

Response ID ANON-4PNA-9RQ8-7

Submitted to **Children in need of help and protection: call for evidence.**

Submitted on **2018-06-01 13:50:03**

Confidentiality of responses

1. Key Information

Name

Add details in the text box provided below:

Lyndon Ashmore

Organisation

Add details in the text box provided below:

Together for Short Lives

Email address

Add details in the text box provided below:

lyndon.ashmore@togetherforshortlives.org.uk

What is your role?

Please specify:

Other

Other-please specify:

Campaigns Officer

Where do you work?

Please specify:

Other

Other - please specify:

Based in South West, but represent members nationwide

How long have you been in a role where you are working with Children in Need?

Please specify:

Less than 1 year

In what capacity are you responding to this call for evidence?

Please specify:

On behalf of my organisation

Which age group of children and young people do you work with?

All

Which classifications do the children you work with fall under?

Disabled children

Which of these best describes the focus of your role?

Please specify:

Other

Other- please specify:

Representing organisations and services that directly work with or support children with life-limiting conditions

May we contact you if we have any follow-up questions?

Please specify:

Yes

In sharing findings from the call for evidence, may we name you/your organisation if we quote your response publicly?

Please specify:

Yes attributable to my organisation

2. Priorities and focus

1 Describe your priorities in what you do to support Children in Need to improve their educational outcomes.

Add details in the text box provided below:

Together for Short Lives is the UK charity for children's palliative care. We are here to support and empower families caring for seriously ill children, and to build a strong and sustainable children's palliative care sector – so that no family is left behind.

Together for Short Lives represents over 1,000 members, including children's hospices, voluntary sector organisations and statutory service providers. We provide a unified voice for the sector, and help services deliver the best quality care and support tailored to each family's needs.

Children's palliative care is about promoting the best possible quality of life and care for every child with a life-limiting or life-threatening condition and their family. Palliative care for children and young people is an active and total approach to care, from the point of diagnosis, throughout the child's life, and beyond their death. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the whole family. It is not just about managing pain and symptoms, but also incorporates the support networks and services that help families of children with life-limiting conditions more broadly.

Children with life-limiting conditions will likely have complex needs and require ongoing medical and social support, which will fluctuate throughout the development of the child. Children with life-limiting conditions are also unlikely to achieve a reasonable level of health and their development is therefore likely to be impaired, placing them within the definition of Children in Need.

There are 49,000+ seriously ill children with different levels of need and different levels of engagement with services. Many of these children will go on to access education and will require extra help and support from special educational needs and disability (SEND) provision.

It is vital to acknowledge that positive educational outcomes for children with life-limiting conditions are only achievable when commissioners, professionals and services take a holistic and comprehensive approach to their health and welfare.

The children's palliative care sector incorporates a wide range of professionals and services, working in children's hospices, the community and in hospitals, who will directly or indirectly have an influence on educational outcomes.

Similarly, the sector extends to different realms of public provision, including social care and transport, all of which can make a profound difference to a child's access, enjoyment and success at school.

3. Theories and research

2 To what extent do you agree with the following statement?

Please specify:

Strongly agree

3 What theories or research do you rely on to inform a plan of how to support a child?

Add details in the text box provided below:

There are a range of academic resources to support certain service provisions in children's palliative care, which we detail on our website:

<https://www.togetherforshortlives.org.uk/changing-lives/supporting-care-professionals/research-abstracts/>

Our insight into prevalence is informed by the study 'Prevalence of life-limiting and life-threatening conditions in young adults in England 2000-2010', by Lorna Fraser et al. The study found that there are 49,000+ children (aged 0-18) in the UK living with a life-limiting or life-threatening condition. The study also usefully outlines prevalence within different local authority areas, including a breakdown by ethnicity and deprivation category. We ask that commissioners and providers of health, social care and education services take the study into account when deciding how to plan and fund services for children with life-limiting conditions.

The National Institute of Health and Care Excellence (NICE) published a resource impact template alongside the guideline on end of life care for infants, children and young people. This tool allows local areas to input their population data and it calculates the overall cost and savings of implementing the new guidelines (<http://bit.ly/2k4V2jZ>).

4. Direct contact and building relationships

4 To what extent do you agree with the following statement?

Please specify:

Strongly agree

5 To what extent do you agree with the following statement?

Please specify:

Strongly agree

6 What approaches and skills do you use to build relationships with Children in Need, and how is this supported by your organisation?

Add details in the text box provided below:

In addition to providing a helpline for carers and professionals, Together for Short Lives publishes a number of resources that are specific to children's palliative care and provide guidance for professionals who are working with children with life-limiting conditions and their families.

Together for Short Lives advocates a care pathway approach to delivering care and support to children and families at whatever stage of their journey – from diagnosis to end of life and into bereavement. We also have a set of self-assessment audit tools relating to each of the pathway standards to enable teams to map how their service currently performs.

More broadly, the children's palliative care sector incorporates a huge number of professionals and services that will nurture relationships with parents and carers to help empower them to make decisions and access services that will help their child. Children's palliative care is about providing holistic support to the child and their families: from diagnosis, throughout illness and beyond death.

Through this contact and support, parents and professionals feel better equipped to deliver the care their child needs, which includes educational support.

7 What approaches and skills do you use to build relationships with adults, and how is this supported by your organisation?

Add details in the text box provided below:

Medical advances mean there are now 55,000 young adults aged between 18 and 40 with life-limiting conditions and this figure continues to grow. However, the transition these young people have to undergo from the comprehensive care offered by children's palliative care to unfamiliar adults' services can be daunting and is often not joined up.

Together for Short Lives is offering financial support to some voluntary sector organisations through our Improving Transitions for Young People Fund (<http://www.togetherforshortlives.org.uk/changing-lives/developing-services/awards-programme/>), and our Transition Taskforce worked for three years to encourage cross-sector collaboration, so young people can have a smooth transition.

Our Transition Hub also features a range of resources and best practice that we developed through this work (<http://www.togetherforshortlives.org.uk/changing-lives/developing-services/transition-adult-services/>).

Together for Short Lives would like to see more being done to prevent the 'cliff-edge' experience that so many young people have when transitioning to adult care services. We want the UK's governments to invest in seed-funding for voluntary sector organisations to set up age-appropriate services for young people transitioning from children's to adult services.

5. Assessment and decision-making

8 How do you identify a child's needs, and make decisions about what support should be in place?

Add details in the text box provided below:

Together for Short Lives does not carry out assessments of these types, but we represent a number of services and professionals that would.

Children with life-limiting conditions - and their families - will meet a number of clinical and non-clinical professionals over the course of their illness. This includes - but isn't limited to - GPs, specialist consultants, education support workers, teachers, hospice workers, and social workers.

Due to the various contact points that a child and their family will have, we think it's crucial for care networks - including health, social care and education - to be integrated and have channels established to share information on the child's condition and needs. This would equip medical, social and education professionals to make decisions about what support should be in place.

The needs of children with life-limiting conditions are not just clinical; social care also forms a crucial cornerstone in their care, with work, leisure and education being additional 'enabling agencies'. A comprehensive local children's palliative care service spans health, social care and education.

9 When deciding what support should be put in place for a child, what evidence do you use?

Add details in the text box provided below:

Together for Short Lives wouldn't make these decisions, but as representatives of the children's palliative care sector more widely, we support organisations and services that are designing support plans for children with life-limiting conditions.

These support plans are designed in concert with a number of different professionals, with children and their families coming into contact with a wide variety of service providers. This is why, as mentioned in question 8, Together for Short Lives is calling for a comprehensive and integrated networks to support the needs of children with life-limiting conditions. This would better equip professionals and carers with the tools to inform education providers as to the specific needs of children. Without this kind of information sharing, children with life-limiting conditions will find it more challenging to readily access the support they require, with a potential negative impact on their educational outcomes.

10 Where a child is disabled, or has special educational needs, what are your priorities in offering support to improve their educational outcomes? (You may refer to children with disabilities, or special educational needs, or both).

Add details in the text box provided below:

Information sharing is vital to provide the child with more rapid access to the correct support, while also diminishing the burden on parents who often have to repeat the details of the support their child requires to numerous professionals.

This could be achieved through regular liaison between education providers, families and children's palliative care professionals or by local authorities creating and coordinating better information sharing networks.

By establishing these networks, schools and carers are empowered to do what they can to support the learning needs of children in need. It would help prevent unnecessary and demoralising obstacles to education.

We would also like to see local authorities commissioning services which provide short breaks for children with life-limiting conditions. The pressure on parents of having a child with a life-limiting condition is immense, with 36% of families experiencing a breakdown (Steele R. [2000] Trajectory of certain death at an unknown time: children with neurodegenerative LTC illnesses. Cancer Journal of Nursing Research 32, 49-67). Every family's needs are different, but short breaks have been shown to relieve stress and provide these families with essential respite.

This could have a direct impact on the educational outcomes of children with life-limiting conditions and their brothers and sisters. Children perform better in educational settings when their lives are free of added stress and strain and, similarly, families are then free to provide more support and guidance.

Additionally, just securing access to education can be challenging for parents of children with complex needs. Children with life-limiting conditions often require specialist, adapted or broad base vehicles for transport which, without financial support, are often beyond the reach of their families. We think it's essential to establish sustainable and accessible mobility help for children with life-limiting conditions. Providing reliable access to education is a simple way to improve educational outcomes.

6. Working with other professionals

11 How do you work with other agencies to improve the educational outcomes of Children in Need?

Add details in the text box provided below:

Together for Short Lives represents over 1,000 members as well as parents, carers and professionals working for children with life-limiting conditions. We also provide resources and case studies for schools, colleges and early-years providers to help them support these children in their educational outcomes.

This includes our resource 'Helping children who need palliative care to access education'

(<https://www.togetherforshortlives.org.uk/resource/helping-children-need-palliative-care-access-education/>), which outlines key actions schools can take to engage families; collaborate with organisations; plan provision; and support the school community. This resource describes the steps available to education providers who want to encourage positive educational outcomes for children and also ensure that the learning environment works well for every pupil and member of staff.

In 2015/16, Together for Short Lives carried out a project which aimed to make sure that children with life-limiting conditions - and their families – benefited from the new special educational needs and disability (SEND) system

(<https://www.togetherforshortlives.org.uk/resource/send-helping-children-access-education-report/>). With funding from the Department for Education we hosted four regional events designed to share ways education providers can help children who need palliative care access education. The project gave some clear examples of what was working for education providers, and what was not - specifically within their experience of multi-agency working.

Delegates repeatedly mentioned the importance of information sharing (between schools, families and healthcare professionals), a person-centred approach, and integration between different service providers.

7. Consistency of professionals

12 In your experience, how long would someone remain working with the same child and family?

Please specify:

13 What impact does consistency of professional have on the child involved and their outcomes?

Add details in the text box provided below:

8. Supporting the whole family

14 To what extent do you agree with the following statement?

Please specify:

Strongly agree

15 What is the nature of your work with adults in the child's life?

Add details in the text box provided below:

Comprehensive children's palliative care extends beyond the child itself to their family and carers. By applying a broad approach such as this, families can feel empowered and equipped to access the care and services that are most appropriate to their child's needs. When this network is in place, the family has more time and resource to dedicate to the child, which has a direct impact on the child's opportunity to thrive in education and beyond.

Short breaks form a crucial part of this family provision. 64% of mothers and 24% of fathers will need to give up work and this, combined with the extra costs of caring for a seriously ill child, means that many families may live in poverty (https://contact.org.uk/media/805120/counting_the_costs_2014_uk_report.pdf). Children with life-limiting conditions – and their families – rely on frequent short breaks for respite to enable them to relieve this stress, spend time as a family and do the things that other families do.

UK-wide research conducted by Julia's House Children's Hospice and Bournemouth University found that most parents (74%) rated short breaks provided by children's hospices as having a direct, positive effect on their relationship with a partner, giving them rare time together as a couple (<https://www.juliahouse.org/services/campaigning>). Having these opportunities for respite means that families are better equipped to support their children to thrive in all areas of their lives.

However, as Together for Short Lives own freedom of information (FOI) requests have found (see report linked on the right-hand side of this page), too many clinical commissioning groups (CCGs) and local authorities in England are failing to plan and fund short breaks. More than one in five (21%) local authorities do not commission short breaks for children with life-limiting and life-threatening conditions, despite having a legal duty to do so. ('Commissioning children's palliative care in England: 2017') <https://www.togetherforshortlives.org.uk/changing-lives/speaking-up-for-children/policy-advocacy/childrens-social-care/>

Together for Short Lives represents organisations that provide some of these services designed to relieve the pressure on families and carers. Families of children with life-limiting conditions rely on the palliative care provided by the voluntary sector, including children's hospices. They provide the specialist care children need in a setting designed for the comfort and support of families, as well as children.

Despite the amazing work of these hospices – and the pressure they take off the NHS – these lifeline services do not receive enough money from the state. The funding they do receive is patchy between local authorities and unsustainable. We would like to see the government and NHS England increase the Children's Hospice Grant to £25million per year, to bring about funding parity between children's and adult hospice services – and make it clear to the NHS and local authorities that they are responsible for funding children's palliative care. This would help provide some security and sustainability to the services that families rely on so much.

Similarly, we represent professionals in health and social care and provide them with resources and guidance on how they can meet the best interests of the children they work with.

9. Evaluation

16 How do you measure and evaluate the impact of your work to address a child's educational outcomes?

Add details in the text box provided below:

17 How do you know your work has been successful, including any before and after measures you use?

Add details in the text box provided below:

18 Do you have comparator groups?

Add details in the text box provided below:

19 In your view, what are the areas that have a strong existing evidence base in improving educational outcomes for Children in Need?

Add details in the text box provided below:

We believe that access to holistic and comprehensive children's palliative care services can help children with life-limiting conditions to access education and achieve positive educational outcomes. We would welcome further government-funded research into the interventions which can help to improve educational outcomes specifically for children with life-limiting conditions.

20 In your view, what are the areas that need a stronger evidence base in improving educational outcomes for Children in Need?

Add details in the text box provided below:

As we set out above, we believe that access to holistic and comprehensive children's palliative care services can help children with life-limiting conditions to access education and achieve positive educational outcomes. We would welcome further government-funded research into the interventions which can help to improve educational outcomes specifically for children with life-limiting conditions.