

Research reveal eating disorder burden weighs on parents

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With eating disorders on the rise among young people, a Flinders University expert is calling for an urgent increase in support for parents as new research reveals the immense burden they often endure.

Dr. Simon Wilksch, a Senior Research Fellow at Flinders University and Clinic Director of Advanced Psychology Services, conducted an Australia-wide survey of [parents](#) whose child (under 18 years old) experienced an eating disorder. The findings are now published in a special report in the *International Journal of Eating Disorders*.

"While extensive research reveals the devastating toll of eating disorders on the young person, it has been far less common to investigate the burden on parents. This is a significant gap, given that the leading treatment for pediatric eating disorders heavily involves parents," says Dr. Wilksch, a credentialed eating disorder clinician.

"However, the parent role extends beyond active treatment to also include first identifying signs of the illness; initial help seeking with a GP; pursuing referral to treatment services; and, navigating physical and psychological health challenges in their child.

"This occurs whilst managing other roles including parenting other children, relationships, work and finances."

In total, 439 parents completed the survey, 91% of them were female. Key findings included parents:

- Were the first person to notice the eating disorder (ED) symptoms in 81.8% of cases
- Had only a 14.7% chance of a helpful experience for their child with both the first general practitioner and first therapist they saw
- Needed to see an average of 3.55 therapists before finding one that could help their child
- Reported worse than normal psychological health (96.0%), [physical health](#) (70.5%), and [romantic relationship](#) (92.7%)
- Required an average of 70.06 days leave from work to care for

their child (per household)

- Need to access treatment in the [private sector](#) (91.8%) at very high rates, with only 8% reporting their child received full treatment in the public sector
- The median out-of-pocket treatment expenses were between \$10,000 and \$20,000. However, the survey was completed prior to the increase in the number of eligible Medicare rebated sessions for eating disorder patients.

Parent responses indicated that 81.9% of the children were diagnosed with anorexia nervosa. The average duration of illness was four years with 96.8% of parents reporting their child was diagnosed with additional psychiatric conditions, including suicidal behaviors (23.8%); and non-suicidal self-injury (29.3%), while over two thirds (67.9%) had been hospitalized for their ED.

Only 18.3% of parents endorsed that their child was recovered, 67.3% reported their child still had an ED, while 14.5% were unsure. Weight loss and food restriction were the most common first signs of the child's illness, followed by changes in mood and personality.

Nearly a quarter (23.8%) of parents reported the ED symptoms started at age 12 years or younger and the mean age of onset was 13.91 years, consistent with other studies.

Dr. Wilksch says this Australian research clearly shows the need for an increased focus on supporting initial symptom detection; improving primary care and treatment experiences; and, increasing the number of skilled ED treatment providers.

"Clinicians and researchers need to urgently look at further ways to support parents and reduce the immense toll they can face.

"If parents can have more helpful experiences with the first GP and therapist they see, this is likely to lead to both a quicker recovery for the child and less distress for the parents.

"Efforts to maintain and improve parent well-being are not only helpful for parents but also vital for their child's recovery."

While the burden of the illness on parents was high, there were some encouraging findings:

- Nearly half of parents (48.8%) had received at least one session of their own support
- These parents were significantly less depressed and anxious than parents who hadn't received their own support
- 88.6% of parents rated the eventual therapist they worked with as Helpful, including 68.2% who said the therapists was either "Extremely" or "Very" Helpful.

Parents of recovered children had significantly better ratings of physical health, psychological health, romantic relationships, and much lower rates of depressive and anxiety symptoms indicating there are numerous improvements for parents post-recovery.

"Parents who receive their own support during their child's treatment experience less distress. This needs to be more readily available during their child's treatment. It would be especially helpful if Medicare items were created for parent-only sessions to make this accessible.

"With access to timely, effective health care and treatment, people can and do recover from an eating disorder. These findings indicate that parent well-being improves significantly after their child recovers."

Dr. Wilksch adds, "Parents are the greatest resource we have in helping

[young people](#) with an [eating disorder](#). We must listen to their experiences, work together, and do more to support them."

More information: Simon M. Wilksch, Toward a more comprehensive understanding and support of parents with a child experiencing an eating disorder, *International Journal of Eating Disorders* (2023). [DOI: 10.1002/eat.23938](https://doi.org/10.1002/eat.23938)

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