

## EXECUTIVE SUMMARY

# PANDEMIC PRESSURES:

The struggles and resilience of families caring for a seriously ill child

**RAINBOW  
TRUST**

SUPPORTING FAMILIES  
WITH A SERIOUSLY ILL CHILD

Caring for a child with a life-threatening or terminal illness at any time brings many challenges to a family, both emotional and practical. The COVID-19 pandemic has piled further pressure onto parents and children at the very time when many services and sources of support have been unable to assist them.

As the UK adapts to the reality of life alongside COVID-19, this report presents the experiences of families caring for a seriously ill child during the pandemic. It explains how Rainbow Trust Children's Charity has shown innovation in the delivery of its support, and will continue to adapt in the months ahead, to ensure that as many families as possible can receive the tailored support that they need.



# EXECUTIVE SUMMARY

As the UK moves into new phases of living with COVID-19, it is vital that the experiences of families caring for a seriously ill child are heard. Understanding their specific challenges over the last seven months should inform decisions about how best to provide them with services and support in the next 12 months and beyond.

This report presents what families have said about their experiences, and how they have juggled the increased demands of caring for a seriously ill baby or child during the pandemic so far. From parenting a critically ill baby at a distance, to maintaining strict shielding as a household for many months, these experiences have been both challenging and exhausting.

To respond to this unique situation, from the very start, and despite a dramatic overnight fall in fundraising income, Rainbow Trust Children's Charity has innovated and adapted its services to provide new forms of virtual and socially-distanced support to meet the evolving needs of families in this highly uncertain time.

With some families advised to keep shielding, and other families cautiously resuming their contact with wider society, with increasing local lockdowns, a mixed model of both virtual and face-to-face support is here to stay, as the shape of the pandemic remains unclear.

Whatever a family's specific situation, Rainbow Trust is committed to providing them with the support that they need throughout the uncertainty that lies ahead. We invite national and local decision-makers to make the same commitment, listening to families' experiences, and tailoring services and support to their particular needs at the most challenging of times.

## KEY FINDINGS:

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- 1. Shielding guidance was issued on 23 March.** Patients considered 'clinically extremely vulnerable' or 'clinically vulnerable' were advised to stay at home and take maximum precautions to avoid contracting the virus. Children in the 'clinically extremely vulnerable' group included those undergoing cancer treatment, children with organ transplants and children with compromised immune systems. Shielding advice extended to the whole household.
- 2. From 1 August, guidance to shield was withdrawn for almost all those previously advised to shield.** Among the small numbers advised to continue to shield are children who have received a transplant, with some told to shield until early or mid-2021. With cases rising, new guidance for the clinically extremely vulnerable was issued in mid-October.
- 3. Urgent treatment for critically ill children has continued.** However, other face-to-face appointments and procedures have been delayed.
- 4. Surveys suggest families have had largely negative experiences.** When families receiving Rainbow Trust support were surveyed in April, just under 80% said that their family situation was 'worse' or 'much worse' than before the lockdown. In June, the outlook had improved slightly with 48% saying the same.

**'I don't know what I would have done without my Family Support Worker.'**

## **‘There’s unparalleled anxiety.’**

- 5. Restrictions on hospital visiting, to prevent the spread of the virus, have been particularly difficult for families where a baby or child has been in an acutely life-threatening condition.** Only one parent could be with a child at the end of their life. Giving birth to a seriously ill baby or experiencing a miscarriage during the pandemic has been a lonely and distressing experience for many.
- 6. During the initial national lockdown, most families lost access to practical and emotional support.** Support was often lost from extended family, local authority services, and health and care professionals. For half of the families who responded to our survey, Rainbow Trust was either the only source of support, or one of two sources of support.
- 7. Parental mental health has often suffered.** Many have felt stretched by juggling the care of both their seriously ill child and their healthy children, while staying at home. Nearly 60% of parents who responded to Rainbow Trust’s surveys said that their mental health was either ‘worse’ or ‘much worse’ than before the pandemic.
- 8. Healthy siblings had to adjust to a world without physical contact with friends, classmates and grandparents.** Some older siblings cared for younger healthy brothers and sisters, or assisted their parent with tasks required to care for their life-threatened or terminally ill sibling.
- 9. Some families, however, reported that they have appreciated the ‘family time’ and temporarily slower pace of life.** They have valued time without the usual demands of appointments, school and work.
- 10. Rainbow Trust has responded to the pandemic with agility and creativity.** From the very start of the lockdown, Rainbow Trust adapted its services to offer families virtual support and ongoing practical support, within the confines of national and local rules. Using video calls, messages and phone calls, Rainbow Trust Family Support Workers have maintained relationships with parents, seriously ill children and siblings.
- 11. Some elements of Rainbow Trust’s service were paused to protect families.** These included support on hospital wards and Rainbow Trust’s volunteer support service.
- 12. Where face-to-face support has again become possible for families who are comfortable receiving it, this has resumed in line with guidance.** In areas where new local lockdowns have been, or may be, imposed, service provision has been, and will be, temporarily switched back to virtual support.
- 13. Innovations have meant families can continue to receive support while shielding or in a lockdown.** Virtual sessions for children have included reading stories, using toys and props, holding competitions or leading craft activities online. These enable parents to take a much-needed break while their children have some fun. Other successful innovations have included moving a Dad’s Group online, which had previously met face-to-face, and bringing siblings together for a fortnightly online sibling group.
- 14. Rainbow Trust Family Support Workers have helped bereaved parents and siblings who have not been able to grieve as they might wish.** Regular phone calls with parents, virtual activities with bereaved siblings, and taking a socially-distanced walk outside, have been much valued.

## RECOMMENDATIONS

The COVID-19 virus will continue to reshape our society, and our health and social care system in particular, for months and years to come.

Rainbow Trust urges decision-makers and commissioners to recognise the value of flexible emotional and practical support, which can be a lifeline for families caring for a seriously ill child in a time of great uncertainty and anxiety.

### **1. The Secretary of State for Health and Social Care should urgently address the long-standing gap in funding emotional and practical support for families.**

At present Rainbow Trust's support is almost always excluded from Local Authority Short Breaks funding streams. At the same time it has historically been deemed ineligible for NHS child palliative care funding streams. This leaves Rainbow Trust to fundraise more than 98% of its income from the public.

The move to commissioning by larger Integrated Care Systems by April 2021 is an opportunity to re-think how emotional and practical support is planned and funded, recognising the savings that such support provides for the wider health, social care and education system, and the benefits for both adult and child well-being and mental health.

### **2. NHS England should advise hospitals, dependent on local transmission rates, to make sure that children and their families are supported to be together when attending appointments or receiving in-patient treatment.**

While we acknowledge that some changes have been unavoidable, we recommend an approach which prioritises keeping children and families together whenever it is feasible.

### **3. The Secretary of State for Education must ensure his department supports schools to respond to individual children's needs by adapting both learning and pastoral support for children with serious illnesses and their healthy siblings, whether they are attending school in person, or have been advised to continue to shield.**

The education of all children has been significantly disrupted in this period. However, we urge the Department for Education to pay attention to the particular needs of this group whose families may be experiencing prolonged stress and anxiety.

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*Cover image: Kelly and her daughter Freya who has a rare metabolic condition. Credit: Drew Cox*

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