

## EXECUTIVE SUMMARY

# PARENTS MATTER:

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



SUPPORTING FAMILIES WITH A SERIOUSLY ILL CHILD

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%).**

**“I felt really isolated and alone.”**

**“I told them, ‘I’m going to have a nervous breakdown.’”**



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## 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.**

### PARENT TIPS

*"The thing that helps the most is the talking."*

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

*"Maintain a friendship."*

\* See full report for all references:  
[rainbowtrust.org.uk/parentsmatter](http://rainbowtrust.org.uk/parentsmatter)

## 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.

### 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](https://rainbowtrust.org.uk/itsabouttime)

#ItsAboutTime

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## #ParentsMatter

[rainbowtrust.org.uk/parentsmatter](https://rainbowtrust.org.uk/parentsmatter)

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