



“It saved our marriage and kept our family together”

A national study of the impact on parental relationships of short breaks provided by children's hospices

About children's hospices in the UK

There are over 40,000 children and young people with life-threatening or life-limiting illnesses within the UK. Fifty-one children's hospices offer palliative care to them and their families.

The services offered by children's hospices include short breaks – in a hospice or at home – whole family support, specialist therapies, advice and information, end of life and bereavement care.

The UK is a world leader in children's and young people's palliative care, yet the sector relies heavily on charities. State support is especially limited for children and young people, compared to adult palliative care.

“There are over 40,000 children and young people with life-threatening or life-limiting illnesses within the UK”



“Seventeen children’s hospices from across England and Scotland took part in the research”



About the study

This national study examined the impact that caring for a life-limited or life-threatened child has on parental relationships. Its focus was on the effect that short breaks provided by children’s hospices have on parents’ relationships.

Seventeen children’s hospices from across England and Scotland took part in the research, which was conducted by Ashley Mitchell of Bournemouth University in partnership with Julia’s House, the Dorset and Wiltshire children’s hospice charity.



Summary



Caring for life-limited and life-threatened children puts pressure on relationships and, unsupported, some parents' relationships do not survive repeated emotional and physical strain. The unrelenting, exhausting cycle of care means couples can end up leading separate lives:

“We stopped having time for each other. He became the breadwinner and I became the carer”

And this division can extend to the whole family:

“The family operates in two halves: mother with siblings and father with affected child”

Most parents in this study rated short breaks provided by children's hospices as having a direct, positive effect on their

relationship with a partner, giving them rare time together as a couple. Others used short breaks to spend time with their other children or just enjoyed time to themselves, regaining some balance in their lives, ultimately benefitting the whole family.

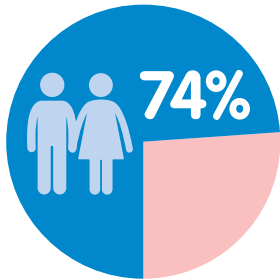
This research found that 64% of divorced or separated parents cited having a child with complex needs as a reason for the breakdown of their relationship. Of those couples, 75% had no access to short breaks at that time.

Couples in empirically measured non-distressed relationships received on average 43% more hours of short breaks from a children's hospice than those in distressed relationships.

The study provides evidence to support the need for an immediate review of Government policy in order to reduce the emotional burden on families, as this frequently leads to parental break-up – and potential economic cost. Family disintegration through divorce or separation becomes an expensive burden on the State. Short breaks provided by children's hospices should form part of a preventative policy solution.

What the study revealed

The results represent one of the few analyses of the relationship needs of parents caring for a life-limited child and provide evidence to demonstrate the benefit to families of hospice services and short breaks in reducing parental breakup.



74% of parents who responded to the question rated the short breaks as having a positive impact on their relationship with a spouse or partner. The remaining 26% mostly used the short breaks to spend time with other children in their family.

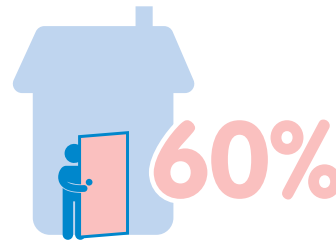


Couples who received more short breaks were more satisfied with their relationships.

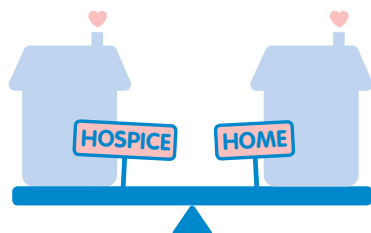
Caring for a life-limited or life-threatened child is physically and emotionally demanding, with parents balancing work with caring for the child (and siblings). Short breaks can allow parents and siblings time out from caring duties, allowing more time to themselves.



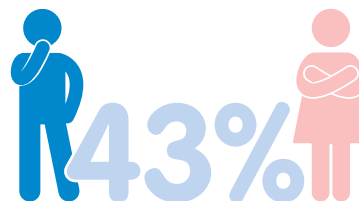
89% did not get support from a family member and only 3% received help from friends. Support for families from relatives and friends is generally insufficient and limited by the complex care needs of their children; parents can feel isolated and unsupported.



60% of parents did not receive short breaks from Social Care; much of the pressure on partner relationships is unseen and unknown by outsiders. There was no significant difference in relationship satisfaction between those that did and did not receive Social Care support.



The benefit to families of hospice care short breaks was the same whether they were provided in a hospice building or in the family home.



43% of couples caring for a life-limited child said they led separate lives with an adverse impact on their relationship.



63% of families had financial difficulties which significantly impacted on relationship satisfaction.



To enable parents to build trust with children's hospice staff, short breaks need to be consistent, and provided by educated and trained staff.

The study also looked at divorced and separated couples:

16% of respondents indicated that caring for a life-limited or life-threatened child was the main reason for the breakdown of their relationship whilst a further 48% said that it was a contributory

factor. With **75% of separated parents not receiving short breaks when their relationship broke down**, there is scope for increasing the level of support to maintain the wellbeing of the family.

How the research was conducted

The research included interviews and an online survey with single parents and couples caring for children and young people with life-limiting or life-threatening conditions who had access to one or more children's hospices. It concentrated on real-life situations, families and their dynamics.

Care was taken to ensure there was a reasonable balance of family and hospice types and location for the interviews. Face-to face interview topics covered the following areas:

- ♥ **The impact of short breaks on relationships between parents**
- ♥ **The level of care provided by parents**
- ♥ **How it feels to be the parent of a life-limited child**
- ♥ **The strain of caring on relationships**
- ♥ **Differences between home and hospice-based short breaks**

The study also included an online survey of 126 parents using short breaks. A widely-used empirical measurement of relationship satisfaction was applied. The research was conducted with the approval of the NHS Research Ethics Committee to protect the privacy of the participants and to ensure they provided their informed consent.

“It has a massive positive impact. It gives us time to spend together, but also time to spend on our individual interests which keeps us sane”





“The Government should urgently consider increasing short breaks support for parents of a child with a life-limiting or life-threatening condition”



Actions and future work

The study is a first step in demonstrating how the benefits of children's hospice care and short breaks can support parents' relationships. Frequent short breaks provided by professionals helps reduce distress between parents, enabling families to stay together. The Government should urgently consider increasing short breaks support for parents of a child with a life-limiting or life-threatening condition as a designated and strategic priority.

A further study will analyse the economic benefits of short breaks provided by children's hospices by measuring increased family wellbeing against the cost savings to Social Care and the NHS mental health budget.

“The hospice became invaluable, not only to our daughter, but also to our relationship. Respite played a vital part in keeping our family from falling apart at the seams”





Acknowledgements

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Pictures in this report are for illustrative purposes only. The families featured are supported by Julia's House but were not part of this study.



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