

PARENTS MATTER:

The impact on parents' mental health
when a child has a life-threatening illness



Parents who have a child with a life-threatening or terminal illness can experience extreme stress and anxiety, often for many months or years. This report sets out the particular challenges that they face at different points at a time of life that can be isolating and traumatic.

Read parents' stories and their advice to others, and find out what needs to change to improve support.

The report also describes how emotional and practical support from a Rainbow Trust Family Support Worker can be a protective factor for a parent's mental health.

ABOUT RAINBOW TRUST CHILDREN'S CHARITY

Rainbow Trust Children's Charity's vision is that every family who has a child with a life-threatening or terminal illness has the support that they need.

We believe that families with a seriously ill child should be fully supported in the way that suits them, from the moment their child becomes ill, during treatment, and if needed, through bereavement.

With more than 30 years' experience, Rainbow Trust provides essential practical and emotional support to families, filling the gaps between hospital, hospice and home.

THANK YOU

Our thanks to all the parents and carers who generously shared their experiences, without which this report would not have been possible. Thank you also to Jagoda Campbell Hewson (Cancer Nurse Specialist), Dr Gail Halliday (Consultant Paediatric Oncologist) and Dr Jonathan Rabbs (Consultant Paediatrician) for providing their professional perspectives, and to our external reviewers, Dame Christine Lenehan at the Council for Disabled Children, and Lizzie Chambers from Together for Short Lives.

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EXECUTIVE SUMMARY

Hearing that your child has a life-threatening or terminal illness is one of the most stressful and traumatic experiences that a parent can have. The nature of life-threatening and terminal conditions in children means that the mental health of parents can be under severe strain for many months or years. It is likely that many will experience feelings of anxiety, distress, depression or even trauma.

This report brings to light the shared experiences of some parents and carers who have cared for a seriously ill child or young person, drawing on in-depth interviews and case studies. It considers what mental health support exists for them, what services these parents were offered, and what they themselves feel would be most helpful.

While little can change the facts of a parent's situation, much can be learnt from parents' experiences and the common themes identified in this report. With the right support at the right time, parents can develop positive strategies to manage their mental health more effectively during an incredibly difficult period. Sometimes this support needs to be psychological therapy or counselling. Sometimes it can be as simple as providing non-judgmental, hands-on support to the whole family, to ease the burden of caring, provide time and to be present for whatever each day holds.

Importantly, psychological and emotional support should be offered more than once, and in a sensitive manner.

We hope this report, quite literally, opens up new conversations, and we urge health and social care commissioners to act to ensure that they are planning and funding local services to meet the mental health needs of parents in these traumatic situations.

KEY FINDINGS:

HOW A CHILD'S SERIOUS ILLNESS CAN AFFECT A PARENT'S MENTAL HEALTH

- 1. A parent's mental health can be under severe strain for many months or years as they care for a seriously ill child.** Parents are likely to experience feelings of anxiety, distress, grief, and depression, and sometimes trauma.
- 2. The duration and uncertain trajectory which can be a feature of a child's serious illness can be a source of heightened stress for parents.** Their children may move quickly from a stable to unstable condition, and the final end of life phase can be hard to predict.
- 3. In the last 18 months, parental mental health was a factor in referral for support in 22% of families referred to Rainbow Trust Children's Charity.** Many more parents chose to receive emotional support after building a trusting relationship with their Family Support Worker. The ability to manage difficult feelings may be affected by a parent's access to support networks, their life stage, geographical location, culture, or economic situation. Complex emotional challenges can arise where a parent has existing or previous mental health problems. Difficulties in coping can be a cause for concern for the safety and wellbeing of both the parents and children.
- 4. In a survey by the Disabled Children's Partnership, more than half (54%) of parent carers said they had been treated by a GP for depression, anxiety or stress, including suicidal thoughts.**
- 5. Mental health services have been prioritised in NHS England's plan for the next decade.** However, for parents of seriously ill children, getting the right support at the right time is likely to remain difficult in light of staff shortages, lengthy waiting lists and cuts to services.
- 6. Psychological support is routinely offered to parents with a child receiving cancer treatment.** Some report, however, that they would have preferred access to support outside the hospital environment or that they most needed the support at a later point, following their child's completion of treatment.
- 7. Parents of children with non-cancer diagnoses risk being overlooked because they have a less structured pattern of involvement with health professionals.**
- 8. Other barriers to accessing support can be both practical and cultural. Some parents fear being judged by professionals if they admit to finding their situation hard.**
- 9. In a survey of parents with children under 18 years old, 48% of parents felt that if their children fell seriously ill, the type of support they would most need would be emotional support or counselling.** This was twice as many parents as those who felt they would most need financial support (23%).

HOW PARENTS DESCRIBE THE IMPACT ON THEIR MENTAL HEALTH

- 10. Drawing on interviews with 12 parents of seriously ill children, many parents described feelings of shock, fear and anxiety.** Some also described frustration at the time it took to get a diagnosis of their child's illness, and a sense of powerlessness in the face of their child's serious condition.
- 11. Close relationships are often put under considerable strain.** Roles often change, with one parent perhaps becoming a full-time carer. Many parents described a loss of identity. Anxiety about how healthy siblings are coping can also be a significant concern for parents.
- 12. Feelings of loneliness and isolation are common.** Some longstanding friends may disappear, perhaps because these friends do not know what to say. Parents may lose touch with wider social networks.
- 13. If a child dies, a parent generally has overwhelming feelings of loss and grief.** Where a child survives a period of crisis, parents may still experience strong feelings of loss as a result of their child having a disability or impairment as a side effect of treatment.

RAINBOW TRUST'S ROLE IN HELPING PARENTS TO MANAGE THEIR MENTAL HEALTH

- 14. Timely access to locally available counselling or psychological therapy is fundamental for parents with mental health problems.** Alongside this, the involvement of a Rainbow Trust Family Support Worker can be a protective factor for a parent's mental health. Their role is not to provide counselling, but their experience of working with families with a seriously ill child can equip them to spot potential mental health issues and to respond at an early stage. Regular support can reduce a parent's need for professional help by enabling the parent to identify possible coping strategies.
- 15. Practical support, such as transport to appointments, sibling support, and ensuring a parent has some time for themselves, can further reduce stress.**
- 16. The cost of emotional and practical support provided by a charity such as Rainbow Trust can be compared to the cost to the NHS when mental health problems require clinical interventions.** The cost to Rainbow Trust of providing three months of support to a parent at three hours per week is £1,014. In comparison, the cost to the NHS of six sessions of face-to-face psychological support is estimated to be £1,062 and service costs for a person receiving treatment for depression are put at £2,085.
- 17. Rainbow Trust Children's Charity receives no funding from national government or NHS England, and must fundraise more than 98% of its income.**

RECOMMENDATIONS

At a point when mental health has become a priority for both government and NHS England, it's about time that every parent of a seriously ill child has the mental health support that they need. We urge health and social care commissioners and professionals to recognise the mental health needs of parents with a seriously ill child, and to take up our recommendations below.

It is also time for all of us – family, friends, neighbours, colleagues, professionals – to play a bigger role in supporting parents during an incredibly difficult period of their lives. We hope that this report contributes to making this a reality.

HEALTH AND SOCIAL CARE COMMISSIONERS

- We urge commissioners to review their commissioning of Short Breaks services to ensure their criteria are sufficiently flexible in scope to allow for the provision of emotional and practical support for parents.
- We strongly encourage commissioners to ensure that the particular needs of parents with seriously ill children are recognised in local mental health services, and that a prompt referral pathway exists to enable access to psychological support or counselling if required.

HEALTH AND SOCIAL CARE PROFESSIONALS

- We encourage all professionals working with parents of children with a life-threatening or terminal illness to review their current practice and adopt our checklist on page 41.

PARENTS OF SERIOUSLY ILL CHILDREN

- Don't be afraid or ashamed to ask for help for yourself as well as for your child or their siblings.
- Know that you are not alone, and try to find people to talk to. Sharing your experiences can help.
- Getting help with your mental health is valid and worthwhile. If you are better able to manage your mental health, it will also benefit your child.

THE PUBLIC

- Keep in touch with parents who have a seriously ill child. It is fine not to know what to say. Saying that you don't know what to say is always better than not keeping in touch at all.
- Know that a parent with a seriously ill child will have different needs at different points in their child's illness. It can take time for a parent to recognise that they could benefit from your help, so offer support more than once, and don't be offended if they decline your offer.
- Make a concrete offer of help, rather than a general offer. Ask if there are any practical tasks you could take on. Helping with housework, meals or school drop offs, can help parents better manage their day to day tasks and give them more time to look after their mental health.
- Donate to Rainbow Trust so that more families can receive much needed support from a Family Support Worker.



For families living with childhood illness, time is everything, which is why we have launched a campaign called *It's About Time* to raise awareness and money. We believe that no family should have to go through this alone, so we are here to change that.

rainbowtrust.org.uk/itsabouttime

#ItsAboutTime

INTRODUCTION

This report brings to light the shared experiences of parents and carers of children with a life-threatening or terminal condition, drawing on in-depth interviews and case studies. It considers what mental health support exists for them, what services these parents were offered, and what they themselves feel would be most helpful.

Section 1 introduces what is known about the impact of serious illness on parents' mental health and the sources of mental health support which exist.

Section 2 presents the experiences of parents under key themes which emerged from interviews and shares a list of parents' tips.

Section 3 explains how the support of a Rainbow Trust Family Support Worker can be a protective factor for parents' mental health.

At a point when mental health has become a priority for both government and NHS England, it's about time that every parent of a seriously ill child has the mental health support that they need. We hope that this report contributes to making that a reality.

METHODOLOGY

Interviews were carried out by telephone with 12 parents and foster carers between June and September 2019, using the research questions: 'How did caring for a child with a life-threatening or terminal condition impact your mental health? What support were you offered, if any, and what support do you feel would have been helpful?'. These included 10 parents who had received Rainbow Trust support and two parents who had not. These parents live in geographically diverse areas of England, and comprise eight biological mothers, two biological fathers, and two foster carers. In eight of the cases the child's diagnosis was a type of cancer; the remaining four had other conditions including Pompe Disease, Costello Syndrome, and chronic lung disease.

Rainbow Trust's Family Support Workers also shared experiences, and desk research further informed the report through consideration of existing studies and surveys. Three health professionals provided input from their experiences.

An online survey was carried out by the market research agency Atomik Research in September 2019. Questions were asked of a sample of 2,002 parents with children under 18 years old.

Note: Throughout this report, we use the term 'parent' to refer to any parent or carer with parental responsibility for a child, which could include grandparents, kinship carers, foster carers or adoptive parents. Names of parents and children have been changed throughout.

SECTION 1: HOW A CHILD'S SERIOUS ILLNESS CAN AFFECT A PARENT'S MENTAL HEALTH

This section provides an overview of:

- what is known about the impact on parents
- the types of support which exist
- the barriers to receiving support.

Good mental health is defined by the World Health Organization as '*a state of well-being in which the individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community*'.¹

Any life stress can have an impact on mental health to a greater or lesser degree.

In the UK, mental health issues are widespread. Some research puts the figure as high as one in four adults having at least one diagnosable mental health condition in a given year.²

In our own survey of 2,002 adults with healthy children under 18, two in five parents (39%) said their mental health, as a parent coping with busy family life, is only 'okay' or worse, with mothers more likely to say this than fathers.

HOW MANY CHILDREN ARE AFFECTED?

Academic research in 2011 suggested that 40,000 children (0-19 years) in England, were living with a life-limiting or life-threatening condition in 2009-2010.³ It is anticipated that these figures will increase significantly when new prevalence estimates are published.⁴ This is partly due to medical advances which are enabling more premature babies to survive with complex medical conditions, and to improved treatment and support which enable more children to live longer.

When a child has a life-threatening or terminal condition, it will be no surprise that mental health problems may result for the parent. However, the duration and uncertain trajectory which can be a feature of a child's serious illness can be a source of heightened stress. Children with a life-threatening or terminal illness may move quickly from a stable to an unstable condition, and the final end of life phase can be much more difficult to predict than with adults at end of life. Time becomes very precious.

In the last 18 months, a parent's mental health was a central reason for referral for support in 19% of referrals to Rainbow Trust Children's Charity. Many more parents chose to receive emotional support after building a trusted relationship with their Family Support Worker.

Difficulties in coping can also be a cause for concern about the safety and wellbeing of both the parents and children.

The ability to manage difficult feelings, while also adjusting to the physical, practical and financial demands of caring for a seriously ill child, will be affected by a variety of factors, as illustrated overleaf.

**TABLE:
FACTORS AFFECTING HOW WELL A PARENT CAN MANAGE DIFFICULT FEELINGS**

EMOTIONAL AND MENTAL HEALTH	
PROTECTIVE FACTORS	VULNERABILITIES
<ul style="list-style-type: none"> • Stable mental health • Has developed own coping mechanisms through life experience 	<ul style="list-style-type: none"> • Previous or existing mental health problems or unresolved emotional issues from earlier life • Addictions • Long duration of illness or sudden changes in a child's condition
CULTURE	
PROTECTIVE FACTORS	VULNERABILITIES
<ul style="list-style-type: none"> • Open to talking about mental health and feelings • Open to seeking support 	<ul style="list-style-type: none"> • Taboo around asking for help and / or being free to grieve
RELATIONSHIPS AND SUPPORT NETWORKS	
PROTECTIVE FACTORS	VULNERABILITIES
<ul style="list-style-type: none"> • Immediate and extended family can help out • Strong relationship between parents /close family • Has local friendship and support networks 	<ul style="list-style-type: none"> • Lack of family or friends • A single parent • Conflict in close relationships
LOCATION	
PROTECTIVE FACTORS	VULNERABILITIES
<ul style="list-style-type: none"> • Live close to services and to child's place of treatment 	<ul style="list-style-type: none"> • Must travel some distance to access services and child's place of treatment • Limited access to transport
FINANCIAL STABILITY	
PROTECTIVE FACTORS	VULNERABILITIES
<ul style="list-style-type: none"> • Able to cope if household income reduced and new costs (e.g. transport, parking, hospital food) 	<ul style="list-style-type: none"> • Little or no financial cushion - will struggle with costs incurred and reduced earning power

WHAT DO PARENTS SAY ABOUT THEIR MENTAL HEALTH?

Through recent surveys and studies, a picture can be built up, showing how parents' mental health can be affected when caring for a child with a serious illness.

WHEN A CHILD IS RECEIVING NEONATAL CARE

Although one in seven babies requires neonatal care, this is often only for a number of days. However, some require treatment for many weeks or months. Parents who were excited about meeting their new child must come to terms with having a seriously ill baby who may not survive. Sometimes this follows a complicated or traumatic birth.

A 2018 survey of parents by the charity Bliss found high levels of mental distress.⁵ Among the parents who responded whose baby had been in neonatal care:

- 80% said that their mental health got worse after their time on the neonatal unit.
- 16% were diagnosed with post traumatic stress disorder (PTSD) after their time on the neonatal unit.
- 14% were diagnosed with postnatal depression after their time on the neonatal unit.
- 39% felt they had developed a mental health condition after their experience on the unit, although they were not officially diagnosed.

WHEN CARING FOR A DISABLED OR SERIOUSLY ILL CHILD

A 2019 survey of parents and carers of disabled children by the Disabled Children's Partnership⁶ (a coalition of charities including Rainbow Trust Children's Charity) received more than 4,000 responses. Participants included parents whose children have chronic conditions or disabilities, as well as parents of children with life-threatening conditions. More than half (54%) of parent carers said they had been treated by a GP for depression, anxiety or stress, including suicidal thoughts.

The large-scale 2019 *State of Caring* survey by Carers UK⁷ found that, of carers looking after disabled children under the age of 18, 36% described their mental health as 'bad' or 'very bad', compared to 27% of carers of all age groups.

Breaks from caring can be essential to maintain healthy relationships. One study of parents of children with life limiting or life-threatening conditions showed that 64% of those who were divorced or separated cited having a child with complex needs as a reason for the breakdown of their relationship. Of those couples, 75% had no access to funded breaks at the time their relationship broke down.⁸

SOCIAL ISOLATION

Social isolation and loneliness can be both a cause and a consequence of mental health issues. A 2018 study by Together for Short Lives found that 84% of families said they have felt isolated and alone since their child's diagnosis, and 90% said their relationship, social life and interactions with friends had been adversely impacted since their child's diagnosis.⁹

80%
of parents said that their mental health got worse after their time on the neonatal unit.

SOURCES OF MENTAL HEALTH SUPPORT FOR PARENTS

Recent years have seen some recognition of the need to expand access to mental health services as the prevalence of mental health problems, and their cost to society, has become clear. NHS England's plan for the next decade commits to increasing funding for mental health services, to expand access to services for common mental health problems, and to improve support for those experiencing a mental health crisis.¹⁰ However, getting the right support at the right time remains difficult for many parents.

PARENTS OF BABIES AND INFANTS

Improving access to mental health care for women in pregnancy or in the first year after giving birth has been a focus of government attention, in part owing to a recognition of parents' distress if there is a miscarriage or a baby dies. NHS England intends to expand specialist perinatal mental health care services to support a greater number of new mothers, and has stated that the mental health of fathers and partners must also be assessed.¹¹

Outside hospital, during pregnancy and after birth, all parents should receive five home visits from a health visitor whose role includes spotting early signs of mental health problems.¹² In reality, budget cuts and staff shortages mean that not all parents receive this support.

PARENTS OF CHILDREN WITH CANCER

During intensive treatment for a child's cancer, families routinely have access to psychological support, in line with national health and care guidance.¹³ Since cancer treatment requires frequent appointments and sometimes inpatient stays, medical staff - such as nurse specialists - have regular opportunities to assess emotional strain. Anecdotally, around half of families may ask for psychological support. Additional support may be offered if a child requires a major procedure, such as a bone marrow transplant. Some units offer group support to parents at specific points, for example, when a child has completed in-patient treatment and will be receiving maintenance therapy at home.

PARENTS OF CHILDREN WITH OTHER DIAGNOSES

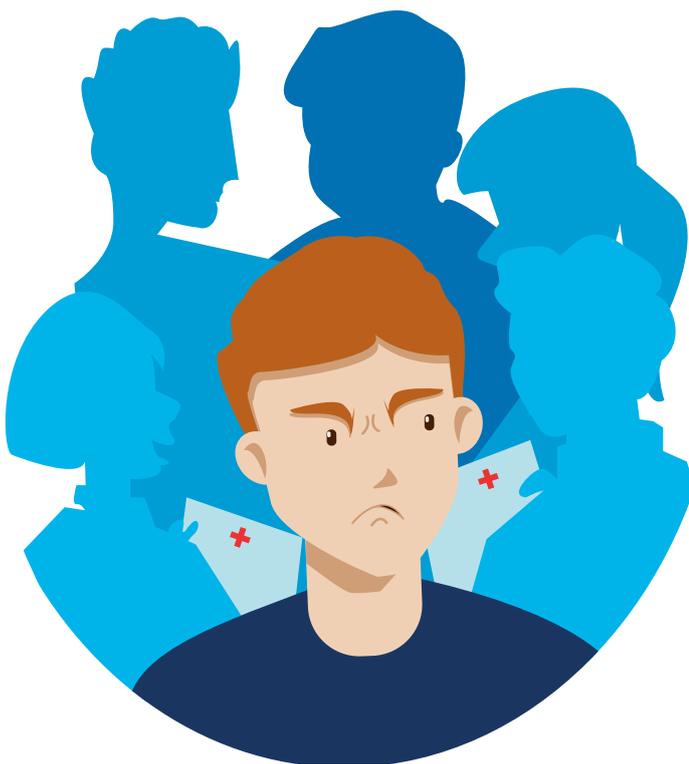
Although not compulsory, there is detailed NICE guidance¹⁴ on best practice when a child is at end of life. This sets out the need to provide parents with information about sources of emotional and psychological support, and how to access it. The guidance also notes that support for grief and loss should be offered.

However, parents of children with non-cancer diagnoses risk being overlooked because of the different pattern of their involvement with health professionals. There will be families whose child's condition is life-threatening or terminal, but whose condition is stable for long periods of time, or bounces between critical and stable phases. These parents may have frequent intensive and traumatic experiences, and may benefit from mental health support long before their child is recognised as nearing the end of life. But they may not be routinely approached with an offer of support, meaning they will need to be proactive in finding an outlet for any mental health problems which arise.

BEREAVEMENT SUPPORT

Grief is a natural process and not a 'mental health problem', but feelings of loss can be overwhelming and difficult to manage. Some parents will benefit from attending bereavement groups or one to one counselling. However, research in 2017 found that 18% of Clinical Commissioning Groups and 72% of Local Authorities do not commission bereavement care.¹⁵ What is available will often depend on local charities and hospices, or whether a parent can afford to pay for private counselling.

The need for support for parents when a baby dies has started to receive more attention, in recognition that hospital care has sometimes lacked compassion and sensitivity. However, evidence suggests that access to specialist psychological support remains patchy.¹⁶



OBSTACLES TO ACCESSING MENTAL HEALTH SUPPORT

- **Child's age and diagnosis:** The type of condition a child has, and the pattern of their treatment and contact with health professionals, may all affect the support that parents are offered or become aware of.
- **Practical barriers:** Initiatives to expand access to mental health provision can be of limited value to parents with inflexible work, those without regular and reliable time off from caring, or with no access to transport or childcare.
- **Location:** The distance to attend appointments can compound the situation, with parents in rural Cumbria, for example, having almost no local support services.
- **Culture and stigma:** Whether a parent feels comfortable seeking help from non-family members may depend on their background, beliefs, and family or community attitudes. Some parents explain that taking antidepressants or receiving counselling is frowned upon within their culture, and this has delayed them in seeking support. Those without English as a first language and those from minority groups, such as the traveller community, are likely to need more targeted services.
- **Fear of judgment:** Parents can fear that by admitting that they find their situation hard, they may be judged by health or social care professionals, and their ability to meet the needs of their child or children may be questioned.

PRACTICAL SUPPORT FOR CARERS

Alongside emotional or psychological support, anecdotal evidence indicates that practical help can reduce the high levels of stress that parents feel because of their child's serious condition and their caring responsibilities. The Department for Health and Social Care¹⁷ and NHS England, have both committed to improve support for carers, and the first ever government strategy for tackling loneliness has recognised carers among potentially vulnerable groups.

However, parent carers are a relatively small group within the UK's overall numbers of adult carers, the majority of whom are carers for older or disabled adults. Parents of children with a life-threatening or terminal condition will rarely benefit from initiatives such as support for carers to return to work, or to request flexible hours, which can be irrelevant for those who provide round-the-clock care for a child with little or no nursing provision. At the same time, parents whose healthy children have become young carers, helping to care for their sick brother or sister, may feel anxious about the impact this is having on them.

Local Authorities are legally obliged to carry out a free 'parent carer's needs assessment' for any adult who cares for someone on a regular basis because they are ill or disabled.¹⁸ However many parents appear not to be aware of their right to be assessed. A Carers UK survey found that, of parents caring for a disabled child under 18, only 17% of parent carers had a Carer's Assessment or review in the last 12 months.⁷

Once assessed, the ability of a local authority to meet a parent carer's needs will vary depending on available services, funding and workforce pressures. Many parents find that they do not meet the rising eligibility criteria for care packages.

WHAT DO THE PUBLIC THINK?

An online survey was conducted by Atomik Research among 2,002 parents of under 18 year olds in September 2019. Findings included:

- Two thirds (65%) said they don't have an idea of how they and their family would cope if one of their children fell seriously ill.
 - If their child fell seriously ill, 48% of respondents felt that the type of support they would most need would be emotional support or counselling. This was twice as many parents as those who felt they would most need financial support (23%).
-



SECTION 2: HOW PARENTS DESCRIBE THE IMPACT ON THEIR MENTAL HEALTH

This section sets out the themes raised by 12 parents during interviews about their experiences. All names have been changed.

FEELINGS OF SHOCK, FEAR, ANXIETY AND HELPLESSNESS

Difficult and overwhelming feelings are to be expected when a parent hears that their child has a life-threatening or terminal condition. Parents have a natural instinct to want to protect their child and 'make things right', but must now entrust their child's health and wellbeing to a team of unknown medical people.

The experience of having a baby born with a life-threatening or terminal condition can be particularly traumatic, whether or not it was anticipated. A time in life when most parents hope to experience joy and celebration becomes a time of great anxiety and fear.

For others, there are vivid memories of the stress and worry they experienced while seeking a diagnosis to explain why their child felt unwell. Parent, Sarah, frequently visited her GP in an 11 month period when her son was often unwell, but she was told there was nothing to worry about. She even started to doubt her own judgment. Such delays can lead to parents having less confidence in medical staff. Sarah explains, *'By the time he needed critical care, you've lost all faith in the medical system. You're on the back foot, not being believed.'*

Another parent, Rachel, recalled that her GP referred her son for a non-urgent scan but she trusted her instinct and took him to Accident and Emergency the next day. As a result, he was more quickly diagnosed with cancer and his treatment began much faster. She added that it worried her to see parents with limited English or limited support around them because she knew that it would be harder for them to advocate for their child effectively.

Many describe the moment of diagnosis as something that nothing could have ever prepared them for. *'At every stage you are aware it might be something serious like cancer, but you don't really think that's going to happen,'* explained Rachel.

From the point of diagnosis, parents felt they simply had to get on with whatever was required of them. *'I went into survival mode. People say, I don't know how you do it. But you don't have a choice, you can't just get up and walk away,'* said mother Kerry.

For some parents, treatment must begin immediately at a specialist hospital, sometimes more than 100 miles away. This means a sudden upheaval for the child and their family. Professionals interviewed reiterated that the impact on family life of a sudden diagnosis and the need for immediate treatment can be huge. As one Cancer Nurse Specialist explained, those with existing mental health problems *'can struggle phenomenally'* with the demands on themselves and the wider family.

Feeling scared is a recurrent theme. One parent, Emily, said she managed her fear by trying to learn as much as possible about her daughter's condition. Another took the approach of being selective in the information she sought. Rachel said, *'I decided early on that, in order to stay sane, I would not look at anything on the internet that wasn't from a source such as CLIC Sargent or the NHS website. I felt I would go crazy and fall into a rabbit hole otherwise.'*

PARENT 1

At the end of the first trimester of pregnancy, Lucy was told that her twin daughters had chronic lung disease and might not survive.

'When I thought the girls may not make it, I felt my world had crashed down around me,' she said. 'I was in a very difficult emotional place. I felt really isolated and alone. It was as if I was fighting a long and lonely battle, despite having people all around me in the hospital.' Lucy found the uncertainty hard to adjust to but didn't want her anxiety to harm her daughters. 'I tried to suppress my feelings during my pregnancy to protect my children.'

She and her fiancé Paolo were advised to prepare for the worst at her 20-week scan. She was given six weeks of bed rest to give her daughters the best chance of survival. *'Those days were the hardest of my life. We had nothing but empty hope and prayer.'*

The non-identical twins, Lydia and Amy, were born 14 weeks early, each weighing less than a kilogramme. They both needed 24 hour oxygen, and were moved to a neonatal intensive care unit (NICU) while Lucy returned home with Paolo.

“I felt really isolated and alone.”

'I fell into a really, really deep depression. I can't explain how dark that place was. It was so bad that I could barely get up even to wash. I was never suicidal but I was definitely hopeless.'

Each day the parents had to ring the hospital to check if the girls had made it through the night. *'There was such a level of fear, a level of depression. It is categorically the worst feeling to be a parent in that situation.'*

She and Paolo would visit their daughters, but she struggled with the situation. *'My immediate feeling was to run. I tried to detach myself. I didn't want to bond with them, I was so scared they might die, then it wouldn't be so bad.'*

She began to make excuses for not visiting them, and Paolo would visit alone. Lucy was embarrassed about her poor mental health, but put on a brave face in front of medical staff. *'I'd go home and I was absolutely collapsing... The doctors had no idea as far as I know.'*

The situation became harder when one daughter improved and was moved to a second hospital, so visits needed to be split between the two locations. She would visit to deliver expressed milk for nurses to give to her daughters, but one day Lucy brought the milk in without wanting to see her daughter at all.

'A nurse asked me if I was OK. I said no.' Lucy was introduced to a psychologist on the ward but did not find it very helpful. *'I went in and she asked me how the babies were. She didn't see me as a person. They saw me as a mum. They didn't see the fear.'*

“I fell into a really, really deep depression. I can't explain how dark that place was.”

Lucy reflects: *'I feel that there's not enough mental health support for parents going through probably the deepest trauma that they'll ever experience. In nature, the mother is never away from their young... It's the most abnormal thing to be away. When I was strong enough to see them, I didn't want to leave them.'*

'It's all well and good to have support in the hospital. The real time you need support is when you're away from that, in your own space, that's when I think you're vulnerable.'

'I feel there needs to be more than just a piece of paper on a noticeboard offering time with a psychologist. I feel parents' mental health is brushed under the carpet. Every parent I spoke to [in the Neonatal Intensive Care Unit] was suffering.'

She believes the mental health of parents is as important to the wellbeing of seriously ill babies as their medical treatment.

Lucy stopped using the expressing room as her daughters moved off breast milk, and she grew increasingly isolated. But then she came across a leaflet introducing Rainbow Trust's neonatal support service and referred herself for support.

'I remember the day somebody [from Rainbow Trust] came to the house. The girls had just come home and were both on oxygen. There was no judgment. The Family Support Worker said, if you want to cry, cry. If you feel crap, it's OK to feel crap. If you want to swear, go ahead.' *'Saying it's OK to feel crap, that in itself is so powerful in helping someone.'*

The Family Support Worker helped the couple to adapt to moving the girls back home, taking them to outpatient appointments, assisting the girls with their oxygen and providing Lucy and Paolo with a break from caring. Lucy's ability to bond with her daughters improved when they were each weaned off oxygen support.

Lydia and Amy are now well, and have no long term health problems. Lucy said: *'I couldn't have done it without my Family Support Worker and Rainbow Trust. Having her visit for a couple of hours was like coming out of deep water and being able to breathe again. Having someone to talk to and who is good with the girls was amazing.'*

PHYSICAL RESPONSES TO STRESS AND ANXIETY

Sustained stress often takes a physical toll. Emily was struck down with a terrible headache for a week following her daughter's cancer diagnosis, and could not stand up without vomiting. In hindsight she suspects this was a physical side effect of the protracted wait for her child's diagnosis.

Kerry described her anxiety as manifesting in chest pain, knotting in her stomach, and sleeplessness. Nine months after her daughter's cancer diagnosis, she asked her GP for anti-depressants which she had previously taken following miscarriages and a bereavement. Another parent recalled frequent mouth ulcers and grinding her teeth at night.

POOR SLEEP

“You're just so tired all the time.”

Parents reported feeling constantly exhausted, either from sleeping on a fold up bed in hospital with their child, or from caring for their child round the clock at home. Parents may need to administer medicine at intervals throughout the night, or may be woken by alarms on medical monitors requiring their immediate attention.

Rachel explained, *'You never sleep that well in hospital. There are tests and observations on the kids every couple of hours, nurses coming in to change lines and the syringe driver beeping.'*

On top of that, eating well can be difficult with parents reliant on food from hospital shops in brief periods when they are away from a child's bedside.

PHYSICAL HEALTH

Prolonged stress can result in physical symptoms including palpitations, sleeplessness or headaches, and links have been made between long term stress and heart disease.¹⁹ At the same time, a parent who needs to move bulky and heavy medical equipment, or transfer a heavy child between a bed, wheelchair or car, can suffer from physical ailments such as back problems.

IMPACT ON ROLES AND RELATIONSHIPS

Statistics suggest that the strain of caring for a seriously ill or disabled child can contribute to family breakdown.⁷ This can be between the parents or, in other cases, the wider family. Parents in a relationship were keenly aware of the strain caused by their everyday life changing drastically to fit around their child's needs. Often more traditional gender roles are adopted, and the father may become the sole breadwinner. Family finances are usually squeezed by the cost of transport, hospital food and car parking, and the loss of any second income, which exacerbates pressure.

Emily felt she had no choice but to stop work when her daughter needed a second round of cancer treatment. She described this as something of a loss but also necessary for 'self-preservation'. As a result, she feels she can support her whole family better without being overloaded. *'We've become very aware of our finite mental, emotional and physical energy. As a team it made sense for me and my husband to divide up the responsibilities so neither of us went under and we could stay strong for the long haul.'*

For some, there was a conscious effort to invest in their relationship. Rachel said, *'We made a decision to be quite kind to each other, compared to normal life when you can be bickering about the towels, and the bins, and so on.'* She was relieved that her partner's previous experience of post-traumatic stress disorder (PTSD) did not return. She felt that her partner was stressed by his work, while her focus was *'cancer, the children, being in hospital'*.

'You are trying to have a balance about care for your child and staying sane enough to deal with life in hospital. In some ways I treated myself and my partner better than in normal life, it was part of making sure we'd function.'

Some fathers can feel left out. Kerry recalls, *'Steve said that all the way through treatment he felt a bit of a spare part. I was in hospital all the time, I was having all the discussions with the doctors, I knew all the medication and the doses.'* Kerry had to explain how much she valued his role. *'I told him, you don't realise what a backbone you are.'*

On the one weekend when she came home, and Steve took her place at their daughter's bedside, Kerry found it 'unbearable' not to be there. She wanted constant updates from him. This gave them a useful insight into each other's day to day lives.

A bereaved father, Robert, who has been with his partner for 15 years, reflected: *'I'm grateful that we've worked hard on our relationship... It requires work, when you're both depressed. Actually, that's not the right word. When you're both totally crushed.'*

"We've become very aware of our finite mental, emotional and physical energy."



PARENT 2

Paul was awarded custody of his two sons after his ex-partner's mental health was judged to be putting their two young sons at risk of neglect. He relocated to take care of them and to live closer to his mother and sister.

The following year his four year old son Noah became unwell. Initially doctors thought he had growing pains. Noah then had fluctuating flu-type symptoms and cold sweats, and his walking became unsteady. Eventually tests brought a diagnosis of Neuroblastoma (a type of cancer).

'Nothing prepares you to find out that your youngest son has something like that,' Paul explained. *'It was extremely tough... From then on it was a bit of a whirlwind Everything goes on hold. You have to do whatever needs to be done.'*

“The whole experience has changed me completely.”

He had practical help from his mother, Noah's grandmother, with whom they lived. She was able to look after Jack, Noah's healthy six year old elder brother.

Life became focussed on hospital appointments and treatment. At one point Paul was in hospital with his son for seven weeks while Noah received high dose chemotherapy to treat cancer in his leg, back and skull. Noah developed liver disease as a side effect, which further extended his hospital stay. Paul was anxious that Jack was suffering from seeing his 'best buddy' in hospital, as well as the change to his routine.

The strain grew as Paul watched his bubbly and outgoing child endure many weeks of treatment. Paul had left behind well-paid work to take custody of the boys, and the family relied on his savings for a period. During Noah's intensive treatment he found that getting work was impossible, which added to his pressure. He then became unwell himself, and was diagnosed with multiple sclerosis.

'I'm a very patient and chilled guy. But it's taken its toll on me. Even now I still wonder how I got through it.' Noah's treatment lasted 18 months overall, and in summer 2019 he was given the all clear. His cancer and its treatment have left Noah with damage to his kidneys and some muscles. He continues to receive physiotherapy and will be under observation for the next five years.

However, around the time that Noah's treatment ended, his mother took her own life. The family is still coming to terms with this. Paul's main concern is his sons' welfare. *'They've been through so much.'*

'The whole experience has changed me completely,' he explained. He found attending a bereavement group useful. *'I like to share my experiences. You can go through hell and still function. I'm still here. I'm still trying to live a normal life... That's my little coping strategy, there is hope.'* He is also determined not to dwell upon whether the cancer might return. *'You can't live your life in fear. You can worry about it when it happens.'*

While he had a positive experience of support in hospital, Paul would have liked to have been signposted to emotional and practical support more quickly. He was referred to both CLIC Sargent and Rainbow Trust Children's Charity. He valued both charities' non-judgmental approach. Importantly, having a Family Support Worker spend time with his sons and take them on 'little adventures' allowed Paul to have some precious down time.

“You can go through hell and still function.”

Paul is still processing his experiences, and has been told to be careful not to let stress worsen the symptoms of his multiple sclerosis. Paul has noticed that he and Jack both get irritated more quickly than in the past. He says small things wind him up, and he has observed his impatience when driving.

Paul is currently on a waiting list for counselling through his GP, but he is clear as to his priorities: *‘I’ve got two kids to raise, and support. I can’t be moping around and feeling sorry for myself.’* For parents, the sick child and their siblings, he feels that *‘mental health is a crunch point. It’s a huge, huge issue. It doesn’t get anything near the support it deserves.’*

DIFFERENT WAYS OF COPING

Several parents described their partners as having a distinctly different coping mechanism from their own. In relation to their twins in neonatal care, Lucy explained: *‘Whenever there was a blood transfusion or an infection or whatever, my fiancé would say ‘They’ll be fine.’ He wouldn’t acknowledge anything. In a strange way, that kept me going.’* However, there was point when she knew that her depression had started to affect him, and he told her he was also starting to feel constantly sad.

Lisa’s husband helps her breathe through moments of panic, but she knows that he is also affected by their son’s illness. *‘When I had a breakdown, he also collapsed at home. He is on antidepressants. He said he has the same feelings that I do, of helplessness.’* Three other interviewees said that they or their partners have been on anti-depressants since their child’s diagnosis.

Another mother, Rehana, said, *‘I think my husband is more used to it, he sees people dying all the time because he’s a doctor. For me, it’s my child... He’s calm. But then you need the balance.’*

WORRY ABOUT HEALTHY SIBLINGS

A striking feature of interviews with parents was their overwhelming concern for the mental wellbeing of their healthy children, over and above their own mental health. Several spoke of the strain of ‘holding it together’ in front of them. Rehana described how her healthy elder son Shahid began to vomit with anxiety when his younger brother was receiving leukaemia treatment. His school put support in place, but she felt he needed more help than was offered by the health service. Paul’s healthy son has experienced not only having a seriously ill brother but also his mother’s death through suicide. Getting mental health support for his healthy son has been his priority.

Kerry explained how initially her elder daughter Clara found it was ‘a bit of an adventure’ having different playdates when her parents could not collect her from school when her sister began urgent cancer treatment. *‘But after a while, she just wanted things to go back to normal... What really broke mine and Steve’s heart was when she’d say, ‘I wish I had leukaemia’ because she saw her sister in bed all day, having her dinner brought to her, getting attention, having rules bent, getting presents. At just six years old she couldn’t understand... Stuff like that you find really upsetting.’*

Another parent, Lisa, explained that her teenage daughter began to refuse to attend school because her brother was having time off for his treatment. She felt she should be able to miss school as well.

CHANGES TO FRIENDSHIPS

The emotional - and practical - support from friends was a strong theme raised by parents in terms of how they coped. Kerry's partner was due to start a new job on the very day of their daughter's diagnosis but managed to delay the start date by one week. *'People were great. One of my friends became my brain. She organised a rota for drop offs and pick ups, and giving [healthy sister] Clara her tea.'* This was particularly important as the family have few relatives. *'People really came together and helped out.'*

Rachel described how small acts of generosity helped her mood during her son's treatment, with one friend buying her a magazine subscription. *'Everything kind of shrank for me in the period when we were mainly in hospital.'* She added, *'It definitely changes your relationships with people. You don't have time for nonsense.'*

However, a child's life-threatening illness can last many months or years. Parents perceive that emotional and practical help from friends and their community is unlikely to last indefinitely. After the initial crisis, a parent's worry, stress and exhaustion does not cease, and parents feel guilty that they are unable to repay favours.

Kerry summed this up: *'As time goes by, it's just, it's hard to say it without sounding mean, but it kind of wears off... Also, there are people who've done so much for you, you just don't feel you can ask them again. I just can't. They've given up so much time already.'*

Emily recalls a day when friends delivered four different meals to the family home during her daughter's first round of cancer treatment. When cancer returned and her daughter needed to start treatment a second time, she felt that a lot of the local community were 'exhausted' by the family's continued suffering.

“It definitely changes your relationships with people.”



PARENT 3

Rehana's son Nadeem was diagnosed with leukaemia just after his second birthday, when he was being treated for pneumonia. Suddenly she was thrown into a new and frightening world.

Nadeem needed a transfusion and a nasal feed, and for a period he was bedbound and unable to talk.

'We had a really hard time,' she said. His pneumonia meant his leukaemia treatment could not start immediately. Then, after treatment began and he was allowed home, Rehana was responsible for his nasal feed, and for administering syringes of water to prevent dehydration.

'That terrified me at the beginning. I was so scared.' She was also worried about Nadeem's healthy brother Shahid who had bouts of vomiting because he felt anxious about the situation.

Rehana had no family nearby and her husband, a doctor, works long hours some distance away. She could not leave Nadeem alone at home and had no way to get her healthy son Shahid to school. She also has a younger daughter. In desperation, relatives from the USA took it in turns to visit and take Shahid to school for a month at a time, as an interim solution. She sought practical help through her health visitor, but was told that no statutory support was available.

"I told them, I'm going to have a nervous breakdown."

'I was very upset... We fought with them a lot. We made our concerns extremely clear. I told them, 'I'm going to have a nervous

breakdown'.' Rehana thinks that her health visitor saw that weekly charitable support was in place from Rainbow Trust and from a local church group, and concluded that the family's needs were not great enough. When Rehana continued to press for help, she was told that if she could not care for her children then they would need to be taken into foster care.

Looking back, her ideal would have been to receive support for her mental health away from the ward treating her son. *'You don't want to cry in front of children. It's a tense atmosphere... The hospital is a place that drains you.'*

Rehana found out about Rainbow Trust's sibling support services through a Rainbow Trust drop-in group at the hospital and soon Shahid received support, both one-to-one and in group activities.

'The biggest thing with Rainbow Trust is that my elder son got to see people with brothers and sisters in the same situation... it was good for Shahid to see other children who had a brother with a tube as well.' Simple pleasures like going out for a bike ride have meant a lot to Shahid as it is extremely hard for Rehana to spend any time away from Nadeem.

Taking steroids has made Nadeem behave more aggressively. *'It's really stressful in the house. There's lots of shouting, screaming... It's hard to talk at home. It gets so loud, you can't think.'* Nadeem doesn't like to share his mother physically, so his brother and younger sister cannot cuddle her as they would like without him reacting. When her Family Support Worker takes Nadeem out of the house, Rehana can enjoy a more relaxed time with her healthy children.

Rehana remains frustrated that statutory support was not available. *'I feel like we were punished for having a higher income. But we were not asking for money, we were asking for support for my mental health and my children's mental health... I was really upset. I'm still upset.'*

LONELINESS AND ISOLATION

The drastic change in a parent's routines, and restrictions on how and where they can spend their time, can result in feelings of loneliness and isolation. Sarah has a son who is in remission from cancer but has ongoing disabilities and mental health issues resulting from his treatment.

'Lots of friends disappear', she said. 'Not deliberately. But things like the WhatsApp group for going to the pub - you get taken off because people know you're in hospital and you can't go. You lose being able to chat in the playground, being part of a community. You're not doing that anymore. It may be for some friends, you become their worst nightmare - it's hard for them to see another child ill. They avoid you. It's not nastiness. People just don't know what to say. Some you thought were friends weren't there anymore. Other people think they're being understanding but they give you lots of advice. That's very draining.' For her, this isolation became more prominent after discharge from hospital.

Some fathers felt that men can be particularly poor at maintaining relationships in a period of crisis. Robert described how a previously close friend did not make himself available to support him during the two years his daughter was treated for cancer. The men are only recently back in touch after an eight year gap. In contrast, an old school friend renewed contact with him and was hugely supportive. 'He is now my closest friend in the world.'

"Lots of friends disappear."

He commented, *'Men, broadly, are useless at maintaining friendships. I look at my wife, and she has friends from across her life, she works hard to maintain those friendships.'*

Another father, Paul, said, *'My best friend of 20 years fell off the radar. It's difficult even getting hold of him... I just wanted someone to talk to.'* He found that his family provided the bulk of the emotional support he needed, rather than his friends. *'It's a shame. There's a real awkwardness.'*

"It's a cliché, but you find out who your friends are."

He suspects that some friends feel they can't chat to him about their lives because their own problems will sound trivial in comparison. The unintended result can be further isolation. *'It's a cliché,'* Robert says, *'But you find out who your friends are.'*

SOCIAL MEDIA

Access to online groups can be a source of support and useful information. But most parents said that they avoided social media because it was damaging for their mental health.

'It can make me feel quite rubbish,' said one mother whose daughter has ongoing disabilities. Another parent described the pain of seeing Facebook images of one of her son's peers diving into a swimming pool to mark his ninth birthday when her own son had lost the ability to swim. A third parent mentioned that a Facebook group for parents of children on a leukaemia ward means she is aware of a number of children who have died since her son started treatment. *'I'm not saying I don't want to know about it,'* she said, *'But I don't want to deal with it.'*

Social media can be especially challenging to navigate in bereavement. Sharing images and memories of their child can be a way for a parent to maintain the continuing bond that they feel. But over time, the 'likes' and messages of support received on important dates and anniversaries may tail off, leaving the parent feeling hurt and isolated.

PARENT 4

Sarah's son Joseph was diagnosed with cancer when he was eight years old. He is now 12 and treatment has left him with disabilities and ongoing health complications. He is unable to attend school full time.

Sarah recalls being introduced to a psychology team when her son was an in-patient, but her impression was that this was about ensuring parents understood the medical situation. She felt that information she received from both health professionals and charities was focussed on practicalities and making parents aware that their children might need future psychological support, rather than whether her own mental health was affected.

Looking back, she observed, *'There can be very good support, if you reach crisis point. But low level support, sibling support and so on, is less easy to access.'*

“You lose all identity... You're not often called by your own name.”

Instead, Sarah found support when she met other parents in the parents' kitchen on the ward, and, as a single parent, Joseph's grandparents were an important source of emotional and practical support.

'But they knew they got to walk away and cry in the car. As a parent you can't do that. We have to keep it together for the kids, for your very poorly child and your other children too.'

Her son was too ill for her to leave his bedside and benefit from small treats like a visiting nail technician who, at Christmas, offered a manicure to parents, but off the ward. *'It would have helped make us feel a bit normal, to have our nails done. You lose all identity. We all become 'the parent of the ill child'. It didn't matter what we'd done before, our studies, our jobs, whether we were married or divorced. They all spoke to you at the same level, in the same way. Somebody coming round and doing your nails - it would have been nice.'*

Sarah suggests that a simple name badge for parents would help. *'You're not often called by your own name. There was a play therapist who got to know us, and on some wards, we did get to know the nurses well. But otherwise it was very, very rarely that people knew my name. I was 'Joseph's mum'.'*

The change to her identity has been hard. *'Your own core sense of integrity, you've lost that. Then you're nobody. I'm the carer for Joseph... You're not anything... I find it difficult. Prior to owning my own business, I'd been a teacher, I'd worked with children with special needs. I was used to being on the other side of things.'*

'It's very isolating, but less noticeable when you're in hospital. Then when you come out, you're grieving, for the life your child had, the life your other children had, your own life. There's a tremendous amount of grief. People give you a little bit of time but they expect you to get back to normal. But what is normal anymore?'

'When you're in hospital you're thinking a lot about the need to get home, what you're looking forward to, but it's actually not like that.' An especially tough memory was telling her brother by phone that she had had to order a stair lift for her son, then aged nine. *'It was so upsetting, remembering my active, healthy boy who now couldn't get upstairs, it just hit me so hard.'*

Back home, daily encounters can stir difficult emotions. *'You find yourself comforting other people. You're in the supermarket and Joseph is in a wheelchair with no hair, and you bump into an old colleague or an old friend who hasn't heard what's happened... Everything becomes a big ordeal.'*

Sarah received some counselling from a local cancer charity but its expertise was in caring for patients and family members of adults with cancer rather than parents of a child.

'As parents we're left, with seriously ill and mentally ill children, to cope alone. And that impacts a parent's mental health.' Understandably, her son experiences low mood and poor self-esteem because of his experiences. *'It is hard. I can rationalise about my own mental health issues, but I can't rationalise about my child's mental health issues.'*

Although Sarah managed to keep her business running during her son's in-patient treatment, she was forced to close it and make staff redundant when her son came home and needed round-the-clock care, including medication every four hours. She is embarrassed to be reliant on benefits, and feels incredibly guilty for putting others out of work.

Her energy is now focussed on securing the services which her son needs. In hospital, a consultant coordinated all aspects of Joseph's treatment, and everyone was accountable to that person. Now she must make separate calls to different services and specialists. One particular outpatient appointment took a year to set up.

'I'm constantly fighting for things. It's a strain... The biggest thing that could help would be a survivorship pathway or plan. Having someone in the system who could help you get things done would take a lot of pressure off.'



ADJUSTING TO A 'NEW NORMAL'

In some situations, discharge from hospital can mark a positive step, with the child's condition no longer seen as life-threatening. However, both the parent and child may feel they have got used to a passive role during in-patient treatment, losing the ability to make their own decisions. Alongside relief, there can be new emotions for parents to manage as they have the space to reflect. Many parents must also take on new responsibilities such as managing their child's life-supporting medicine regime or equipment, full time.

Feelings of trauma and loss are common. Frequently parents describe feelings of grief as they start to recognise that their child's life - and their own - will never be the same again.

'Now that everything is finished, so many people say, 'you can go back to normal,' explained Kerry. 'We don't really know what normal is anymore. It feels like there's this really weird hole... It's been a massive part of our lives and now it's gone. I don't really know what to do with myself. I thought I'd be skipping about, full of joy. We're incredibly relieved and happy that it's over for her so she can get on with being little. But it's really odd. I don't think it's talked about. You're kind of grieving something.'

Similarly, Paul described the period after his son completed treatment as *'a very peculiar feeling. I'm now left picking up the pieces'*. After 18 months of intense treatment, he asked, *'Do I pretend it didn't happen? Do I go back and try to get a job? You're thrust into this world and then it's taken away from you.'*

For a long time Emily's main concern was her daughter Jessica's survival. When Jessica was well enough to be discharged, the parents had to confront the fact their daughter had lost her sight. They began to think about her education and Jessica's quality of life going forward. *'The focus shifts from the immediate crisis to the longer term. There's a grieving process. It's a really anxious time, that period when you come out of treatment.'*

As primary carer, Emily continues to be focussed on her daughter's needs. She must stay on top of her daughter's blood counts, and has to carry a large folder of medical notes between numerous appointments with different specialists.

BEREAVEMENT

For Robert, the death of his two year old daughter was followed by depression. *'My GP offered to refer me for some counselling which, in hindsight, I should have taken up.'* Instead he took antidepressants for about six months. However, he disliked how the medication could 'flatten you' and how it disabled his ability to experience more positive emotions.

Speaking some years later, he says he knows that suicide is the biggest killer of middle-aged men. *'Nothing that dark ever crossed my mind, but I was in a very low place.'* He recalled a morning when he sat on a bench for several hours, unable to go into work. Robert is grateful that he was brought up in a family where talking about mental health was not taboo. For him, the key is to be able to seek support. *'There's no shame in asking for help... I think a lot of men struggle to talk about their emotions generally. The thought that you're not coping is hard for them.'*

“There's no shame in asking for help... I think a lot of men struggle to talk about their emotions generally.”

OFFERS OF PSYCHOLOGICAL SUPPORT: TOO LITTLE, TOO LATE?

Most parents interviewed for this report felt that the professional support they were offered for their mental health was not at the most helpful time.

Many received an offer of psychological support in hospital if their child was receiving cancer treatment. Kerry sought help when she was feeling both the emotional and practical strain about three months into her daughter's treatment. *'You're incredibly anxious about what's going to be happening [medically] to your daughter,'* she explained. Although psychological support was offered, she felt the hospital setting was unhelpful. At one point a psychologist visited her when her daughter Lily had just woken from an anaesthetic and was throwing things around the room. This made it very difficult to speak, in addition to the fact that Kerry did not feel comfortable talking about her own mental health in front of her daughter.

On another occasion the psychologist rang her at home to discuss her feelings but within a few minutes Kerry was being disturbed by her two children. *'That set up may work for others but not for me.'*

'All we wanted to do was just be there,' said Robert. He recalls meeting a psychologist at the hospital treating his daughter, and having two counselling sessions through their local hospice. He found these useful, although he let a third session lapse amid the demands of returning to work. In contrast, another mother felt that access to psychological support in the same hospital as they attended for their child's treatment was valuable as the staff would be familiar with what parents would be encountering.

Most parents suggested that being offered support again at a later stage, either when their child's condition was no longer critical, or following bereavement, would have been beneficial. Yet contact with previously familiar professionals is reduced on discharge and can cease altogether if a child dies, compounding feelings of isolation. Some parents had sought counselling through their GP or bereavement support from a charitable or private source, but were aware of long waiting lists.



PARENT 5

Emma has been a foster carer for more than a decade, and lives in a rural village. Just four months after the last child placed with her had died from a complex condition, she was asked to care for a baby boy named Harry.

Harry had been born prematurely and was known to be unwell, but the extent of his illness did not fully come to light for a further six months. By that time doctors said his condition was life limiting. He was dependent upon oxygen and at different times had nasal feeding tubes. He was often highly agitated and would obsessively attempt to rip his tubes out which required a carer being by his side constantly. Simply going to the toilet or making a cup of tea was impossible.

Although there were regular meetings with social workers, at the earlier stages Emma was told the child did not meet the criteria for nursing support at home. Despite several applications for support, nothing was put in place until coping with his needs had reached crisis point.

“We were both physically and mentally exhausted.”

‘At one stage, without warning, it was proposed that the child would be moved and the reason given was that we were tired,’ explained Emma. This was devastating for the couple, who felt judged for admitting the ‘weakness’ of needing sleep and regular breaks. Fortunately, senior managers at the local authority disagreed with the proposal and allowed the placement to continue.

‘Obviously it did affect us as a couple, we were quite low due to the massive demands. We were both physically and mentally exhausted. Our sleep was constantly disrupted and many nights we had to make a dash to hospital to have tubes reinserted, returning in the middle of the night, and my husband having to get up two hours later to go to work.’

Without the support they needed, Emma’s husband reduced his self employed working hours to help out, which reduced their household income. *‘At no stage did we consider turning our back on this little boy as our commitment to our special needs foster children is absolute.’*

Harry died in early 2019. Emma has had private bereavement counselling, and continues to receive visits from a Rainbow Trust Family Support Worker and a Rainbow Trust Family Support Volunteer.

‘The additional few hours a week that the Rainbow Trust charity provided in the last year of the baby’s life was outstanding. Nothing was ever too much trouble... When I was at my lowest ebb, they were there.’

The couple found the experience ‘quite traumatic’ because of the initial difficulty in accessing enough support from statutory health and social care services. The foster carers are proud that they were able to provide Harry with a loving home environment for the duration of his short life, but acknowledge that this was only possible due the charities and volunteers who supported them. The couple intend to continue fostering special needs children. *‘We love what we do and have a lot to offer to these children.’*

PARENTS' TIPS FOR MANAGING THEIR MENTAL HEALTH

I'd say ask for help, you're not alone. Just ask.

Maintain a friendship.

There is some light at the end of the tunnel. In the first stages, you don't see the light at all.

I like to gather information and that helped Jessica's journey, me being on top of what's going on.

You do adjust to the new normality... It's life-changing but you do discover strengths in yourself you wouldn't imagine in your wildest dreams. You'll probably amaze yourself!

My advice is, if someone offers you help, not to be too proud. You can never be too proud to ask for help if you're not coping.

The one thing I can guarantee is that it will get better. It sounds trite but it's true. I don't miss Charlotte any less than I used to, but I now know how to deal with it.

Don't be afraid to accept help.

There will come a point when things will get better. You do get through them. People do support you... There is hope for the parents.

Know that you are doing the best you can for yourself and your child.

The thing that helps the most is the talking... Talk to other families... You must find other people to talk to.

Never be afraid to ask for what you think is needed for your child.

Try to believe in yourself. If you go to an appointment and you're not sure, never take no for an answer.

Talk! Find someone you click with, another parent, a friend, a nurse, family support worker and tell them how you feel! Use professionals, as they may be able to help you even more. This is how we found Rainbow Trust.

You can go through hell and still function. I'm still here. I'm still trying to live a normal life. To me, that helps me. That's my little coping strategy, there is hope.

It's OK to feel how you feel. It's OK to be authentic with how you feel.

Look after yourself. Make the time to get out of the hospital.

I would say to be a little bit kinder to yourself. I did beat myself up a lot, that I couldn't be the parent I wanted to be to both of my children at the same time. It was something that did upset me a lot.

Take all the help you can and don't feel guilty about it.

Human resilience is incredible.

SECTION 3: RAINBOW TRUST'S ROLE IN HELPING PARENTS TO MANAGE THEIR MENTAL HEALTH

Timely access to locally available counselling or psychological therapy is fundamental for parents with mental health problems when a child is seriously ill.

Alongside this, the involvement of a Rainbow Trust Family Support Worker can be supportive of a parent's mental health in a number of ways.

THE ROLE OF A FAMILY SUPPORT WORKER

Rainbow Trust's Family Support Workers provide both emotional and practical support. This can include:

- keeping a sick child entertained with one-to-one support
- spending time with healthy brothers and sisters so they do not feel forgotten
- being present with parents as they go through their child's diagnosis and treatment
- helping around the home, taking the pressure off parents
- providing transport to and from appointments
- listening to parents as they share their emotions
- offering bereavement support if needed.

Support is flexible and can be scaled up or down as a family's needs change over time, with the ability to respond quickly at times of crisis. A Family Support Worker's non-judgmental approach, and their independence from the health and social care system, is valued by parents who may feel they have to 'put on a brave face' in front of other professionals involved in their child's care.

It is not the role of a Family Support Worker to provide counselling, but their experience of working with families with a seriously ill child can equip them to spot potential mental health issues and to respond at an early stage. Regular support can reduce a parent's need for professional help by enabling the parent to identify possible coping strategies. When

a parent has significant issues, their Family Support Worker can help them to seek a referral to mental health or counselling services.

The most effective support for families happens when Family Support Workers are invited to professionals' meetings so that all those involved in a family's care and support are able to share information, and jointly identify how any needs for additional support and services could be met. This is especially important because the Family Support Worker may be frequently offering support within the family home and can provide a different perspective to other professionals on any areas of concern.

LIMITED SUPPORT NETWORKS

Many parents who seek Rainbow Trust support live far from relatives, if they have any. This means that local services, friends and community support can play a vital role. Rainbow Trust's 2019 snapshot survey of 87 parents found that 44% of parents had no other support than Rainbow Trust.²⁰

One participant commented that their Family Support Worker is '*the only person besides me whom I trust fully with my son*'.

UNMET NEED

It is impossible to know how many parents need support but are not yet receiving it. Many referrers and parents tell Rainbow Trust that they are not aware of any similar services in their area. What is clear is that Rainbow Trust could support many more parents if it had sufficient funding to open teams in new parts of England.

**DIAGRAM:
HOW REGULAR SUPPORT FROM A FAMILY SUPPORT WORKER CAN
HELP A PARENT TO MANAGE THEIR FEELINGS BETTER**



THE COST OF RESPONDING TO MENTAL HEALTH PROBLEMS

There are numerous costs to the healthcare system when parents' mental health problems escalate to the point of requiring clinical interventions. These costs can be compared to the cost of funding a Family Support Worker who can support the whole family when a child is seriously ill, and whose support may enable a parent to develop their own coping strategies.

Estimated average costs for treatment for depression or anxiety through the NHS' Improving Access to Psychological Treatments' programme:

Six 'low intensity' sessions at £99 per session (e.g. guided self-help)	£594
Six 'high intensity' sessions at £177 per session (e.g. face-to-face Cognitive Behavioural Therapy)	£1,062 ²¹
Inpatient hospital care: mental health care for one bed day	£410 ²²
Service costs for a person receiving treatment for depression	£2,085 ²³
Prescription cost for one year course of common antidepressant drugs	£10- £360 ²⁴
Bereavement: one counselling session	£99 ²¹
Estimated cost to the economy for every life lost to suicide	£1.67m ²⁵

COST OF PREVENTATIVE SUPPORT THROUGH THE FUNDING OF RAINBOW TRUST FAMILY SUPPORT:

Cost to Rainbow Trust of providing one hour of Family Support Worker's time	£26 ²⁶
Example - three months of support to a parent at three hours per week	£1,014

Rainbow Trust receives no funding from national government or NHS England, and must fundraise more than 98% of its income. Rainbow Trust's only statutory income comes from just two Local Authority Short Breaks funds out of 152 across England.

This is despite a conservative estimate that Rainbow Trust services are saving at least £2 million for the health and social care system each year in multiple ways.²⁷

HOW EMOTIONAL AND PRACTICAL SUPPORT ARE COMBINED

Parents are often referred to Rainbow Trust initially because they are struggling with the practical demands of their child's care and treatment. When these burdens are eased, parents often find they can more effectively manage their mental health.

TRANSPORT AND HOSPITAL SUPPORT

Help getting to appointments, or to visit a baby or child in hospital, can be vital for parents without a car. If a family doesn't have a car, help with transport can reduce the significant costs that arise when families must travel by taxi to avoid the risk of infection to a child with a compromised immune system using public transport. Avoiding the need to make a stressful journey into a busy city on their own with their sick child is much valued, as is the emotional support Family Support Workers often provide in the car.

'I can't even let myself think about what it'd be like without our Family Support Worker's support. She's made our lives so much easier,' said Kerry. She appreciated having a reliable source of transport, 'not a random cab driver'. *'It set my mind at rest. Lily clearly felt more relaxed as well as she got to know the Family Support Worker. I'm not worrying if the cab will turn up on time. Straight away, that was a relief.'*

Despite her initial apprehension that it might be awkward to have a Family Support Worker sit with her in her daughter's small hospital cubicle, Kerry soon changed her mind. *'I noticed I felt so much less stressed because our Family Support Worker would stay in the hospital with us.'* A full day of tests and appointments could commonly last from 8am to 6pm, but the Family Support Worker kept her daughter fully occupied, playing with her and distracting her.

SIBLING SUPPORT

Another trigger for families to be referred to Rainbow Trust can be that a parent sees that healthy brothers and sisters are in distress and are struggling with changes to their routine and reduced parental attention. This can be a persistent source of guilt for parents.

Receiving sibling support can enable a healthy child to express their worries and frustrations, and to have some much needed fun and attention, with someone who is there purely for them. Attending a sibling group or outing can be important for a healthy brother or sister to meet other children with a seriously ill sibling, reducing their feelings of being different.

As Rachel explained, *'Having someone to help out with [healthy brother] Oscar made a huge difference'*. For her, this took away that *'extra worry, feeling Oscar had someone, which was important for me.'*

Rehana said, *'Rainbow Trust was there in those hard times. At the end of the day, you're neglecting the siblings. I'm so grateful for Rainbow Trust support. You can't do it all. There needs to be more attention on that. It's not just an illness for the child, the whole family is affected.'*

“You can't do it all.”

PARENT 6 SUPPORTING A PARENT WITH A HISTORY OF MENTAL HEALTH PROBLEMS.

Lisa experienced postnatal depression after the birth of her first child. She has since been formally diagnosed with borderline personality disorder, obsessive compulsive disorder and complex post traumatic stress disorder, linked to difficult experiences in her childhood.

She has four children, including Owen, aged 18, who has a rare form of cancer, a daughter, and two other sons with autistic spectrum disorder. Owen first became ill aged 12, and spent long periods in hospital in intensive care and receiving chemotherapy before he returned home.

Three years ago, Owen's condition worsened again. A further round of intensive treatment began, but coincided with the death of two of Lisa's older relatives. Lisa tried to kill herself, resulting in her being detained in a psychiatric hospital for six weeks. It was after her return home that a Rainbow Trust Family Support Worker was introduced to the family by a CLIC Sargent social worker. Lisa was struggling to visit Owen as an in-patient while also parenting her two other teenage children, and her medication means she is not able to drive. The household finances were also hit by costs of £500 for fuel, parking and food while Owen was in hospital. The Family Support Worker drove Owen and Lisa to and from hospital, and began to provide emotional support to Lisa.

Owen's cancer treatment is ongoing, and the rare nature of his condition means that his doctors cannot follow a well-established treatment plan. This creates uncertainty and frustration for the family.

'The impact of Owen's illness on my mental health is horrendous ...As a mum all you want to do is fix your child. If they fall, you stick on a plaster. If they break a bone, you take them to A&E. With Owen, there's nothing I can do.'

Lisa is taking antidepressants and sleeping tablets. She used to receive weekly therapy from adult mental health services, but was encouraged to put that on hold and to use local bereavement services instead after her father died in early 2019. Her Family Support Worker helped her to find bereavement support through a local hospice, but Lisa is now being supported by adult mental health services once more, in recognition of her complex needs.

Lisa knows that her day-to-day coping mechanisms are not always enough, and that she panics more than most people. *'I imagine the worst case scenario because of the way that I am...What I say is I put my wall back up. I've got this wall that covers everything inside. I'm quite good at putting up a barrier, pretending I'm ok.'*

Her mental health can mean that some days Lisa does not get dressed and there are weeks when she does not go out. Her Family Support Worker reminds Lisa to eat properly, and is available to listen to her worries, helping her to manage her feelings of panic and depression. On one occasion, Lisa told her Family Support Worker that she did not want to return home after leaving her son's hospital bedside, and she felt completely hopeless.

“As a mum all you want to do is fix your child.”

Her Family Support Worker spent time with her, and stayed with her until 10pm to help her talk through her feelings.

As a result of the coping techniques that Lisa has learnt, and the support she receives from her husband and her Family Support Worker, she has so far avoided needing further in-patient mental health treatment.

“The impact of Owen’s illness on my mental health is horrendous.”

A TRUSTING RELATIONSHIP

With regular visits, one or both parents may find that they start to share their emotional concerns and mental health issues.

Sarah explains, *‘Our Family Support Worker would spend time with Joseph on the ward, and as [the Support Worker] left, I’d walk out with him and we’d have a chat. It wasn’t counselling but getting to know him and building trust was really helpful.’*

Drawing on their experience of parents in similar situations, a Family Support Worker can also sensitively open up discussions as to future decisions that a parent may need to make, or different scenarios that may arise. This can help prepare parents mentally for potentially stressful situations or for a bereavement. It can allow a parent time to ask questions or reflect on their options.

TIME TO REST

Importantly, Family Support Workers can provide parents with the necessary time and energy they need to develop their own coping strategies. A break from their caring role can allow a parent to focus on their own needs, which shores up their own identity, or simply gives them a much needed rest.

Kerry remembers that on one occasion her Family Support Worker noticed she looked tired and encouraged Kerry to go to bed while she played with both daughters at home. *‘It’s a small thing but I really needed it... I just knew how Lily will be absolutely fine with this person, so I felt comfortable.’*

Lucy felt that having a rest was crucial for her to get her mental health back on an even keel. *‘What Rainbow Trust offers in terms of practical support is undoubtedly the best kind of support... If I didn’t have that respite for a couple of hours, I would have been in a far worse place.’*

“If I didn’t have that respite for a couple of hours, I would have been in a far worse place.”

PARENT 7 SUPPORTING A SOCIALLY ISOLATED PARENT THROUGH THEIR CHILD'S END OF LIFE

Aminah's one year old son Javed was left with severe neurological problems, including epilepsy, after a seizure while visiting family in Pakistan. He needed a tracheostomy to help him breathe and a gastrostomy tube for nutrition. He lost the ability to communicate verbally. After long stays in hospital in both Pakistan and the UK, he was brought home.

When a Rainbow Trust Family Support Worker first met the family, Aminah was shy and spoke limited English. Her husband worked long hours away from home. Their wider family and friends lived some distance away. The Family Support Worker drove Javed and his mother to hospital appointments and provided practical help at home. The Family Support Worker would play and sing with Javed, using massage and sensory toys, and watching for subtle facial reactions to understand what he enjoyed. Aminah watched and began to learn how she could respond to him as a "mum" and not a nurse.

This support gradually helped to build Aminah's confidence so she could leave the house briefly while others cared for Javed. Having initially relied on the Family Support Worker to speak with medical professionals, Aminah became able to communicate both her and Javed's needs. Community nurses started providing medical respite care as Javed grew older. Aminah gave birth to two more children over time, and the Family Support Worker provided sibling support.

Aged six, Javed's health deteriorated, and the family was told that Javed may be at the end of his life. Weeks of anxious

watching turned into months. Javed was unresponsive. During this same period, Aminah gave birth to a fourth child, but continued to care for Javed around the clock. She did not go out of the house for fear of Javed's condition deteriorating.

On the morning of Javed's death, the Family Support Worker was present, and was able to support Aminah in person as the shock of his death sank in. The Family Support Worker looked after the other children while the parents went to the hospital. Javed's sudden death meant a delay in signing the death certificate because both his GP and his consultant were on leave. As a result his parents were unable to carry out Islamic traditions, such as the ritual washing of the body, which was painful for them. The police also had to visit the house as is usual when a child dies suddenly.

At the funeral, the Family Support Worker comforted the distressed and confused young siblings alongside their mother, and she has continued to provide bereavement support since then. Validating Aminah's feelings of loss has been important because, according to her faith, her son is now in heaven and some community members felt she should not express grief as a result.

Adapting to life without Javed has not been easy for Aminah. After years of caring for Javed, Aminah had never taken her other children out of the house on their own, or taken them to nursery or school.

'With my support, Aminah is finding her way through new routines and challenges, and is growing in confidence as she is starting to work through daily problems of "normal" family life challenges,' explained the Family Support Worker.

TEA, CAKE AND 'ME TIME'

Peer-to-peer support can help parents build their own support networks. One Rainbow Trust team holds a small 'craft-ernoon' group two or three times each term, and run for free by a professional teacher. The aim is to give parents the opportunity to relax in a safe environment for a bit of "me" time.

In a two hour session, parents can learn how to make memories from old pieces of children's clothing. Parents have so far made flowers and pom pom keyrings, and future plans include making a patchwork cushion as a memento.

The Family Support Manager explains, *'Parents find it very relaxing and soon open up about what they are going through. If they need to bring along a pre-school child that is fine as a Family Support Worker will either take them out, or play with them during the workshop. We provide tea and cakes which we find contributes to the feeling of wellbeing and pampering.'*

Parents often plan to come but must cancel at the last minute for a hospital appointment or because their child is ill. However, in a small group it can be easier for parents to share their experiences. Two mothers have become good friends and now meet each other for coffee independently.

In other parts of the country Rainbow Trust teams have developed groups when there is a natural hub for parents to meet. For example, one team holds a weekly parents' drop-in group on two hospital wards, fuelled by tea, cake and biscuits. This gives parents a chance to chat with each other, or with a Family Support Worker.

ENHANCING SUPPORT WITH VOLUNTEERS

Rainbow Trust's support for families in and around Bristol is enhanced by a team of 14 volunteers. Support is often practical, but as a result, many parents report that they feel better able to manage their emotions.

In one example, two volunteers have spent time visiting a child with severe brain damage in a hospital 40 miles from the family home. The mother is a single parent with four children. The volunteers read and sing to the child in hospital which allows the mother to keep on top of other tasks and to support her other children, confident that her seriously ill child is not alone. The volunteers also provide emotional support when the mother visits the hospital.

In another instance, a volunteer makes weekly visits to a family where a boy has a severe disability. His bulky equipment dominates the family living space, meaning his sisters have less space to play or relax in. The volunteer helps the sisters with their homework, takes them to the park or plays board games with them. As a result, the parents feel less guilty about the lack of time and energy that they have for their daughters.

“Parents find it very relaxing and soon open up about what they are going through.”

CONCLUSION AND RECOMMENDATIONS

The nature of life-threatening and terminal conditions in children means that the mental health of parents can be under severe strain for many months or years. It is likely that many will experience feelings of anxiety, distress, depression or even trauma.

Without attention, a parent's anxiety, stress or depression may escalate over time into more serious problems, with detrimental impacts for the whole family, including the seriously ill child.

We hope this report, quite literally, opens up new conversations. With the right support at the right time, parents can develop positive strategies to manage their mental health more effectively during an incredibly difficult period. Sometimes this support needs to be psychological therapy or counselling. Sometimes it can be as simple as providing non-judgmental, hands-on support to the whole family, to ease the burden of caring, to provide time and to be present for whatever each day holds. Sometimes it can be the opportunity to meet other parents in the same situation over a cup of tea.

While little can change the facts of a parent's situation, much can be learnt from parents' experiences and the common themes identified in this report. Importantly, psychological and emotional support should be offered more than once, and in a sensitive manner. There must be full consideration of when and where a parent can access any support, and what may stand in the way of accessing it.

At a point when mental health has become a priority for both government and NHS England, it's about time that every parent of a seriously ill child has the mental health support that they need. We urge local health and social care commissioners to recognise the mental health needs of parents with a seriously ill child, and to take up our recommendations below.

But it's also time for all of us – family, friends, neighbours, colleagues, professionals – to play a bigger role in supporting parents during an incredibly difficult period of their lives.

RECOMMENDATIONS

HEALTH AND SOCIAL CARE COMMISSIONERS

- We urge commissioners to review their commissioning of Short Breaks services to ensure their criteria are sufficiently flexible in scope to allow for the provision of emotional and practical support for parents.
- We strongly encourage commissioners to ensure that the particular needs of parents with seriously ill children are recognised in local mental health services, and that a prompt referral pathway exists to enable access to psychological support or counselling if required.

HEALTH AND SOCIAL CARE PROFESSIONALS

- We encourage all professionals working with parents of children with a life-threatening or terminal illness to review their current practice and adopt our checklist on page 41.

PARENTS OF SERIOUSLY ILL CHILDREN

- Don't be afraid or ashamed to ask for help for yourself as well as for your child or their siblings.
- Know that you are not alone, and try to find people to talk to. Sharing your experiences can help.
- Getting help with your mental health is valid and worthwhile. If you are better able to manage your mental health, it will also benefit your child.

THE PUBLIC

- Keep in touch with parents who have a seriously ill child. It is fine not to know what to say. Saying that you don't know what to say is always better than not keeping in touch at all.
- Know that a parent with a seriously ill child will have different needs at different points in their child's illness. It can take time for a parent to recognise that they could benefit from your help, so offer support more than once, and don't be offended if they decline your offer.
- Make a concrete offer of help, rather than a general offer. Ask if there are any practical tasks you could take on. Helping with housework, meals or school drop offs, can help parents better manage their day to day tasks and give them more time to look after their mental health.
- Donate to Rainbow Trust so that more families can receive much needed support from a Family Support Worker.



For families living with childhood illness, time is everything, which is why we have launched a campaign called *It's About Time* to raise awareness and money. We believe that no family should have to go through this alone, so we are here to change that.

rainbowtrust.org.uk/itsabouttime

#ItsAboutTime

APPENDIX 1

CHECKLIST FOR HEALTH AND SOCIAL CARE PROFESSIONALS:

Many parents say they put on a brave face in front of professionals and their children. It may not be obvious how much a parent is struggling underneath.

When working with parents of a child with a life-threatening or terminal illness:

1. Do you feel confident that you could spot the signs of a parent or carer struggling with their mental health?

2. Do you regularly offer access to psychological support or counselling?

3. Is the offer of support repeated at different stages, rather than being one-off?

4. Is support offered in a sensitive and discrete manner, so parents do not feel singled out?

5. When parents are interested in accessing psychological support or counselling, do you discuss with them whether there are practical barriers, such as transport or childcare needs, which need to be addressed?

6. Do you include all relevant professionals in discussions about how families are managing, to ensure that support is provided in a joined up manner?

7. Have you considered how you can ensure that information is shared effectively between professionals involved with a family?

8. Are you able to signpost parents to relevant charities or support groups which offer emotional and practical support?

APPENDIX 2: EXISTING RESEARCH

Academic research has examined the mental and physical impacts on parents when a child has disabilities or a serious illness. Where studies focus on only one condition, this tends to be childhood cancer.

One study found that parents face pressures managing a child's long-term condition, collaborating with professionals and coordinating services. Parents cited confusion, disbelief, anxiety, turmoil and a loss of identity following their child's diagnosis, commonly followed by an enduring grief or 'chronic sorrow' and feelings of being physically and emotionally overburdened.²⁸ Post Traumatic Stress Disorder has been linked to parenting a child who has received intensive care. One study concluded that 'both children and parents have alarmingly high rates of...post traumatic stress' following a child's admission to intensive care.²⁹ Such findings are echoed in other studies on parents of pre-term babies and of children with life-threatening conditions such as cancer.

Providing early and adequate support to parents who are vulnerable to post-traumatic stress will help not only the parents, but also their children, one study concluded.³⁰ Another study looking at psychological distress in parents of children with advanced cancer found that parents who believed their child was suffering highly, and who reported great economic hardship, suffered more distress. Distress was lower among parents who understood the likely outcomes for their child and the aims of their treatment.³¹

Some studies have considered the impact on relationships. For instance, a US study found that having a child of poor health decreased the probability that parents lived together at 12 to 18 months after a child's birth.³² Studies of fathers indicate that particular obstacles can prevent men from seeking support for their mental health, even where a child is healthy. For example, fathers may not feel informed about what services

are available, may feel excluded by health professionals, or may be constrained by inflexible working practices or their own self-imposed barriers.³³

More research is needed to identify the most effective forms of psychological support for parents. A study of parents of childhood cancer survivors recommended treatments that target post-traumatic stress symptoms and potentially also worry, anger, sorrow and relationship problems.³⁴

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**RAINBOW
TRUST**

**SUPPORTING FAMILIES
WITH A SERIOUSLY ILL CHILD**

**RAINBOW TRUST HAS EIGHT CARE TEAMS
ACROSS ENGLAND. THEY ARE:**

- **Central London** - covering certain central London boroughs
- **Essex** - covering Essex and North East London
- **North East** - covering Cleveland, Co. Durham, Northumberland, Redcar, Teesside and Tyne & Wear
- **North West** - covering Manchester, the wider Greater Manchester region, West Lancashire and Cumbria
- **Southampton** - covering Dorset, Hampshire, West Berkshire, West Sussex and South Wiltshire
- **South West** - covering Bath, Bristol, North East Somerset, South Oxfordshire and North Wiltshire
- **Surrey** - covering Kent, South East/South West London, Surrey and Sussex
- **West London** - Covering nine North West London boroughs, South Buckinghamshire, East Berkshire, and South Hertfordshire.

rainbowtrust.org.uk/parentsmatter

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