



Preventing suicide among parent carers

Executive summary

The first UK study of suicide risk in parents caring for children with disabilities (and long-term illnesses) has found that while caring for a disabled child:

- 41% of parents had thought about killing themselves
- 8% of parents had made a plan to kill themselves
- 2.5% had attempted to kill themselves

Of those who experienced suicidal thoughts and behaviours while caring:

- Two-thirds had thought about killing themselves in the last 12 months
- One-third had made a plan to kill themselves in the last 12 months

More than 50% of parent carers who had thought about or attempted suicide had never told anyone about these experiences.

Fear, judgement, and stigma were the main barriers to disclosure, particularly the fear of having their child removed.

Policy recommendations

1. **Carers must be prioritised in the national suicide prevention strategy**, to ensure resources are directed toward improving data collection on deaths by suicide and providing tailored support for carers contemplating suicide (see more on these below). The strategy currently acknowledges carers only in their capacity as a source of support for other people at risk of suicide, not as **an at-risk group in their own right**.

2. Tackling the high rates of suicidal ideation in unpaid carers must be identified as a **priority area in a national carer strategy**.
3. Suicidal and homicidal thoughts and behaviours should be **routinely assessed in Carers Assessments and in primary care**. There is currently no routine screening of suicidal or homicidal ideation in unpaid carers.
4. Parent carers who are contemplating suicide must be provided with **emergency respite care and urgent psychological support**. They must not be subject to *unnecessary* safeguarding, *inappropriate* child removal, or *unreasonable* prosecution.
5. **Caring status must be included in the demographic characteristics collected when a death by suicide occurs**. The number of deaths by suicide in unpaid carers should then be regularly collated and published by the Office for National Statistics. Although this study provides clear evidence of suicidal thoughts and attempts, there is currently no routinely collected data on deaths by suicide in unpaid carers.

Call for more funding

6. More funding must be allocated to ensure that support for disabled children is:
 - Proactive (not reactive)
 - Timely
 - Appropriate
 - Affordable
 - Provided by dedicated multi-agency teams, comprising health, social care, and education professionals.

7. More funding must be allocated to ensure that all parent carers can access:
- Timely, appropriate, affordable, and regular **respite care**
 - Timely, appropriate, and affordable **mental health support**
 - Opportunities to **safely relinquish care**.

About the research

A growing body of research has identified unpaid carers as a high-risk group for suicide. Only a handful of studies, however, have focused on parent carers and none of those were conducted in the UK. The results of the current study are ground-breaking and should raise serious concerns about the needs and experiences of parent carers in the UK.

A survey was conducted between 2021 and 2022. People in England who were caring for a child under 18 with a long-term illness or disability were invited to participate. 750 parent carers completed the survey, with 18 of those taking part in follow-up interviews. A wide range of illnesses and disabilities were represented, including cerebral palsy, Down's syndrome, autism, rare genetic conditions, ME/CFS, cancer, developmental delays, and epilepsy. More than 25% of participants had multiple caring roles (that is, they were caring for more than one disabled child or caring for another ill or disabled family member).

Findings

Key risk factors for suicidal thoughts and behaviours in parent carers included: depression; feeling trapped in the caring role; using dysfunctional coping strategies; and having a mental health diagnosis prior to becoming a carer.

Although current and previous mental health problems are a risk factor for suicidal thoughts in parent carers, **more than half** of the parent carers who reported suicidal thoughts and behaviours while caring **had not received a**

mental health diagnosis prior to caring and more than one-third did not have a current long-term physical or mental illness. This indicates clearly that psychiatric and psychological therapies will not be enough to reduce suicide risk in parent carers. Instead, **an holistic, multi-agency approach must be taken**, ensuring that children with disabilities and their families are supported at every stage of their journey by an interconnected network of health, social care, and education professionals who have undertaken carer-specific suicide prevention training.

Although love for their child prevented many parent carers from acting on suicidal thoughts, **the inability to act increased their distress.** In some cases, it also led to thoughts **homicide-suicide (i.e. killing their child and then killing themselves)**. Interview participants also noted that, if circumstances worsened, love would no longer be enough to prevent them from acting on suicidal thoughts.

The study was funded by an NIHR Research for Social Care Grant and led by Associate Professor Siobhan O'Dwyer (University of Birmingham). Four parent carers were co-investigators on the project.

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More information

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