



RAINBOW TRUST CHILDREN'S CHARITY BRIEFING:

Isolation and loneliness amongst families who have a child with a life-threatening or terminal illness:

The impact on parents: finances, employment and support networks.

SUMMARY

- Parents and carers who manage to stay in paid work experience high levels of isolation and loneliness from their colleagues.
- Parents and carers who do not manage to stay in paid work experience a significant loss of income, which contributes to their isolation and loneliness.
- Parents and carers whose children are seriously ill experience high levels of isolation and loneliness amongst their inter-personal relationships, including with their partners/spouses, family and friends.
- The right support from employers and charities like Rainbow Trust makes a demonstrable difference to families' lives, avoiding the loss to the economy of skilled workers, as well as enhancing emotional and mental health.

INTRODUCTION

Being told that your child is so seriously ill that they might die is one of the most traumatic experiences a parent can go through. Rainbow Trust Children's Charity understands the devastating impact of this news, not just for the child but for the whole family. Dealing with everyday activities and supporting each other can be completely overwhelming both practically and emotionally.

The isolation and loneliness this causes for parents and for their children has not previously been addressed within the context of loneliness interventions, nor has there been a proportionate response from health, social care, employers and education to meaningfully support families in these circumstances.

On behalf of the families we support, we call on the Government to grasp this issue and address the recommendations we have outlined in this briefing.

“ People like [family support worker] and ... Rainbow Trust need a big pat on the back. ... Having this help has massively changed my feelings of isolation. Don't get me wrong, I still get down but I know I can pick up that phone and [family support worker] will listen. ”

THE ISSUES FOR PARENTS:

- A childhood illness with sudden onset or deterioration can be incredibly traumatic for parents with little or no time to prepare and seek support to mitigate the significant long-term challenges on their mental health, their relationships and work.
- Round-the-clock caring leaves few opportunities for respite. This can lead to relationships deteriorating, being strained or lost or, leading to increasing feelings of isolation and loneliness, during an already difficult time.
- In many cases, a child's treatment may need to begin immediately, meaning families have to uproot their lives to centre around in-patient care, in some cases, many miles away from home.
- Balancing work alongside the care of a seriously ill child is challenging. Parents and carers may feel they have no option but to take annual leave or sick days, taking unpaid leave, or give up work entirely to attend and stay in hospital or care for their sick child at home.

OUR FINDINGS

Isolation at work:

We surveyed parents and found:

- those in work show high levels of isolation and loneliness. Our workplaces are part of our wider networks and part of how we stay socially connected, which is why it is so important that workplaces make better offers of support so that parents feel less isolated. Working where we feel valued, included and supported is good for us.

Our survey found that:



of parents felt
“very isolated”, or
“extremely isolated”,
at work.



of working
respondents said their
colleagues don't know
what to say to them

Rainbow Trust recommends to employers that they:

- make an enhanced offer of pastoral support to employees who are going through difficult and unpredictable circumstances.
- continue to provide support from an employee's line manager and HR, which will always be important.
- introduce a buddy role, where appropriate, so that the employee can informally stay in touch with what's going on at work when forcibly absent because of their child's illness.
- signpost to areas of support such as trusted local charities like Rainbow Trust, and an Employee Assistance Programme.

The impact of work on finances:

Our findings show:

high rates of those leaving
the workplace as a result of
the needs of their sick child,
with a resulting detrimental
impact on family finances.



45% of parents had
had to leave paid employment
to meet the needs associated
with having a seriously ill child.

“I took leave
without pay.”

“I have been sacked from
two jobs due to my son's
needs. I have also left two jobs
due to his needs.”

“I cannot go back
to work because
my child needs too
much attention.”

Rainbow Trust recommends to employers that they:

- go beyond the statutory minimum requirements in legislation such as the Employment Relations (Flexible Working) Act (2023) and the Carer's Leave Act (2023), where they can.
- follow those leading employers who are already offering enhanced flexible working and enhanced carers' leave (paid and unpaid). Rainbow Trust has introduced a "Random Working" policy, to help where standard flexible working policies are insufficient for parents with a seriously ill child. Our employees in exceptional circumstances can vary their work location and hours of work, enabling them to still contribute and earn.

If more employers could offer enhanced flexible working and carers' leave, this would avoid the loss to the economy from experienced, skilled and talented workers who need to leave work or reduce their hours. The cost for employers in hiring and training new employees, and the cost to the Exchequer of higher benefit claims, is potentially avoidable.

Loss of social networks:

Parents caring for their sick child routinely experience feeling a loss of control and being powerless. Isolation from existing social networks can be a major determinant to their health, as it impacts both mental and physical wellbeing, at a time when parents are experiencing strong emotions, such as sadness, anger, loneliness and grief.

Our findings show:

68% of parents of seriously ill children felt isolated within their relationship with their partner or spouse,

with **32%** feeling very or extremely isolated

95% of parents felt isolated from their extended family

62% of parents felt very or extremely isolated from friends

“ Relationship with my husband broke up during my child's treatment. **”**

“ People just don't understand the constant hospital appointments, the stress and the worry of 'what ifs' all the time. **”**

“ My family don't understand the impact my daughter's health has on me, my friends don't understand unless they are friends in a similar boat, I've had to stop working to care for my daughter. **”**

“ People sometimes don't know how to support you or what to say. People find it hard to manage their own feelings. They can break away when you need them most. That was the hardest thing. **”**

“ I didn't talk to anyone because it was just [my son] and I in the room. The nurses come in to give him the chemotherapy so we chat for a few minutes. That's how terrible it is. I cannot talk to [my son], he wouldn't understand. I don't want to show that to my son so I kept myself happy all the time. [Talking about the family's Rainbow Trust support worker] We chat about different things, not just about [my son]. Sometimes, when you are dealing with sickness you don't want to talk about it all of the time because it's sad. **”**

OUR POLICY RECOMMENDATIONS

The Department of Business and Trade should:

- **encourage employers to help employees stay connected to work, and signpost to emotional and practical support.**

Encouraging employers to make an enhanced offer of pastoral and signposting support to employees who are going through difficult and unpredictable circumstances would be a useful start.

- **encourage employers to make an enhanced offer of flexible working and carers' leave to employees with a seriously ill child.**

Encouraging employers, where they can, to go beyond the statutory minimum of new rights for employees to work flexibly and take unpaid carer's leave would help.

- **extend Carer's Leave and make it paid leave.**

While the Carer's Leave Act (2023) is welcome, it only provides up to five days' unpaid leave, which many families can go through quickly. In addition, the loss of pay is another financial impact on families.

The Government, through the Department for Work and Pensions, should make a financial offer of support for parents in these circumstances.

- The sudden illness of a child is not predictable, many families cannot afford to save, or are self-employed, and even among parents who can afford to save, savings dwindle quickly.
- Many families are not eligible for benefits, and where they are, they are not at adequate levels for income replacement.

The Government should ensure that there are appropriate levels of funding for local authorities and the NHS, no matter the commissioning mechanism.

This will mean that that families can access short breaks, children's palliative and end of life care, and appropriate mental health support, including in bereavement.

Integrated Care Boards must recognise that children's palliative and end of life care goes beyond building-based care, and commission fairly, so that all local providers, including charities, can benefit.

The Department for Culture, Media and Sport should consider targeting parents of seriously ill children in their campaigns to reduce loneliness, signposting to support, as well as encouraging the public and employers to connect more.

This is because people in this demographic are at higher risk of feeling lonely compared to other parents and will be less likely to find advice and support.

SOLUTIONS AND CONCLUSION

- Rainbow Trust believe that some of the solutions to the issues parents face can be easily implemented, as outlined in our policy recommendations above. Some of our recommendations do require a more comprehensive solution, but are, nevertheless, achievable by the government, and we are ready to offer our support to them, local authorities and the local NHS to enable this to happen.
- The good news is that the right support can make a difference to parents, including in employment and staying in further education. Commissioning support that focuses on reducing parents' isolation and their ability to stay in work, would pay dividends.

Almost
1 in 10 employed parents
supported by Rainbow Trust said we
enabled them to work.

65% of parents said
that the most important aspect
of support that Rainbow Trust
provided was someone to talk to

“ Rainbow Trust enabled me to complete my degree. I would be lost without their support. ”

- In conclusion, a child's ill health is a profound challenge that significantly impacts the finances, emotional and psychological well-being of families, including isolation. The right support systems at home and in work can play a huge part in alleviating this isolation, and by working together with government, councils and the NHS, Rainbow Trust can make a truly tangible difference in the lives of these parents.
- Our policy recommendations are deliberately targeted across a range of government departments and structures, so that parents' needs can be addressed holistically. While some of what we advocate for is increased funding for family support, both financial and practical, introducing peer support at work, and more effective support from employers would also help.
- By implementing these recommendations, we can create a more supportive environment that not only addresses the immediate challenges faced by parents during their child's serious ill health, but also contributes to long-term familial resilience and financial wellbeing. It is our hope that these efforts will lead to a society where no parent of a seriously ill child feels alone in their journey or financially disadvantaged, and that every family can access the support they need to navigate these difficult times.

ABOUT RAINBOW TRUST CHILDREN'S CHARITY

- Rainbow Trust Children's Charity is a UK charity who has been pioneering a holistic approach to children's palliative care for nearly 40 years. We provide tailored practical and emotional support for families caring for a child who has been diagnosed with a life-threatening or terminal illness. Last year, Rainbow Trust supported over 1,200 families.
- The type of care Rainbow Trust provides, social palliative care, is unique. We match families with a Family Support Worker, who provide a wide variety of emotional and practical support to parents, the unwell child, siblings and the wider family. Our support extends into bereavement.
- Rainbow Trust provides support to families across the UK. We support families physically via our face-to-face services in nine areas of England (Essex, Greater Manchester, Lancashire & South Cumbria, Liverpool, London & the South East, North East, Southampton, South West, and Thames Valley,) as well as digitally via our Online Support Team.
- Rainbow Trust receives no central Government funding, and despite providing palliative and end of life care and support, we are not widely commissioned by local authorities and the NHS as part of local end of life commissioning. We are proud of our record and would love to be able to support more families at diagnosis and beyond with the unique care and support we provide.

Methodology:

- In 2023, Rainbow Trust conducted a small survey of parents we supported, and this briefing is based on their voices.
- While our research was based on a small sample size, the findings still provide invaluable insights into parents' experiences and views.

FOR MORE INFORMATION:

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