

# FEELING FORGOTTEN:

## Parental mental health concerns exacerbated by the COVID-19 pandemic whilst caring for a seriously ill child

**RAINBOW  
TRUST**

SUPPORTING FAMILIES  
WITH A SERIOUSLY ILL CHILD

Isolation and loneliness are all too familiar feelings when caring for a child with a life-threatening or terminal illness, but the COVID-19 pandemic has further compounded parents' feelings of uncertainty and anxiety.

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. Rainbow Trust highlighted this in their January 2020 report, *Parents Matter: The impact on parents' mental health when a child has a life-threatening illness*.\* **But at that time, no one could have predicted the impact of COVID-19 and what that means for these already traumatised parents.**

Some families told us that Rainbow Trust was their only constant source of emotional support during the March to June period.

### Parental mental health when caring for a seriously ill child

When parents were interviewed for Rainbow Trust's *Parents Matter* report, many described feelings of shock, fear and anxiety. Some 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.

Close relationships are often put under considerable strain. Roles can 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, with parents feeling guilty about having less time and energy for them. Feelings of loneliness and isolation are common. Some longstanding friends may disappear, perhaps because these friends do not know what to say or how to help.

The duration and uncertain trajectory which can be a feature of a child's serious illness can be a source of heightened stress.



Seriously ill children may move quickly from a stable to unstable condition, and the final end-of-life phase can be hard to predict. 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.

## The additional impact of caring during the COVID-19 pandemic

Families caring for a child in the 'clinically most vulnerable' group were required to shield as a household from 23 March. Examples include children undergoing cancer treatment, children with organ transplants and children with compromised immune systems. Other families chose to avoid social contact during the height of the pandemic fearing the effect contracting COVID-19 may have on their sick child.

Rainbow Trust conducted two snapshot surveys with families receiving its support at those times, seeking their experiences and views about how the lockdown had affected their family. 120 parents responded to the first survey, and 74 parents responded to the second.

- Across both surveys, nearly 60% of parents who responded told us that their mental health is either worse or much worse than before the pandemic.
- In our first survey in April, just under 80% said that their family situation was worse or much worse than before. The outlook had improved slightly with 48% saying the same in June, but this is still almost half of respondents.
- Since the start of the lockdown in March, many of the services that families previously accessed, in both health and social care, have fallen away or changed significantly, leaving families feeling forgotten.
- For half of the families who responded, Rainbow Trust is either the only source of support, or one of two sources of support.
- Concerns included worry about their child or themselves contracting the virus, adjusting to a loss of routine, the need to collect essentials, delays to medical care and appointments, and family finances.
- Social distancing means that many families have lost their usual support networks of friends and family while they shield. People in local communities who originally rallied around when the pandemic first hit have since started to return to normal.
- Some parents commented that, despite the challenges, having time together as a family was a positive, especially if they had previously had periods of time apart with a child in hospital. They appreciated the temporary slower pace of life, without the usual demands of appointments, school and work.

## What parents told us

### Feeling the strain

*'It has put a massive strain on us financially. Having a child with leukaemia means they are on chemo and steroids which both make him very hungry all the time... We are spending £150-200 per week on groceries with no financial income and awaiting Universal Credit payment. It's putting immense pressure on our mental health as parents, constant parental mode, no time off for ourselves.'*

*'Lack of routine. Lots of arguing, worrying about children catching it, or us. Missing family and friends.'*

*'I feel shielding is becoming more difficult as lockdown is lifting. It feels as though leaving the house will be more of a risk.'*

### Reduced services and support

*'We had a call from the NHS team at the onset of the lockdown, but there is little they can do from a distance for our particular family, now treatment is complete. My close family all live too far away to help or are in isolation themselves.'*

*'No respite. No school. No hospice. No nurses. Initially our care was withdrawn but we have just had two out of six weekly visits reinstated. An utter dependence on others for food and meds.'*

*'My biggest challenge is being a single parent juggling complex and opposing needs of two severely disabled children. One shielding, the other vulnerable. One needing to be inside, the other needing to be outside all the time. Complete and utter withdrawal of all care and respite with no notice.'*



## An anxious future

*'Frightened to go back to work as we are worried about taking the virus home.'*

*'As the lockdown restrictions start to ease, we do feel forgotten. Being an extremely vulnerable family, I feel there should be places that only we can go to get some fresh air.'*

*'We're worried about the easing of the lockdown and can't understand how it's safer for shielded people to be able to go outside. I would have thought it to be more dangerous now that there are more people out and more people feeling it's safe now not to follow guidelines.'*

*'I feel safer inside and more anxious about going back out into the world again.'*

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## How Rainbow Trust Family Support Workers have responded

Throughout the pandemic and lockdown, Family Support Workers have adapted their service provision in light of the ever-changing situation to provide families with virtual support, using WhatsApp, video calls and phone calls to parents, seriously ill children and siblings.

- Parents have valued personal communications and regular 'check-ins' from Rainbow Trust at a time when many report feeling forgotten by other services. Receiving messages and phone calls from their Family Support Worker has given parents an outlet if they wish to share their worries and emotions amid the pressure of the whole family being at home and the need to provide round-the-clock care for their child.
- Virtual support sessions for children, such as reading stories or leading craft activities online, have enabled parents to take a much-needed break.
- Family Support Workers have delivered breast milk from self-isolating new mothers to their babies on neonatal wards, in situations where they are unable to visit.
- For some parents whose children died during the lockdown period, their Family Support Worker was the only emotional support available to them as they faced the distressing prospect of holding a very different funeral for their child than they would have anticipated in normal circumstances.
- In Lancashire, a Dads Group, which had been meeting in person, switched to meeting online during the lockdown, enabling fathers to share their feelings with others who understand what they are going through.
- In a typical week in May, Rainbow Trust provided 32 substantive support calls (of 30 minutes or more), 2 episodes of end-of-life support and 23 episodes of bereavement support within 471 family interactions.

**A big thank you for all your help and support. It's made a massive difference to our family.**

*It was a huge relief to talk to someone else (just someone who's not a member of our household!) who knows us well and can understand through their work some of the extra challenges we are facing.*

*The video calls have been an unexpected lifeline.*

**In the current Covid-19 environment I think Rainbow Trust Children's Charity is an essential lifeline, especially from a mental health perspective... for my children and for me... The way they adapted (within days!) to remain an essential lifeline of support to my family is laudable.**

The calls [our Family Support Worker] has with [my seriously ill daughter] have literally been the only time that I have been able to relax and know that she is well cared for whilst I can have some time off/ time with her sister... They are the only childcare we have and they have been really really helpful.

## How both emotional and practical support can benefit parents' mental wellbeing

The unprecedented situation created by COVID-19 has reinforced what families were telling us before the pandemic. Emotional support from a trusted Family Support Worker with non-judgmental approach, combined with practical support which can ease the day-to-day burden of caring, is much valued. With the right support at the right time, parents can develop positive strategies to manage their mental health more effectively. Where needs escalate, a Family Support Worker can help a parent access formal psychological therapy or counselling.

Some families told us that Rainbow Trust was their only constant source of emotional support during the March to June period. Ordinarily, parents of children with cancer would be offered psychological support during their child's treatment. However, parents of children with non-cancer diagnoses have always risked being overlooked because they have a less structured pattern of involvement with health professionals, which is likely to have been exacerbated during the pandemic.

Other barriers to support can be both practical and cultural. Some parents fear being judged by professionals if they admit to finding their situation hard, while others simply cannot prioritise their own mental health during an intense period of diagnosis and treatment, or while caring for a child around the clock.

## Rainbow Trust's ongoing commitment to families

It is clear that the uncertainty and anxiety brought on by the pandemic will compound the mental health strain on parents for many months or even years to come. We know that some families are being advised to continue shielding in light of their child's serious condition. Other families are being told that they can stop shielding from 1 August but report feeling highly anxious and unsure about leaving the house because of the risk of bringing the virus home.

NHS appointments and treatment will continue to be disrupted by the demands of the pandemic, and many families are likely to experience additional pressure on their incomes as a result of the economic downturn. Parents will also need to consult clinicians and make decisions about members of the household returning to school and workplaces. Supporting parents to manage their emotions and the stress of their situation will be central to Rainbow Trust's continued response.

In all cases, Rainbow Trust will continue to provide the consistent, non-judgmental support that parents value so deeply, in whichever way families request it, virtually or face to face. Rainbow Trust will work closely with other services to ensure vulnerable families are not forgotten during this period and that parents are signposted to specialist mental health support if required.

## RECOMMENDATIONS

- 1** Rainbow Trust is calling for parental mental health and respite services for families to be prioritised by local and national government in the post-COVID-19 recovery.
- 2** Rainbow Trust is calling for mental health services to pay particular attention to the needs of parents who have been caring for seriously ill children during the pandemic, to ensure psychological support or counselling is available for those parents whose mental health is under severe strain as a result of the pressures that they face.

\* Our first report on parental mental health was: *Parents Matter: The impact on parents' mental health when a child has a life-threatening illness*, available to download from [rainbowtrust.org.uk/parentsmatter](https://rainbowtrust.org.uk/parentsmatter)

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

#feelingforgotten

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