



DEBATE PACK

Number CDP-0010, 28 January 2019

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

Summary

A Westminster Hall debate on support for children with life-limiting and life-threatening conditions and their families has been scheduled for 29 January 2019 at 9.30am. It will be led by Jim Shannon MP.

This debate pack contains a Library summary of the issues, relevant reports, press and parliamentary coverage, and links to further reading. The paper looks at health services in England, principally palliative care, and outlines local authorities' duties towards 'children in need.' Links to guidelines in the devolved administrations is also provided.

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.

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1. Background

1.1 Care for children and young people with life limiting conditions in England

It is estimated that more than 40,000 children and young people (aged 0-19) in England have a life-limiting or life-threatening condition.¹ In addition to the care provided by families and unpaid carers, palliative care² for children and young people with life limiting conditions are delivered by a range of health and social care providers.

A significant proportion of care is delivered in the voluntary sector, including children's hospices, which only receive part of their funding from the NHS. NHS services include medical consultants with expertise in the child's condition, and with access to specialist hospital care, and community children's nursing teams. 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 in England may also be entitled to a joint Education, Health and Care Plans. Charities working in this area include Together for Short Lives, CLIC Sargent and The Teenage Cancer Trust.

In England, clinical commissioning groups (CCGs) and local authorities are responsible for commissioning appropriate respite and palliative care services for children with life-limiting conditions. NHS England works with NHS bodies and local authorities to ensure the health and care needs of specific patient groups, including children's palliative care services, are planned collaboratively. This includes working with commissioners, clinicians, voluntary, community and social enterprises, local authorities and people with lived experience, reflecting collective responsibilities across health and social care. Recent PQ responses note that work to refresh the children's palliative and end of life care service specification and the commissioning pathway is expected to continue until spring 2019.³

CCGs are expected to commission services in accordance with the [National Institute for Health and Care Excellence](#) guideline *End of life care for infants, children and young people with life-limiting conditions*. To support implementation of the guidance [NHS England](#) commissioned [Together for Short Lives](#), a leading children's end of life care charity, to examine services across the country to identify best practice in implementation of the guidance, as well as barriers, through interviews

¹ 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/wp-content/uploads/2018/01/ExRes-Childrens-Hospices-Ethnicity-Report-Leeds-Uni.pdf>

² 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.

³ <https://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Commons/2018-11-21/194164/>

with local NHS services. More information about this work can be found at the following link:

www.togetherforshortlives.org.uk/changing-lives/supporting-care-professionals/introduction-childrens-palliative-care/nice-guidelines/

The NHS website provides information on [How to care for children with complex needs](#). Together for Short Lives note that many children with life-limiting or life-threatening conditions need the same universal services as disabled children. However, they add that the increased likelihood or certainty of death in childhood or young adulthood for a child with a life-limiting or life-threatening condition adds a degree of complexity and urgency to the care that is needed for the child, and the increased support that is needed for the family.⁴

NICE guideline

The [National Institute for Health and Care Excellence \(NICE\)](#) guideline *End of life care for infants, children and young people with life-limiting conditions* was published in December 2016. This guidance includes details on the planning and management of end of life and palliative care for infants, children and young people (aged 0–17 years) with life-limiting conditions. It aims to involve children, young people and their families in decisions about their care, and improve the support that is available to them throughout their lives.⁵

This guideline includes recommendations on:

- [Advance Care Planning](#)
- [emotional and psychological support and interventions](#)
- [managing distressing symptoms](#), such as [pain](#), [agitation](#), [seizures](#) or [respiratory distress](#)
- [hydration](#) and [nutrition](#)
- [recognising that a child or young person is likely to die within hours or days](#)
- [care and support for parents, carers and healthcare professionals after the death of a child or young person](#)
- [care at home](#)

NICE have also published a [Quality Standard](#) for infants children and young people's end-of-life care (September 2017), which includes the six following 'quality statements':

[Statement 1](#) Infants, children and young people with a life-limiting condition and their parents or carers are involved in developing an advance care plan.

⁴ Together for Short Lives [A Guide to Children's Palliative Care](#), 2018 (4th edition)

⁵ The NICE guideline does not cover children and young people without a life-limiting condition who die unexpectedly (for example, accidental death).

[Statement 2](#) Infants, children and young people with a life-limiting condition have a named medical specialist who leads and coordinates their care.

[Statement 3](#) Infants, children and young people with a life-limiting condition and their parents or carers are given information about emotional and psychological support, including how to access it.

[Statement 4](#) Infants, children and young people with a life-limiting condition are cared for by a multidisciplinary team that includes members of the specialist paediatric palliative care team.

[Statement 5](#) Parents or carers of infants, children and young people approaching the end of life are offered support for grief and loss when their child is nearing the end of their life and after their death.

[Statement 6](#) Infants, children and young people approaching the end of life and being cared for at home have 24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care.

Government commitments for end of life care

In 2016 the Department of Health published '[Our Commitment to you for end of life care](#)', it's response to the Review of Choice in End of Life Care. This stated that 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." The Commitment reflects that "...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."⁶

The commitment for end of life care document highlights the differences between adult and children's end of life care. It recognises that children's palliative care can be longer term, and is particularly dependent on this good collaboration between clinical and non-clinical services across a variety of settings:

There are recognised differences between adults' and children's end of life care. Often, the type and complexity of the condition, the duration of illness, the involvement of the whole family, the need for ongoing access to education and employment and the changing development of the child throughout present particular challenges for children's end of life care. On top of these difficulties, care delivery can be more challenging as there are fewer patients over a larger geographical area.

Moreover, thanks to improvements in medical science, children with complex needs and life-limiting conditions are now living into adulthood in ways which were seldom possible in the early years of the children's hospice movement. As a result, without necessarily requiring end of life care, children and their families can benefit immensely from access to expert care and support, including respite care, delivered in a children's hospice setting, by community palliative care services, or 'hospice at home' services.

⁶ DH, [Our Commitment to you for end of life care](#), July 2016

Children's palliative care is particularly dependent on good collaboration between different clinical and non-clinical services across a variety of different settings. These might include community children's nursing, paediatric inpatient services, specialist palliative care consultant-led teams, hospices, GPs and the wider network of supporting services such as school services and the voluntary sector, including Together for Short Lives, CLIC Sargent and the Teenage Cancer Trust. Community-based services and forms of support for children and their families can provide the kind of flexibility, responsiveness, continuity of care and care coordination that support children to have independence and choice. As children with life-threatening or life-limiting conditions live more and more into adulthood, continuity and coordination are all-important in ensuring that the transition from child to adult end of life care services is smooth.⁷

The commitment also notes the importance of bereavement services for families, especially parents and siblings:

A further critically important component of palliative and end of life care for children and their families is support around bereavement, both before and after a child dies. The death of a child at any age is a tragedy and can have a long-term lasting impact on their families. The care and support parents and families, especially siblings, receive at this time is, of course, critically important.⁸

The Department of Health published an update, [One year on: The Government response to the review of choice in end of life care](#), in August 2017.

Together for Short Lives, A Guide to Children's Palliative Care

The children's end-of-life care charity Together for Short Lives published a new edition of their [Guide to Children's Palliative Care](#) in 2018 (the last edition was published in 2009).⁹ It sets out a vision for the future sustainable development of children's palliative care, it covers essential information on the definition and provision of children's palliative care, on service planning, workforce issues, and an enhanced section on research, acknowledging the need to expand the evidence base for children's palliative care. The introduction to the guide provides the following overview:

This fourth edition comes as children's palliative care provision is relatively well established in the UK, with a recognised medical specialty. It describes the current state of the field and advocates for the next phase of its development, for example embedding the key principles and approach of children and young people's palliative care across all levels of service and in a variety of settings. These include neonatal units, hospital wards, hospices, community paediatrics, community children's nursing teams, social care teams, in adult services and in general practice as well

⁷ *Ibid.*

⁸ *Ibid.*

⁹ Within this Guide Together for Short Lives use the term children to also refer to infants and young people.

as reaching out to members of the public to support families in their communities. It also advocates for an increase in research, as the evidence base has not kept pace with the developments in clinical provision and practice of children's palliative care.¹⁰

The Guide also sets out some of the key differences between palliative care for children and palliative care for adults:

1.1.4 Palliative care for children is different from adult palliative care in several ways:

- The number of children dying is small, compared with the number of adults.
- Many of the individual conditions are extremely rare with diagnoses specific to childhood or young adulthood.
- Many of the illnesses are familial. There may be more than one affected child in the family.
- Parents bear a heavy responsibility for personal and nursing care and siblings are especially vulnerable.
- A characteristic of childhood is continuing physiological, emotional and cognitive development. Children's palliative care providers need to understand and be responsive to the impact of a child's physiological development on handling of medications as well as each child's changing levels of communication and ability to comprehend their illness, treatments and prognosis.
- Provision of play for all children is essential and education is a legal entitlement.¹¹

However, the Guide also notes there are many elements in common between children's and adults' palliative care, such as similar approaches to symptom management and the need for care to embrace the whole family.

Expenditure on palliative care

The Government has noted that figures for the total cost of palliative care service for children are not available. Much of the palliative care patients receive will be provided either in outpatient or community settings, by nurses, community teams or general practitioners (GPs) as part of general NHS services provision, rather than as an identified palliative care service. In such services, data are either not available or does not identify palliative treatment. In addition, as noted earlier, social and voluntary sector organisations also provide support to patients at the end of life.¹²

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

¹⁰ Together for Short Lives [A Guide to Children's Palliative Care](#), 2018 (4th edition)

¹¹ *Ibid.*

¹² [PQ 33332 \[Palliative Care\], 11 April 2016](#)

£473 million. Data for subsequent years has not been published, however.¹³

Hospice UK estimates that on average children's hospices in the UK receive 15% of their funding from the Government.¹⁴ Children's hospices receive, on average, less statutory funding than adult hospices due to differences in their development and type of non-NHS supportive care they provide. A recent PQ response states that in addition to NHS funding for services commissioned locally, children's hospices will receive £11 million in 2018/19 through the Children's Hospice Grant, which is awarded and administered annually by NHS England. In the NHS Long Term Plan (7 January 2019), NHS England announced plans to increase funding for children's hospices to as much as £25 million a year over the next five years:

3.41. Children's palliative and end of life care is an important priority for the NHS. But local NHS funding has not kept pace with growth in clinical care costs or inflation, and NHS England's children's hospice grant programme currently provides an annual contribution of £11m. Over the next five years NHS England will increase its contribution by match-funding clinical commissioning groups (CCGs) who commit to increase their investment in local children's palliative and end of life care services including children's hospices. This should more than double the NHS support, from £11 million up to a combined total of £25 million a year by 2023/24.¹⁵

Palliative care policies in the rest of the UK

Scottish Government, [Strategic Framework for Action on Palliative and End of Life Care](#) (2015)

Welsh Government, [End of Life Care Delivery Plan](#) (2017)

Northern Ireland Department of Health, [A Strategy for Children's Palliative and End-of-Life Care 2016-26](#) (2016)

Statistics

Together for Short Lives report that around 40,000 children and young people in England have life-limiting conditions, with the figure for the UK of 49,000 children and young people. The latter figure is based on applying [Fraser et al's \(2012\)](#) national prevalence rates for life-limiting conditions among 0-19 year olds in England to the population of the UK aged 0-19 years. The Fraser et al rate was 32.2 per 10,000 population.¹⁶

The Fraser et al study is the only available robust study that attempts to quantify the prevalence of life limiting conditions among children and

¹³ *Ibid.*

¹⁴ ['Facts and figures'](#), Hospice UK webpage

¹⁵ [NHS Long Term Plan, 7 January 2019](#)

¹⁶ 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.

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 \(2015\)](#)

1.2 Support for ‘children in need’ (England)

What is a “child in need”?

The term “child in need” is a statutory term as set out in the *Children Act 1989* as amended (the “1989 Act”). Any child can be a “child in need”, even if they are living with their family.

There is no need for a court order to be made in order for a child to be determined as being in need. It is the role of a local authority’s children’s services department (formerly called social services) to assess and provide services in respect of children in need.

Being a child in need is not the same as being a “looked after child” (where a child is in local authority care further to a care order, or provided with accommodation by the local authority under section 20 of the 1989 Act).

A child for these purposes is defined as someone who is under 18 years of age.

Section 17 of the 1989 Act defines a child in need as follows:

- a) he is unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining, a reasonable standard of health or development

without the provision for him of services by a local authority under this Part;

- b) his health or development is likely to be significantly impaired, or further impaired, without the provision for him of such services; or
- c) he is disabled

Some support can also be provided to a child's family, namely "any person who has parental responsibility for the child and any other person with whom he has been living".

Support available to a child in need and their family

In cases where need is "relatively low level", then "individual services and universal services may be able to take swift action". However, for more "complex needs, help may be provided under section 17 of the Children Act 1989 (children in need)".¹⁷

In addition to the services that local authorities provide for all children (such as family centres and recreational activities), the 1989 Act specifies the range of services that can be made available for a child in need:

- advice, guidance and counselling;
- occupational, social, cultural, or recreational activities;
- home help (which may include laundry facilities);
- facilities for, or assistance with, travelling to and from home for the purpose of taking advantage of any other service provided under the 1989 Act or of any similar service;
- assistance to enable the child concerned and his family to have a holiday;
- maintenance of the family home if the child is in need (but is not a looked after child) and is living apart from their family (in order to either to enable the child to live with their family, or to promote contact between the child and their family);
- day care for if the child is under 5 years of age but is not yet attending school;
- care or supervised activities (either outside school hours or during school holidays) for a child attending any school;
- providing accommodation to a child and their family;
- giving assistance in kind or in cash.¹⁸ The Family Rights Group notes that "practical help (including cash) for example help to buy essential equipment for children, food and other necessities or

¹⁷ HM Government, [Working Together to Safeguard Children](#), March 2015, p15, para 15

¹⁸ *Children Act 1989* (as amended), sections 17 and 18, Schedule 2, paras 8, 10

even help with housing costs. Each Children's Services department will have its own guidance about this form of help".¹⁹

Any service listed above (except day care or care or supervised activities) may also be provided to any member of the child in need's family, "if it is provided with a view to safeguarding or promoting the child's welfare".²⁰

In response to the question, "Can I decide what support my child gets?", the Family Rights Group notes:

Not exactly. Generally,²¹ families don't have the right to insist on a particular type of support being provided and, in practice, final decisions on what help will be offered to meet the assessed needs of children in need, are often made at internal funding panels within Children's Services. You won't be invited to this meeting.²²

Charging for support provided

Local authorities are allowed to seek recoupment of the cost of providing services to a child in need and their family (except costs relating to advice, guidance or counselling). A local authority "may" recover "such charge for the service as they consider reasonable" under section 29 of the 1989 Act as amended; the use of the word "may" in the legislation means that a local authority is not under a duty to recover the costs.

In addition, if a local authority is "satisfied that that person's means are insufficient for it to be reasonably practicable for him to pay the charge, they shall not require him to pay more than he can reasonably be expected to pay".²³

The Family Rights Group notes that "to work out what is 'reasonable' they must look at your family's weekly income and expenses. They can only ask you for a contribution towards the cost of support for your child out of any income that is left".²⁴

For a child under 16 years of age, the parents of the child can be liable; for a child over 16 years of age, the child themselves can be liable. If a service is provided for a member of the child's family, the family member can be liable.

However, the 1989 Act also states that persons in receipt of certain welfare benefits and tax credits cannot be charged for services provided

¹⁹ Family Rights Group, [Family Support](#), factsheet 4, 23 March 2016, p20

²⁰ *Children Act 1989* (as amended), section 17(3)

²¹ "There are some circumstances when families do have a right to support for their children:

- Families of eligible disabled children have a right to direct payments; and
- Families of children with special educational needs who have an education, health and social care plan (EHC plan)) have a right to the support identified in the statement/plan for their children".

[Family Rights Group, [Family Support](#), factsheet 4, 23 March 2016, p21]

²² Family Rights Group, [Family Support](#), factsheet 4, 23 March 2016, p21

²³ *Children Act 1989* (as amended), section 29(2)

²⁴ Family Rights Group, [Family Support](#), factsheet 4, 23 March 2016, p27

to children in need, namely if the service was provided at a time when the person was in receipt of:

- universal credit (except in such circumstances as may be prescribed);
- income support;
- any element of child tax credit other than the family element;
- working tax credit;
- income-based jobseeker's allowance; or
- income-related employment and support allowance.²⁵

Short breaks

Under their responsibilities to promote the upbringing of children in need by their families,²⁶ local authorities should provide services that

assist individuals who provide care for such children to continue to do so, or to do so more effectively, by giving them breaks from caring.²⁷

The *Breaks for Carers of Disabled Children Regulations 2011* sets out the types of services that must be provided:

(1) In performing their duty under paragraph 6(1)(c) of Schedule 2 to the 1989 Act, a local authority must provide, so far as is reasonably practicable, a range of services which is sufficient to assist carers to continue to provide care or to do so more effectively.

(2) In particular, the local authority must provide, as appropriate, a range of—

- a) day-time care in the homes of disabled children or elsewhere,
- b) overnight care in the homes of disabled children or elsewhere,
- c) educational or leisure activities for disabled children outside their homes, and
- d) services available to assist carers in the evenings, at weekends and during the school holidays.²⁸

The Department for Education has published [Short breaks for carers of disabled children](#) (March 2011), which looks at

- who should be considered for access to breaks from caring;
- the need for local authorities to publish a 'short breaks services statement'; and
- how eligibility criteria for services should be developed and used

²⁵ *Children Act 1989* (as amended), section 29(3)

²⁶ *Children Act 1989* (as amended) section 17 (1)

²⁷ *Children Act 1989*, schedule 2, paragraph 6

²⁸ The [Breaks for Carers of Disabled Children Regulations 2011 No. 707](#), regulation 4

The charity Contact, which supports families with disabled children, has also published a briefing on [Local authority responsibilities to provide short breaks](#) (March 2016) and has a webpage on [Short breaks](#).

1.3 Devolved administrations

Scotland

The Scottish Government has published [The Children \(Scotland\) Act 1995 Regulations and Guidance: Volume 1 Support and Protection for Children and Their Families](#).

Citizen's Advice has also written a guide called [Children who need local authority services](#) which looks at Scottish local authorities' duties.

Wales

Social care legislation has recently been changed in Scotland.²⁹

The Information and Learning Hub has published an [overview of the Social Services and Well-being \(Wales\) Act 2014](#), and also provides links to the [statutory guidance accompanying the law](#).

Northern Ireland

Northern Ireland has a similar framework to England: more details can be found on the Department of Health's website, [Children in Need](#).

1.4 Further information

The Library briefing paper on [Local authority support for children in need \(England\)](#) has more information on support for children in need, including the assessment process and how to complain about a decision.

There are a number of organisations which can provide advice to parents, such as:

- Child Law Advice – childlawadvice.org.uk, 0300 330 5480
- Contact a Family (for parents of disabled children) – www.cafamily.org.uk, freephone 0808 808 3555
- Family Rights Group – www.frg.org.uk, freephone 0808 801 0366;
- Contact - <https://contact.org.uk/>, freephone: 0808 808 3555

²⁹ [Care and support in Wales is changing](#), Welsh Government website, 24 August 2017

2. News articles

[Children's hospices to receive funding boost under NHS plans](#),
Telegraph, 27 December 2018

[Dying children face 'postcode lottery' with inconsistent quality of end-of-life care, MPs warn](#), Independent, 22 October 2018

[Hospices care for 200,000 people a year, but they're powered by voluntary effort](#), Guardian, 8 October 2018

[Respite care: families at breaking point as councils slash funds](#),
Guardian, 22 August 2018

[Together for Short Lives calls for a funded and integrated national children's palliative care strategy](#), Together for Short Lives, 1 February 2018

[New data leads to call for urgent review into support for children with complex needs](#), Common Space, 15th January 2019 [Scotland]

3. Parliamentary material

3.1 Written parliamentary questions (PQs)

General

[Disability: Children](#), PQ 194150, 28 Nov 2018

Asked by: Hardy, Emma | **Party:** Labour Party

To ask the Secretary of State for Health and Social Care, what plans he has to improve the quality of health and social care services for disabled children.

Answering member: Caroline Dinéage | **Party:** Conservative Party | **Department:** Department of Health and Social Care

In 2014, the Government introduced a new statutory framework requiring local authorities and clinical commissioning groups to commission jointly services for children with special educational needs and disability, across health, social care and education. Since 2014, £327 million has been given to local areas to support implementation of these new arrangements, in addition to the high needs budget for placements for pupils with complex special educational needs.

In addition to their role inspecting providers, Ofsted and the Care Quality Commission are jointly inspecting every local area's arrangements. The inspections assess the effectiveness of joint arrangements by commissioners of health, education and social care to support children with special educational needs, with written statements of action required where improvement is needed.

Improving wheelchair access for children has been included as a 'must do' in NHS England's planning guidance for clinical commissioning groups (CCGs) for 2017/18 – 2018/19, which was issued in September 2016. Each CCG is required to set out improvement plans showing how they would halve the number of children waiting 18 weeks by Q4 2017/18 and eliminate 18 week waits for wheelchairs by the end of 2018/19.

In April 2018, we announced investment of £1.5 million in child sports prostheses across 2018/19 and 2019/20 for the provision of child sports prostheses and research.

In 2019 we will be consulting on introducing mandatory learning disability training for health and care staff.

[Disability: Children](#), PQ HL11262, 15 Nov 2018

Asked by: Lord Judd | **Party:** Labour Party

To ask Her Majesty's Government what steps they are taking to analyse (1) those elements of health and social care which need to be strengthened, and (2) those aspects of entitlements for disabled children and their families and carers which need to be clarified; and what consequent action they are taking.

Answering member: Lord O'Shaughnessy | **Party:** Conservative Party | **Department:** Department of Health and Social Care

The commissioning of health and social care services for children with disabilities is the responsibility of clinical commissioning

groups and local authorities respectively. Local commissioners are best placed to assess the needs of the local population and which areas may need strengthening. Clinical commissioning groups must ensure that they secure health services to meet the needs of disabled children to a reasonable extent.

Children's social care is the responsibility of the Department for Education. All disabled children are regarded as children 'in need' under the Children Act 1989 and may receive social care from the local authority. The Children and Families Act 2014 placed a duty on local authorities to assess whether a parent carer in their area has needs for support.

[Disability: Children](#), PQ 162033, 17 Jul 2018

Asked by: Wilson, Sammy | **Party:** Democratic Unionist Party

To ask the Secretary of State for Health and Social Care, what recent assessment has been made of the adequacy of the level of funding allocated to the provision of (a) equipment and (b) treatment for disabled children.

Answering member: Caroline Dinelage | **Party:** Conservative Party | **Department:** Department of Health and Social Care

The commissioning of health and social care services is the responsibility of clinical commissioning groups and local authorities respectively. Local commissioners are best placed to assess the needs of the local population, and commission accordingly. While waiting times for accessing some individual services for children are reported, there is no overall waiting time measure for access to services for disabled children.

Information is collected on wheelchair services; the latest published data for quarter four 2017/18 shows 82% of children whose episode of care was closed in that period received their equipment in 18 weeks or less. NHS England is working with clinical commissioning groups (CCGs) to understand what is contributing to waits above 18 weeks, and consider what actions will help to reduce these.

In 2014, the Government introduced a new statutory framework requiring local authorities and CCGs to commission jointly services for children with special educational needs and disability, across health, social care and education. Since 2014, £327 million has been given to local areas to support implementation of these new arrangements, in addition to the high needs budget for placements for pupils with complex special educational needs which is £6 billion this year – the highest it has ever been. Every local area's arrangements are being inspected jointly by Ofsted and the Care Quality Commission, in addition to their role inspecting providers.

The 2015 Spending Review made available more than £200 billion until 2020 for councils to deliver services to local communities, including for provision of social care services for disabled children. The Government is conducting a review of the relative needs and resources of local authorities that will develop a robust, up-to-date approach to distributing funding across all local authorities in England at Local Government Finance Settlements, including for children's services.

Social care

[Children: Social Services](#), PQ 208745, 22 Jan 2019

Asked by: Lammy, Mr David | **Party:** Labour Party

To ask the Secretary of State for Education, how many disabled children received social care in each of the last three years.

Answering member: Nadhim Zahawi | **Party:** Conservative Party
Department: Department for Education

The number of children in need at the 31 March 2018 with a disability recorded is published in the annual 'Characteristics of Children in need' publication. The most recent publication is available on the following link:

<https://www.gov.uk/government/statistics/characteristics-of-children-in-need-2017-to-2018> and a table summarising the last three years is attached.

[Social Services: Children](#), PQ 166434, 25 Jul 2018

Asked by: Blunt, Crispin | **Party:** Conservative Party

To ask the Secretary of State for Education, what estimate he has made of the gap between demand and provision of social care services for disabled children and their families; what steps he is taking to address any such gap; and if he will make a statement.

Answering member: Nadhim Zahawi | **Party:** Conservative Party
Department: Department for Education

Working Together to Safeguard Children (<https://www.gov.uk/government/publications/working-together-to-safeguard-children--2>) sets out how local authorities should provide effective, evidence-based services to protect and promote the welfare of children, including disabled children. The guidance was updated on July 4 2018 and states that it is better to provide services addressing needs early, rather than reacting later. The statutory duty to provide short breaks, introduced in 2011, falls on local authorities. In the transition up to 2015, £880 million was provided to local authorities; funding for short breaks is now an un-ring-fenced part of the wider local government finance settlement.

The 2015 Spending Review made available more than £200 billion until 2020 for councils to deliver the local services their communities want to see, including services for disabled children. In February, Parliament confirmed the 2018-19 settlement for local government which has provided a £1.3 billion increase in resources to local government over the next two years - £44.3 billion in 2017-18 to £45.6 billion in 2019-20. This recognises both the growing pressure on local government's services and higher-than-expected inflation levels.

The Department for Education has committed almost £270 million since 2014 in addition to the core local government funding settlement, to help local authorities learn from what works and to support improvement in the children's social care sector. This includes £200 million for the Innovation Programme, which is funding the Ealing project to provide interventions in the form of therapeutic breaks, to disabled children and young people that reduce the risk of escalation, and provide long-term solutions to children and families. Learning from innovation projects is

published on the Children's Social Care Innovation Programme website (<http://innovationcsc.co.uk>).

The government is conducting a review of the relative needs and resources of local authorities that will develop a robust, up-to-date approach to distributing funding across all local authorities in England at local government finance settlements, including for children's services. To inform the review, the Department for Education and the Ministry for Housing, Communities and Local Government have jointly-commissioned a data research and collection project on cost and demand pressures for children's services, to understand local authorities' relative funding needs. We are working towards implementation in 2020-21, while keeping this date under review as our work progresses.

Health

[Palliative Care: Children](#), PQ 205969, 15 Jan 2019

Asked by: Double, Steve | **Party:** Conservative Party

To ask the Secretary of State for Health and Social Care, what steps he is taking to ensure that (a) clinical commissioning groups and (b) local authorities take account of demand for children's palliative care in planning and funding services.

Answering member: Caroline Dinelage | **Party:** Conservative Party | **Department:** Department of Health and Social Care

Work undertaken by NHS England and system partners at a national level includes supporting sustainability and transformation partnership (STP) planning to address end of life care in all settings, providing key data on services and populations to support appropriate planning and funding of end of life care. STPs bring together National Health Service, local authorities and other partners to agree system-wide priorities, and to plan collectively.

NHS England is actively working to improve support to commissioners in funding and delivering children's end of life care, and hospice care. In April 2017 NHS England made available a new specialist palliative care currency, one for adults and one for children, to support local areas in planning and delivering services, including hospice services. The currency can help local services better understand the complexity of palliative care and the investment needed to deliver it.

NHS England also commissioned Together for Short Lives to promote the adoption of important new guidance from the National Institute for Health and Care Excellence, which sets out best practice on the care and treatment of children at the end of life.

NHS England has established an Expert Group to bring together knowledge and expertise in children's end of life care to consider the development of commissioning models suitable for this vulnerable group of patients. NHS England has identified clinical commissioning groups to pilot the new models and work is expected for completion in spring 2019.

[Palliative Care: Children](#), PQ 205854, 15 Jan 2019

Asked by: Hodgson, Mrs Sharon | **Party:** Labour Party

To ask the Secretary of State for Health and Social Care, what funding is available to support the siblings of children with palliative care needs.

Answering member: Caroline Dinéage | **Party:** Conservative Party | **Department:** Department of Health and Social Care

In December 2016, the National Institute for Health and Care Excellence (NICE) published the guideline 'End of Life Care for Infants, Children and Young People: Planning and Management'.

This guidance emphasises the need to be aware that siblings will need support to cope with their brother's or sister's condition and death and the effects of their parents' or carers' grieving. This may include social, practical, psychological and spiritual support.

To support implementation of the guidance NHS England commissioned Together for Short Lives, a leading children's end of life care charity, to examine services across the country to identify best practice in implementation of the guidance, as well as barriers, through interviews with local NHS services. More information about this work and a copy of the NICE guidance can be found at the following links:

www.togetherforshortlives.org.uk/changing-lives/supporting-care-professionals/introduction-childrens-palliative-care/nice-guidelines/
www.nice.org.uk/guidance/ng61

Hospices providing children and young people's palliative care can also provide important support to the families of those caring for children with life limiting conditions. NHS England has recently announced plans to increase funding for children's hospices to as much as £25 million a year over the next five years, as part of the NHS long term plan.

[Palliative Care: Children](#), PQ 205853, 15 Jan 2019

Asked by: Hodgson, Mrs Sharon | **Party:** Labour Party

To ask the Secretary of State for Health and Social Care, what assessment his Department has made of the needs of siblings of children with palliative care needs as part of the programme of work to deliver the Carers Action Plan.

Answering member: Caroline Dinéage | **Party:** Conservative Party | **Department:** Department of Health and Social Care

The Government is committed to making sure young carers are not left behind. While some caring can be rewarding for young carers, they can experience poorer mental and physical health and miss out on opportunities in education and employment. We want to make sure that all young carers receive the support that they need.

The Carers Action Plan aims to do this by focusing on improving the identification of young carers; improving their educational opportunities and outcomes; providing support to young carers, particularly to vulnerable children; and improving access to services.

In December 2016 the National Institute for Health and Care Excellence published the guideline 'End of Life Care for Infants, Children and Young People: Planning and Management'. The

guidance emphasises the need to be aware that siblings will need support to cope with their brother's or sister's condition and death the effects of their parents' or carers' grieving. This may include social, practical, psychological and spiritual support.

[Palliative Care: Children](#), PQ 196694, 05 Dec 2018

Asked by: McCabe, Steve | **Party:** Labour Party

To ask the Secretary of State for Health and Social Care, pursuant to the Answer of 8 November 2018 to Question 189538 on Palliative Care: Children, what processes (a) NHS England and (b) his Department have in place to assess the level of collaboration between the relevant authorities and organisations.

Answering member: Caroline Dinéage | **Party:** Conservative Party | **Department:** Department of Health and Social Care

NHS England and the Department do not currently have any processes for measuring or monitoring collaboration between services involved in delivering children's palliative care. NHS England and the Department would expect all the partners involved to be regularly talking to, and working with, relevant organisations, given their remit to identify overall local need and to join up services.

As with the vast majority of NHS services, the funding and commissioning of palliative and end of life care is a local matter over which individual National Health Service commissioners have responsibility. Local commissioners are best placed to understand the needs of local populations and commission services to meet those needs accordingly. The only exception to this are small numbers of specialist paediatric palliative care inpatient services, commissioned nationally by NHS England from eight centres across England as part of its remit to deliver specialised services.

To support effective service collaboration locally, NHS England has worked with Public Health England and the Care Quality Commission to provide bespoke end of life care data and support packs to sustainability and transformation partnerships to plan for, and improve, end of life care services.

[Palliative Care: Children](#), PQ 194164, 28 Nov 2018

Asked by: Morgan, Nicky | **Party:** Conservative Party

To ask the Secretary of State for Health and Social Care, whether he has taken steps to encourage Clinical Commissioning Groups and local authorities to jointly commission (a) short breaks for respite and (b) other children's palliative care services.

Answering member: Caroline Dinéage | **Party:** Conservative Party | **Department:** Department of Health and Social Care

NHS England and the Department expects clinical commissioning groups (CCGs) and local authorities to work collaboratively to commission appropriate respite and palliative care services for children with life-limiting conditions, to make the most efficient and effective use of health and social care funding.

NHS England's 'Choice Commitment for end of life care' document recognises that children's palliative care is particularly dependent on this good collaboration between clinical and non-clinical services across a variety of settings. NHS England has also

provided support to CCGs in this area in the form of a joint NHS 10 Point Efficiency Plan with NHS Improvement.

NHS England is also working with colleagues across the National Health Service and local authorities to ensure the health and care needs of specific patient groups, including children's palliative care services, are planned collaboratively where appropriate. This includes working with commissioners, clinicians, voluntary, community and social enterprises, local authorities and people with lived experience to refresh the children's palliative and end of life care service specification and the commissioning pathway to reflect collective responsibilities across health and social care. Work will continue on this until spring 2019.

[Palliative Care: Children](#), PQ 189832, 19 Nov 2018

Asked by: Pollard, Luke | **Party:** Labour Party · Cooperative Party

To ask the Secretary of State for Health and Social Care, if Health Education England will (a) make an estimate of the demand for nurses from voluntary sector children's palliative care organisations and (b) include that demand in its planning models.

Answering member: Caroline Dinéage | **Party:** Conservative Party | **Department:** Department of Health and Social Care

In 'Facing the Facts, Shaping the Future', Health Education England's (HEE) draft health and care workforce strategy for England, HEE set out the intention to collect workforce data and develop planning processes that recognise the full range of settings within which clinical staff are employed, which will include areas such as palliative care in the voluntary sector.

[Palliative Care: Children](#), PQ 189538, 14 Nov 2018

Asked by: McCabe, Steve | **Party:** Labour Party

To ask the Secretary of State for Health and Social Care, what steps his Department is taking to monitor how effectively (a) sustainability and transformation partnerships, (b) integrated care systems, (c) clinical commissioning groups and (d) local authorities are supporting children's palliative care in accordance with their legal duties.

Answering member: Caroline Dinéage | **Party:** Conservative Party | **Department:** Department of Health and Social Care

Sustainability and transformation partnerships and integrated care systems are made up of bodies including local authorities and clinical commissioning groups, which retain statutory responsibility for providing health and care services for the populations they serve. These include a range of services involved in children's palliative care.

NHS England and the Department would expect all of these partners to be regularly talking to, and working with, relevant organisations given their remit to identify overall local need and to join up services.

NHS England is also working with commissioners, clinicians, voluntary, community and social enterprise organisations and people with lived experience to refresh the children's palliative and end of life care service specification and the commissioning pathway, to reflect collective responsibilities across health and

social care. Work will continue on this until spring 2019. NHS England is also making available guidance across the sector to support good practice, including sharing examples.

[Palliative Care: Children](#), PQ 186396, 07 Nov 2018

Asked by: Harris, Carolyn | **Party:** Labour Party

To ask the Secretary of State for Health and Social Care, what steps he is taking to ensure that guidance given to NHS and social care commissioners on how to commission children's palliative care reflects National Institute for Health and Care Excellence guidance and quality standards.

Answering member: Caroline Dinéage | **Party:** Conservative Party | **Department:** Department of Health and Social Care

'End of Life Care for Infants, Children and Young People: Planning and Management', published by the National Institute for Health and Care Excellence (NICE) in December 2016, sets out best practice for local services to deliver end of life and palliative care for infants, children and young with life-limiting conditions. The guidance was developed with the help of children at the end of their lives, as well as their brothers and sisters, in order to reflect what they felt was important from their care.

Local commissioners, who are responsible for delivering the majority children's palliative and end of life care, should take NICE guidance into account when planning services for local populations. To support implementation of the guidance NHS England commissioned Together for Short Lives, who are the leading children's end of life care charity to examine services across the country to identify best practice in implementation of the guidance, as well as barriers, through interviews with local NHS services. Together for Short Lives has now provided a suite of solutions to enable local areas to meet the needs of children at the end of life. More information about this work can be found at the following link:

www.togetherforshortlives.org.uk/changing-lives/supporting-care-professionals/introduction-childrens-palliative-care/nice-guidelines/

In September 2017 NICE published a Quality Standard (QS), based on its clinical guideline on end of life and palliative care in for infants, children and young with life-limiting conditions. Qs are important in setting out to patients, the public, commissioners and providers what a high-quality service should look like in a particular area of care. Whilst providers and commissioners must have regard to NICE Qs in planning and delivering services, they do not provide a comprehensive service specification and are not mandatory. Both the clinical guideline and QS can be found at the following links:

www.nice.org.uk/guidance/ng61

www.nice.org.uk/guidance/qs160

[Palliative Care: Children](#), PQ 179138, 18 Oct 2018

Asked by: Eagle, Ms Angela | **Party:** Labour Party

To ask the Secretary of State for Health and Social Care, pursuant to the Answer of 11 October 2018 to Question 76002 on

Palliative Care: Children, what the value of funding was that was allocated to the eight centres for the delivery of specialised paediatric palliative care services.

Answering member: Caroline Dinéage | **Party:** Conservative Party | **Department:** Department of Health and Social Care

There are 10 centres across the country currently delivering children's specialised palliative care services. These are:

- Alder Hey Children's NHS Foundation Trust;
- Birmingham Women's and Children's Hospital NHS Foundation Trust;
- Cambridge University Hospitals NHS Foundation Trust;
- Great Ormond Street Hospital for Children NHS Foundation Trust;
- Guy's and St Thomas' NHS Foundation Trust;
- Leeds Teaching Hospitals NHS Trust;
- Sheffield Children's NHS Foundation Trust;
- Shrewsbury And Telford Hospital NHS Trust;
- Taunton And Somerset NHS Foundation Trust; and
- University Hospitals Bristol NHS Foundation Trust.

Given the way in which paediatric specialised palliative care is commissioned, it is not possible to separate or break down the related expenditure at each of the 10 hospitals from within the NHS England accounts.

In the previous answer given on 11 October, we incorrectly stated that there were eight centres which deliver specialised paediatric palliative care services. NHS England has advised that the correct figure is 10 centres and we will arrange for the record to be corrected.

[Disability: Health Services](#), PQ 166436, 25 Jul 2018

Asked by: Blunt, Crispin | **Party:** Conservative Party

To ask the Secretary of State for Health and Social Care, if he will establish a disabled children's fund to improve health services for disabled children.

Answering member: Caroline Dinéage | **Party:** Conservative Party | **Department:** Department of Health and Social Care

The commissioning of health and social care services for children with disabilities is the responsibility of clinical commissioning groups and local authorities respectively. Local commissioners are best placed to assess the needs of the local population, and to mitigate any shortfalls.

In 2014, the Government introduced a new statutory framework requiring local authorities and clinical commissioning groups to commission jointly services for children with special educational needs and disability, across health, social care and education. Since 2014, £327 million has been given to local areas to support implementation of these new arrangements, in addition to the high needs budget for placements for pupils with complex special educational needs which is £6 billion this year, the highest it has ever been.

Every local area's arrangements are being inspected jointly by Ofsted and the Care Quality Commission, in addition to their role inspecting providers.

There are no plans to establish a disabled children's fund. Funding for the National Health Service will grow on average by 3.4% in real terms each year from 2019/20 to 2023/24; by 2023/24 the NHS budget will increase by over £20 billion a year in real terms compared with today.

3.2 Oral parliamentary questions

[Disabled People: Social Care](#), HL deb 20 Feb 2018 volume 789, c12

Asked by: Baroness Brinton (LD) | **Party:** Liberal Democrats

My Lords, the charity Together for Short Lives last year put in a Freedom of Information Act request and found that one in five local authorities and one in six CCGs have absolutely no provision for respite care short breaks for the most seriously ill and disabled children. Since then we have received reports from across the country of more and more centres under threat or actually closing, such as Nascot Lawn, which I have raised in your Lordships' House before, which is in court again tomorrow to try to save it. What is happening about this social care and nursing care provision for children? Normally, for adults, there is a negotiation between the NHS and the local authority

about what is nursing and what is social care. But for these children there seems to be no such relationship; both local authorities and the NHS just point fingers at each other, and the result is children and their families not getting breaks.

Answered by: Lord O'Shaughnessy | **Party:** Conservative Party

I am very aware of this issue. Indeed, we have had the opportunity to speak about it in specific cases. Local authorities of course are obliged to provide respite care. The noble Baroness highlights an important point about care, which seems in a way to slip between the boundaries of the two. I shall write to her about the general policy work that is going on, but I know that we need to solve this because we have children who are now living longer who before might not have lived so long and who require care, as do their families. It is essential that they get the care that they deserve.

[Carers: Health and Well-being](#), HL deb 12 Jun 2018, volume 791 c1577

Asked by: Lord Touhig (Lab) | **Party:** Labour Party

My Lords, almost 50,000 babies, children and young people need palliative care, yet children's hospices receive less statutory funding than adult hospices, and the lack of collaboration between support services is a major challenge. Carers and those they care for would benefit if we had a children's palliative care strategy that was family-centred and had a holistic focus on health, education and social care. Does the Minister agree with that?

Answered by: Lord O' Shaughnessy | **Party:** Conservative Party

Children's hospices do an extraordinary job. They get less statutory funding as a percentage of their total; there are good

reasons for that, both historically and to do with the type of care they provide. The Government are providing £11 million of support in 2018-19 through the children's hospices grant to support them, in addition to funding from local clinical commissioning groups. But I will take his proposal for a palliative care strategy back to my right honourable friend the Minister for Care. I know that she is very interested in this issue.

3.3 Debates

[Carers Action Plan 2018-20: Supporting Carers Today](#), HL deb 21 June 2018, volume 791, cc2104-2134

[Disabled People](#), HL deb 28 June 2018, volume 792, cc299-336

[Support for Life-shortening Conditions](#), HC deb 07 June 2016, volume 611, cc31WH-56WH

3.4 Early Day Motions

[Support for Children's Hospices in England](#), EDM #1564, Tabled 04 September 2018, 2017-19 Session

That this House notes that across England, 40,000 babies, children and young people with life-limiting and life-threatening conditions rely on palliative care to enhance their quality of life, manage symptoms and provide their families with much needed help and rest; expects demand for children's palliative care to grow as the number of children with life-limiting conditions increases; is concerned that the funding for services has not kept pace with this demand and has become a postcode lottery; further notes the NICE calculation that investing £12.7 million in end of life care for infants, children and young people, would release non-cash savings worth £34.7 million back into the NHS in England and therefore calls on the Government to increase the Children's Hospice Grant to at least £25 million per year, which would cover 14 per cent of the cost of the clinical care provided by children's hospices, equal to the contribution originally made by the Department of Health in 2006; and urges the Government to address the funding disparity between children's and adult hospices, whereby children's hospices currently receive only 22 per cent of their funding from statutory sources, compared to 33 per cent in adult hospices and put in place a funded children's palliative care strategy to ensure that seriously ill children can access the care and support they need, when and where they need it, in hospitals, children's hospices and in the community.

3.5 Parliamentary publications

[Deposited Paper DEP2018-0371](#), 08 Mar 2018

- Letter dated 08/03/2018 from Lord O'Shaughnessy to Baroness Brinton regarding the provision of respite care short breaks for the seriously ill and for disabled children.

4. Further reading

4.1 Official/public material

[Sector-specific guidance: Hospices for Children and Young People](#), CQC, 2018

[Carers action plan 2018 to 2020: supporting carers today](#), Department of Health and Social Care, 5 June 2018

[End of life care for infants, children and young people: Quality standard](#), NICE, September 2017

[Palliative and end of life care report for children and young people in the West Midlands: Commissioned by NHS England](#), The Strategy Unit, August 2017

[One year on: The Government response to the review of choice in end of life care](#), Department of Health, August 2017

[Guidance for using the Children's Palliative Care Currency](#), NHS England, 2017

[End of life care for infants, children and young people with life-limiting conditions: planning and management](#), NICE, 7 December 2016

4.2 Sector comment

[A Guide to Children's Palliative Care: supporting babies, children and young people with life limiting and life threatening diseases: Fourth edition](#), Together for Short Lives, November 2018

[End of life care: strengthening choice: an inquiry report by the All Party Parliamentary Group \(APPG\) for children who need palliative care](#), APPG, October 2018

[Synopsis: International digest of children's palliative care research abstracts](#), Together for Short Lives, July 2018

The Council for Disabled Children has published some relevant reports:

- [Understanding the needs of disabled children with complex needs or life limiting conditions](#) (February 2017 - a review of national data)
- [Children and Young People's views on the NHS constitution](#) (March 2015)

Wales

[Hospice Care in Wales 2018](#), Hospice UK, December 2018

[Inquiry: Inequalities in access to hospice and palliative care](#), Cross Party Group Hospices and Palliative Care, July 2018

Scotland

[Children's Hospices across Scotland: reaching every family in Scotland 2017-2020](#), CHAS, 2017

[Meeting local and national priorities for adults and children with terminal and life shortening conditions in Scotland: A Hospice UK Briefing](#), Hospice UK, December 2017

[A children in Scotland evaluation of the Diana Children's Nurse Service: Final report](#), Children in Scotland, November 2017

4.3 Library publications

[Children's social care in England](#), Commons Library debate pack, 15 January 2019

[Supporting children in need into adulthood](#), Commons Library debate pack, 5 September 2018

[Findings of the Care Crisis Review](#), Commons Library debate pack, 4 September 2018

[Support for Carers](#), Lords Library debate pack, 14 June 2018

[Carers](#), Commons Library briefing paper, 23 November 2017

[Support for children and young people with life-shortening conditions](#), Commons Library debate pack, 2 June 2016

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