under five to walk unsupervised in unfamiliar surroundings. Therefore, it would be inappropriate to extend the lower-rate mobility component to such children.

In a written answer in June 2013, the then DWP Esther McVey said that the 2010 Government had "no plans to extend eligibility for the mobility component of disability living allowance to disabled and life-limited children under the age of three" (HC Deb 6 June 2013 c1250w).

In a written answer in November 2015, the Minister for Disabled People, Justin Tomlinson, said that the current Government had no plans to change the age rules:

The principle underpinning Disability Living Allowance (DLA) is that payments are made to families who incur extra costs as a result of meeting the additional care and/or mobility needs of a disabled child.

In deciding to set the lower age limit for entitlement to the higher rate mobility component at 3 years of age, the department considered views of medical advisors and independent research that the majority of children could walk at the age of 2½. By the age of 3 it was realistically possible in the majority of cases to make an informed decision as to whether an inability to walk was the result of disability.

We have no plans to make changes to DLA for children under the age of 3.⁷

Statistics

The figure cited by Together for Short Lives that around 49,000 children and young people in the UK are expected to have short lives, appears to be based on applying [Fraser et al's \(2012\)](#) national prevalence rates for life limiting conditions among 0-19 year olds in England to the current population of the UK aged 0-19 years. The Fraser et al rate was 32.2 per 10,000 population.

ONS mid-year population estimates for 2014 give the population of 0-19 year olds in the UK as 15.3 million. Applying the rate of 32.2 per 10,000 to this figure gives around 49,000.

The Fraser et al study is the only available robust study that attempts to quantify the prevalence of life limiting conditions among children and young people in England. It is based on identifying children and young people with hospital episodes involving ICD-10 diagnostic codes that relate to life limiting conditions. A further study has attempted to quantify figures for Scotland. [Fraser et al \(2015\)](#) also used the hospital episodes method of the English study, but also all included individuals who appeared in community prescribing records as receiving medication for life threatening conditions.

As the table below shows, the comparable hospital episode only based prevalence for Scotland showed higher prevalence rates for Scotland than England. The “complete” prevalence rate for Scotland – based on hospital episodes and community prescribing rates was higher in all age groups. Both differences suggest that the UK estimate of 49,000, based on Fraser et al’s (2012) England prevalence rates, is likely to be conservative.

Prevalence of life limiting conditions per 10,000 population 2009/10

	England	Scotland	
		Hospital based	Complete
Under 1 year	125.7	158.4	195.0
1-5 years	34.1	54.6	122.9
6-10 years	24.8	32.0	69.1
11-15 years	24.0	29.2	54.5
16-19 years	23.6	26.2	53.8
All aged 0-19	32.2	n/a	n/a

Sources:

[Fraser et al \(2012\)](#)

[Fraser et al \(2015\)](#)

⁷ PQ 13360 [on Disability: Children], 2 November 2015

2. Together for Short Lives Budget 2016 Representation

Together for Short Lives is the leading UK charity for the 49,000 babies, children and young people with life-shortening conditions and all those who support, love and care for them. We support families, professionals and services, including children's hospices. Our work helps to ensure that children can get the best possible care, wherever and whenever they need it.

The number of children and young people with life shortening conditions is increasing but this is not being reflected in budget setting nor in the better coordination of services that they need. For example, a 2015 report showed a 25% increase in children with life-shortening conditions in Scotland in just 4 years – from 12,039 in 2009/10 to 15,404 in 2013/14.⁸

Children's palliative care is different to palliative care for adults. Whereas the majority of adults only need palliative care at the end of their lives, children with life-shortening conditions require palliative care over a much longer period, often from birth as they live with the instability of their condition. It is common for their conditions to fluctuate and, as such, it is often much more difficult to identify when a child is moving into their end of life phase. Children with life-shortening conditions often have complex disabilities, while the range of health conditions which results in children requiring children's palliative care is more diverse. Children's palliative care is an approach to care in conjunction with curative treatments.

We welcome the Chancellor's recognition of the value of the children's palliative care sector, when he said "I am a great admirer of the tremendous work that these charities do to support children with life-threatening and life-limiting medical conditions, and those who love and care for them".⁹ These comments were made as the Treasury announced that the government would donate VAT on sales of the X Factor charity single, which was a fantastic boost for the children's palliative care sector. We also welcomed the Treasury's decision to introduce the VAT refund scheme for hospices.

We estimate that palliative care costs for children and young people amount to £200 million per year. Yet the only figure committed from statutory sources in England is a hospice grant of a £11million a year and this is only committed to on a year-on-year basis. Funding from NHS clinical commissioning groups (CCGs) varies from area to area,

⁸ Fraser et al. (2015). Children in Scotland requiring Palliative Care: identifying needs and numbers. Available to download from: <http://bit.ly/1Krn2EU>

⁹ HM Treasury (2015). Government to donate VAT on X Factor charity single. Available at: <https://www.gov.uk/government/news/government-to-donate-vat-on-x-factor-charity-single>

contributing an average of just 10% of children's hospices' care costs compared to 30% for adult hospices.¹⁰

A summary of our representation

We would like the government to:

- set out a long-term plan to fund children's palliative care services fairly and sustainably that reflects the growing demand for these services
- enable local authorities to increase funding for short breaks for disabled children – providing vital respite and support that in the long term save the State money by reducing the number of hospital visits as well the incidence of family breakdown
- provide seed-funding to voluntary sector organisations to set up age-appropriate services for young people transitioning from children's to adult's services – an area where there is currently a gap described as 'a cliff edge' for young people.
- change the eligibility criteria for the mobility component of Disability Living Allowance so that 0-3-year-old children with life-shortening conditions dependent of heavy or bulky medical equipment can access adapted vehicles

Our representation

Setting out a long-term plan to fund children's palliative care services fairly and sustainably

1. We are concerned that the government has not yet set out how children's palliative care services will be fairly and sustainably funded in the long-term. State funding for children's palliative care services varies widely across the UK and the 2011 Palliative Care Funding Review found that this was due to the lack of a clearly defined funding model. The government is yet to respond to the recommendations of this report.¹¹

2. This is illustrated by funding arrangements for children's hospices in England. Our own surveys found that funding from CCGs is patchy and inconsistent and that they contribute an average of 10% of children's hospices' care costs compared to 30% for adult hospices.¹²

3. NHS England is currently testing a new per-patient funding currency for children's palliative care; a non-mandated currency will be available

¹⁰ Together for Short Lives and Hospice UK (2015). Commissioning and statutory funding arrangements for hospices in England: Survey results 2015. Available to download from: <http://bit.ly/1NbjiwD>

¹¹ 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/XOBIE7

¹² Together for Short Lives and Hospice UK (2015). Commissioning and statutory funding arrangements for hospices in England: Survey results 2015. Available to download from: <http://bit.ly/1NbjiwD>

for commissioners to use from April 2017. We are very concerned that it is limited to the medical elements of care and omits crucial non-clinical elements **such as short breaks and bereavement support**. Short breaks are essential to relieve some of the pressures on families of children with life-shortening conditions - most relationships will suffer, with 36% experiencing a breakdown of the family.¹³

4. Following its inquiry into **end of life care in England, the House of Commons Health Select Committee recommended** that the government makes sure that future funding proposals fully recognise the importance of the voluntary sector and to specifically set out how it intends to ensure sustainable, long term funding for the hospice sector.¹⁴ We would like to government to commit to providing the children's hospice grant during the transition to the new funding system and to do so on a long-term basis. Currently it is committed to on a year-on-year basis. Our survey in 2015 found that 89% of children's hospice organisations may be forced to reduce their services if this grant stops.¹⁵ The grant should be increased to reflect inflation and the increasing demand for children's palliative care services from the growing number of children and young people with life-shortening conditions.

5. We have four measures of success for a new funding approach:

I. Every baby, child and young person with a life-shortening or life-shortening condition - and their family - has access to palliative care services, which are sustainable and fairly funded.

II. The new approach reimburses providers of children's palliative care according to the activity they undertake.

III. CCG commissioning of the general clinical aspects of children's palliative care through an NHS currency - and subsequently any tariff - complements NHS England's commissioning of specialised children's palliative care and local authorities' commissioning of the social elements of children's palliative care; together, this should create an overarching system whereby providers are commissioned for providing all of the elements of children's palliative care - including the clinical and non-clinical aspects of short breaks (respite) and bereavement care.

IV. The approach provides a clear incentive for both commissioners and providers to make sure that palliative care is provided in a child's home, in the community or in children's hospice settings - if this is consistent with the child or their family's preferences and is clinically appropriate.

6. Children's palliative care in England is funded by:

¹³ Steele R. (2000) Trajectory of certain death at an unknown time: children with neurodegenerative LTC illnesses. *Cancer Journal of Nursing Research* 32, 49-67.

¹⁴ House of Commons Health Committee (2015). End of Life Care Fifth Report of Session 2014–15: report together with formal minutes relating to the report. Available to download from: <http://bit.ly/1N5ehV4>

¹⁵ Ibid

- NHS England, which should commission specialised children's palliative care consistent with its own service specification Eh38; NHS England also provides the £11million children's hospice grant.
- CCGs, which should commission general children's palliative care.
- local authorities, which should commission the social elements of children's palliative care (such as short breaks and bereavement care for siblings and families).

As part of the new special educational needs and disability (SEND) system, services also receive statutory funding from personal budgets which meet agreed outcomes in education, health and/or care.

Consistent with the aims of the SEND reforms, the government should make sure that funding for children with life-shortening conditions from health, social care and education is co-ordinated and complementary - and not siloed into different government departments. Funding should also be focussed on improving outcomes for children, young people and their families.

Enabling local authorities to increase funding for short breaks for disabled children

7. We are disappointed that the government's new **2% Council Tax precept that local authorities can levy is to be limited to adult social care**. The needs of children with life-shortening conditions are ignored in this formulation as the extra funding will not be extended to children's services. With local authorities struggling to cope with rising demand, social care services that families rely on to keep going, including short breaks, will become much more scarce. Our 2015 survey found that over half (58%) of children's hospices found it either difficult or very difficult to apply for short breaks services.¹⁶ This will become even more difficult amid the cuts that local authorities face. We would like the government to set out how funding will be directed to local areas to support them to provide the range of services required to deliver high-quality children's palliative care.

8. In December 2010 the government committed £800m in funding for short breaks to make sure local authorities could meet their legal duties under The Regulations for Breaks for Carers of Disabled Children 2011 over the course of the parliament. However, the Every Disabled Matters (EDCM) partnership found that 58% of local authorities who responded to their freedom of information requests had **cut their short breaks spending during this period**, by an average of 15%.¹⁷ This has a direct impact on families - the same survey found that only 9% of respondents to the survey of parent carers agreed or strongly agreed that families with disabled children can access the short breaks they need. We would like the government to repeat the £800m funding and

¹⁶ Ibid.

¹⁷ Every Disabled Child Matters (2015). Short Breaks in 2015: An uncertain future. Available to download from: <http://bit.ly/1OTPWyt>

to provide guidance to local authorities on how this funding should be used.

Providing seed-funding to voluntary sector organisations to set up age-appropriate services for young people transitioning from children’s to adult’s services

9. Medical advances mean more young people with a range of life-shortening conditions are living into adulthood. There are 56,000 young adults aged between 18 and 40 with life-shortening conditions and this figure continues to grow.¹⁸ The transition from the comprehensive care offered by children’s services to unfamiliar adults’ services can be daunting as they have to forge relationships with new agencies and professionals. Furthermore, for many young people with life-shortening conditions, this transition coincides with a rapid decline of their condition and eventual death. As such, they have specific needs which differ from both younger children and older adults, yet there is a lack of age and developmentally-appropriate palliative care services for these young adults. We would like the government to commit to provide seed-funding to stimulate voluntary sector organisations to provide these services.

Changing the eligibility criteria for the mobility component of Disability Living Allowance (DLA) so that children with life-shortening conditions can access adapted vehicles

10. The government’s DLA benefit recognises that families of disabled children over the age of three may need financial support to access appropriate transport. Families can apply for the DLA ‘mobility component’, available at a higher and lower rate.

11. The principle underpinning DLA is that payments are made to families who incur extra costs as a result of meeting the additional care and/or mobility needs of a disabled child.¹⁹

12. In setting the lower age limit for entitlement, DWP considered views of medical advisors and independent research that the majority of children could walk at the age of 2½. By the age of 3 it was realistically possible in the majority of cases to make an informed decision as to whether an inability to walk was the result of disability.

13. However, babies and young children under the age of three with life-limiting conditions often depend on ventilators, large equipment or other types of technology to stay alive. This equipment is big and heavy. Some babies and young children have permanent wheelchairs and are not able to use buggies suitable for well children of the same age. These wheelchairs are heavy because of the equipment and they need to be fixed into a vehicle.

¹⁸ Fraser LFK, Miller M, Aldridge J, PA, Parslow RC (2013). Prevalence of life-shortening conditions in young adults in England 2000-2010; final report for Together for Short Lives. Available to download from: <http://bit.ly/1z24VQQ>

¹⁹ Sourced from the answer to a written parliamentary question tabled by Sarah Wollaston MP (13360, 26 October 2015) and answered by Justin Tomlinson MP on 2 November 2015.

14. These additional mobility needs are already recognised in other areas of government policy: children under the age of three who depend upon bulky medical equipment, or need to be near their vehicle in case they need emergency medical treatment are eligible for a blue parking badge.

15. Giving this group of children access to the mobility component would enable their families to access an adapted car. Using a blue badge, families could park their car close by, meaning that they could get their child to a place of safety and care quickly and without delay in an emergency.

16. A freedom of information request made of the Department for Transport in 2014 showed that there were just 1,530 'children under the age of three who are dependent upon bulky medical equipment, or need to be near their vehicle in case they need emergency medical treatment' who have a blue parking badge in each upper-tier local authority in England. This is the same group of babies and young children who we would like the DLA mobility component to be extended to. If all were accessing the higher rate mobility component of £57.45, this would be an annual weekly investment of £87,898.50 - or £4.57million per year; the spending would be offset by savings in the NHS: paediatric hospital beds would be freed-up as families were able to transport their children to other care settings, such as their home or a children's hospice.

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3. Press articles

Guardian, 13 May 2016

[Palliative care for children should not be a bewildering lottery;](#)

[Commissioners should ensure that everyone, everywhere is offered the same level of care regardless of their age or complexity of diagnosis](#)

Nursing Times, 21 March, 2016 *

[Better endings: a review of end-of-life services](#)

Social Care Institute for Excellence (SCIE), 18 March 2016

[Supporting children and young people with life shortening conditions - & their families](#)

Independent, 12 January 2016

[The UK's crisis in palliative care for children makes the Give to GOSH appeal vital and timely](#)

Guardian, 9 July 2015

[How schools support children with life-limiting illnesses](#)

One child in every 270 has a condition that is life-threatening or life-limiting.

Nursing Times, 23 June, 2015 *

[Nursing for terminally ill children let down by lack of resource](#)

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4. Parliamentary questions, debates and EDM

4.1 PQs

[Palliative Care: Children](#)

Asked by: Tracey, Craig | **Party:** Conservative Party

To ask the Secretary of State for Health, if he will take steps to ensure that all health and social care staff involved in providing care to children and young people with life-shortening conditions receive specialist training.

Answering member: Ben Gummer | **Party:** Conservative Party | **Department:** Department of Health

A review of the allocation methodology of the annual children's hospice grant is being considered to support an equitable, transparent and evidence based formula making use of data from all children's hospices in 2016/17. The aim is to provide clear advice to hospices on the grant for 2016/17 and a proposed way forward to review the formula and how hospices can contribute to that process.

Adult hospices, including voluntary sector hospices, receive on average around a third of their funding from the National Health Service and it is for local commissioners to ensure that the services they commission meet the needs of their local populations, including in end of life care.

Clinical commissioning groups (CCGs) have responsibility for ensuring that they are meeting the needs of those requiring children's palliative care services, considering the full range of local provision, both statutory and voluntary sectors, and the wishes of children and young people and their families. CCGs will need to make sure that they provide information on the support available locally for children with palliative care needs and their families.

Many maternity units have specialist bereavement midwives and dedicated bereavement suites to support parents but we know that this support is not available in every unit and we are currently considering the actions that we can take to improve bereavement services further. For families of older children and young people chaplaincy services may be able to provide support.

It is the responsibility of the professional regulators to set the standards and outcomes for education and training and approve training curricula to ensure newly qualified healthcare professionals are equipped with the knowledge, skills and attitudes to provide high quality patient care. It is the responsibility of employers to ensure staff receive appropriate development to deliver safe and effective healthcare. This includes training in providing care to children and young people with life-shortening conditions.

[Palliative Care: Young People](#)**Asked by:** Timms, Stephen

To ask the Secretary of State for Health, what steps he is taking to support young people who have been receiving palliative care and are transitioning from children's to adults' services.

Answering member: Ben Gummer

The Department has provided grant funding to Together for Short Lives which is the membership organisation for children's hospices to support the Transition Taskforce to provide guidance and training that supports good transitions locally between children's and adult services for those with life-limiting conditions or needing palliative care.

11 Feb 2016 | Written questions | 26248

[Palliative Care: Children](#)**Asked by:** Phillipson, Bridget | **Party:** Labour Party

To ask the Secretary of State for Health, pursuant to the Answer of 28 October 2015 to Question 12730, what steps his Department is taking to improve palliative care for children in England.

Answering member: Ben Gummer | **Party:** Conservative Party |**Department:** Department of Health

NHS England has continued to provide £11 million to children's palliative care providers through the annual Children's Hospice and Hospice-at-Home Grant.

The Department has also provided grant funding to 'Together for Short Lives' to support the Transition Taskforce, which is developing improved approaches to providing care and support to young people with life-limiting or life-threatening conditions.

NHS England has led work on behalf of the Government in developing draft currencies for palliative care (for all ages) which are now being tested with provider organisations. The aim is to put funding for children and adult hospices on a more equitable and sustainable footing, by clearly identifying the costs of care, so that it can be commissioned locally by clinical commissioning groups.

17 Dec 2015 | Written questions | Answered | House of Commons | 19794

4.2 Debates

[End of Life Care](#)

02 Mar 2016 | HC Deb | 606 cc1060-1042

[Access to Palliative Care Bill \[HL\]](#)

23 Oct 2015 | HL Deb | 765 cc908-945

[Children's Palliative Care](#)

03 Mar 2015 | HC Deb | 593 cc271-9WH

[Hospices \(Children and Young People\)](#)

18 Dec 2013 | HC Deb | 572 cc251-276WH

4.3 EDM

[CHILDREN'S HOSPICE WEEK 23 TO 29 MAY 2016](#)

That this House welcomes and supports the advent of Children's Hospice Week, the UK's awareness and fundraising week for the 49,000 children and young people with life-shortening conditions, their families and the palliative care services that support them; recognises the huge contribution that hospices and children's palliative care charities play in supporting the most vulnerable children and their families; further recognises that, overwhelmingly, the majority of funds to support this vital care is not through the NHS but through generous public donations; notes that whilst statutory funding and support for these children with the most complex conditions is patchy and unsustainable, the number of children and young people with life-shortening conditions is increasing; further notes that clinical commissioning groups (CCGs) and other funders have a limited knowledge of this population and that local authorities are funding fewer and fewer short breaks which provide vital respite for families; and calls on the Government to ensure that children with short lives are not short changed and that adequate long-term funding and support is provided through CCGs and others to ensure a quality of life and a quality of death for these children and young people that befits a good society and puts families first.

23 May 2016 | Early day motions | Open | House of Commons | 54
(session 2016-17)

Primary sponsor: Tami, Mark | **Party:** Labour Party

5. Further reading

Together for Short Lives:

- [A Core Care Pathway for Children with Life-limiting and Life-threatening Conditions](#) (2013)
- [List of childrens' hospices/palliative care support in the UK and map of services;](#)
- [Jointly commissioning palliative care for children and young people aged 0-25 including short breaks: a guide for local areas in England](#) (2015);
- [Commissioning children's palliative care A guide for NHS Clinical Commissioning Groups](#) (2015); and
- [Commissioning and statutory funding arrangements for hospices in England Survey results](#) (2015)

Department of Health, [National Framework for Children and Young People's Continuing Care](#) (February 2016)

Department for Education / Department of Health, [0 to 25 SEND code of practice: a guide for health professionals, Advice for clinical commissioning groups, health professionals and local authorities](#) (March 2016)

Department for Education, [Supporting pupils at school with medical conditions](#), Statutory guidance for governing bodies of maintained schools and proprietors of academies in England (April 2014)

Department for Education, [Education for children with health needs who cannot attend school](#), Statutory guidance for local authorities and departmental advice for others ensuring children with health needs receive education (May 2013)

Department for Education, [Short breaks for carers of disabled children – Departmental advice for local authorities](#) (2011)

Every Disabled Child Matters, [Challenging cuts to short break services](#) (January 2015)

[The Association for Paediatric Palliative Medicine \(APPM\)](#)

[The Council for Disabled Children](#)

NHS England, [2013/14 NHS Standard Contract for Paediatric Medicine: Palliative Care](#)

NICE, [Clinical guideline on end of life care for infants, children and young people](#) (expected publication date end of 2016)

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