





Together for Short Lives' family life and perceptions report

Hidden Lives: tackling the social exclusion of families caring for a seriously ill child




I tried to shut myself out emotionally



We don't really talk, unless it's about our child



I was lonely too. I had no friends who visited



My husband describes me as a recluse



My friends have stopped inviting me to social events



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Hidden Lives: tackling the social exclusion of families caring for a seriously ill child

Introduction

49,000 children and young people are living in the UK with health conditions that are life-limiting or life-threatening – and the number is rising.

Hearing the news that your child has a life-limiting condition and is likely to die young is devastating. It's an incredibly distressing and confusing time. These children have very complex and unpredictable conditions and often need round-the-clock care, seven days a week. Families have to cope with the knowledge that their child will die before them, and daily life for the whole family can become challenging.

Families provide most of their child's care at home themselves, which can be exhausting. One parent may have to give up work to care for their child at home, and may face financial hardship on top of the emotional impact of knowing their child will die young. Families need regular breaks and support to make this sustainable, as well as access to 24/7 care when their child is at end of life. Families often tell us that they can't find the information they need about help and support. Parents, carers, brothers, sisters, grandparents and other relations and friends all need support in coming to terms with the news. They can feel alone and isolated and have to fight to get vital care and support.

Exploring isolation and public perceptions of children's palliative care

In Together for Short Lives' work with families, we regularly hear families say that caring for a child with a life-limiting condition can be isolating and, at times, very lonely. Families often say it's difficult to talk about their child's diagnosis with friends and acquaintances in their community because they don't understand what they are going through, or find it difficult to know what to say or how to react. Together for Short Lives wanted to explore how many families experience feelings of isolation and social exclusion, and to gauge the public's understanding of children's palliative care and children's hospice services.

Together for Short Lives carried out a survey to capture the impact of caring for a child with a life-limiting or life-threatening condition on family members' social lives, relationships and interactions with others. This survey was carried out in December 2016 and shared with families caring for seriously ill children and bereaved families who are part of the charity's family community. We then carried out a public perceptions survey to find out what people know about children's hospices and children's palliative care and to what extent people are comfortable with talking about serious childhood illness and death. Our UK-wide public perceptions survey was conducted by YouGov Plc in April 2017.

Key findings

Family Life Survey: isolation, social exclusion and relationship breakdown

- 84% of families caring for a child with a life-limiting or life-threatening condition say they have felt isolated and alone since their child's diagnosis
- 90% said their relationships, social life and interactions with friends had been adversely impacted since their child's diagnosis
- 74% said their relationship and interactions with their partner had been adversely affected
- 87% said their relationship and interactions with their immediate family had been adversely affected
- For bereaved families, over 50% reported that relationships with their wider family had been affected a great deal, and 50% said that their relationships with friends had been impacted adversely.

The impact on families' social life

- 80% said that they were less likely to go out socially since their child's diagnosis
- 58% said they go out socially less than once a month, with 20% going out once per month.

Public perceptions and experiences of children's palliative care

- Over a quarter of the public (26%) say they don't understand what children's palliative care means or understand what children's hospices are for
- Over one in three people (38%) would not feel comfortable talking to a friend whose child had been diagnosed with a life-limiting or life-threatening condition. Women more likely than men to feel comfortable talking to a friend in this situation (60% versus 52%)
- 35% of the public say they have had, or know someone who has had, some experience of serious childhood illness or a child dying young, with more than 1 in 10 (11%) saying this has happened to them or a family member at some point in their life.



Part one: Family Life Survey

Introduction

Together for Short Lives' Family Life Survey was shared with family members (parents and carers) who care for one or more child with a life-limiting or life-threatening condition. (These families were already known to Together for Short Lives.)

We asked families to complete a short online survey throughout December 2016. 52 family members responded; 51 were female, with one male respondent. We asked respondents' permission to share their detailed comments anonymously. We have only included family quotes and comments from those who agreed to share their information.

The survey questions included:

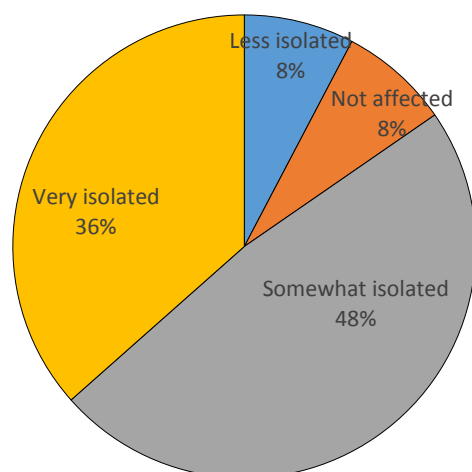
- To what extent having a child with a life-limiting illness had impacted on their social life, interactions or relationships
- To what extent parent/carers felt isolated since their child's diagnosis
- To what extent parent/carers go out socially since their child's diagnosis – and was this more or less frequently than before?
- Families were asked to share examples of how having a seriously ill child had impacted on their family life and relationships with their partner, family members and friends
- Bereaved family members were also asked how their bereavement had impacted on their relationships, interactions and social life.

Feelings of isolation

Many of the UK's 49,000 seriously ill children have very complex conditions and need care around the clock. Families caring for children with life-limiting conditions usually provide most of their child's care at home.

Together for Short Lives survey found that **84% of families** caring for a child with a life-limiting or life-threatening condition said they have felt either somewhat or very isolated and alone since their child's diagnosis.

Figure 1 – Families were asked to rate how isolated they felt following their child's diagnosis



Families talked about feelings of loneliness and friends dropping off over time.

"I was lonely too. I had no friends who visited, and I didn't know any of the mums at the nursery my eldest daughter went to. I hadn't been about to take her [to nursery] because of my nursing responsibilities. That sense of isolation was really brought home when the only guests at my child's first birthday were her two community nurses."

"This must be the loneliest job in the world. Friends and families get tired of hearing how things aren't getting any better. Even on a good day our 'normal' is very intense, providing a high level of care for our son."

"I found it incredibly difficult to interact and acknowledge what limited and fragile future we faced as a family (he was our 1st child) so I tried to shut myself out emotionally from others to care the best I could for my son meaning I isolated myself straightaway from life."

8% of families said they had felt less isolated since their child's diagnosis. We do not know the reason for this; it could be, for example, because close friends and family have rallied around or there are just more people involved in their day-to-day lives.

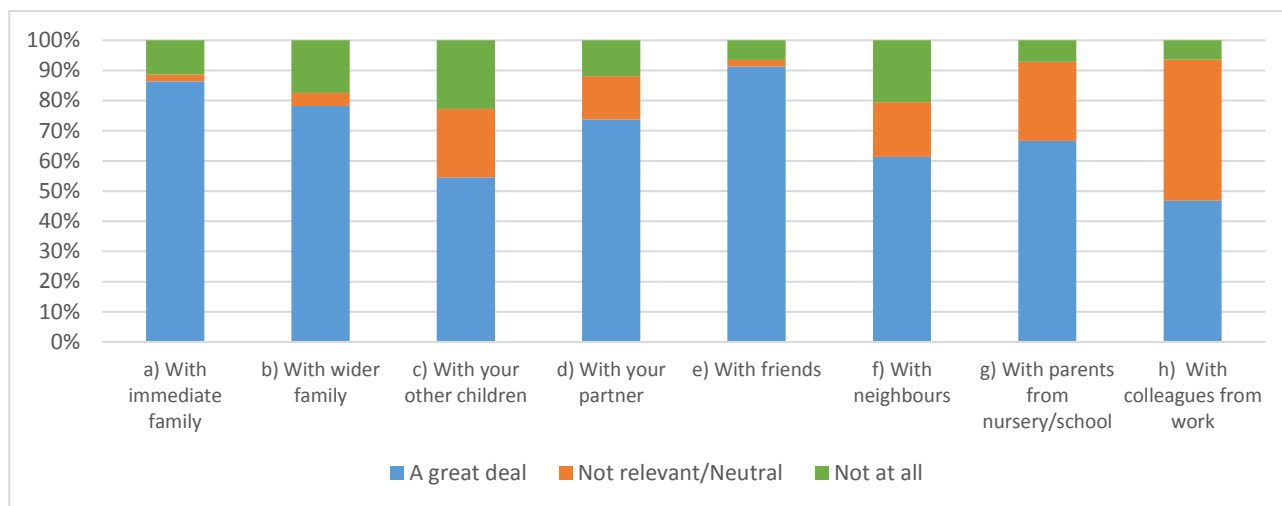
Impact on families' social life, interactions and relationships

Together for Short Lives asked families to rate to the extent to which having a child with a life-limiting illness impacted on their social life, interactions or relationships. Families were asked to rate this impact across a scale from "not at all" to "a great deal". Respondents had the option to state that this was not relevant or where there was no impact.

The results showed that most family members said that having a seriously ill child had a significant impact on their relationships, social life and interactions with their friends, partner and their immediate family.

- 90% said their relationships, social life and interactions with friends had been impacted since their child's diagnosis
- 87% said the same for their relationship with their immediate family
- 74% said the same for their relationship with their partner
- 78% said the same for their relationship with the wider family
- For bereaved families, over 50% reported that relationships with their wider family had been affected a great deal, and 50% said that their relationships with friends had been impacted adversely.

Figure 2 – Please rate to what extent having a child with a life-limiting illness has impacted on your social life, interactions or relationships



Family relationship breakdown

Some parents talked about the breakdown of their relationship with their partner, and how the stress of caring for a seriously ill child at home can take its toll. Nearly three-quarters of families (74%) said their relationships, social life and interactions with their partner had been impacted since their child's diagnosis. Over half, 53%, said that their relationship with their other children had been adversely affected.

"My husband describes me as a recluse, a pattern that I've found continued even two years after my son's death."

"It's hard to keep a marriage going when you can't do fun things. We don't really talk, unless it's about our child. With one of us working and the other trapped between four walls, we're both very tired..."

"For a long time my child's condition was undiagnosed, a stressful experience for me that resulted in depression, isolation and arguments which finally culminated in divorce."

Relationships with people in local communities

Thinking about relationships within the families' communities, families said that their local relationships, social life and interactions with neighbours and parents from their child's school/nursery were affected.

- 66% said their relationship, social life and interactions with parents from school/nursery had been impacted since their child's diagnosis
- 61% said the same for their relationships with neighbours.

The findings from Together for Short Lives' perceptions survey also showed that over one in three people (38%) would not feel comfortable talking to a friend whose child had been diagnosed with a life-limiting or life-threatening condition. And over a quarter of the public (26%) say they don't understand what children's palliative care means or what children's hospices are. Fear around talking to families with a seriously ill child could compound families' feelings of loneliness and isolation.

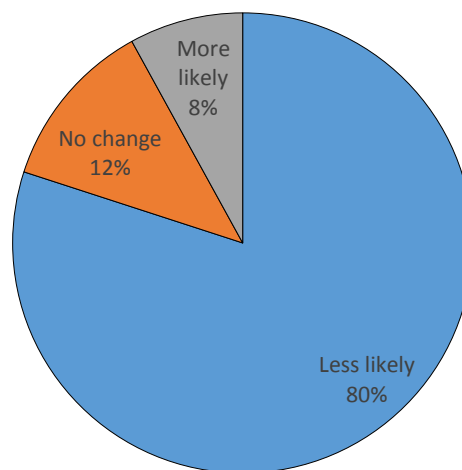
Families said that their relationships with colleagues from work (48%) were least affected. However, it should be noted that for families rating the impact on relationships with work colleagues, 48% rated this as either not relevant - for example because many of the mothers/female carers who completed the survey are not working as they are caring for their child 24/7.

Impact on a parent's or carer's social life

Together for Short Lives asked parents and carers two questions about their social life. Firstly, to what extent they were more or less likely to go out socially since their child's diagnosis. Secondly, we asked families how often they go out socially.

"My friends have stopped inviting me to social events because I nearly always have to cancel at the last moment due to my child's illness or my exhaustion."

Figure 3 - To what extent are you more or less likely to go out socially since your child's diagnosis?



The majority (80%) of parents and carers said that they were less likely to go out following their child's diagnosis. A few (8%) said they were more likely to go out, and 12% said there was no change in social life since their child's diagnosis.

Of those who said that their social life had deteriorated, some of the reasons cited for this included feelings of exhaustion, not having the energy to get ready to go out, or being emotionally drained.

"I often don't want to go out because getting support takes a huge effort, and I don't have the energy to get dressed up or go anywhere. Sometimes I worry that I'll just be miserable if I do go out, so I find excuses not to go to social events. I don't get asked any more."

Families talked about how much time and energy goes into having a night out; for example, arranging for all the care their child needs and putting all the plans in place. Some families said they didn't want to go out because they didn't want to leave their seriously ill child with someone else – fearing that they would fret about them or not enjoy themselves.

Some families said it was difficult to be spontaneous or go out without endless planning months in advance – and the unpredictability of their child's condition meant that social events were often cancelled.

"There isn't any excitement or spontaneity, and that impacts on my son, family and friends."

“When you’re looking after a life-limited child, it’s impossible to do anything on the spur of the moment. When you do get to go out, we often have to leave earlier than we would like to because the carer has to leave.”

Some families said it was difficult to find someone they could trust to look after their child when they went out. Others talked about how hard it is to get into social chit-chat or talk about anything trivial when your life revolves around caring for your child and juggling day-to-day life.

“Even though friends’ problems are important to them, some just seem so trivial. It’s hard for me not to sound dismissive or sound bitter. Sometimes it’s easier to stay in our own ‘bubble’ at home where everything is normal.”

One parent talked about the importance of talking to other parents who are in the same position and understand what life is like.

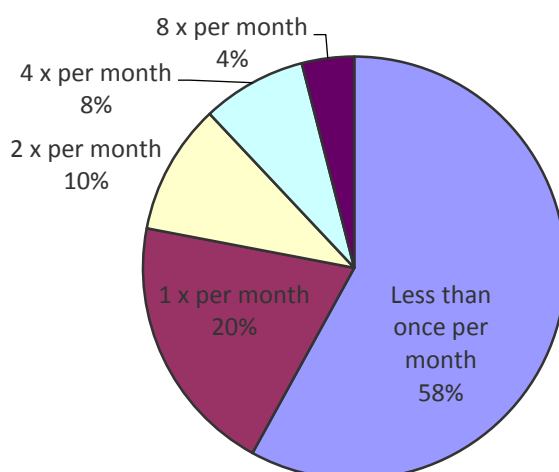
“I feel like I can only share my true thoughts and feelings with parents who have a child with a similar condition. I’m part of a closed Facebook group, and the people there lend an empathetic ear and a shoulder to cry on.”

Many families said that it’s sometimes hard for them to go out as a family or for trips out because of problems with accessibility or because planning to go out requires “military preparation” - getting all the life-sustaining equipment, medicine and mobility equipment ready for the simplest of journeys.

“As our son grows, it’s becoming harder to visit friends and family. Our home is adapted, but hardly any homes are accessible to him. Changing him has also started to limit our ability to get out and about. Most of the time we end up having to cut trips short as we need to go home and change him.”

“When occasionally the family is invited out, there are restrictions that others do not understand. An invite to someone’s house for a social gathering is impossible as they do not have ramp access.”

Figure 4 - How often do you go out socially without your children?

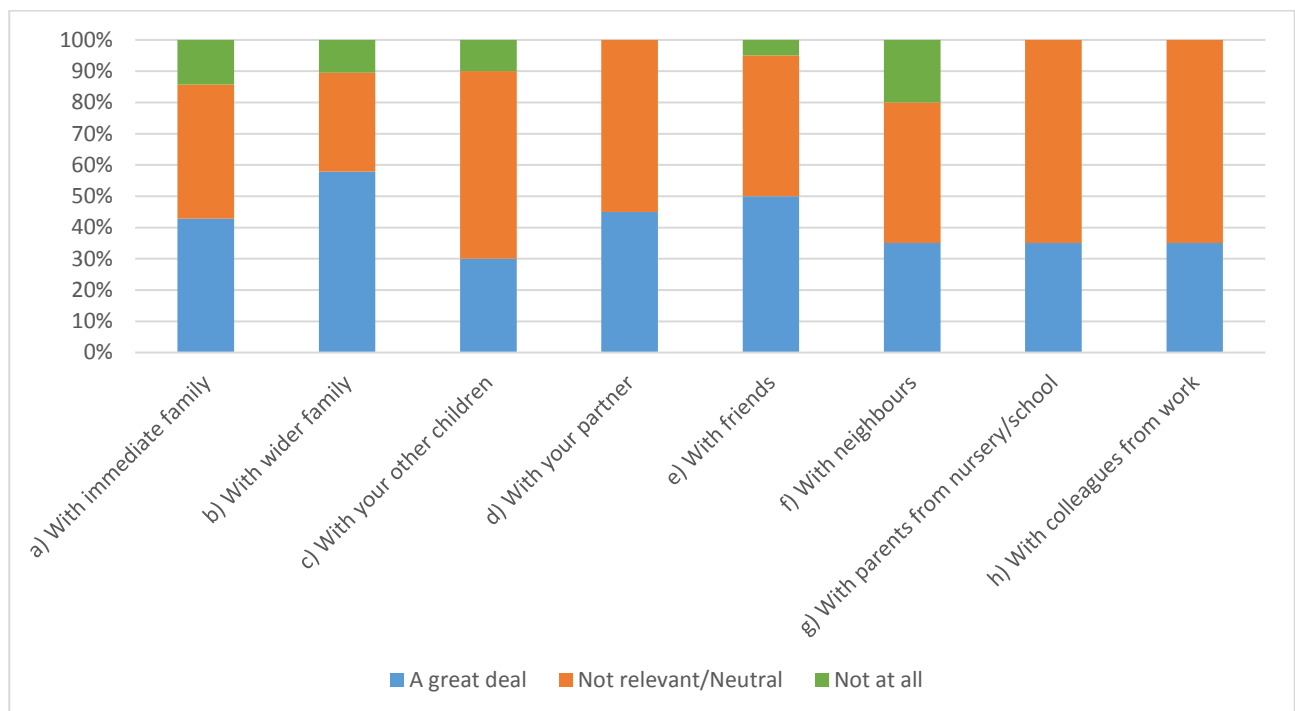


Overall nearly 80% of families surveyed said they only went out once per month or less, and nearly 60% said they go out socially less than once a month.

Relationships, interactions and social life for bereaved families

Bereaved parents and carers were asked how their bereavement affected their social life, interactions or relationships. They were asked to grade this along a scale from 'not at all' to 'a great deal'.

Figure 5 - For bereaved families: How has your bereavement impacted on your interactions and relationships



Perhaps, unsurprisingly, all categories scored less than the responses from those families who are actively caring for a child with a life-limiting condition. However, across all eight categories, at least a third reported that bereavement still impacted upon these aspects of life. This highlights the importance of continued support for families following the death of their child.

Part two: Perceptions about children's palliative care survey

Together for Short Lives wanted to explore the public's understanding and perception of children's palliative care and children's hospice services, and to find out how comfortable the public is in talking to families about death in childhood.

Together for Short Lives commissioned a UK-wide public perceptions survey that was conducted by YouGov Plc in April 2017. We recognised the sensitivity of asking questions about childhood death and respondents were given the option to skip any of the three questions they felt uncomfortable with. We signposted respondents to our helpline and other supportive organisations. Respondents were given information to help them understand the questions fully.

Questions and sample size

The three questions we asked were:

1. Which words or phrases would you associate with the terms 'Children's Hospice' and 'Children's palliative care'?
2. In general, how comfortable or uncomfortable would you feel talking to a friend about their child who had been diagnosed with a life-limiting or life-threatening condition?
3. Have you had any experience of a child who is living with a life-limiting or life-threatening condition, or who has died aged 18 or younger due to a life-limiting/life-threatening condition?

The total sample size was 2,013 adults, aged 18+. Fieldwork was undertaken between 10th - 11th April 2017 via an online survey. Not all respondents chose to answer all the questions. The figures have been weighted and are representative of all GB adults.

The results below are annotated with the number of respondents answering the questions as follows:

1. From 1,573 adults who agreed to take part and expressed an opinion
2. From 1,566 adults who agreed to take part and expressed an opinion

Survey results

Question 1

Lack of awareness and misconceptions

Together for Short Lives asked people which words or phrases they associate with children's hospices and children's palliative care. Over a quarter of people (26%) simply said they didn't know how to answer the question. Those who did answer this question offered a wide range of views which suggests that people have very different ideas about what children's hospices and palliative care for children mean; there is little consensus. The survey also shows there are still unhelpful myths about children's hospice care with people associating it with negative words or phrases such as 'pain', 'suffering', 'tragic' and 'distressing'.

Question 2

Taboos about childhood illness and death

The findings also reveal that over one in three people (38%¹) who answered would not feel comfortable talking to a friend about their child who had been diagnosed with a life-limiting or life-

threatening illness, with women more likely than men to feel comfortable talking to a friend in this situation (60%¹ versus 52%¹).

Question 3

Experience of children's palliative care

The data showed that over a third (35%²) of those who answered had some experience, either personally or through someone they know, of a child who is living with a life-limiting or life-threatening condition, or who has died young due to a life-limiting or life-threatening condition. More than 1 in 10 (11%) said this has happened to them or a family member at some point in their life.

Despite the high number of people with experience of knowing a seriously ill child, one in three people in the whole sample were not comfortable talking to families affected by serious childhood illness.

Discussion: How taboo compounds feelings about isolation, and myths about children's palliative care

Families caring for seriously ill children often say they feel lost and alone when coming to terms with the news that their child may not reach adulthood. This is on top of the stress and strain of providing 24/7 round-the-clock care, seven days a week. The taboos around serious childhood illness and death in childhood can leave families feeling isolated, lonely and vulnerable without support. Having someone to talk to and a helping hand could make a big difference.

“When someone didn't find a way to show us that they cared, we assumed that they didn't... At times, it felt like I was struggling to hold on to my sanity because of my distress over Leah's illness... I appreciated it when people said things like 'I've heard about Leah's illness, I'm really sorry, this must be so difficult for all of you.' ...Leah and I spent months in isolation and messages of support from friends penetrated our sense of aloneness and helped us to face each day knowing that others cared and were praying for us or thinking about us.”

The survey uncovers what people know about children's hospices and reveals how uncomfortable people are talking about serious childhood illness and death. The data shows a lack of public understanding about what children's hospices and palliative care means. It reveals that people are uncomfortable talking about childhood death and serious illness; these taboos could compound the feelings of isolation that many families caring for a seriously ill child feel.

Conclusions and recommendations

Together for Short Lives' Family Life Survey confirms anecdotal evidence that families caring for seriously ill children often feel alone and isolated following their child's diagnosis. Although the sample size is small, there is a high level of consistency about the negative impact on personal relationships with both immediate family members, friends, neighbours and on families' ability to maintain a social life.

The results of Together for Short Lives' perceptions survey about children's palliative care shows that one in three members of the UK's public are uncomfortable interacting with families caring for children with life-limiting and life-threatening conditions. There is an evident lack of understanding around what children's palliative care means, and what services like children's hospices provide. A quarter of respondents simply did not know what words to associate with this. It also revealed that myths around children's hospices and palliative care still abound with people associating them with negative words, such as pain and suffering.

A lack of understanding about children's palliative care combined with people not feeling comfortable talking to families could compound the loneliness and isolation that families feel, not only with their close family and friends but in wider society.

We have a long way to go in breaking down taboos and to help the public feel more comfortable in reaching out and talking to families in need of support.

Together for Short Lives wants to ensure that these families get all the support they need, so they can make the most of every moment. That's why we are calling on the public to reach out to families in their local communities - and on the UK's governments to invest in improving the lives of seriously ill children and the families that care for them.

Together for Short Lives will continue to:

- Bring families together through our family community and secure Facebook group, helping them to connect with one another so they feel less isolated
- Raise awareness of the needs and experiences of families caring for seriously ill children
- Break taboos and myths about children's palliative care and children's hospices to increase understanding and to help families get the support they need
- Support families through our helpline and information hub, so families know they are not alone and can be signposted to local support services
- Promote innovative ways of supporting families caring for a seriously ill child; for example, through volunteering initiatives.

We are asking the public to:

- Reach out to families caring for seriously ill children in local communities by being a supportive neighbour or offering a helping hand with day-to-day activities, such as gardening, shopping or housework – whatever is needed. A friendly smile and a conversation could make families feel less isolated

- Share support information locally so families know help is out there; for example, by sharing Together for Short Lives' helpline information on social media or in local GP surgeries
- Find out how you can volunteer to support seriously ill children in your community via your local children's hospice or palliative care service
- Support Together for Short Lives by making a donation and joining our UK movement to help children and families get the very best care and support.

We are calling on professionals and services who care and support for seriously ill children and their families to be aware of the risk and impact of loneliness and isolation, and provide specific support to families to help them develop and maintain social networks.

We are calling on the UK's governments, the NHS and local authorities to work together to:

- Plan and fund children's palliative care services which offer families caring for seriously ill children a range of short breaks (respite) when and where they need them
- Stage a summit comprising the UK's governments and relevant health and social care agencies to tackle isolation among families who so often feel they are facing the demands of providing 24/7 care alone
- Produce guides in each UK country to help the NHS and local authorities develop strategies to tackle isolation among families caring for seriously ill children
- Work with Together for Short Lives and other voluntary sector organisations to deliver awareness campaigns to make sure that the public better understand and are more willing to help families of seriously ill children.

About Together for Short Lives

49,000 children and young people are living in the UK with health conditions that are life-limiting or life-threatening—and the number is rising.

Hearing the news that your child has a life-limiting condition and is likely to die young is devastating. It's an incredibly distressing and confusing time. These children have very complex and unpredictable conditions and often need round-the-clock care, seven days a week.

Families have to cope with the knowledge that their child will die before them, and daily life for the whole family can become challenging. Although there are many excellent services helping them, these families still have to fight to get the care and support they need.

Together for Short Lives is a UK-wide charity that, together with our members, speaks out for all children and young people who are expected to have short lives. Together with everyone who provides care and support to these children and families, we are here to help them have as fulfilling lives as possible and the very best care at the end of life. We can't change the diagnosis, but we can help children and families make the most of their time together.

Together for Short Lives connects families with services and professionals who can provide care for them in their community.

Together for Short Lives is here for every one of these children and their families, being a companion to parents on their journey so they know where to go for support and have the information to help them make the right choices about their child's care. We are here to help children and their families access specialist children's palliative care and other essential support services.

Together for Short Lives also supports all the professionals, children's palliative care services and children's hospices that deliver lifeline care to children and families across the UK. By working together with professionals and organisations, we provide a strong and unified voice and help services deliver the best quality care and support tailored to each family's needs.

Together for Short Lives has over 900 members - individuals, teams and organisations interested in and committed to supporting children and young people (and their families) with life-limiting conditions. These include children's hospices, voluntary sector organisations and statutory service providers.

Support for families

Together for Short Lives offers a range of support and information for parents, carers and family members who support a child with a life-limiting or life-threatening condition.

Information hub

On our website, Together for Short Lives has a dedicated family information hub. You can find lots of helpful information and you can also search for support in your local area.

<http://www.togetherforshortlives.org.uk/families>

Together for Families newsletter

Together for Short Lives publishes a family newsletter with helpful information about new resources, developments and changes in policy. Contact helpline@togetherforshortlives.org.uk

Together for Families helpline

If you are a parent or carer who looks after or knows a child or young person who is expected to have a short life, have any questions or want support, please contact our [Together for Families Helpline](#)

free on 0808 8088 100.

The helpline works on a call-back basis and is open **from 10am until 4pm, Monday-Friday.** Outside these hours and on Bank Holidays, you can still leave a message on our answerphone and we will return your call as soon as we can when the helpline re-opens.

Email Together for Short Lives

You can also send an email to info@togetherforshortlives.org.uk with your helpline query and someone will respond as soon as possible.

Join our closed family Facebook group

If you are a parent/carer supporting a child with a life-limiting or life-threatening condition, you might be interested to join our private family Facebook group. To find out more, email helpline@togetherforshortlives.org.uk or call our helpline on 0808 8088 100.

Appendix One

Family Life Survey

Together for Short Lives' **Family Life Survey** was shared with family members (parents and carers) who care for one or more child with a life-limiting or life-threatening condition. These families were already known to Together for Short Lives. We asked families to complete a short online survey throughout December 2016. We shared the survey through the following channels:

- Via a link in our Together for Families newsletter
- Via email to our network of Family contacts
- Via a link shared on our closed/private Facebook group

We asked respondents' permission to share their detailed comments anonymously. We have only included family quotes and comments from those who agreed to share their information.

Survey questions included:

- Basic information about the respondent and about their child's age and condition.
- To what extent having a child with a life-limiting illness had impacted on their social life, interactions or relationships.
- To what extent parents/carers felt isolated since their child's diagnosis.
- To what extent parents/carers go out socially following their child's diagnosis – and was this more or less frequently than before.
- Families were asked to share examples of how having a seriously ill child had impacted on their family life and relationships with their partner, family members and friends.
- Bereaved family members were also asked how their bereavement had impacted on their relationships, interactions and social life.

Appendix Two

Public Perceptions Survey

Together for Short Lives commissioned YouGov Plc to conduct a survey about people's perceptions of children's palliative care and to find out how comfortable they are in talking about childhood illness and child death.

We asked three questions, and respondents were given support information around the sensitivity of asking questions about childhood illness and death and given the option to skip questions they felt uncomfortable with. We signposted respondents to our helpline and other supportive organisations. Respondents were given information to help them understand the questions fully.

Questions and sample size

Which words or phrases would you associate with the terms "Children's Hospice" and "Children's palliative care"?

In general, how comfortable or uncomfortable would you feel talking to a friend about their child who had been diagnosed with a life-limiting or life-threatening condition?

Have you had any experience of a child who is living with a life-limiting or life-threatening condition, or that has died aged 18 or younger due to a life-limiting/ life-threatening condition?

All figures, unless otherwise stated, are from YouGov Plc. Total sample size was 2013 adults. Fieldwork was undertaken between 10th - 11th April 2017. The survey was carried out online. The figures have been weighted and are representative of all GB adults (aged 18+).

1. From 1,573 adults who agreed to take part and expressed an opinion
2. From 1,566 adults who agreed to take part and expressed an opinion

Together for Short Lives is a UK-wide charity that, together with our members, speaks out for all children and young people who are expected to have short lives.

Together with everyone who provides care and support to these children and families we are here to help them have as fulfilling lives as possible and the very best care at the end of life.

We can't change the diagnosis, but we can help children and families make the most of their time together.

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