RAINBOW TRUST
SUPPORTING FAMILIES
WITH A SERIOUSLY ILL CHILD

PANDEMIC PRESSURES:

The struggles and resilience of families caring for 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.

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 treatments 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 who generously shared their experiences, without whom this report would not have been possible.

Cover image: Kelly and her daughter Freya who has a rare metabolic condition. Read more about Rainbow Trust’s support for Freya’s brother Freddie on page 32 (credit: Drew Cox)

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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 their specific situation, Rainbow Trust is committed to providing families 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:

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.

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.

INTRODUCTION

As the COVID-19 virus continues to reshape our society, following an unknown trajectory, it is essential that the health and care system prioritises the concerns of families caring for a child with a life-threatening or terminal condition by learning from their experiences.

This report sets out how families have juggled the increased demands of caring for a seriously ill child during the pandemic so far. It also explains the new forms of support that Rainbow Trust quickly adopted to enable families to continue to receive emotional and practical support within the constraints imposed by the pandemic, including the use of digital media.

Section 1 presents what families have said about their experiences of caring for a seriously ill baby or child since March 2020. This includes how families have coped while shielding as a household, the impact on their child's treatment and support services, and the consequences for the wellbeing and mental health of the whole family including parents and siblings.

Family stories provide detailed examples of particular situations, from parenting a critically ill baby at a distance, to maintaining strict shielding as a household for many months.

Section 2 sets out the innovations and changes which Rainbow Trust swiftly adopted in response to the pandemic and the changing needs of families, and which will continue to be offered as society lives alongside the virus. This has included the provision of virtual play sessions, socially-distanced emotional support and bereavement support, practical support, and transport support.

METHODOLOGY

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

Eight parents took part in interviews by telephone in July and August 2020. In addition, Rainbow Trust Family Support Workers have contributed examples of situations in which they have supported families. Where names have been changed, this is stated.

SECTION 1:
FAMILIES CARING FOR A SERIOUSLY ILL CHILD DURING COVID-19

Caring for a child with a life-threatening or terminal condition brings a high degree of stress and anxiety to a family at any time. Since the onset of the COVID-19 pandemic in March 2020, families are facing new emotional and practical pressures on top of their ongoing concern for their seriously ill child.

There are many thousands of families in this situation. New research has confirmed that the number of children in England with life-limiting or life-threatening conditions trebled over the last 17 years to 86,625 in 2017/18.[1] Of these, at any one time, many will be a stable phase of their condition, but a significant number will require intensive treatment and support, and may experience episodes when their condition becomes critical.

SHIELDING GUIDANCE

The UK went into lockdown on 23 March 2020. Patients considered 'clinically extremely vulnerable' or 'clinically vulnerable' were advised to shield and take maximum precautions to avoid contracting the virus. Examples of children in the 'clinically extremely vulnerable' group included those undergoing cancer treatment, children with organ transplants and children with compromised immune systems. Many parents and siblings followed the same guidance to avoid bringing the virus into their home.

For some families, this has brought financial hardship. In one instance a father lost his job when he chose to shield at home because one of his seven children was awaiting a double lung transplant. The family has been supported by Rainbow Trust to apply for emergency grants to cope with the loss in income.

Other families were not formally advised to shield, but chose to avoid social contact during the height of the pandemic, fearing the effect that contracting COVID-19 may have on their already seriously ill child, and worried about who would care for their child if parents themselves were to contract it.

From 1 August, guidance to shield was withdrawn for almost all those previously advised to shield. Among families supported by Rainbow Trust, many of those 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.

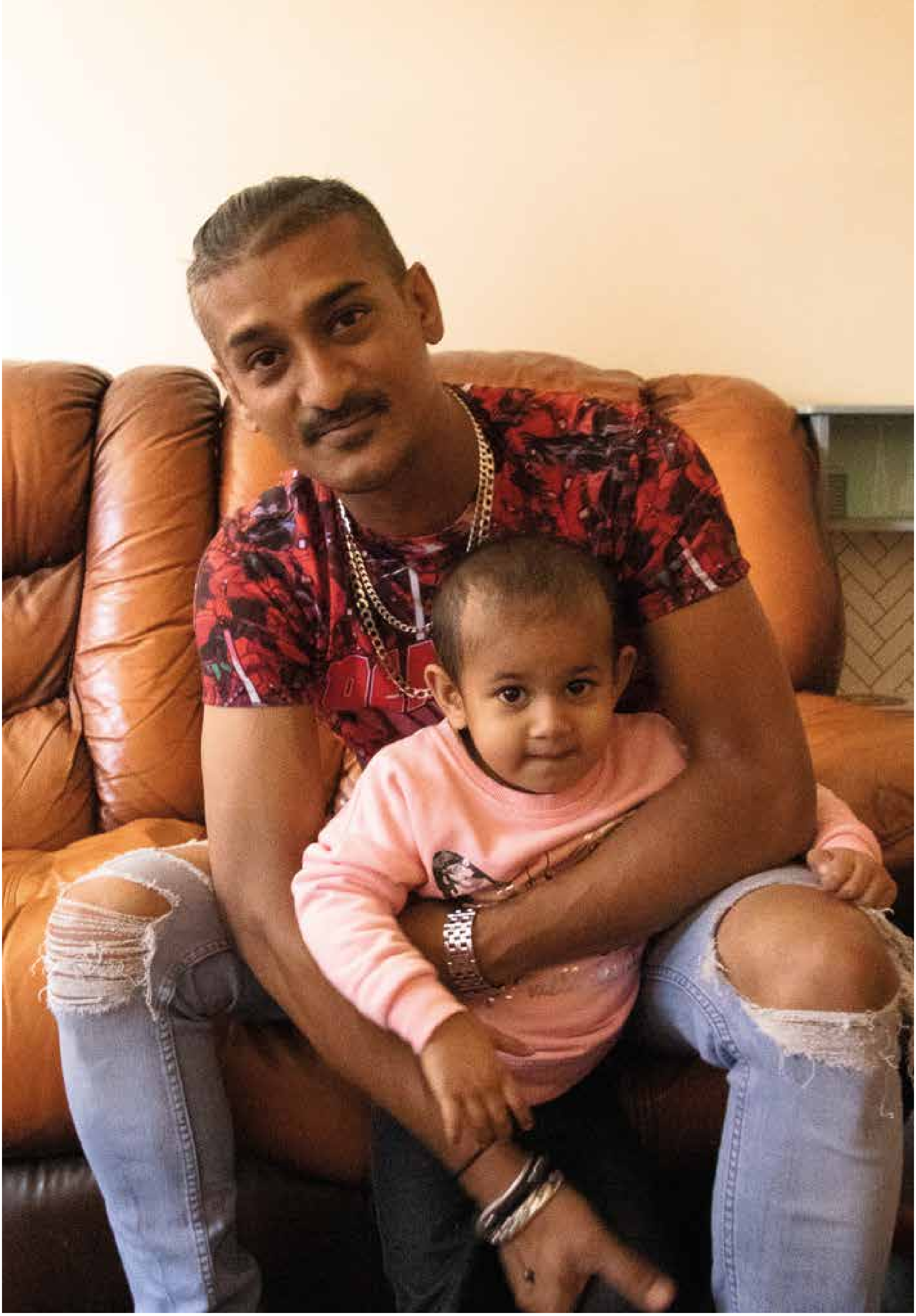
SURVEY FINDINGS

Rainbow Trust conducted two surveys in April and June with families receiving its support at that time.

In April, just under 80% of respondents said that their family situation was 'worse' or 'much worse' than before. In June, the outlook had improved slightly with 48% saying the same.

Concerns included:

- worry about their child or themselves contracting the virus
- delays to medical care and changes to appointments
- the loss or pausing of health and care services
- loss of practical support from family and friends outside their own household
- adjusting to a loss of routine
- the need to collect essentials, such as food and medication
- family finances
- the demands of caring for their children and of home-schooling school-age children.



Four-year-old Kareena with her father, Lebu, who were supported by Rainbow Trust during lockdown

FAMILY STORY 1: 'THE VIRUS HAS NOT GONE AWAY. FRANK IS STILL VERY VULNERABLE'

Rachel's 12-year-old son Frank has Batten Disease, and the family was accustomed to shielding him from infection well before the pandemic. Frank is completely reliant on others for his care as he cannot move himself or communicate. He is especially vulnerable to chest infections which means COVID-19 is a grave threat to his health.

Back in March, Rachel and her husband chose to keep Frank at home a week before his special needs school shut its doors. '*He's been close to death twice with para-influenza* [a type of flu],' she explains. '*He is a very complex child. We knew the NHS would be very stretched, and there were so many anxieties for us, so we went into our own lockdown.*'

Her daughter, then aged 16, chose to stop going to college out of concern for Frank's health, and her son then aged 19 stopped the work he was doing which brought him into social contact with others. Rachel stresses that her older children made these decisions for themselves. '*It's really lovely. They are quite exceptional*,' she says.

'*As a family, we're used to being isolated,*' Rachel reflects. '*We can't be spontaneous, we can't just go out. As a parent of a profoundly disabled and medically complex child, I'd argue in some ways the lockdown wasn't such a massive change.*'

However, an overriding fear in the early months was that if Frank became hospitalised, strict hospital visiting rules to minimise the spread of COVID-19 meant that parents might not be allowed to accompany a seriously ill child. '*The idea of him being alone was awful… He's someone who relies on us to communicate for him.*' They were also concerned as to whether he would be prioritised for treatment at a time of high demand within the NHS.

'*There's unparalleled anxiety… We know that Frank's lifespan is going to be short. Coronavirus is so frightening because it raises questions about the sort of treatment that Frank would get. In the past when he's been seriously ill in hospital, the hospital has done everything they can to support him and manage his recovery. Now I don't know what they'd do.*'

Rachel was kept awake at night worrying as to how they would manage if she or her husband became ill. Importantly, Frank's parents decided to continue having trusted NHS-funded carers coming into the house to help care for Frank. Having the carers come in, especially overnight, helped the family continue to function.

In case she or her husband became ill, Rachel also ran through Frank's medication with her older children, his personal care, and how to position him if needed. '*They were prepared to do everything they could, and they had to have a crash course in how to do things… I'm sure that was quite daunting for them.*' She remembers her daughter being especially concerned not to be responsible for skilled medical procedures like suction which involves putting a tube 12-15cm down Frank's nose or throat to keep his airway clear of saliva.

Frank's family have received support from Rainbow Trust since 2013, and their Family Support Worker was able to do the family's grocery shopping before the government priority deliveries were set up, as well as keeping in touch by phone and text. '*Knowing someone is there is helpful*,' says Rachel. Their local authority key worker has also kept in touch, and community nurses have been '*fantastic*', coming to the house when needed. But Rachel is acutely aware that the community nursing team only operate Monday to Friday, meaning less support at the weekend if needed.

> **"There's unparalleled anxiety."**

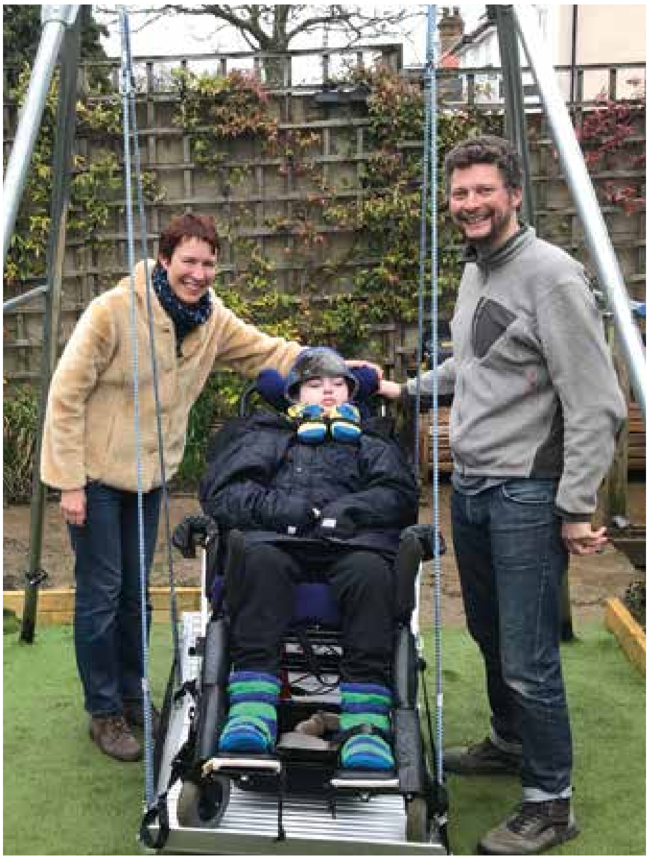
"As a parent of a profoundly disabled and medically complex child, in some ways the lockdown wasn't such a massive change."

Rachel also says she feels '*adrift*' since their local children's hospice has temporarily had to close as resources have been reallocated during the pandemic. Knowing it was an option had been a comfort in the past. '*It's tied up with the whole worry about how we'd cope if Frank was really sick. In the past, when Frank's been really sick, his grandmother could drive 280 miles to come over... We feel a bit lost with the hospice closed.*'

For Frank himself, life has been one of small pleasures such as enjoying a soak in the bath or using his wheelchair swing in his garden. '*I think he's done well,*' says Rachel, although various medical appointments have been delayed or cancelled, and Rachel chose to cancel one important appointment herself, preferring to wait until the risk of infection has declined.

Rachel has found the official guidance confusing, despite working in the NHS herself. '*At some point Frank is going to have to merge back into the world. But it's been really unclear. I don't know how we're going to navigate going back to normal things... I guess we'll just figure it out as we go along.*' One source of reassurance has been the enforced use of masks by members of the public.

Looking ahead, Rachel continues to feel anxious and will remain vigilant. '*The virus has not gone away. Frank is still very vulnerable.*'



Above, 12-year-old Frank, below, Frank enjoys his wheelchair swing with his parents (credit: Thompson family)

DELAYS TO MEDICAL CARE AND CHANGES TO APPOINTMENTS

Urgent treatment for seriously ill children has continued during the pandemic, such as treatment for cancer. However, changes to the health system to prepare it for, and to respond to, the pandemic, as well as to cut the risk of transmission when attending appointments or receiving treatment unrelated to COVID-19, have meant that some consultations and procedures have been delayed for children with a life-threatening or terminal illness.

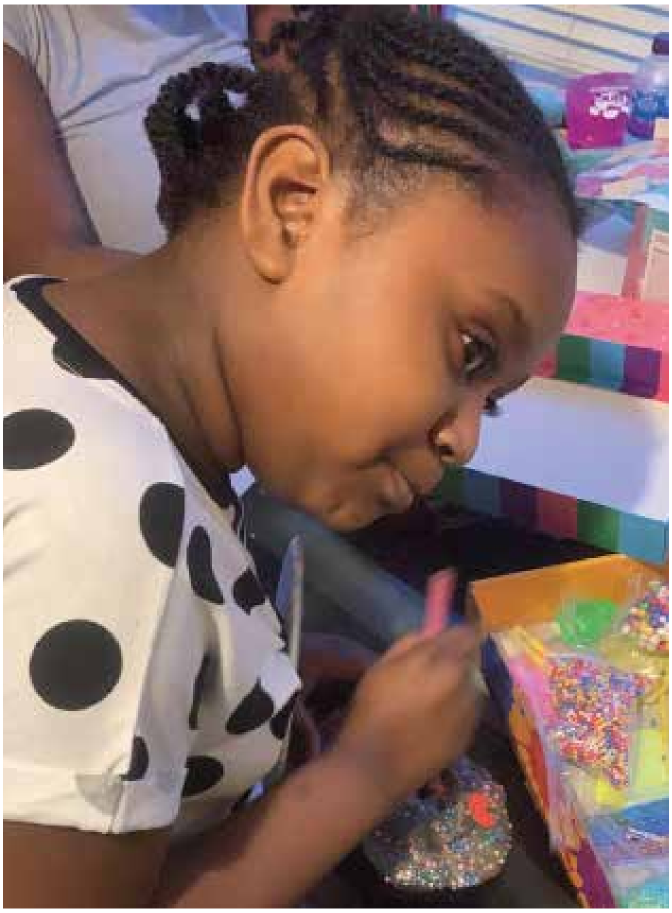
This has added to the worry for parents who are anxious that their child receives timely treatment. Among families interviewed for this report, some children, like two-year-old Oliver (story on page 28), are waiting for an organ transplant, but such operations have been delayed by the focus on the pandemic and waiting lists have grown. For Frank (page 9), the pandemic has meant a delay to a procedure to manage his secretions, and for Hassan (page 21) this has meant some delays to treatment to help him weight bear.

Clearly, the impact on treatment for children with life-threatening or terminal conditions will be felt for many months to come, as the NHS struggles with lengthening waiting lists,[2] the impact on capacity as a result of increased infection control measures, and pre-existing pressures such as staff shortages. Alongside this are many unknowns, such as future rates of COVID-19 transmission and hospitalisation, already increasing.

Where feasible, less critical appointments have been converted to telephone or virtual appointments to minimise the need for face-to-face contact. Without the need to travel, perhaps with a wheelchair and bulky breathing or monitoring equipment, and no longer needing to organise transport and childcare, virtual appointments bring some valuable benefits. As one parent explained, '*Historically a lot of things were done via physical appointments... it was a Churchillian effort to leave the house.*' However, not all families will have access to a computer or reliable internet for video calls, and for families where English is a second language there may be a risk of poor communication between parents, child and consultant.

Unfortunately, there have been instances when safeguarding alerts have been raised because a parent has not taken a seriously ill child for planned appointments, despite the parent informing clinicians that the household is shielding. Where this has happened, we know that it had a detrimental impact on the parent's mental health.

> **"Historically a lot of things were done via physical appointments... it was a Churchillian effort to leave the house."**



During lockdown nine-year-old Aalaeya enjoyed virtual play sessions with her Rainbow Trust Family Support Worker

RESTRICTIONS ON HOSPITAL VISITING

National guidance issued at the start of the lockdown advised hospitals to restrict numbers to one parent only when accompanying a child to appointments or procedures, or visiting a child who is an in-patient. This has been particularly difficult for families where a child has been in an acutely life-threatening condition or known to be at the end of their life. As a result, families have had to choose which parent will be with their child, an unbearable decision when death was known to be close.

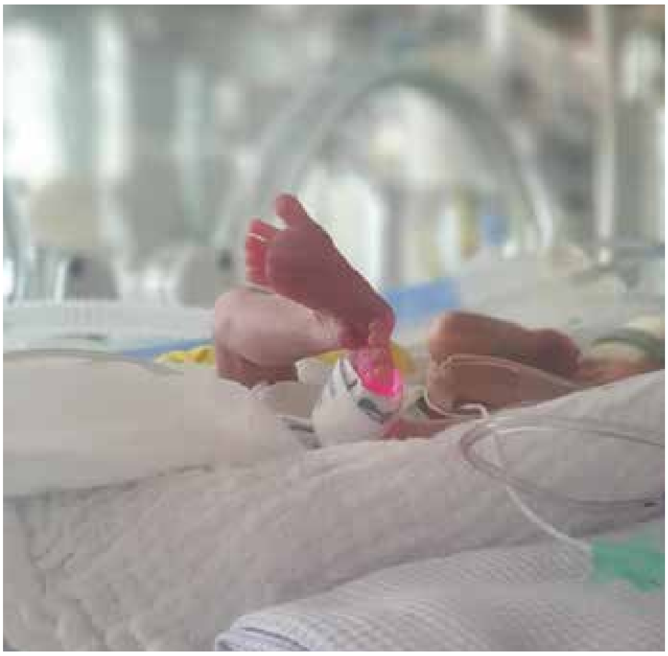
Where a child has a compromised immune system and is receiving dialysis or preparing for or recovering from a transplant, the situation would ordinarily be stressful and anxious for families. In the time of COVID-19, the strain has been magnified as rules have been tightened further to protect patients with compromised immune systems from any risk of contracting the virus. In one instance, a child is undergoing a second bone marrow transplant, and the hospital where they are receiving treatment is 30 miles from the family home. The mother has stayed by her child's bedside, but at the cost of not seeing her other children and missing her baby's first birthday. Without a car, there was a period when the father visited by bus but had to bring the family's other four children with him, aged between one and 14-years-old. Restrictions were then tightened, and the father and siblings are no longer able to visit at all. The mother is only occasionally able to leave the ward and receive emotional support from a Family Support Worker just outside the hospital.

A lack of transport and difficulties finding childcare for healthy children are frequent challenges for families caring for a seriously ill child who needs to attend a hospital. However, these obstacles have been further exacerbated during periods of full lockdown when the option of help from friends or family outside of their own household has not been available.

NEONATAL CARE DURING THE PANDEMIC

It has been an especially difficult time for pregnant women and their partners, and parents of seriously ill babies. To protect patients and staff, hospitals introduced restrictions on access to clinics and wards. A ban on partners attending check-ups with their pregnant partner meant that if a problem was detected, some women received difficult news alone. A rule of only one person from the same household as the mother being present during a birth has meant other close family being unable to provide support. Giving birth to a seriously ill baby or experiencing a miscarriage during the pandemic has been a lonely and distressing experience for many. In most cases, only one parent at a time has been allowed to visit a seriously ill baby in neonatal care. Some neonatal units have started to relax their rules, but restrictions continue on many units.

Visiting can be further complicated by the distance that parents may need to travel to see a seriously ill baby. The charity Bliss calculates that on average parents travel 27 miles to visit their baby in neonatal care but some families travel up to 100 miles.[3] Short and infrequent visits can be a barrier to establishing and maintaining breastfeeding, and other caring and bonding activities such as skin-to-skin contact, which can assist in a baby's development.



(credit: Stoor family)

FAMILY STORY 2: 'COVID HAS MADE IT INCREDIBLY DIFFICULT'

On 12 March at only 23 weeks pregnant, and as the country prepared for the COVID-19 pandemic, Kelly gave birth to her daughter Kaia, weighting just 765g. Kaia was immediately taken away from Kelly and her husband Max to be put on breathing support. When Kelly was discharged from hospital the 30-mile trip to see Kaia posed a challenge. Kelly does not drive, and tight visiting rules meant Kaia's three siblings could not meet their new sister. In the same week, Kelly's mother-in-law died of cancer. It was a tumultuous time.

As Kaia's condition deteriorated only Kelly was able to visit her. She says, '*I could see how gravely ill she was, she looked awful.*' She was urgently transferred to Southampton Hospital for bowel surgery, now 50 miles from the family home. Doctors feared she had necrotising enterocolitis, a serious illness in which tissues in the intestine (gut) become inflamed and start to die.

Kelly paced at home waiting for news during the five-hour operation to remove 15cm of the inflamed bowel. She desperately wanted to visit her daughter but getting to Southampton was impossible. The family had no childcare for their three other children, and hospital accommodation for parents was closed to minimise transmission of COVID-19. For four weeks Kelly was unable to visit Kaia. She was receiving photos from the neonatal ward, but she pined to be with her baby.

> **"It was the worst day of my life, it really was horrible."**

The hospital referred Kelly to Rainbow Trust and a Family Support Worker got in touch with her and explained that she could take Kelly on the 100-mile round trip to visit Kaia once a week.

'*She was an absolute life-saver, she was amazing,*' says Kelly. She especially valued the flexibility of her Family Support Worker to let her decide how long she needed to stay at the ward.

After a period of improvement Kaia then became seriously ill again, swelling up, developing sepsis and requiring seven hours of surgery. During the operation Kaia's breathing tube got dislodged, one of her lungs collapsed, and another 10cm of bowel was removed. Kelly was rung at 5am and she remembers she could only pray. Kaia's second lung collapsed and her blood was not clotting as it should. '*It was the worst day of my life, it really was horrible.*'

Thankfully, Kaia's condition stabilised. When Kelly managed to visit a few days later, she found it incredibly lonely with no one else allowed to accompany her. Infection control measures meant that nurses could not comfort her as they might in ordinary times.

'*To go through it on my own was really hard. To see her in intensive care again and on a ventilator, incredibly swollen, cannulas and wires everywhere… I didn't even know how to touch her. Going through all that and not having my husband next to me was horrendous. I absolutely hated every minute of it.*'

Kelly remembers a particularly hard day when she was finding it too much to cope with. Her Family Support Worker met her for the drive back home. '*We talked the whole way, and that really helped.*'

Kaia's elder siblings had still not met their sister, and Kelly felt she was living two separate lives. '*Juggling the three children at the same time was really difficult. It was like a rollercoaster with Kaia but then you've got three other children you've got to be a parent to.*'

Steadily, Kaia's condition improved, and finally, after eight weeks in which Max had not seen his baby daughter, there was a change to the hospital's visiting rules.

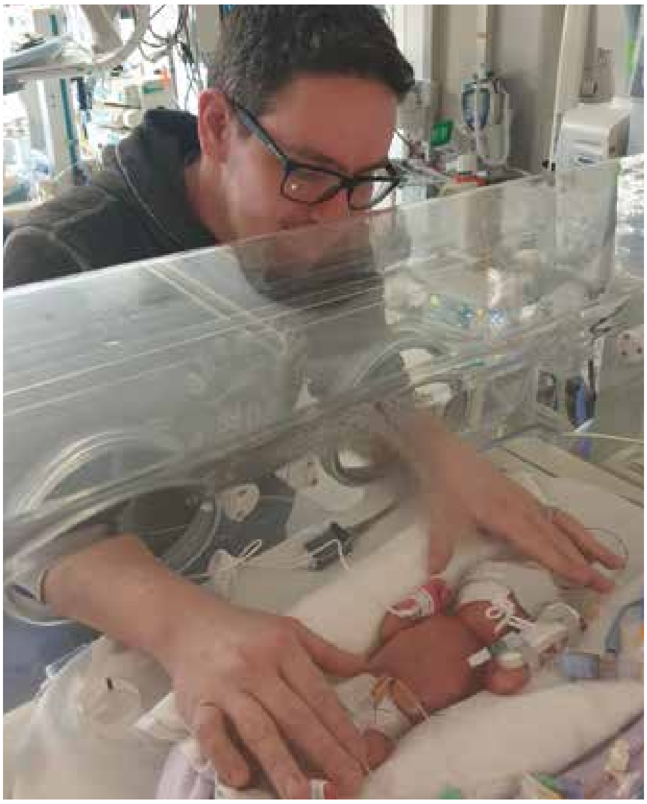
“Mentally it was a massive strain.”

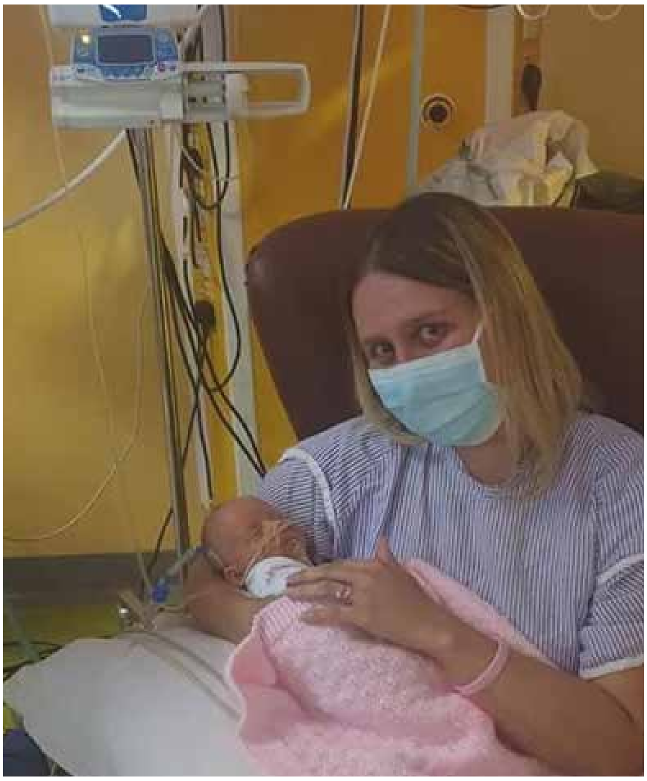
Max was able to visit, while Kelly’s mum was able to mind the older children. Only one parent could be on the ward at any time, and a rota system spread out visitors to minimise the risk of transmitting COVID-19. When the couple could drive themselves, they also had to cope with ‘*astronomical*’ petrol costs, says Kelly, and unlike parents who lived closer to the hospital, they could only make use of one of the two visiting slots each day.

Day 88 was a milestone when Kaia’s parents could finally hold her in their arms. Kaia was now back in Portsmouth hospital, closer to the family home. Wearing facemasks reassured them, along with weekly COVID-19 tests required of parents by the hospital. After 117 days of neonatal care, Kaia was at last discharged. Kelly and Max did not tell Kaia’s siblings that she was coming home so they could enjoy the surprise when they came in the door. ‘*It was a lovely moment*,’ she says, ‘*with lots of tears*’. Kaia is still on medication and she will need a further operation on her stomach in future, but she is doing well.

Looking back, Kelly says, ‘*I’m not sure how I kept my head above water... Mentally it was a massive strain*’. She feels their situation was made far harder by the visiting restrictions, which meant ‘*the other person has to take a backseat*’, denying her husband the chance to bond with their daughter for so long. On top of that, social distancing measures kept parents apart from other parents visiting the neonatal wards, which could have been another source of comfort.

‘*COVID has made it incredibly difficult and a much lonelier journey than it ever should be... We watched the government briefings and nobody ever mentioned it, nothing was ever mentioned about parents with babies in neonatal care.*’



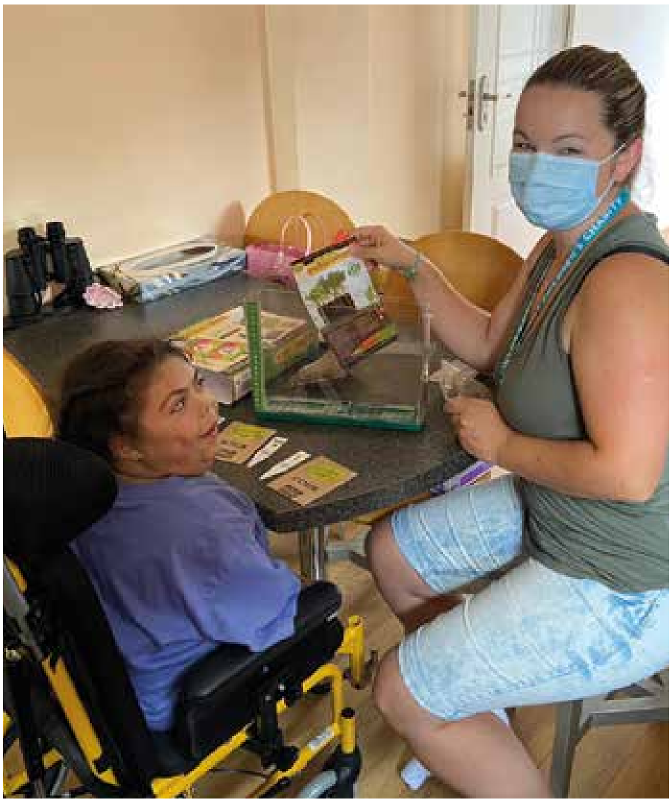


Parents Max and Kelly spending precious time with their daughter Kaia in hospital (credit: Stoor family)

FAMILY EXPERIENCES OF CONTRACTING COVID-19

Where a child or family member contracts COVID-19, the individual must self-isolate. In one example, in a family receiving support from Rainbow Trust, a two-year-old girl tested positive for the virus and had to pause her daily chemotherapy for her leukaemia treatment. In another example, a new mother had to self-isolate on the Isle of Wight while her baby was seriously ill in hospital on the mainland.

In a third example, both a seriously ill one-year-old girl and her parents had COVID-19 symptoms at the very start of the pandemic. The child was moved to intensive care more than 80 miles away and her mother was not allowed to visit while awaiting their daughter's test result. This proved to be negative. The parents also had symptoms but were unable to access tests for themselves in this time, which meant that they were apart from their child for two weeks altogether. This proved highly distressing for the family.



Erin has multiple long term and life-threatening conditions and has been supported by a Rainbow Trust Family Support Worker during lockdown.

FAMILY STORY 3: 'NOW SOME PEOPLE CAN RESUME NORMALITY, BUT IT CAN'T BE LIKE THAT FOR US'

Amelie, aged 15, has complex health needs including Quadriplegic Cerebral Palsy, Epilepsy and Scoliosis. Her sister Ella is ten years old. Their mother Lucy contracted COVID-19 in spring 2020, and this has informed Lucy's perspective on its risks for her family.*

'I had COVID early on and was ill a few days before lockdown… It was scary. Very bad. If I had not had my Rainbow Trust Family Support Worker and Rainbow Trust volunteer supporting me in my recovery from that, I do not know where I would be. I turned to them more than my family… I cannot thank them enough. Our Family Support Worker picked up a prescription for me, and also delivered activity packs to the girls. Just her standing on my front path for an hour and talking to me - to have that face-to-face contact at a safe distance – that was helpful.'

Lucy is proud of how her daughters coped when she was ill. '[My healthy daughter] *Ella was a star and took on a caring role. Amelie had a sixth sense and knew what was going on. I managed it at home and was in contact with the medical professionals, but we had no idea what was going to happen… It was touch and go at one point.'* She explains that after she herself recovered, Amelie was then quite poorly but the family were refused a COVID-19 test for her at that time.

"No-one has really experienced the very extremes of isolation like we have."

The main problems for Lucy during the lockdown were both psychological and practical. Lucy had begun some counselling for herself just before the initial national lockdown. While shielding as a household, she has felt extremely isolated, and has not been able to go food shopping, or pick up Amelie's prescriptions from the pharmacy. Her confidence in official decision-making has been low. '*I am struggling to trust anything the Government does on this, which I am sure others are too.*'

A frustration for the family is that a series of check-ups for Amelie's Scoliosis in spring and summer 2020 have been delayed, as has a planned procedure to change her feeding tube. Getting to appointments is difficult as Amelie's epilepsy means that car travel brings on Dystonia, a movement disorder in which a person's muscles contract uncontrollably. Her complex conditions are more severe in the winter months, and the hope had been for Amelie to have appointments and procedures earlier in the year.

For her daughters, Lucy feels the time together in lockdown was positive, and that connection between them has been enhanced. When the guidance changed in June, Lucy was also able to 'bubble up' with her sister who was a paid carer for Amelie before the pandemic. Because her sister has three children, this has enabled Ella to have more social interaction. '*The practical measures we've put in place are beyond ridiculous. We were always very cautious anyway, but I would not have imagined the extremes we would go to, even with my own sister*,' remarks Lucy.

Lucy's hope that the pandemic would improve people's awareness of the difficulties for families who must isolate for health reasons is now fading. '*No-one has really experienced the very extremes of isolation like we have, when you are doing all you can to protect your loved ones, unless they have experienced it first-hand. I was hoping it would change, when everyone had experienced a degree of isolation in lockdown, so that they could understand how hard life can be for some. Now people can resume normality, but it can't be like that for us. I am not sure the understanding is there. It's not that I want sympathy, I just want a certain level of understanding.*'

'*I do not feel safe enough to take my girls out or feel confident enough that people will give us space. There will always be that one person walking down a path towards you who will not move, and I cannot move with the wheelchair. Part of me felt while the infection figures were lower and the weather was milder, we should have made more of the opportunity to get out. But the risk outweighs that – especially as I know what it feels like to have COVID-19. I feel that my fear now comes from knowing what it is like to have it and I am thankful I recovered. I will continue doing what I feel is right.*'

"I do not feel safe enough to take my girls out or feel confident enough that people will give us space."

Although schools resumed, Ella is continuing to study from home, supported by her teachers, to keep her sister safe.

While other services have stepped back, Lucy's Family Support Worker and a Rainbow Trust volunteer have provided up to two hours of emotional support by phone each week. '*Rainbow Trust is the only charity focusing on me and my needs as a mum… I often wonder where we would be if Rainbow Trust had not stepped in.*'

*Names have been changed.

THE LOSS OR PAUSING OF HEALTH AND CARE SERVICES

When the lockdown began many of the services that families had previously accessed, in both health and social care, were paused or changed significantly. Routine contact from health and social care professionals, where it continued, was generally provided by telephone, while therapies such as physiotherapy sessions were often put on hold. Some children's hospices stopped being able to provide respite services or hospice-at-home support. At the same time, social distancing measures meant that families in lockdown lost their informal support networks of friends and family, whether or not they were shielding

For half of the families who responded to our surveys, Rainbow Trust was either the only source of support, or one of two sources of support, at the time of being surveyed.

Some families could not have regular NHS-funded carers come into their house during the strictest period of the lockdown as families sought to minimise the risk of infection entering the home. For example, Dominic's son Oliver would usually have a carer for six hours a week, to assist one of his parents. For a period during the lockdown, no carers visited the house at all and the family had to cope alone.

THE IMPACT ON PARENTS' MENTAL HEALTH

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 often further compounded parents' feelings of uncertainty and anxiety. Across both of Rainbow Trust's surveys, nearly 60% of parents who responded told us that their mental health was either 'worse' or 'much worse' than before the pandemic.

Parents responding to Rainbow Trust's survey in April commented:

> *'[My seriously ill daughter] has recently come out of hospital recovering from pneumonia & an infection so is still quite weak. We decided to self-isolate following advice from the community nurse and we cancelled our carers accordingly. It's been hard without the carers, adjusting to new health requirements like oxygen dependency but my husband and I work well as a team.'*

> *'We have lost our regular carers for our disabled child and lost all routine.'*

> *'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.'*

Responses to the first survey in April provided a picture of many parents feeling stretched and exhausted:

> *'It's putting immense pressure on our mental health as parents, constant parental mode, no time off for ourselves.'*

> *'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. My family all live too far away to help or are in isolation themselves.'*

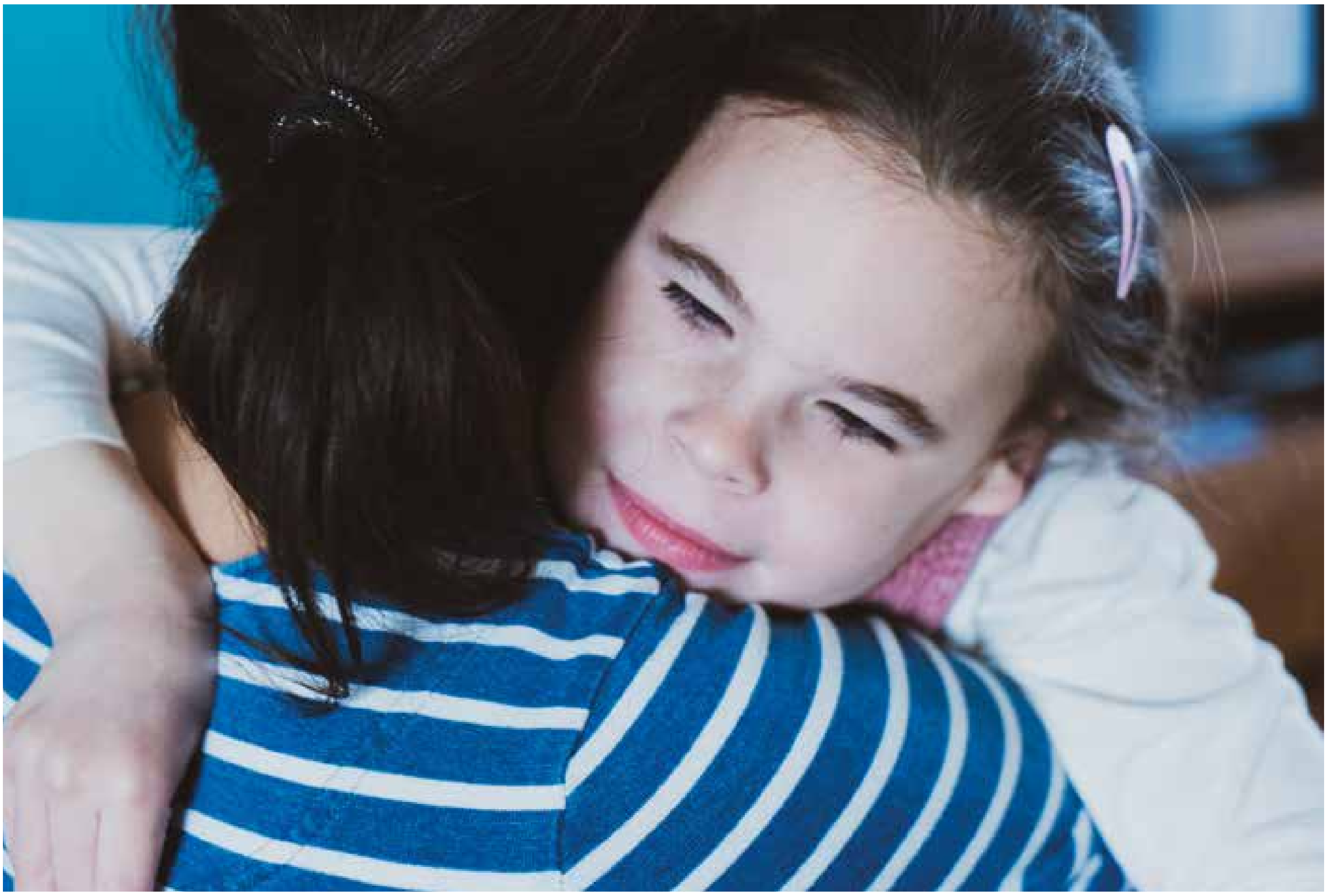
Responses to the second survey in June suggested a slight improvement in parents' outlook, perhaps reflecting their adjustment to the situation. When asked about the challenges they were facing, responses included:

> ***'Home educating and providing play and 24/7 care etc for our complex medical child, his [profound and multiple learning difficulties] sibling and the older sibling.'***

> ***'Looking after my children and making sure we clean everything and are extra careful.'***

> ***'[Missing] the support from our families. We have been unable to have physical contact at this difficult time which put extra strain on our mental health - not just us as parents but the children as they are so close to my family too.'***

Many of these concerns were echoed by the initial findings of the ongoing SHARE study being carried out with parents by Together for Short Lives in collaboration with Martin House Research Centre and the University of Southampton. This found that 93% of families felt isolated during the pandemic, and 95% were fearful that their child would catch the virus from their parent.[4]



Kelly and her daughter Freya who has a rare metabolic condition. Read more about Rainbow Trust's support for Freya's brother Freddie on page 32 (credit: Drew Cox)

THE IMPACT ON HEALTHY SIBLINGS

Siblings can experience a range of emotional and practical issues as a result of their family's need to focus on the care of their seriously ill brother or sister. During the tightest period of lockdown, healthy brothers and sisters no longer had access to activities and services which might usually provide them with much-needed time away from pressures within their home. Most siblings of seriously ill children lost the routine that nursery or school would normally provide. Where grandparents and other relatives were previously able to help out, this support was suddenly removed as the lockdown began.

For older siblings, the pandemic may have meant they took on a caring role at home in light of a pause in NHS-funded carers coming into families' homes, and with nurseries and schools closed. Older siblings may have cared for healthy brothers and sisters or assisted their parent with tasks required to care for their life-threatened or terminally ill sibling.

Some of these concerns were echoed in a survey by charity Sibs UK, which supports siblings of disabled children.[5] 75 per cent of parents responding to a survey about the impact of the lockdown on siblings reported that the mental health of a sibling was worse than before lockdown. Just 18 per cent felt the sibling's mental health had not changed. More than half of parents said that their sibling children were having to provide more care and support in lockdown than normal.

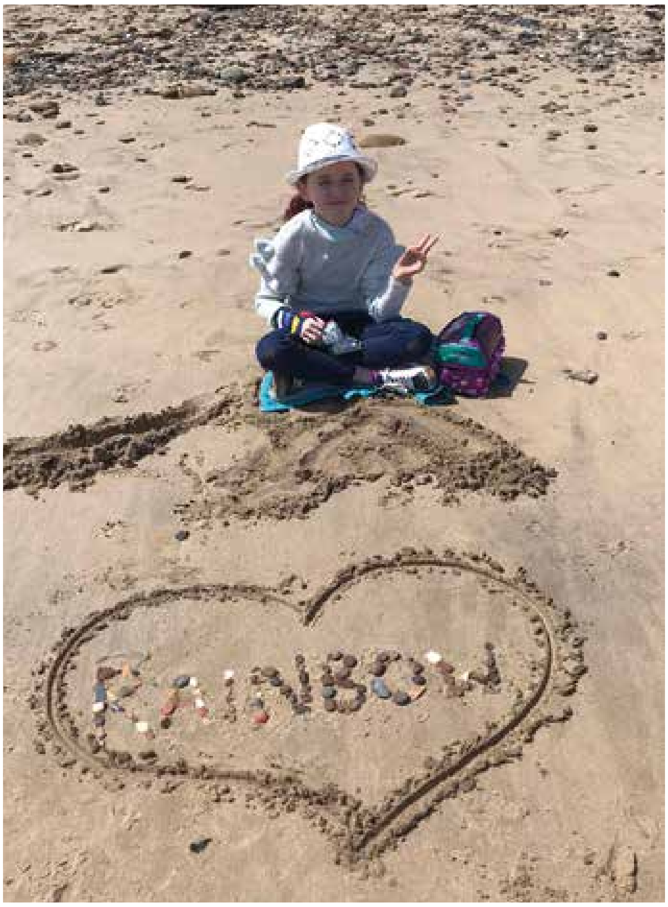
Comments from parents responding to Rainbow Trust's survey in April included:

> *'[My seriously ill child] requires 24/7 care and it has greatly increased the care I need to give as she isn't going to school and I'm not getting a break. [Her healthy sister] was due to be having counselling but this has obviously halted. So dealing with [her healthy sister's] issues 24/7 is proving testing.'*

> *'The children are struggling with not being able to do normal things and go out. They get upset that they cannot see grandparents or their dad except through a window.'*

> *'We have completely isolated and only my husband has left the house to do the grocery collection by car. It is hard for [my seriously ill child]'s siblings but they are coping well despite missing their friends, school and change of routine.'*

> *'Our eldest daughter is finding it really hard not seeing her friends or wider family.'*



Erin is ten years old, and her brother Jackson is five. He has an undiagnosed condition. He is connected to oxygen 24 hours a day and has very complex needs. In late June, Erin's Family Support Worker took her on a trip to Cambois beach in Northumberland. It was the first time Erin had gone beyond her garden since the coronavirus pandemic started four months before.

'*We walked along the shore chasing the waves and collecting shells and stones. We then did some sand art and had a picnic,*' explains the Family Support Worker.

After four months of staying at home to protect her brother, Erin enjoyed a trip to the beach

APPRECIATION OF FAMILY TIME

While some parents could not find any positives in their situation when surveyed, others appreciated the 'family time' and temporary slower pace of life, without the usual demands of appointments, school and work.

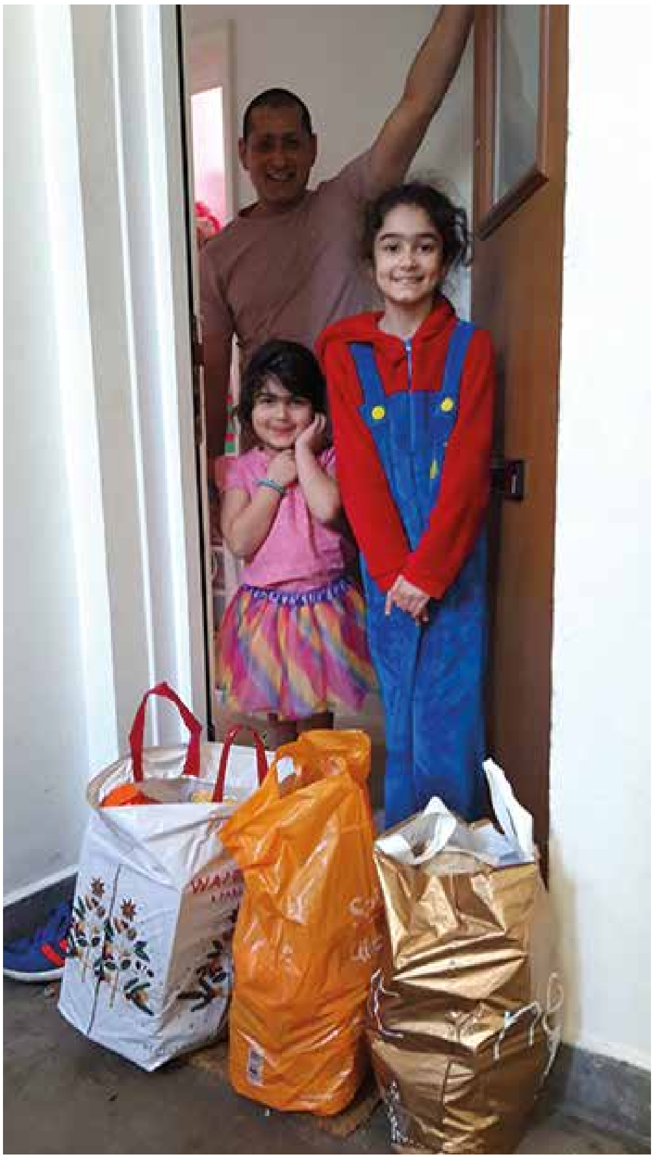
This fits with Rainbow Trust's experience that families can often express a resilience despite the challenges of their situations.

'My children have bonded more as siblings.'

'We had been separated as a family most of 2019 due to my son being in hospital away from home. This has given us lots of family time together in our own home.'

'My husband has had to be at home because of our son. That has been the biggest positive as he has bonded more with our children and I feel that they are happier because of this.'

'We have been able to sit together as a family more at mealtimes as we are all at home.'



Poppy and her family after being given a food drop-off by their Rainbow Trust Family Support Worker. The food delivery was donated by Richard Challenor School.

FAMILY STORY 4: 'THE RESTRICTIONS HAVE LIFTED BUT I FEEL THE ANXIETY HAS TAKEN THEIR PLACE'

Hassan is nine years old and has severe epilepsy and global development delay. He has frequent seizures, which are worse if he is tired or has a slight temperature. He also has respiratory issues and congestion in his chest.

He was deemed 'extremely clinically vulnerable' and the household was advised to shield in March 2020. Hassan has two sisters, 13-year-old Mahnoor, and three-year-old Zainab.

Hassan's mother, Mehwish, knows that his seizures could be fatal without her vigilance. He cannot be left alone at any point. '*He has no sense of danger. He can crawl and he can pull himself up*.' Overnight, his father, who works full time, must be up three or four times to check on him.

While Mehwish says that Hassan's routine medical support has been '*really good*', she is worried that the change to NHS services during the pandemic has delayed Hassan receiving much-needed treatment for his feet, as currently his feet are unable to bear his weight. '*It could be life-changing for Hassan, whether he can stand up or not put any weight on his feet*.' It has taken many months to have an appointment with an orthopaedic surgeon to plan his treatment.

"Nothing was making him satisfied… he was very upset."

The pandemic has inevitably added to the pressures on Mehwish. For a period the NHS-funded carers that used to help at weekends were unable to visit. Aside from calls from Hassan's medical team and support from Rainbow Trust, the family has had no other contact with services. Hassan's father was on furlough leave from work until June, and he would go out of the house just once a week to do a grocery shop.

With her mother focussed on Hassan's needs, and with school and nursery closed, elder sister Mahnoor looked after Zainab. Mahnoor is a bright teenager who takes her studies seriously. She recently won an arts competition, with a talent for writing, poetry and drawing. But studying was almost impossible around caring for her three-year-old sister. She completed her schoolwork in the evenings instead. For a while Mahnoor was only able to use a mobile phone to access her schoolwork but later a Young Carers organisation provided her with a laptop.

Mahnoor has been '*a godsend*', explains Mehwish. '*She says she's like a second mum to her little sister.*' But Mehwish feels that the demands brought by the pandemic did become a struggle for Mahnoor. Mahnoor has also recently told her mother about events in her childhood that she missed, when Hassan's needs had to take priority. '*When you have a child with special needs, or a seriously ill child, it changes the whole perception of your life. It does affect the whole family, siblings as well... I never knew it would affect Hassan's sister that much,*' Mehwish reflects.

As the lockdown stretched on, Mehwish sensed that Hassan was unhappy and was missing social contact. '*Nothing was making him satisfied... he was very upset. There was something going on all the time. He couldn't get a break from us,*' she says. She rang his school and he was able to attend for a couple of days before the end of the summer term.

For Mehwish the situation became overwhelming when she received the news that her father had died in Pakistan. '*I didn't even get a time to grieve properly,*' she explains. Travelling to the funeral was obviously impossible. '*I was struggling, Hassan was struggling as well, and then there was Zainab being only three-years-old.*'

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

During the pandemic their Family Support Worker provided video calls and fortnightly parcels for Zainab with activities, puzzles and toys which excited her and kept her occupied. Mehwish says the deliveries were the highlight of Zainab's day. The Family Support Worker also collected medicines for the family.

In August 2020 Hassan was moved from the 'extremely clinically vulnerable' category to the larger 'clinically vulnerable' group. Mehwish says, '*I feel really anxious about going out. At least we were safe during lockdown. The restrictions have lifted but I feel the anxiety has taken their place.*' As a family they are avoiding crowded places which is not easy with Hassan using a wheelchair.

Looking to the future, the family are cautious but hopeful. Mehwish really valued her Family Support Worker being in touch and able to listen to her, even if there was not anything practical that that she could do during the strictest periods of the lockdown. '*I have to say, I don't know what I would have done without her.*'

Meetings of Mahnoor's Young Carer group, paused during the lockdown, restarted online in the summer, and she was excited to return to school in September. Hassan is now able to go to his special school too, part time, and their Family Support Worker collects Zainab from nursery twice a week to make life that bit easier for the family.

LOOKING FORWARD

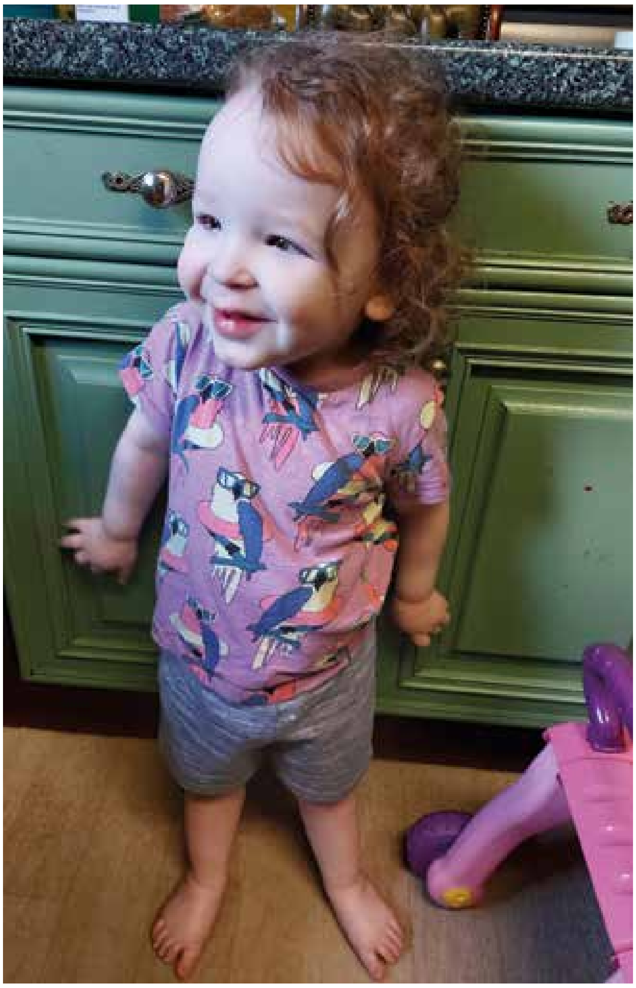
COVID-19 has brought much uncertainty to the lives of people everywhere. Many people long for a return to more 'normal' times. However, there is no 'normal' for families caring for a seriously ill child whose lives revolve around helping their child to make the most of the time that they have.

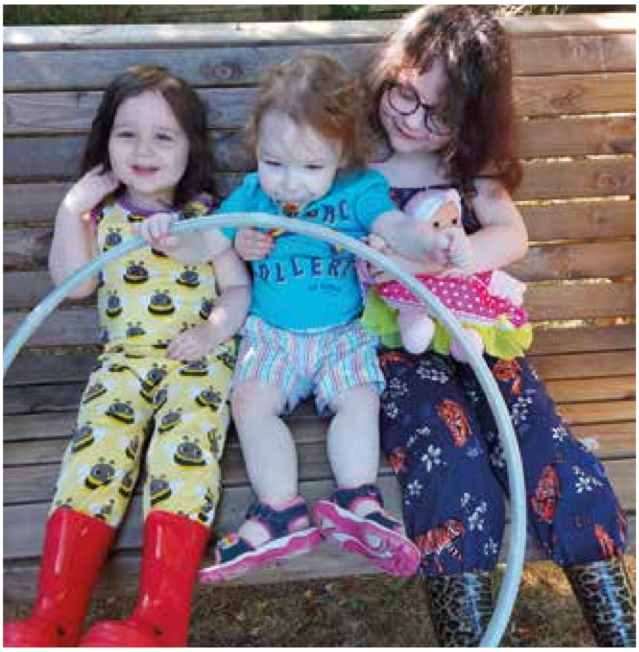
Rather than anticipating a future return to activities that they miss, many families caring for a child with a life-threatening or terminal condition are making decisions according to their child's medical advice and individual circumstances.

At the time of publication, a number of families have been advised to continue shielding because of their child's medical condition. Nationally, around 5,000 children and young people under 18 are expected to remain on the shielding list and will be advised to shield in the event of a local outbreak, if not already shielding.[6] Rainbow Trust supports some families who have been told that their child should shield until spring or summer 2021.

Some parents have been cautiously willing for both their healthy children and their seriously ill child to return to nursery, school and college settings. However, provision at some special schools is only part time or has been delayed in light of the difficulties for schools to ensure procedures can be carried out safely. Often parents have been reassured by the advice they have been given by their child's clinical lead, and acknowledge the impact of COVID-19 on children is lower than on many adults.

Others remain wary, while new waves of the pandemic spread and the future remains highly uncertain. Some families are anxious that they may be fined for not returning a child to school, and we know of one family with a seriously ill toddler who feel under pressure from their healthy children's school to send their other healthy children to school despite their anxiety. An understandable concern for some parents and siblings is that they could bring infection into the house.





Asher at home, above, and with his sisters, below (credit: Asher's family)

FAMILY STORY 5: 'WE ARE SAFE IN OUR BUBBLE, WE FEEL PROTECTED WHERE WE ARE'

Tara's three-year-old son Asher has a very rare endocrine disorder and thyroid cancer. Both he and Tara were instructed to shield at the start of the pandemic because of their health. She sees this as a 'double risk factor' for the household. As a result, the family, including dad, Paul, and daughters Tallulah and Esme, aged 7 and 4, have all been shielding. '*We're extremely cautious*,' says Tara, who fears contracting the virus as Asher's main care-giver as well as in light of her own health.

The family have not left their house and garden since 15 March, except for essential face-to-face medical appointments for Asher. '*In the beginning, shopping was a battle*,' says Tara. '*I spent a lot of time worrying about how we'd manage for food, for Asher's medicines, and so on*.' It took some time for the family to be added to the government's priority shopping delivery list. They live in a small village and were allocated a volunteer by a local coronavirus support line. The volunteer has collected prescriptions for them and made trips to the post office.

'*Unfortunately we found out in lockdown that Asher's tumour markers have gone up*,' explains Tara. His extremely rare condition means there are many questions about his prognosis and treatment. Asher is monitored with telephone calls from their GP and several video calls with clinicians, with a small number of face-to-face appointments at Great Ormond Street Hospital. For these appointments, she describes leaving the home as '*like a military operation*' because of Asher's wheelchair, his equipment for feeding and monitoring his blood sugar, plus the wearing of visors and other Personal Protective Equipment (PPE).

Their local hospice was not able to provide its usual respite care, with staff redeployed in the NHS.

> **"Our safety net has gone... Caring for Asher rests solely on our shoulders."**

'*Our safety net has gone... Caring for Asher rests solely on our shoulders*,' says Tara, '*And we have to risk assess everything that we do*.'

Living at the end of a country lane, in a fairly remote location, has its benefits. '*But the flipside is that sometimes it can be a bit isolating*', explains Tara. She adds that it has been '*very challenging*' to have the whole family at home, with it feeling like a '*pressure cooker*' at times. '*Particularly at the beginning, there was a lot of camaraderie with the children, being at home, baking and so on, but you run out of steam after a few weeks.*'

Since the initial lockdown their Family Support Worker has provided video calls with Tallulah and Esme to keep in touch with them and provide some activities. In August she drove Tara and Asher to a hospital appointment, and has visited the girls in their garden. Tara says, '*It was lovely for the girls to have that*.'

'*It's been really, really, really tough... but it's a completely unusual situation*,' reflects Tara. The family will continue to stay at home as much as possible while the pandemic continues. Her husband, a vicar, has restarted church services while carefully following guidance to keep the family safe. This has required multiple levels of planning and organisation. Tallulah and Esme are not going to school while the risk of contracting COVID-19 remains.

'*We've taken the decision, looking at the facts and figures, to carry on doing what we're doing. In my mind it's absolutely crazy that people are returning to normal... We are safe in our bubble, we feel protected where we are*.'

WHAT CHILDREN TOLD US ABOUT THE COVID-19 LOCKDOWN

What did children miss during the initial national lockdown?

Seriously ill children and their siblings told us:

- ‘Swimming’
- ‘Going to school and seeing my friends in person’
- ‘Playing football matches for my local team’
- ‘Spending time with my friends.’

What did children enjoy during the initial lockdown?

- ‘Being with my family’
- ‘I enjoyed my lockdown birthday’
- ‘Having time to play my guitar. I even got to have a go on my Dad’s electric guitar!
- ‘Online dance classes.’

PARENTS’ TIPS TO OTHER PARENTS IN THE EVENT OF SHIELDING OR LOCKDOWN

‘One thing I’d say is take any offers of assistance, and ask people for help. People often want to help and often don’t realise the impact of offers to help with things like shopping.’

‘Don’t be shy to ask questions of health or educational professionals who are involved with your child.’

‘Take up a new skill, learn something. Keeping your brain active definitely helps. Learning something new is so good for you.’

‘Take one day at a time. I had plans, I’m going to do this, and that, but nothing got done. There’s only so much you can do.’

‘Join a Facebook group, they’re helpful. Establish an online network, they’re very important. The use of social media is very important for people in isolation.’

‘Don’t feel alone… There will be lots of people in the same situation.’

‘Parents need to try to find ways to look after themselves.’

SECTION 2:
HOW RAINBOW TRUST HAS RESPONDED TO COVID-19

From the very start of the initial national lockdown, Rainbow Trust adapted its services to offer families virtual support and ongoing practical support.

Many families told us that Rainbow Trust was the only service still in touch with them in this period and the only source of support for them when other services paused. Although the pandemic resulted in a temporary slowing of new families being referred to the charity, and the charity had no choice but to put some staff on furlough leave, Rainbow Trust teams continued to deliver more than 500 instances of family support each week during April, May and June.

DELIVERING THE SERVICE IN NEW WAYS

Using video calls, messaging and phone calls, Family Support Workers maintained relationships with parents, seriously ill children and siblings. Family Support Workers have also established new relationships with families being referred to the service, or families whose usual Family Support Worker has been on furlough leave. Support has been delivered within the confines of national and local rules, with new policies developed to ensure best practice in safeguarding when communicating with children electronically, for example, and the use of Personal Protective Equipment (PPE) when required. Support by Family Support Workers on hospital wards had to stop, as well as Rainbow Trust's volunteer support service.

As the initial national lockdown eased in July 2020, the resumption of face-to-face support became possible for families who are comfortable receiving it, with Family Support Workers observing social distancing rules and infection control 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.

EMOTIONAL SUPPORT

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.

A particularly successful innovation was moving a Rainbow Trust Dad's Group in Lancashire, which had been meeting in person, to meeting online during the lockdown (see page 28). Some mothers have also met up online during lockdown to talk and play bingo.

VIRTUAL SUPPORT FOR CHILDREN

Providing virtual sessions for children, such as reading stories, using toys and props, holding competitions or leading craft activities online, enable parents to take a much-needed break while their children have some fun. Family Support Workers have also dropped activity packs to families' doorsteps, to brighten children's days.

Depending on their location, for some families it has been possible for virtual support to be more frequent than their previous face-to-face support. Siblings in the North West and North East have been brought together in a Rainbow Trust facilitated online sibling group. This group met by video every two weeks during the summer holidays with six to nine children and young people joining each time. They took part in activities such as a scavenger hunt within their home, a Disney quiz, chats about how they have been spending their time, and chances to share their experiences of lockdown.

PRACTICAL SUPPORT

Throughout lockdown Family Support Workers have helped families by buying groceries and collecting prescriptions where families have been strictly shielding. Family Support Workers have collected and delivered breast milk from self-isolating new mothers to their babies on neonatal wards, in situations where the mothers are unable to visit. They provided hospital transport for families with no other way to attend important appointments.

SIGNPOSTING FAMILIES TO FURTHER SUPPORT

Helping families to access benefits and grants has been more important than ever during the pandemic with many households vulnerable to the economic downturn. This is on top of the well-established negative impact on family finances that can accompany caring for a seriously ill or disabled child.

For instance, in one family both the parents and their two-year-old daughter, being treated for leukaemia, contracted COVID-19. Despite needing to self-isolate, the father's employer put pressure on him to return to work, and the family were in financial distress without his income.

Their Family Support Worker enabled them to access two grants and to apply for benefits. She also collected food and medicine for the family while they were self-isolating. The mother was distressed and benefitted from the emotional support, and the Family Support Worker dropped round fun activities for the daughter to do when she was feeling better. The daughter has since completed her cancer treatment and is doing well.

Esther and Zac welcome the delivery of essentials by their Family Support Worker

A DAD'S GROUP GOES DIGITAL

Before the COVID-19 pandemic, Rainbow Trust's North West team had set up a Dad's Group which began to meet every fortnight in a pub. Michael, whose 11 year old son has Juvenile Tay Sachs, had no interest in attending at first. His wife told him about it, and he remembers thinking, '*I don't need to talk to anyone*'. However, he eventually agreed to give it a go.

'*I turned up, and it was actually fine. I've been looking forward to it ever since.*' At one get-together before the lockdown, just he and the Family Support Worker met up and they played pool. '*I thoroughly enjoy his company… he understands the situation.*'

Michael wasn't sure how well the group would translate when it was suggested that they try meeting on Zoom when face-to-face meetings were impossible, but he became a convert. '*It was good, we had a bit of fun.*'

'*You can say whatever you want to the other dads,*' says Michael. '*The best thing about it is we're all in the same boat. My mates at work, they can try to understand but they aren't living it. In the Dad's Group we can get upset if we want. Us dads, we think we're superheroes, but at the end of the day we're not!*' While Michael's family has lived with their son's condition for over five years, some of the other fathers are still adjusting to their child's diagnosis.

Michael is looking forward to returning to work now that his son is no longer required to shield. But his family is still very careful when going shopping, and he adds, '*Even when I go back to work I will be watching what people are doing.*'

Another dad in the group is James. He has a three-year-old daughter Lucy who has a rare and serious condition called Myoclonic epileptic encephalopathy, which causes seizures and developmental delay. She has had respiratory issues in the past and was classed as 'clinically vulnerable', when the lockdown began. Lucy's disabilities have long restricted what the family can do. He and his wife Anna also feel '*perpetually tired*' since Lucy's seizures are mostly at night, and she requires constant monitoring and attention during the day.

'*Although I do speak to my friends, they don't really get it,*' says James. He knows they can go back to their normal lives. The value of the group for James is '*just to have people to talk to. Because when you're at home, there's no switching off.*' He adds: '*I'm doing OK for now but I wasn't for about six months* [when Lucy was first diagnosed].'

For James, the gradual easing of lockdown has highlighted the difference that their family feels every day. '*We very much felt the lockdown gave the rest of society a sense of what we are used to. Initially it felt quite nice… we felt a bit more normal.*' When the national lockdown was eased, he says they almost felt that they were being left behind again. '*It was quite stark.*'

A third father, Dominic, has a two-year-old son called Oliver, who has a complex condition and has been categorised as 'clinically vulnerable' during the pandemic. Throughout the initial national lockdown Oliver needed to be taken into Manchester to receive dialysis twice a week, a minimum 90 minute journey each way.

Oliver's mother and brother had to stay away when a two week visit to family became a six week stay after many of the family were suspected to have COVID-19. Dominic had to cope alone, and for part of this time Oliver was kept in hospital because of a temperature. Oliver is due to have a kidney transplant in early 2021 but Dominic fears this may be delayed as the NHS struggles to deal with its waiting lists.

For Dominic, the Dads' Group is '*like a break*'. He explains, '*It's way above most people's heads. There's some conversations you can't really have with dads not in our situation.*'

RAINBOW TRUST FAMILY SUPPORT WORKERS DELIVERED THE FOLLOWING OCCASIONS OF FAMILY SUPPORT IN THE SIX MONTHS FROM APRIL TO SEPTEMBER:

9706
family interactions

438
substantive support calls

574
virtual play sessions

436
face-to-face support sessions where possible

96
new families contacted

316
journeys to hospital or medical appointments

88
essential medication drops

548
activity pack drops

197
grocery drops

117
support to access benefits

320
episodes of bereavement support

20
episodes of end of life support

PARENTS' EXPERIENCES OF RAINBOW TRUST SUPPORT DURING THE PANDEMIC

'[Our Family Support Worker] has made video calls to my daughters and played games with them. It has been so so helpful for me to have that hour 'off' and leave them in her very capable hands. It also provides continuity for the girls as many of their regular support networks have been taken away.'

'...The video calls with [our Family Support Worker] are AMAZING and a total distraction for the kids. The video calls also spur me into motivation to achieve tasks/calls whilst the kids are occupied.'

'Rainbow Trust is the only charity actively supporting my family at present. Whilst in long term isolation I know my three young kids have something to look forward to, and I know I have an adult who understands my family and my daughter's needs.'

'Our children have loved all their WhatsApp calls and activities with [our Family Support Worker], they really look forward to it!'

'[Our Family Support Worker] has been brilliant chatting to [my daughter's] siblings through Zoom on a weekly basis. It gives me a bit of a break once a week after a frantic day of attempting home-schooling. I can use this time to attempt to get on top of [my daughter's] physio regime.'

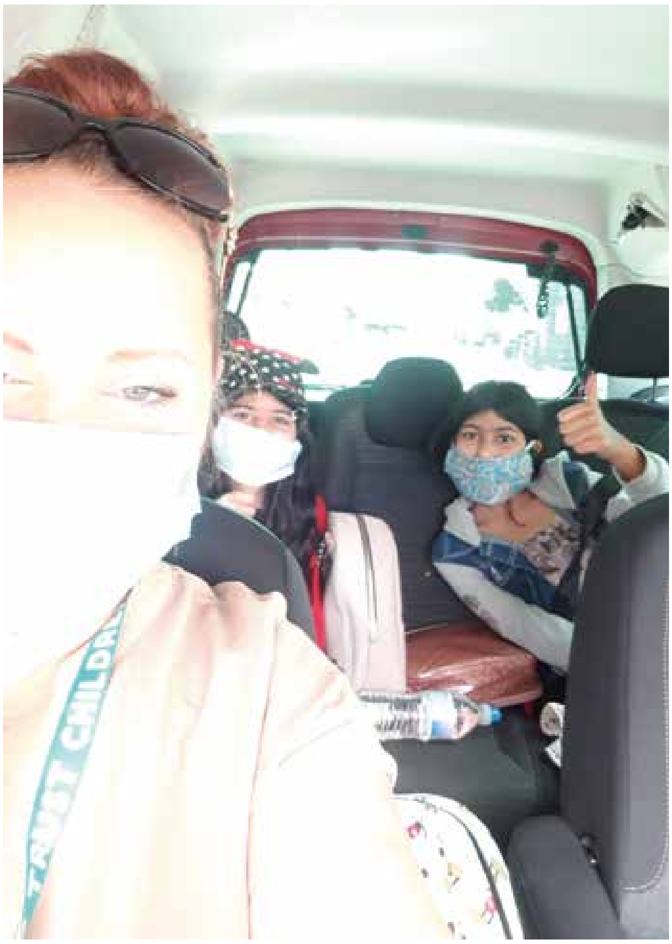
'The calls [our Family Support Worker] has with [my daughter] have literally been the only time that I have been able to relax and know that she is well cared for whilst I can have some time off or time with [her healthy sister]... They are the only childcare we have and they have been really really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

'Knowing that we can call on you to collect things for us means we have a safe back up and I really do appreciate that, thank you.'

FAMILY SUPPORT WORKERS REFLECT ON THE CHANGE IN THEIR ROLE IN A TIME OF CRISIS

> *“All of a sudden, we became a million things that we weren't before... it became a completely different job for a while... We filled in all those gaps that other organisations simply could not.*
>
> *Some of the things I have done have been so ‘out there’, and it is great that we have been able to do those things.*
>
> *This included helping a family move house in full PPE on one of the hottest days of the year because they were unable to find a removal company, doing a supermarket run juggling the lists of five different families, making contact with a hospital and an interpreter to help a parent have a pregnancy scan, and sitting with a recently bereaved parent for two hours in their front garden so they could talk when family could not visit.*
>
> *Without that, some of the families we support would not have got through this emotionally and mentally.”*

> *“Bereavement support is always a difficult part of my role. The COVID-19 guidelines have made this support so much harder - to sit with a crying parent, to see them in so much pain and not be able to offer them a physical form of comfort, a hug, a hand on their shoulder. Sometimes there are no words, and so much of a person's empathy is shown through physical contact. To sit two metres away, although keeping us safe, can be painful.”*



Aisha and Zahra on a special day out with their Family Support Worker, after strictly shielding for months to protect their younger sister

VIRTUAL PLAY AS EXPLAINED BY A FAMILY SUPPORT WORKER

Enabling children to have fun has been crucial while families have stayed at home to shield. For children who are unwell, or for siblings whose home lives are dominated by their brother or sister's medical needs, having dedicated time to play with a trusted adult is vital. Using toys or puppets, or getting messy with paint, is relaxing and enjoyable, but also makes a child feel valued and worthy of an adult's full attention.

> **"Every child is different, but most of them jump straight into the world of play."**

Before the COVID-19 pandemic, Family Support Worker Charlotte was using child-led play to support seriously ill children and their siblings. When the lockdown began, it was suddenly necessary to switch these sessions to video calls. Charlotte provided 13 families with this support, virtually playing each week with children between the ages of three and 14. She also had video calls with a non-verbal child who was in hospital, providing emotional support to the child's mother and talking to the child to reduce any feelings of isolation.

The sessions allowed parents to step away while their children were occupied and entertained, as well as offering an important outlet for seriously ill children and their siblings.

'Whilst enjoying playing together with a sibling of a little girl who is recovering from cancer, she unexpectedly said to me, "Charlotte, I would really like to talk to you about my feelings". Every child is different, but most of them jump straight into the world of play, and I will end up going wherever that takes us. I've been on a virtual pony trek (fashioning a pony from a stool!), pretended to be a Teenage Mutant Ninja Turtle, had a teddy bear's picnic and even hosted a birthday party for the Gruffalo!'

Freddie is five-years-old, and his older sister Freya has a very rare inherited metabolic condition. Playing virtually with Charlotte and a Gruffalo puppet has been particularly special.

Speaking in June, Freddie's mother Kelly said, *'Freddie was very surprised and excited to find an invitation and a party bag that had been dropped off on our doorstep. When Charlotte video-called that day, she hosted an amazing birthday party for the Gruffalo – which included playing musical statues, singing, even candles and cake!'*

'Freddie sees the Gruffalo as a friend. In lockdown, it's been quite difficult. We haven't been out in over 10 weeks to shield Freya, and of course this impacts on Freddie. Having the Gruffalo each week to look forward to has helped us all. It gives him someone else other than me to speak too, and he even recently said to me, "I know if I am sad, I can talk to the Gruffalo".'

Charlotte is continuing to provide a mix of virtual and face-to-face support depending on each family's circumstances.

ADAPTING END-OF-LIFE AND BEREAVEMENT SUPPORT DURING COVID-19

Rainbow Trust Family Support Workers swiftly adjusted their working practices at the start of lockdown to use new ways to provide support to families whose child was at the end-of-life, and to families who have been bereaved. Family Support Workers have no longer been able to be with families on hospital wards alongside a child in a critical condition or at the end of their life, but at times of great distress have been able to meet parents just outside the hospital for a socially-distanced walk together, providing much valued emotional support at an overwhelming time.

Families have been restricted in the activities they might have wished to carry out to mark their child's funeral or to remember them subsequently. During the tightest period of the lockdown a significant source of distress was the restriction on numbers attending funerals, which were initially as low as ten people, and required different households to sit apart. Families were also unable to have visitors to their home and funeral practices required by faith or expected within a particular culture could not always be carried out in their usual way.

Whether their child died before or during the national lockdown, bereaved parents and siblings have not been able to grieve as they might wish. Feelings of being isolated in their grief have intensified. The support that parents or siblings would usually receive from friends, family, professionals or schools was made impossible or was severely limited by social distancing measures and periods of lockdown, ruling out hugs from family and friends outside their household or support bubble.

HOW RAINBOW TRUST HAS PROVIDED SUPPORT

Rainbow Trust Family Support Workers have helped families to navigate their way through this added dimension to their loss, providing both emotional support and practical help. Regular phone calls with parents, virtual activities with bereaved siblings, and taking a socially-distanced walk outside to talk through their feelings, have all been valued by families during the pandemic.

In one example, Rainbow Trust has been supporting a father whose child died of cancer during the initial national lockdown. The father is deaf, and the bereavement has brought stress to relationships within the wider family. With his usual Family Support Worker on furlough leave, the father was unsure about receiving support from a different member of the Rainbow Trust team. However, a trusting relationship was gradually established with the new Family Support Worker, and this proved valuable when he was unexpectedly bereaved of his own mother just four weeks after his child had died. The Family Support Worker has provided emotional support, and helped the father to access funding to help pay for his son's headstone. The Family Support Worker is in touch at least once a week, and sometimes more, and has dropped round activity packs for the family's other child.

In another example, a Family Support Worker offered bereavement support to a single parent whose two-year-old son died of Acute Myeloid Leukemia in January 2019. The mother is in poor physical health. Initially she was wary about receiving support from a different member of the team, but she gradually found it comforting to speak by telephone with a new Family Support Worker. She wanted to talk over the gruelling treatment that her son underwent, but she also shared happier memories of her child. At the same time, the Family Support Worker has got to know the mother's teenage daughter, who has shared how difficult lockdown was without the chance to spend time with friends, as well as caring for her mother. Emotional support for the family has been provided in a weekly phone call lasting around half an hour, and will continue for the foreseeable future.

One Family Support Worker was able to visit a grave on behalf of a family who now live abroad. Jasmine died on Christmas Eve 2019, aged five, after unsuccessful treatment for a neuroblastoma (a type of cancer). Their Family Support Worker had been a trusted companion during their child's illness, and the family were hugely comforted that while COVID-19 prevented them from visiting their daughter's grave, the Family Support Worker was able to take flowers to the cemetery, paint a stone and play music of special meaning to the family.

Tania, Jasmine's mother, wrote in an email, '*I can't begin to tell you how much all of this means to us and touches our hearts… It means the world to us that someone we love and trust has been there when we cannot. Thank you so much for sharing everything.*'

SIGNPOSTING SUPPORT

As well as emotional support, signposting families to sources of bereavement support, financial aid and memory-making activities, can help families cope better both with the practical demands of arranging a funeral and the emotional demands of adjusting to their child's death.

In one example, on behalf of the parents, a Family Support Worker collected the impression of the footprints of a baby who had died. Family Support Workers have made families aware of the government's Children's Funeral Fund, for example, and relevant charitable funds, as well as the potential to pay other funeral expenses with payment plans which are often not well publicised by funeral directors.

EXAMPLE OF BEREAVEMENT SUPPORT DURING LOCKDOWN

For one family, the day of the national lockdown, 23 March, had particular significance. It was the day of their three-year-old son's funeral. He had died after unsuccessful treatment for a genetic condition. At short notice, the number of people allowed to attend the funeral was severely restricted, and grieving relatives from different households were unable to hug each other and show support as would be normal. Wanting to show their sympathy, the local Rainbow Trust team each lit a candle in their own homes. A photo was then shared with the family showing how people had marked the child's funeral in this way, even though they could not attend in person.

Rainbow Trust's support continued during the lockdown, with phone calls to the grieving family, and activity packs dropped off for the child's seven-year-old twin sisters. The mother has been struggling with her grief while also caring for her toddler and daughters without the usual help that grandparents would be able to provide.

Since lockdown measures have eased, the mother has been meeting up with her Family Support Worker for a walk on the coast nearby. She has said that being able to talk about her loss is helpful because she feels that she makes other people sad when she expresses her grief, even in her own family. The lockdown was helpful, she says, as she did not have to make excuses not to see friends and family.

Alongside this, Rainbow Trust's practical help has reduced the day-to-day demands on this parent, such as walking the toddler in a park while the mother and twin daughters attended an appointment.

CONCLUSION

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.

Before the pandemic began, families frequently said that they felt overlooked. Some expressed a hope that, as a result of the situation, the rest of society might finally understand a little of the anxiety, uncertainty and social isolation that can accompany a child's life threatening or terminal illness. However, those hopes have begun to fade as other parts of society have sought to resume aspects of more normal behaviour. For many families, the sense of crisis continues.

Our report shows that delays to treatment, restrictions on visiting or accompanying a baby or child to hospital, the practical challenges entailed by shielding, and the isolation and anxiety experienced by all family members, have taken their toll. For those bereaved of a child, the distress has been multiplied.

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 nimbly 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.

By regularly reflecting on these new ways of working, and identifying learnings to share across our teams, our flexible emotional and practical support has been provided to as many families as possible within the constraints posed by COVID-19. 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.

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 support 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.

ENDNOTES

1 *Make Every Child Count: Estimating current and future prevalence of children and young people with life-limiting conditions in the United Kingdom*, Fraser, L., Gibson-Smith, D., Jarvis, S., Norman, P. , Parslow, R., published by The True Colours Trust/ Together for Short Lives, April 2020. **www.togetherforshortlives.org.uk/wp-content/uploads/2020/04/Prevalence-reportFinal_28_04_2020.pdf**

2 See for example, *NHS performance summary: July – August 2020*, Nuffield Trust, 10/9/20. **www.nuffieldtrust.org.uk/news-item/nhs-performance-summary-july-august-2020**

3 *It's not a game: the very real costs of having a premature or sick baby*, Bliss, 2014. **https://www.bliss.org.uk/news/2014/parents-of-premature-and-sick-babies-face-crippling-costs**

4 The SHARE study is a collaboration between Together for Short Lives, Martin House Research Centre and the University of Southampton. News item on initial finding from 44 parents published in June 2020. **www.togetherforshortlives.org.uk/forgotten-families-families-feel-more-isolated-than-ever-under-lockdown/**

5 *"Coming second all the time": Life in lockdown for siblings of disabled children*, Sibs UK, June 2020. 876 parents responded. **www.sibs.org.uk/supporting-young-siblings/parents/how-has-lockdown-affected-your-sibling-child-children/**

6 Comment by Professor Simon Kenny, NHS National Clinical Director for Children and Young People, speaking during an online meeting of the All Party Parliamentary Group for Children on 16 July 2020.

RAINBOW TRUST
SUPPORTING FAMILIES
WITH A SERIOUSLY ILL CHILD

Anna, aged ten, has a visit from her Family Support Worker (credit: Drew Cox)

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Cassini Court
Randalls Way
Leatherhead
Surrey KT22 7TW

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