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Give me a break

How the UK Government can improve parental health and reduce health inequalities by allocating short break funding for seriously ill children in England at the Comprehensive Spending Review

A report by Together for Short Lives and Julia's House Children's Hospice

Foreword

Families who care for seriously ill children rely on short breaks for respite provided by a range of statutory and voluntary sector organisations. However, in too many cases these families can't access the short breaks they need. Too few resources, in terms of both money and workforce, are available to children's palliative care providers to enable them to deliver short breaks. This means that too many parents are reaching physical and mental breaking point and need care and support from the NHS and other agencies. In extreme cases, their children may need to be taken into care.

The COVID-19 pandemic has worsened the situation for families of seriously ill children; it has isolated them further and removed many of the services they previously relied on. Many are in urgent need of a break from their caring responsibilities.

This report, which cites important new research from Pro Bono Economics, in association with volunteers from Compass Lexecon, proves that short breaks for respite for seriously ill children reduce the risk of parents experiencing poor physical and mental health. This reduces their demand for NHS services and the number of sick days that they need to take off work. There are significant economic benefits of short breaks which cannot be quantified accurately. These include reducing the risk of siblings - many of whom are young carers - experiencing poor physical and mental health outcomes throughout the whole of their lives. Other benefits would arise from reducing the economic impact to the state of breakdowns in parental relationships.

Seriously ill children need short breaks which can meet their often complex physical, emotional, social and spiritual needs. We estimate that in the UK, there are approximately 25,000 children who at any one time need short breaks delivered by palliative care providers.

Despite the compelling case for short breaks, prior to the coronavirus pandemic, the way in which they were planned and funded by the NHS and local authorities in England was patchy, unsustainable and depended on where families lived. In too many cases, short break commissioning is not joined up across health and social care. Research by the Disabled Children's Partnership shows that COVID-19 has significantly worsened the problem.

Making sure that parents with seriously ill children can access the breaks they need is the very least we, as a society, can do for families facing their worst nightmare. We call on the Chancellor of the Exchequer to use the Comprehensive Spending Review to create a dedicated, annual ring-fenced disabled children's social care grant from which local authorities can fund short breaks.



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Executive summary

Regular short breaks for respite that meet their complex physical, emotional and spiritual needs are a lifeline for seriously ill children and their families. They improve parents' physical and mental health and reduce their demand for NHS care. They also reduce the number of sick days parents need to take off work, improve productivity and provide additional tax revenue (see paragraphs 22-31). They are likely to have a positive impact on siblings and reduce the risk of parental relationships breaking up.

Existing legislation and government policy is clear that local councils in England should make sure families can access short breaks (see paragraphs 32-38). However, too many cannot, which is a serious health inequality (see paragraphs 39-42). The way in which short breaks are planned, funded and provided is patchy and unsustainable. Local authority funding for children's hospices was cut by 12% in 2019/20 (see paragraphs 43-50). Isolated during the pandemic without access to many of the services they previously relied on, many families desperately need a break.

Making sure that vulnerable families facing their worst nightmare can access the breaks they need is the very least we, as a society, can do. We call on the government to deliver on the benefits of short breaks by filling the £434 million gap in funding for social care services for all disabled children in England and their families by creating an annual ring-fenced grant (see paragraph 55-59). Local authorities would be able to use this money fund short breaks for seriously ill children equitably and sustainably.

- Children with life-limiting conditions – and their families – rely on frequent short breaks for respite. The pressure on parents of having a child with a life-limiting condition is immense, so short breaks which can meet their often complex physical, emotional, social and spiritual needs are vitally important to relieve this stress, spend time as a family and do the things that other families do. These are provided by a range of statutory and voluntary sector organisations, including children's hospice and palliative care charities.
- Short breaks for seriously ill children are proven to reduce the risk of their parents experiencing poor mental health. New evidence from Pro Bono Economics, in association with volunteers from Compass Lexecon, has found that 11 per cent of parents of children who need short breaks delivered by children's palliative care providers would experience a significant reduction in stress if they received them – moving them out of the 'most stressed' category of society.
- This builds on prior research by Julia's House Children's Hospice and Bournemouth University which found that most parents (74 per cent) rated short breaks provided by children's hospices as having a direct, positive effect on their relationship with a partner. The other 26 per cent all spent that time in other restorative ways.
- The new research also finds that reduced stress leads to better physical health among parents, leading to fewer GP visits. Demand for GP services declines by 8 per cent as a result of an individual moving out of the most stressed category.
- Reduced stress also leads to better mental health among carer parents, which in turn reduces the use of mental health services. Demand for mental health services falls by 49 per cent as an individual moves out of the most stressed category.
- Improved work attendance can be measured in reduced number of sick days taken, which leads to improved productivity and additional tax revenue. For every working parent who

experiences a reduction in stress, it is likely that this will reduce the number of days taken off work by around 2-3 days per year.

- **These benefits do not count the huge additional impact on the state that short breaks achieve by reducing the risk of parental relationships breaking down, helping parents to remain in work and lessening the impact on siblings.** The economic impact of parents with disabled children having to leave work, for example, is placed at £685 million per annum.
- Existing legislation and government policy is clear that local councils in England should ensure families can access short breaks. The NHS Long Term Plan sets out the need to maintain the mental health of both children and adults. Regulations set out how local councils in England must provide breaks from caring for carers of disabled children.
- However, too few local authorities in England plan and fund short breaks for children who need palliative care. The Disabled Children's Partnership (DCP), which Together for Short Lives is part of, has found that even before the COVID-19 pandemic, the core services that families with disabled children relied on were being squeezed more than ever. Families struggling with the impact of cuts were often only being offered support once they reached crisis point. **Only 38 per cent of families of disabled children were getting support from their local council or NHS such as a short break (respite) to help care for their child prior to the lockdown.** This is a serious health inequality.
- The way in which short breaks for seriously ill children are planned, funded and provided is patchy and unsustainable. For example, average funding for children's hospices in England from local authorities was cut by 12 per cent between 2018/19 and 2019/20. Children's hospices received an average of just £53,800 from their local authorities in 2019/20. This represented just 1 per cent of their average charitable expenditure. More widely, there is a £434 million funding gap in social care services for disabled children. As Together for Short Lives has also previously found, there too few professionals with the skills, knowledge and experience need to provide short breaks.
- Together for Short Lives and Julia's House Children's Hospice call for:
 1. HM Treasury to fill the £434 million disabled children's social care funding gap in England by creating an annual ring-fenced disabled children's grant. From this, local authorities would be able to make an equitable and sustainable funding contribution to short breaks for seriously ill children.
 2. The government to establish a £41 million Disabled Children's Innovation Fund. This would provide financial backing to organisations delivering ground-breaking support and approaches in early intervention, such as short breaks for respite.
 3. All organisations that provide short breaks for seriously ill children and their families to use the new evidence from Pro Bono Economics to make a case for equitable and sustainable funding. They should provide short breaks which can meet the needs of a diverse range of families, including those from all ethnic backgrounds and socio-economic groups. Only by reaching out to all seriously ill children and families can they reduce parental stress, lower demand for NHS services and improve parents' productivity. Together for Short Lives is committed to helping them to do so.

It is in no-one's interests to wait for parents of seriously ill children to split up or to experience crises in their physical or mental health.

Case study 1: Elisa and Dan

Elisa's dad Dan gave up his career to become her full-time carer after she was born with cerebral palsy. Here he talks about the impact this has had on his life – and how Julia's House have provided him with a lifeline:



Elisa, seven with her dad Dan and mum Maiju

“When you give up work to care for your child you lose your status, the support and friendship of colleagues and your income. You become so isolated it’s like falling out of society – and once you are out it is really difficult to find your way back in. I was trapped in a cycle of exhaustion and anxiety. Sleep is virtually impossible. You try not to think about it but you go to bed every night not knowing if your child will wake up in the morning.

“I would go to work worrying about Elisa, having only managed two or three hours sleep and got to the point where I just could not carry on. It became impossible to balance work with my relationship, Elisa’s care and my mental wellbeing.

“When your child has a life-threatening condition there is no peace of mind, no break from the sickening worry. It would be horrific for us if this service did not exist. With Julia’s House we always have that respite to look forward to, the hope of a bit of time to recover.

“When Elisa’s nurse and carers come to our home it is our only chance to have a meal together as family, really simple everyday stuff like that – but it’s these little things that make the difference.

“Without Julia’s House the heart would be ripped out of the care available to families like ours. Many families would be completely lost, cut adrift without a lifeline.

“When you have a disabled child an awful lot of doors close – society judges you. You constantly have to explain what’s wrong with your child and people usually just give you a wide berth. I suppose they think they are being kind by giving us some space – it’s like an invisible shield around us.

“It is hard enough going out anyway because of all the logistics: will there be changing facilities? Can we park close enough? What is the going like – sand, gravel? It is like planning a military operation. It is all too easy to just give up and not go anywhere because the thought of trying to organise everything becomes overwhelming – it’s a big part of that feeling of isolation.

“Julia’s House is the entrance into a new world full of friendship. I find it astounding that we have to rely on charity for this support; when you think what it is bringing to families – and what it saves too.

“If I had a breakdown and was unable to look after Elisa, if she had to be put in care and I needed medical support for my mental health, the financial burden on the government would be huge – just a small percentage of that cost could fund the care to stop it happening in the first place.

“It is so short-sighted that funding is focused on being reactive, not pro-active. It is mental health firefighting and is never going to win. It makes so much more sense to avoid the crisis in the first place, to be there from the beginning, supporting families before they drown.

“Knowing someone is there for you, your child, all of you, just makes the most unbelievable difference to the mental and physical wellbeing of the whole family.

“Thank God we live somewhere where this care is not only available but also free. We would never be able to afford care like this. If it hadn’t been for Julia’s House we would have had nowhere to turn.”

Case study 2: Noah and Emma

Noah's epilepsy got so bad during lockdown that he nearly died. His mum Emma was thankful to have the support of his Julia's House nurses during some traumatic and distressing days...



"Julia's House is a massive piece of a jigsaw that was missing from our lives for years. I cannot put into words what it means to us to have that support now.

"Noah has been socially disconnected being away from the Julia's House hospice and school because that is where his friendships are. Those two elements are his life and mean everything to him.

"Having care at home every week during lockdown has helped him through that – and been amazing for us. The Julia's House nurses are so respectful of our home and express their gratitude for being able to spend some time with our son. There is such warmth in everything they do.

"It has been tough for us over the past few months. Since lockdown Noah has been rushed to hospital several times – once with an air ambulance doctor who travelled with him to keep him safe. We had to prepare for the real possibility he might die. At one point he suffered 18 hours of seizures and doctors were talking about putting him into an induced coma.

"We had a tough meeting with all the medical professionals involved in Noah's care. We talked about an end of life care plan, which was very distressing for us. Having Nail and Harriet, Noah's Julia's House nurses there to support us helped make all those difficult discussions that tiny bit easier.

“There is a bumpy ride ahead but just knowing they are around and that they understand what we are facing is such a comfort.

“When Noah’s seizures were bad he just wasn’t eating, getting weaker and weaker. We were told he needed an operation to fit a peg, a button into his stomach so that he could be tube fed. It was the only way we would be able to get enough nutrition and fluids into him to help him stay strong.

“I felt very emotional about the thought of another operation. Every time he goes through those doors into theatre we have to say our goodbyes, give him one last kiss.

“We were so upset and anxious about it, but Noah’s nurses talked us through the whole procedure really calmly, explaining how it would work and the benefits for Noah and were just so kind.

“They took all the fear and stress away. It is this side of the service that people do not see. It is so much more than just caring for sick children. The Julia’s House team are a joy to have around and a total Godsend.

“The nurses and carers totally ‘get’ us as a whole family, know what is right for us and can read our mood. They work within our normal and our normal can be a horrible place and worrying at times but they listen, they understand and they pre-empt our needs.

“They have a sense of humour too which is important when you are facing such a grim reality. We don’t want people around us who will bring the mood down. Julia’s house nurses can turn the day around and leave us all feeling so much better able to cope.

“After the operation Noah wasn’t well enough to play but Laura and Harriet would sit by his bed and talk to him and read him stories. Although their faces are covered by masks and they wear all the protective clothing, he recognises their voices.

“The Julia’s House nurses are Noah’s safe people. He knows why they are here and what they are going to do. Even in full PPE he is comforted just having them around.

“Some days they would be here for a four-hour care session in sweltering heat in all that protective clothing, and plastic masks and I could not even offer them a drink. I am just full of admiration for how the whole Julia’s House team has carried on supporting families in such difficult circumstances.

“While Noah is having his care I have spent a little time in the garden or gone out with my husband, Chris. Four hours does not seem like a lot but we look forward to those breaks so much.

“Because we’ve been able to continue with our Julia’s House visits isolating has not affected us as dramatically as other people. We have been in lockdown for 11 years, caring for a really ill child so this is normal for us.

“Our life has always been about the wellbeing of our family and the simple things, not the artificial. None of that superficial stuff matters when you constantly face life or death situations.”

About Together for Short Lives

1. When a child's life is expected to be short, there's no time to waste. Together for Short Lives is the UK charity that is here to make sure the 99,000 seriously ill children and their families can make the most of every moment they have together – whether that's for years, months or only hours. Many of these children have complex conditions and need specialist care 24 hours a day, seven days a week.
2. We stand alongside families, supporting them to make sure they get the vital care and help that they need.
3. Together with our members we champion, improve and support children's hospice and palliative care services and professionals. By working together, we have a strong and unified voice, and help services deliver the best quality care and support tailored to each family's needs.

About Julia's House Children's Hospice

4. Julia's House is a Children's Hospice in Dorset and Wiltshire. We are an award-winning children's hospice charity dedicated to bringing comfort and care to families across the two counties.
5. Each family we support is unique and so is the care we provide. When a family finds out that their child has a very serious medical condition, which is life-limiting or life-threatening, their world falls apart. Julia's House exists to help these children and their families.
6. We provide practical and emotional support, tailoring our care to the needs of each individual child and their family, providing frequent and regular support in their own homes, in the community or at our hospices. We take our care wherever it is needed throughout Dorset and Wiltshire.

Why we are publishing this report together

7. In 2017, *Can We Fix It?!: Understanding the Impact of Children's Hospice Short Breaks on Parental Relationships of Life-Limited and Life-Threatened Children and Young People* by Ashley Mitchell with Bournemouth University and Julia's House was published. This study showed that insufficient time off together for parents with a life-limited child was a major factor in splitting up.
8. From our inception, Together for Short Lives has been keen to make sure that seriously ill children and their families have access to short breaks to respite – and to ensure that they are equitably and sustainably funded. We worked with Julia's House to highlight the findings of Dr Mitchell's work and together we have sought to secure further research which demonstrates the positive outcomes that short breaks can achieve for children, families and taxpayers. As the UK Government undertakes its Comprehensive Spending Review, we are publishing this report to help ministers use the opportunity to invest in short breaks.

9. This report builds on previous research, which has shown:

- the quality of the interparental relationship, specifically how parents communicate and relate to each other, is increasingly recognised as a primary influence on effective parenting practices and children's long-term mental health and future life chances¹.
- parents see respite care, including that provided by children's hospice and palliative care charities, as essential to enable the family to continue to cope².
- while children of separated parents may experience positive outcomes (for example if an abusive parent leave the family home), they are also statistically more likely to experience poor outcomes including:
 - growing up in poorer housing
 - experiencing behavioural problems
 - performing less well in school and gaining fewer educational qualifications
 - needing more medical treatment
 - leaving school and home when young
 - becoming sexually active, pregnant or a parent at an early age
 - reporting more depressive symptoms and higher levels of smoking, drinking and other drug use during adolescence and adulthood³.

10. It is in no-one's interests to wait for parents of seriously ill children to split up or to experience crises in their physical or mental health.

11. With short breaks policy sitting with the Department for Education, short break commissioning sitting with local authorities, the NHS picking up the bill for poor mental health, and the Department for Work and Pensions picking up the welfare costs, we believe a coordinated, cross-government approach is needed.

The terms we use in this report

12. In this report, we use the term "seriously ill children" to mean babies, children and young people with life-limiting or life-threatening conditions. We explain what life-limiting and life-threatening conditions in children are in appendix one. We use the term life-limiting and life-

¹ Harold G, Acquah D, Chowdry H and Sellers R. 2016. 'What works to enhance interparental relationships and improve outcomes for children?' A report of research carried out by Early Intervention Foundation on behalf of the Department for Work and Pensions. Available to download from: <https://www.eif.org.uk/report/what-works-to-enhance-interparental-relationships-and-improve-outcomes-for-children>

² Craft A and Killen S. 2007. Palliative care services for children and young people in England: an independent review for the Secretary of State for Health. Available to download from: https://www.nsf.no/Content/662668/PALLIATIVE_CARE_SERVICES_FOR_CHILDREN.pdf

³ Pryor J, and Rodgers B, Children in Changing Families, Oxford: Blackwell, 2001. Cited in Mooney A, Oliver C and Smith M, Impact of Family Breakdown on Children's Well-Being: Evidence Review, London: Department for Children, Schools and Families, June 2009, p7

threatening conditions in the main body of the report where it is part of the name of a published document.

13. We also use the term “children in the UK who at any one time need short breaks delivered by palliative care providers”. This is because a large proportion of the total number of children in the UK with life-limiting or life-threatening conditions (99,000) are relatively stable. Some may make a complete recovery from their illness. While their conditions could deteriorate very quickly, at present they are unlikely to need short breaks delivered by children’s palliative care providers.
14. In September 2020, Children’s Hospices Across Scotland (CHAS) published the findings of the CHISP 3 study⁴. This is the latest of a series of pieces of work that CHAS has commissioned to enable it to better understand the prevalence of life-limiting and life-threatening conditions in children in Scotland, the demographic profile of these children and the phases of their illnesses. The study has identified that there are approximately:
 - a total of 16,700 children in Scotland aged 0-21 with a life-limiting or life-threatening condition
 - 10,900 (65%) of these children are relatively stable; despite this, their conditions have the potential to deteriorate very quickly
 - 5,800 (35%) of these children attend regularly attend hospital, of which 2,100 (13%) are unstable, deteriorating or dying.
15. In its new strategic plan⁵, CHAS identify children with life-limiting and life-threatening conditions who regularly attend hospital as the group for which they will provide “medically-supported planned respite care at home and in hospice.”
16. For the purposes of their study, Pro Bono Economics and Compass Lexecon have estimated that, in the UK, there are approximately 25,000 children who at any one time need short breaks delivered by palliative care providers⁶. They use research that estimates a prevalence rate of 15 per 10,000 children (0.15%) that ‘are living with conditions likely to require palliative care’⁷. This assumption has been adopted in other research issued by the National Institute of Clinical Excellence (NICE)⁸ which broadly assumes a similar ‘prevalence

⁴ Children’s Hospices Across Scotland. 2020. Children in Scotland Requiring Palliative Care (ChiSP) 3. Available to download from: <https://chas-assets.s3.eu-west-1.amazonaws.com/sites/59dde5b10f7d33796f8cd11b/assets/5f577c690f7d336192ff22ca/ChiSP3-Report.pdf>

⁵ Children’s Hospices Across Scotland. 2020. Reaching every family in Scotland: Our strategic plan for 2020 to 2023. Available to download from: <https://chas-assets.s3.eu-west-1.amazonaws.com/sites/59dde5b10f7d33796f8cd11b/assets/5f5792c20f7d337d33f1c6bb/CHAS-Plan-20-23-web.pdf>

⁶ The number of children in palliative care in the UK is calculated as the prevalence rate multiplied by the population of children from the Office of National Statistics (“ONS”). The prevalence rate is 16 per 10,000 and is provided by Craft, A., & Killen, S. (2007). Palliative care services for children and young people in England. Secretary of State for Health, p.21. Retrieved from: https://www.nsf.no/Content/662668/PALLIATIVE_CARE_SERVICES_FOR_CHILDREN.pdf on 25 June 2019

⁷ Craft, A., & Killen, S. (2007). Palliative care services for children and young people in England. Secretary of State for Health, p.21. Available to download from: https://www.nsf.no/Content/662668/PALLIATIVE_CARE_SERVICES_FOR_CHILDREN.pdf

⁸ National Institute for Health and Care Excellence. 2016. Resource Impact Report. End of life care for infants, children, and young people with life-limiting conditions: planning and management (NG61).

rate' but assumes a lower child population in the UK – leading to a lower estimate of approximately 17,400 children requiring palliative care.

17. Together for Short Lives acknowledges that 25,000 figure is based on research that is now several years old and which could be contested. However, it is arguably the best available to us to use at the present time. We use it to try to give a broad sense of the demand for short breaks delivered by children's palliative care providers – and to achieve a sense of the costs and savings that could be achieved by short breaks. We are very keen to establish a more accurate and reliable figure as soon as we can and are working with our partners to try to facilitate this important modelling work.

What short breaks for respite for seriously ill children are

18. Short break care has three main functions:

- To support the family in the care of their child in the home or an alternative community environment such as a children's hospice.
- To provide the seriously ill child or young person with an opportunity to enjoy social interaction and leisure facilities.
- To support the family in the care of their child in the home or an alternative community environment such as a children's hospice.
- To provide opportunities for siblings to have fun and receive support in their own right.

19. Short breaks may offer the whole family an opportunity to be together and to be supported in the care of their child or it may offer care solely for the child or young person.

20. Specialist short break care refers to a setting of care, a programme of care or a service that provides additional care for highly complex or technology dependent children who may otherwise be excluded from short breaks provided by social care. It may take place in the child's home or in a setting outside of the home such as a long-term care facility or hospice. It may include overnight breaks, or breaks lasting only a few hours.

21. Specialist short break care provides the support required to meet the child's holistic care needs and enables children and families to access short break services. Specialist short breaks will often address some aspects of symptom management. Specialist short breaks should also meet the functions described under general short breaks.

“It’s important to understand that short breaks even up the balance and create more of a normal and bearable life. Many of these families don’t get to go on holiday in the same way that others do – they can’t. They don’t have easy access to the things that the rest of us take for granted - the swimming pool, the park, going to the pictures with their mates, they don’t bounce on a trampoline in the back garden. Children with disabilities and their families can have rich and wonderful lives but sometimes they can only stare at the four walls and each other much of the time. A short break isn’t a treat, it’s a very occasional pale imitation of the things in life that the average family takes for granted on a day to day basis and without it life can get to feel like torture, and then you can’t cope and then you really start to get expensive in terms of calls on services.”

Ryan Campbell CBE, Chief Executive, Demelza Hospice Care for Children

Short breaks achieve positive outcomes for seriously ill children and their families

22. Research conducted by Bournemouth University and Julia’s House Children’s Hospice⁹ has examined the impact that caring for a child with a life-limiting or life-threatening condition has had on parental relationships. 18 children’s hospices from across England and Scotland took part. The research has found that:

- 64% of divorced or separated parents cited having a child with complex needs as a reason for the breakdown of their relationship
- of those couples, 75% **had no access to short breaks at that time**
- 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; all the others used short breaks to spend time with their other children or just enjoyed time to themselves, regaining some balance in their lives, ultimately benefitting the whole family
- couples whose relationships were identified as ‘non-distressed’ by the research were found to have received on average **43% more hours** of short breaks from a children’s hospice compared to those who were in distressed relationships.

23. New evidence from Pro Bono Economics, in association with volunteers from Compass Lexecon¹⁰, has estimated that 11.7% of parents of children in palliative care would experience a significant reduction in stress as a result of providing them with short breaks.

24. As the UK experiences the second wave of the COVID-19 pandemic, short breaks are more important than ever. Research by the Martin House Research Centre, Together for

9 Mitchell, AJE. 2017. ‘Can we fix it?’ Understanding the impact of children’s hospice short breaks on parental relationships of life-limited and life-threatened children and young people. Bournemouth University in association with Julia’s House.

10 Pro Bono Economics in association with volunteers from Compass Lexecon. 2020. The economic benefits of short breaks for families of children with life-limiting and life-threatening conditions.

Short Lives and the University of Southampton¹¹ found that, during the first phase of the pandemic:

- 93% of families of seriously ill children felt isolated
- 59% had struggled to get nursing support during the pandemic
- 66% struggled with in-home care
- 86% had experienced difficulties accessing therapies like physio for their child.
- 95% were worried about nurses or carers coming into their own home.

25. Parents remain anxious. Many are at breaking point having been forced to provide 24/7 care to their seriously ill child for several months without the support they previously relied on. Many children still cannot access education settings because too few professionals have the guidance they need to manage the infection risks created by undertaking complex aerosol generating procedures (AGPs) in schools and colleges.

26. It is vital that short break providers are given equitable and sustainable funding now. Only by doing so can we make sure that families are able to access the breaks they urgently need.

How much short breaks cost to provide

27. It is currently not possible to calculate precisely how much it would cost to make sure that every family of a seriously ill child who needed a short break could receive one. The number of short break hours that a family needs depends on the complexity of their needs.

Short breaks achieve some savings for the taxpayer

28. Pro Bono Economic's approach drew on existing evidence to quantify the impact of short breaks on clinical measures of parental stress. The research team then linked this reduction in stress to economic benefits through three key channels. The research highlighted that the three channels used in the research would not be the only channels through which positive impacts would occur. However, the research has focused on those channels where robust and relevant evidence could be found – with those wider benefits expressed qualitatively:

- Improved physical health: reduced stress leads to improved physical health among carer parents, which in turn leads to reduced number of GP visits and cost-savings to the health system.
- Improved mental health: reduced stress leads to improved mental health among carer parents, which in turn reduces the use of mental health services and the associated costs.

¹¹ Martin House Research Centre, Together for Short Lives and the University of Southampton. 2020. Forgotten families: Families feel more isolated than ever under lockdown. Available to download from: <https://www.togetherforshortlives.org.uk/forgotten-families-families-feel-more-isolated-than-ever-under-lockdown/>

- Improved work attendance: this can be measured in reduced number of sick days taken, which leads to improved productivity and additional tax revenue.
29. The estimated annual £5 million taxpayer benefit of short breaks is calculated on the basis that:
- Reduced stress leads to better physical health among parents, leading to fewer GP visits. Demand for GP services declines by 8% as a result of an individual moving out of the most stressed category. This is likely to reduce expenditure on GP visits by around £41 per parent.
 - Reduced stress also leads to better mental health among carer parents, which in turn reduces the use of mental health services. Demand for mental health services falls by 49% as an individual moves out of the most stressed category. This is likely to reduce mental health expenditure by around £900 per year per parent.
 - Improved work attendance can be measured in reduced number of sick days taken, which leads to increased productivity and tax revenue. For every working parent who experiences a reduction in stress, it is likely that this will reduce the number of days taken off work by around 2-3 days per year. This is estimated to generate around £687 of added value for the economy, of which £130 could be realised by government based on the marginal corporate tax rate.
30. Pro Bono Economics have calculated the total potential benefits to taxpayers from delivering short breaks to all parents of seriously ill children in the UK who need them from children's palliative care providers could be in the region of £5 million per year. However, they also find that this could be in the range of £3.7 million and £13.8 million depending on assumptions on the impact of short breaks on stress levels.
31. **These savings do not count the huge extra costs that the state incurs as a result of the breakdown of parental relationships, parents being unable to work and the impact on siblings associated with a lack of access to short breaks.** For example, the economic impact of parents with disabled children having to leave work is placed at £685 million per annum¹². **The research recognises that the estimate of benefits should be considered a relatively narrow measurement – illustrating how wider benefits are supported against the cost of provision.** We acknowledge the need for further research so that we may better understand the costs and benefits of short breaks for seriously ill children – the Pro Bono Economics report has made a good start in this process.

The policy imperative for the state funding short breaks

32. There are a number of indicators in the Public Health Outcomes Framework¹³ for England related to mental health and wellbeing.
33. The NHS Long Term Plan sets out the need to maintain the mental health of both children and adults¹⁴. **It identifies that the cost of poor mental health to the economy as a**

12 Working Families. 2018. [Parents of disabled children and paid work](#).

13 Public Health England. 2020. Public Health Outcomes Framework. Available to download from: <https://www.gov.uk/government/collections/public-health-outcomes-framework>

14 NHS Long Term Plan. 2019. Available to download from: <https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/>

whole is estimated to be far in excess of what the country gives the NHS to spend on mental health. It states that reducing the impact of common mental illness can also increase national income and productivity.

34. The Short Breaks Regulations¹⁵ set out how local authorities in England **must** provide breaks from caring for carers of disabled children. Breaks should support carers to continue to care for their children at home and to allow them to do so more effectively. The regulations require local authorities to do three things:
- I. Ensure that, when providing short breaks, they have regard to the needs of different types of carers - not just those who would be unable to continue to provide care without a break.
 - II. Provide a range of breaks, as appropriate, during the day, night, at weekends and during the school holidays.
 - III. To provide parents with a short breaks services statement detailing the range of available breaks and any eligibility criteria attached to them.
35. In 2011, an [Independent Palliative Care Funding Review](#)¹⁶ was commissioned by the government. On page 59, the team recommends that short breaks which provide respite for the carers and families of children requiring palliative care should be funded by local authorities and the NHS under their respective legal short breaks duties.
36. Although there is no equivalent short breaks duty for adults, under the Care Act 2014, local authorities **must** ensure:
- the provision of preventative services
 - the diversity and quality of care and support services for adults
 - the provision of information and advice on care and support locally.
37. The NICE 'End of life care for infants, children and young people with life-limiting conditions: planning and management' clinical guideline N61 that was published in December 2016 sets out the range of services that children and young people should be able to access.¹⁷ Section 2.28 of the guideline states that children and young people with life-limiting conditions and their parents or carers have varied social and practical support needs, and that those needs may change during the course of their condition. This may include practical support, such as access to respite care.

15 Department for Education. 2011. Short breaks for carers of disabled children: departmental advice for local authorities. Available to download at: <http://bit.ly/1EmRyvM>

16 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: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215107/dh_133105.pdf

17 The National Institute for Health and Care Excellence. 2016. End of life care for infants, children and young people with life-limiting conditions: planning and management - NICE guideline [NG61]. Available to download from: <https://www.nice.org.uk/guidance/ng61>

38. In 'Our Commitment to you for End of Life Care: The Government Response to the Review of Choice in End of Life Care'¹⁸, the Department of Health set out what they expect commissioners to achieve for children who need palliative care. **This includes short breaks (respite care)**, delivered either in a children's hospice setting or at home by community palliative care services, or by 'hospice at home' services.

Too many families are unable to access the short breaks they need

39. Too often, families of seriously ill children are only offered access to short breaks which do not meet their needs. They are not provided by specialist professionals with skills, knowledge and experience needed to provide them. In some instances, parents are required to provide the care and support their child needs, which means that they do not receive a proper break.
40. A survey of directors of children's services found that 89% were finding it increasingly challenging to fulfil their statutory duties under Section 17 of the Children's Act. And where children are in touch with services, interventions are focused on child protection concerns, rather than on identifying and responding to a broad range of needs¹⁹.
41. During May 2020, the Disabled Children's Partnership (DCP) surveyed families of disabled children and young people aged from birth to 25 years old²⁰. It found that prior to lockdown, **only 38% of respondents said they were getting support from their local council or NHS** such as a short break (respite) to help care for their disabled child.
42. These findings represent a serious and unwarranted inequality. It cannot be right that some families of seriously ill children can access the short breaks they need, while others cannot.

Local authority spending on short breaks is being cut

43. We do not know the total amount that the state is spending on short breaks for seriously ill children in England, either through the NHS or local authorities. However, we do know how much the state is spending on children's hospice and palliative care services in England. While, on average, funding from NHS clinical commissioning groups is increasing, funding from local authorities has been cut.
44. Of the 29 children's hospice organisations that responded to Together for Short Lives' 2020 survey, on average they received, in 2019/20, £53,810 from their local authorities. This represented just 1% of their average charitable expenditure. This was 12% lower than the £61,092 they received in 2018/19, which represented 2% of their charitable expenditure.
45. Evidence also shows that the way local authorities fund children's hospice and palliative care charities is patchy and inconsistent across local areas. Shockingly, 14 children's hospice organisations responding to our 2020 survey received nothing at all from their local

¹⁸ Department of Health. 2016. 'Our Commitment to you for end of life care: The Government Response to the Review of Choice'. Available to download from: <http://bit.ly/2oOU5fj>

¹⁹ National Children's Bureau. 2017. All Party Parliamentary Group for Children - No Good Options Report of the Inquiry into Children's Social Care in England. Available via:

<https://www.ncb.org.uk/sites/default/files/uploads/No%20Good%20Options%20Report%20final.pdf>

²⁰ Disabled Children's Partnership. 2020. #LeftInLockdown - Parent carers' experiences of lockdown. Available to download from: <https://disabledchildrenspartnership.org.uk/wp-content/uploads/2020/06/LeftInLockdown-Parent-carers%E2%80%99-experiences-of-lockdown-June-2020.pdf>

authorities during 2019/20. That is nearly half (48%) of all children's hospice organisations. This is despite the fact they are providing social care as part of the short breaks for respite they deliver to seriously ill children and their families.

46. More widely, in November 2017 the Disabled Children's Partnership commissioned research by Development Economics to quantify what the current funding gap is for disabled children's services, including short breaks. They concluded that an estimated additional £433.9 million needs to be allocated to disabled children's social care services by local authorities²¹.
47. In terms of spend on early intervention, evidence shows a **40% real terms decrease in local authority spending on early intervention between 2010/11 and 2015/16** and 7% real terms increase in local authority spending on late intervention between 2010/11 and 2015/16²².
48. There have been positive developments in NHS funding for children's palliative care services in the past two years. In July 2019, NHSE/I decided to increase the Children's Hospice Grant to £25 million by 2023/24 and ring-fence this money specifically be for children's hospices²³.
49. In addition, the NHS Long Term Plan commits NHSE/I to match up to £7 million of CCG funding for children's palliative care, including children's hospice services, by 2023/24²⁴.
50. In contrast, this government has not provided ring-fenced funding for the social care elements of children's palliative care. The most recent package allocated by the UK Government to local councils specially for the purpose of funding short breaks was in December 2010. This is when the government committed £800 million²⁵ to make sure local authorities could meet their legal duties under the short break regulations²⁶.

Too few children's palliative care services are sustainably staffed

51. Worryingly, however, too few children's palliative care services in England are sustainably staffed. There are too few professionals available who have the specialist skills, knowledge and experience needed to care for children with life-threatening conditions. This means that too many children and families are missing out on the care and support they need,

21 Disabled Children's Partnership. 2018. Secret Life Of Us Campaign: The case for a Disabled Children's Fund. Available to download from: <https://disabledchildrenspartnership.org.uk/wp-content/uploads/2018/07/Case-for-a-Disabled-Childrens-Fund.pdf>

22 Action for Children, The Children's Society and the National Children's Bureau. 2017. Turning the tide. Available via: https://www.ncb.org.uk/sites/default/files/uploads/documents/Turning%20the%20tide%20report_final.pdf

23 NHS England and NHS Improvement. 2019. Children's hospices to receive £25 million a year as part of NHS Long Term Plan. Available to download from: <https://www.england.nhs.uk/2019/07/childrens-hospices-to-receive-25-million-a-year-as-part-of-nhs-long-term-plan/>

24 NHS Long Term Plan. 2019. Available to download from: <https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/>

25 Department for Education. 2010. Government announces £800 million to support families. Available to download from: <https://www.gov.uk/government/news/government-announces-800-million-to-support-families>

26 Department for Education. 2011. Short breaks for carers of disabled children: departmental advice for local authorities. Available to download at: <http://bit.ly/1EmRyvM>

including short breaks for respite. There is a children's palliative care workforce crisis.

52. **In 2019, Together for Short Lives found²⁷ that the growing nursing vacancy rate in children's hospice charities was higher than in the NHS – and posts were increasingly difficult to fill.** The average vacancy rate for children's hospices charities in England was 12.2%, compared to just over 11% in 2016 and 10% in 2015. The NHS nursing vacancy rate at the time was 11%, which was also worryingly high²⁸. Over two thirds (67%) of vacant posts were proving hard to fill (vacant for three months or more). This was an increase on the 65% who reported that posts were hard to fill in 2016, and the 57% who reported the same in 2015. A quarter (25%) of posts had been vacant for over 12 months.
53. **There were too few skilled children's nurses to fill vacant posts in children's hospices:** Over half (58%) of children's hospices cited an overall lack of children's nurses as a significant factor in the vacancy rates they are experiencing.
54. **There were shortages among other health and care professionals who support seriously ill children and their families:** in England, the vacancy rate for allied health professionals (AHPs, including physiotherapists, occupational therapists, and psychological therapists) was 14%. In 2018, the overall vacancy rate for children and family social workers in England was 16%, which was unchanged in 2019²⁹.

The action that we ask ministers to take as part of the Comprehensive Spending Review

55. We join the DCP in calling on HM Treasury to fill the £434 million gap in funding for social care services for all disabled children in England and their families by creating an annual ring-fenced disabled children's grant for local authorities.
56. Alongside filling the funding gap, there needs to be **transformational change to the way that disabled children's health and social care services are delivered to save money and resources**. There needs to be a greater emphasis on identifying needs earlier and rather than at crisis point. This should involve recognising and meeting the needs of the family as a whole, rather than the child in isolation.
57. We are therefore also joining DCP in calling on the government to establish a Disabled Children's Innovation Fund. An innovation fund model would provide financial backing to organisations delivering ground-breaking support and approaches in early intervention.
58. This would be based on the Early Intervention Foundation's definition of identifying and providing effective early support to children and young people who are at risk of poor

²⁷ Together for Short Lives. 2019. A workforce in crisis: children's palliative care in 2019. Available to download from: <https://www.togetherforshortlives.org.uk/changing-lives/speaking-up-for-children/policy-advocacy/childrens-palliative-care-workforce/>

²⁸ As NHS Digital acknowledge, due to the COVID-19 pandemic, there has been a significant disruption to recruitment activity within the NHS during 2020/21. This is apparent from the significantly lower reported advertised vacancies between March and June 2020. As such, the latest reported NHS nursing vacancy rate of just over 10% May 2020 is not necessarily a reliable comparator with the figure we cited in our report in October 2019.

²⁹ Department of Education. 2020. Official statistics: Children and family social work workforce in England, year ending 30 September 2019. Available to download from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/868384/CSWW_2018-19_Text.pdf

outcomes to prevent problems occurring or getting worse. This should also consider key transition or escalation points in a child's life. The Fund would promote whole-family care, with a long-term view to 'scaling up' successful programmes into sustainable provision.

59. Our ask for an Innovation Fund is timely as Government is currently reviewing the SEND system and is committed to delivering a National Disability Strategy which we hope includes much needed support for disabled children and their families. Alongside this, the Children's Commissioner is working with NHS England on reducing the number of children with a learning disability and/or autism and challenging behaviour in in-patient units.

The action that we ask others to take

60. We ask that NHSE/I develops a commissioning framework for integrated care systems (ICSs), sustainability and transformation partnerships (STPs), CCGs and local authorities. This should guide them on how to plan and fund children's palliative care, including short breaks for respite, for seriously ill children in the areas they serve. We ask these organisations to act on the guidance and commission the lifeline short breaks that these families rely on. They should make sure that they are equitably and sustainably funded, whether they are provided by the statutory or voluntary sectors.
61. We call on all organisations that provide short breaks for seriously ill children and their families to use the new evidence produced by Pro Bono Economics³⁰, to make a case to ICSs, STPs, CCGs and local authorities for equitable and sustainable funding. We ask them to make sure they provide short breaks which can meet the needs of a diverse range of seriously ill children, including those from all ethnic backgrounds and socio-economic groups. Only by reaching out to all seriously ill children and families can they realise the twin outcomes of reduced parental stress and cost-savings for the taxpayer.
62. To help them do so, Together for Short Lives and Julia's House are committed to supporting all those providing short breaks for seriously ill children. We will do so by continuing to produce resources, share best practice and provide opportunities for short break providers to share their successes and the challenges they encounter.

30 Pro Bono Economics in association with volunteers from Compass Lexecon. 2020. The economic benefits of short breaks for families of children with life-limiting and life-threatening conditions.

Appendix one: life-limiting and life-threatening conditions in children and young people

What are life-limiting and life-threatening conditions? How do they affect children and young people?

1. Life-limiting conditions are those for which there is no reasonable hope of cure and from which people are expected to die. Life-threatening conditions or episodes are those for which curative treatment may be feasible but can fail. People with life-limiting conditions need continuing palliative care throughout the trajectory of their illness.
2. Life-limiting and life-threatening conditions in children and young people can be defined by the following four categories **Error! Bookmark not defined.**
 - I. Life-threatening conditions for which curative treatment may be feasible but can fail – such as cancer or congenital heart disease.
 - II. Conditions where premature death is inevitable but where there may be prolonged periods where the child is well – such as Duchenne muscular dystrophy.
 - III. Progressive conditions without curative treatment options, such as Batten disease.
 - IV. Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death – such as severe brain injury.

Transition to adulthood for young people with life-limiting conditions

3. The needs of young people with life-limiting conditions and their families are complex. As a result, many find transition daunting. On leaving the comprehensive care offered by children's services, they will often have to deal with and establish important relationships with a range of unfamiliar agencies and professionals. The result can be gaps in services or fewer or less appropriate services³¹.
4. Like all young people, many of those with life-limiting conditions want to establish their independence; some want to be able to spend time away from older adults; some hope to go into further or higher education and attain qualifications and skills; some wish to get a job, move into their own home, develop a social life and have relationships. Some young people also want to use their experiences to make things easier for other people in similar situations³¹. However, some young people will be cognitively impaired and will depend on their parents, carers or residential care until the end of their life.
5. For many young people with life-limiting conditions, transition into adult services often coincides with a rapid decline of their condition and eventual death. Young people should have plans in place where it is unclear whether their condition will stabilise, deteriorate or enter the end of life phase; this is known as 'parallel planning'.
6. Young people with life-limiting conditions require holistic support from a range of providers spanning health, social care, education, leisure and housing services. There is a general dearth of age and developmentally appropriate short break services for young people with life-limiting conditions in England. The Together for Short Lives Transition Taskforce has

31 Marie Curie Cancer Care and Together for Short Lives. 2012. Don't let me down: ensuring a good transition for young people with palliative care needs. Available to download from: <http://bit.ly/1uRYCey>

conceptualised the way that the five key agencies should work together as a 'pentagon of support' (see appendix two)³². This pentagon is underpinned by health and social care working closely together to provide a foundation for all the other provision, with work, leisure and education being the two 'enabling agencies' on either side and independent living as the 'capstone' at the top.

How many children and young people with life-limiting conditions are there?

7. Fraser et al³³ highlight the prevalence of life-limiting conditions in children and young people for every local authority district in England. Overall, Fraser et al estimated that more than 86,625 in children (0–19 years) in England in 2017/2018 were living with a life-limiting or life-threatening condition.
8. There was some evidence in these data that this increase in prevalence was driven by both an increase in recording of these diagnoses and an increase in survival in this population. The former may reflect a change in coding practice rather than a true increase in incidence.
9. The prevalence of life-limiting conditions (LLCs) was highest in the under one-year age group at 226.5 per 10,000 in 2017/18.
10. The prevalence of LLCs was highest for congenital abnormalities which by 2017/18 was 27.2 per 10,000 more than twice the next most prevalent group, neurological disorders (10.8 per 10,000).
11. The prevalence of LLCs was significantly higher among boys (72.5 per 10,000 vs girls 60.0 per 10,000 (2017/18) although there was no difference in the rise in prevalence between sexes over time.
12. Prevalence of LLC are highest amongst children of Pakistani origin (103.9 per 10,000) and lowest among children of Chinese origin (32.0 per 10,000) in 2017/18.
13. More children than expected with a LLC lived in areas of higher deprivation (13% most derived versus 8% in least deprived). The deprivation categories were population weighted therefore you would expect approximately 10% of children to have a LLC in each category.

32 Transition Taskforce. 2015. Stepping up: a guide to enabling a good transition to adulthood for young people with life-limiting and life-threatening conditions. Available to download from:

<http://bit.ly/1J0mMLA>

33 Fraser LK, Gibson-Smith D, Jarvis S, Norman P, Parslow RC. 2020. 'Make Every Child Count: Estimating current and future prevalence of children and young people with life-limiting conditions in the United Kingdom.' Available to download from: <https://www.togetherforshortlives.org.uk/resource/make-every-child-count/>

Appendix two: were seriously ill children and their families receiving the short breaks they needed prior to the coronavirus pandemic?

1. Even before the pandemic, families with disabled children were facing a dual crisis. Firstly, they were seeing core services squeezed more than ever.³⁴ Secondly, families struggling with the impact of cuts and stripped back support were **not getting the help they needed to do the best for their children, and were often only being offered support once they reached crisis point.**
2. Together for Short Lives' own freedom of information (FOI) requests have found³⁵ too many clinical commissioning groups (CCGs) and local authorities in England were failing to plan and fund short breaks. 84% of CCGs reported that they commissioned short breaks for children who need palliative care. **However, more than one in five (21%) local authorities did not commission short breaks for children with life-limiting and life-threatening conditions, despite having a legal duty to do so.**
3. We do not know how many seriously ill children and their families were receiving the short breaks they needed from the statutory and/or voluntary sectors before the pandemic began. Many were, including an estimated 4,807 children in England who received short breaks from children's hospices in England in 2018/19³⁶. However, we believe that many families are not receiving the breaks they need, leaving parents at higher risk of mental health problems and their relationships at greater risk of breakdown.

34 On the evidence for this, see Disabled Children's Partnership. 2018., [Secret life of us campaign: the case for a disabled children's fund](#).

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

36 Together for Short Lives. 2019. Statutory funding for children's hospice and palliative care charities in England 2018/19. Available to download from: <https://www.togetherforshortlives.org.uk/wp-content/uploads/2019/06/190614-FINAL-Statutory-funding-for-children%E2%80%99s-hospice-and-palliative-care-charities-in-England-2019.pdf>

Appendix three: What impact has the coronavirus pandemic had on short breaks?

1. During the initial phases of the pandemic, in order to keep children, families and staff safe and to prioritise emergency care, children's hospice and palliative care charities across the UK cancelled planned inpatient short breaks for respite. Some continued to offer short breaks to families in emergency situations, for example where parents or carers became unwell and were unable to care for their children. Many families of seriously ill children have felt – and still feel – anxious about admitting professionals to their homes to provide them with short breaks.
2. During May 2020, the Disabled Children's Partnership (DCP) surveyed families of disabled children and young people aged from birth to 25 years old about the impact that the coronavirus pandemic and lockdown was having on them³⁷.
3. DCP received 4,074 responses from across the UK. 87% were from respondents living in England, with 13% from Scotland, Wales and Northern Ireland. 16% of responses were from families of children with life-limiting or life-threatening conditions.
4. DCP found that prior to lockdown, **only 38% of respondents said they were getting support from their local council or NHS** such as a short break (respite) to help care for their disabled child. Of those, **over three quarters (76%) said all support stopped during lockdown**. 8% said support had stayed the same. 16% said that they had been offered an alternative such as online or direct payment.
5. When asked about the impact of this change in support, parents described extreme exhaustion, stress and sleepless nights. Respondents described feeling pushed to the limits, with an overwhelming feeling of '**being abandoned by society**' to deal with often complex care and medical procedures on their own. Many were trying to provide therapies such as physiotherapy at home themselves. **Respondents very often described how their non-disabled children were having to take up the slack.**

37 Disabled Children's Partnership. 2020. #LeftInLockdown - Parent carers' experiences of lockdown. Available to download from: <https://disabledchildrenspartnership.org.uk/wp-content/uploads/2020/06/LeftInLockdown-Parent-carers%E2%80%99-experiences-of-lockdown-June-2020.pdf>

Appendix four: what additional impact is the lack of access to short breaks having on the economy?

1. Evidence shows that, for disabled children and their families:
 - the economic impact of **parents with disabled children having to leave work** is placed at **£685 million** per annum³⁸
 - **intervening late** with children and young people experiencing a range of emotional, social, and health difficulties costs government services **£17 billion** per year³⁹
 - providing just 22 children at risk of entering the care system with short breaks can generate savings of up to £1,851,550⁴⁰.
1. The main body of our report does not take into account the positive impact that short breaks have on the siblings of seriously ill children. While we do not currently have evidence to quantify the economic impact of short breaks on siblings, previous reports have highlighted the positive role they play.
2. In 2019, Rainbow Trust Children's Charity found⁴¹:
 - At least 32,000 families in England with a seriously ill child have one or more siblings according to our best estimate. Some will have little or no access to sibling support depending on where they live.
 - The need for support appears to be growing, based on the experience of both Rainbow Trust and of children's hospices in England.
 - Many parents do not identify their healthy siblings as young carers. This means that many are likely to be hidden from official data on young carers, and yet this is what they are.
 - The emotional and practical impact on siblings can have enduring consequences for a child's wellbeing and life chances. A parent will often have less time to focus on the healthy sibling(s) and routines have to change to fit around the needs of the seriously ill child.
 - While some studies show positives such as a raised sense of self-worth, a sibling may experience feelings of isolation, anger, jealousy, guilt and anxiety. A sibling can become withdrawn as they try to protect their parents from additional worry. If not addressed, a sibling's mental health could be affected.
 - School can be a welcome break from a pressured home environment, but for some, sleep disruption could affect their focus and concentration. Keeping up with homework can be difficult, with time and energy at a premium.

38 Working Families. 2018. [Parents of disabled children and paid work](#).

39 Early Intervention Foundation. 2018. [Realising the potential of early intervention](#); Early Intervention Foundation. 2016. [The cost of late intervention: EIF analysis 2016](#).

40 Together for Disabled Children. 2011. [Impact of the short break programme on the prevention of disabled children entering the looked after system](#).

41 Rainbow Trust Children's Charity. 2019. See Us, Hear Us, Notice Us: The Case for Supporting Siblings of Seriously Ill Children. Available to download from: https://rainbowtrust.org.uk/uploads/other/pdfs/Full_Report_See_Us_Hear_Us_Notice_Us.pdf

- A sibling's education can be affected by difficulties in maintaining school attendance, because their parents are focussed on their brother or sister's care. Siblings can be at greater risk of being teased or bullied than other children. School holidays can be a particularly hard time with many siblings unable to leave the house as much as they would like.

EMBARGOED