

Raising the Alarm: Carers Need Care Too

"This is the hardest thing I have ever done or faced."



Butterfly
Foundation for Eating Disorders

MAYDAYS
FOR EATING DISORDERS

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EXECUTIVE SUMMARY

The aim of this research was to provide a broad and nuanced understanding of the experience of carers caring for someone with an eating disorder. The report serves to broaden understanding of the impacts of being a carer, and also what types of support carers need. It also aims to inform the type of support Butterfly advocates for, on behalf of carers, to lessen the burdens of caring on the carer.

The intense and what appears to be long-lasting negative impacts of the caring, for many of the carers, suggests that there is a crucial need to also put resources into supporting carers so that they receive the self-care that they need in order to fulfil their roles as carers.

“It is a very isolating illness and most people don’t understand its complexities.”

METHODOLOGY

A mixed-methods approach using both qualitative and quantitative approaches was employed. This included:

- A survey comprised of both closed and open ended questions – 468 participants completed an anonymous online survey targeted at carers of individuals experiencing eating disorders. The survey contained 18 questions focused on exploring the carer’s role, access to support systems and the impact of caring on the quality of their lives.
- Qualitative semi-structured phone interviews – a purposive sample of 13 participants who were carers of individuals who had/have experienced eating disorders.

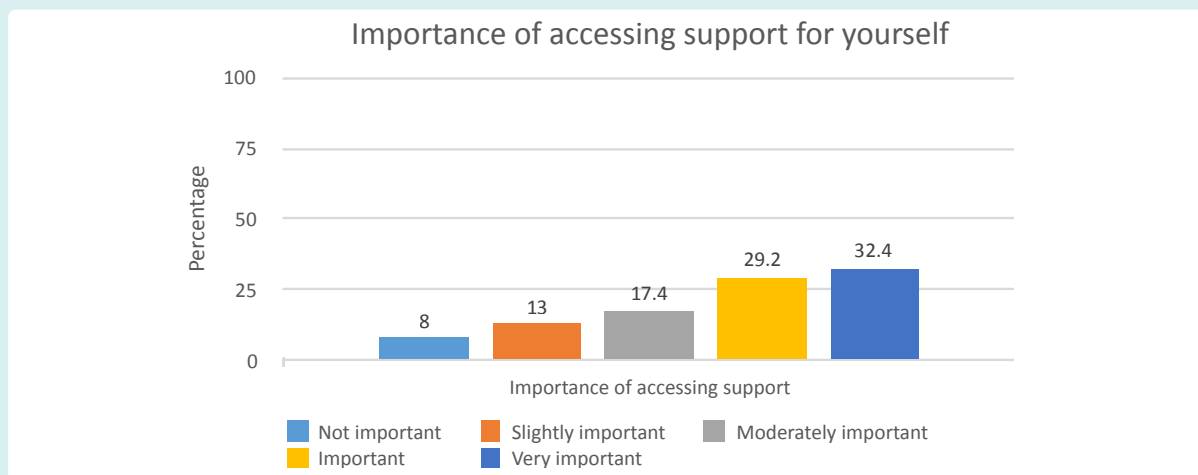
“It affects our family psychologically. . . . Carers to long term eating disorder sufferers are rarely given any thought at all. We need psychological support and respite.”

FINDINGS

Quantitative Findings (Survey)

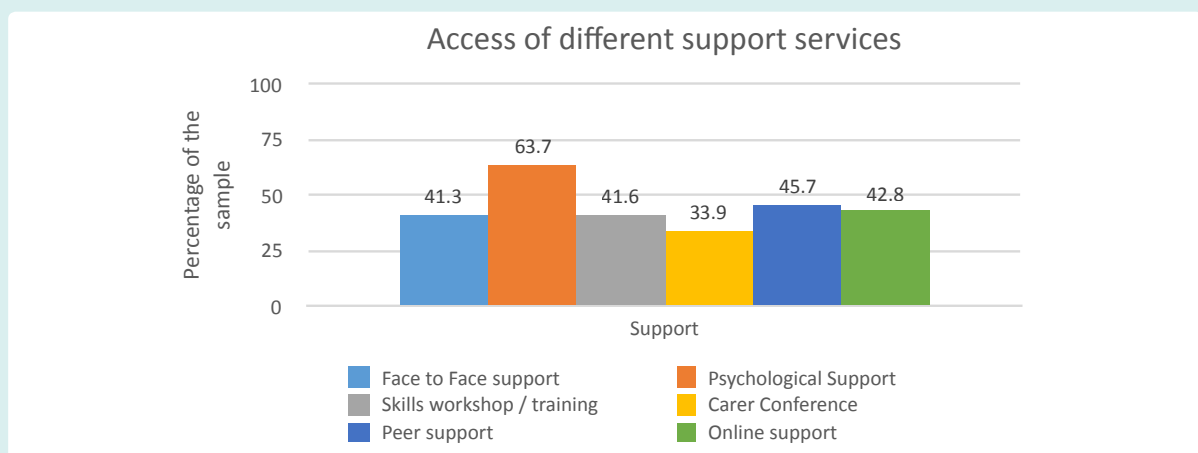
Support for the carer

The majority of carers who completed this survey recognised the importance of a carer also having to access support for themselves, with over 60% of respondents rating it as 'important' or 'very important' to access support for themselves.



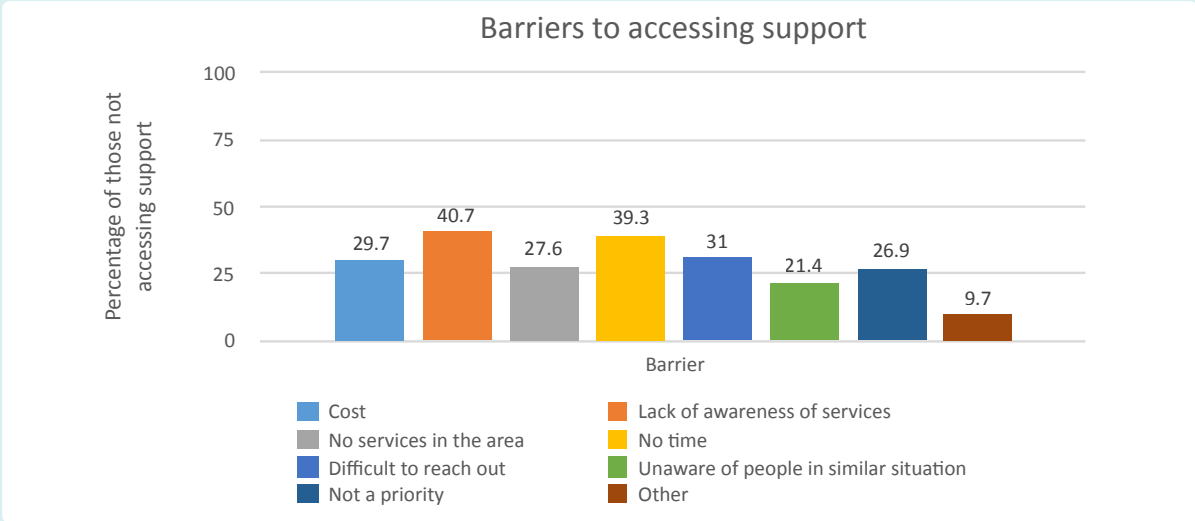
The types of care and level of satisfaction

Of those who reported having accessed help, psychological support (64%) was the most frequently accessed.



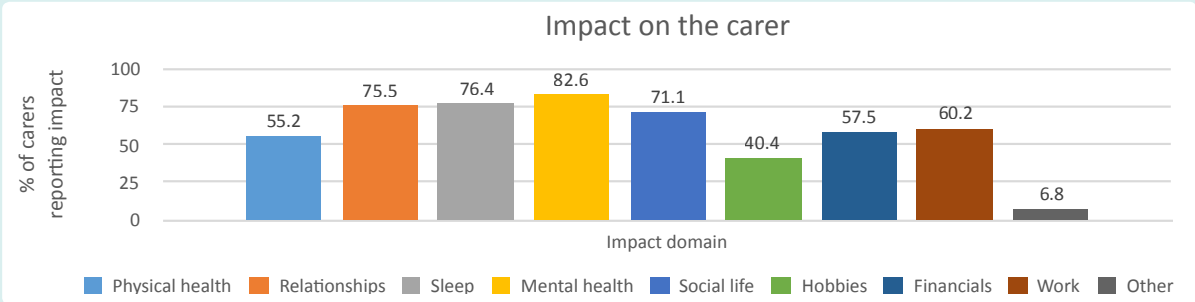
Barriers to accessing support services

The 145 respondents who had not accessed a service were asked to nominate different barriers that may have prevented their access. The two main barriers were lack of awareness of services (41%) and lack of time (39%).



Impact on carers

The four areas which have the greatest impact are mental health (83%), sleep (76%), relationships (76%) and social life (71%).

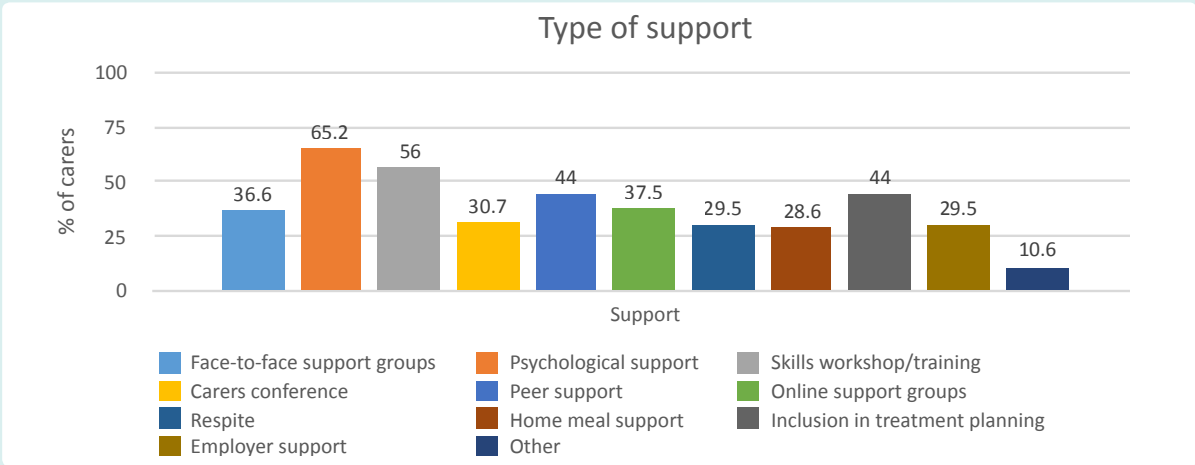



How well equipped did they feel to support their loved one?

Only 18% of carers felt they were equipped to a 'great extent' to support their loved one. The vast majority felt 'somewhat' equipped (60%). Concerningly, 16% felt 'very little' equipped and 6% felt 'not at all' equipped.

What kind of support would help you in your role as carer?

In the role of carer, the majority of people felt that psychological help (65%) and skills training/workshops (56%) would help them in their role as carer.



A photograph of a man and a woman, likely a carer and a care recipient, looking directly at the camera. The man is in the foreground, and the woman is slightly behind him to the right. The image has a blue tint. The text is overlaid on the left side of the image.

78%
of carers
have given up work or
study due to the level
of support needed.

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Qualitative Findings (Interviews)

1. THE PERSON WITH THE EATING DISORDER

Carer experiences of getting help

The carers had mixed experiences with the healthcare system with some relaying that they felt totally failed by it; others experiencing a mixture of good and bad care; and others receiving very good care.

“I’m drowning, feel helpless, powerless and lost, and have no idea how or where to get help, and feel unable to ask, because when I have sought help, my concerns and distress are dismissed.”

Prior experience of eating disorders

Most of the carers did not have prior knowledge about eating disorders. One carer had experienced an eating disorder himself and another had a relative who had experienced one.

“No, we knew nothing. So, it was a bit of a shock. A bit of a shock. Yeah, a really scary experience actually.”

Changing roles of the carer

Carers spoke about their changing roles as carers according to both the geographical proximity of the person with an eating disorder, the age of the person and the stage of the illness. Some of the parent carers played less of a role as their children grew older.

“Provide support from a distance as we live interstate. Our daughter requires support over the phone sometimes during meals, at night, emergency hospital admissions.”

Balancing individual’s rights with carers need for knowledge

Another issue that was raised in the interviews was that once the person that was being cared for was over eighteen, the carers did not have access to information about their children’s medical sessions. This made it more difficult to care for their loved one.

“We had to bribe our daughter to find out what was happening – like she could use the car if she kept us informed. How can we help if it’s secretive? It’s upsetting and distressing.”

Stigma

Participants also spoke about the stigma around eating disorders. This stigma seemed to exist particularly if the person with the eating disorder was male due to the stereotype that eating disorders are only experienced by females.

“I think so, more so with a male because it’s a female oriented condition. I’m not macho but to say my son had anorexia – to say it was embarrassing is harsh, but it’s the word that I would use.”

2. SUPPORT FOR THE CARERS

Accessing support

There were numerous reasons that respondents provided for not seeking formal and informal support. Reasons included not knowing that support was available, perceiving support to be inadequate/irrelevant and finding that the support was inaccessible.

“I live regionally where there are no support systems in place for carers. Online forums are too difficult to find and access is usually paid or is too difficult to navigate using a phone.”

Prioritising the person experiencing the eating disorder

Many of the carers deprioritised getting support for themselves with several of the carers having not accessed any support. Some said that they did not get support because they believed that they needed to prioritise the person they were caring for and put all available resources into facilitating this.

“I tend to feel that it’s a little self-indulgent to worry about myself.”

Family and friends

Most turned to their families and friends. Friends appeared to either be a great source of support or completely unsupportive. Some were judgemental and offered unsolicited advice. For other carers, they did not have the time available to invest in their friendships and lost friends along the way.

“I spoke to friends mainly. I did not seek professional advice. At the time, I did not know much about eating disorders. It was the first time I had come across it so I didn’t even know there were avenues to help.”

Experiences of connecting with other carers

Some people did talk to people with lived experience and found this helpful. The notion of needing to maintain hope came up a number of times during the interviews with some carers indicating that they had/would have liked to talk to people who had cared for people who have ‘recovered’ from eating disorders in order to give them hope.

“It would be nice to be able to talk to people who had gone through it, know how to deal with it. It wasn’t meant to be heavy handed, we just didn’t want him to do damage. We didn’t know of any place with other carers.”

Validation

Carers spoke of feeling validated and like they were not alone as a result of connection with others who were sharing similar experiences. Feeling validated and ‘not alone’ was raised by participants who would have liked to connect with other carers.

“It’s so important. Support for carers. It’s valuable to learn that other people are in your position. You don’t get that validation otherwise.”



Almost 64%
of carers
feel they need
psychological help
themselves, but often
don't seek help.

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Support in an ideal world

Respite

Multiple carers spoke about the importance of respite.

“During the darkest times, I would really have appreciated respite care, being able to talk openly in the community about her diagnosis – she felt terribly stigmatised, and we felt judged negatively.”

Talking to people who are carers for people who have recovered – HOPE

A few participants mentioned wanting to be given a sense of hope through connecting with others who had cared for individuals who were now recovered as a type of support that they would value.

“The value of peer support is so great. I would’ve gone to group support groups if I knew about them. Just to see that recovery is possible. I would’ve liked that support where hope could’ve been instilled in me.”

Financial support

“Financial support to access psychological and workshop/training; mental health care plan rebates only cover a small proportion of the overall cost of services (which are long term in nature).”

3. IMPACTS OF CARING ON THE CARER

“I have said things to people that were completely inappropriate because I was completely, I don’t know where I was... They don’t speak to me anymore now but that is fine. I was just in a terrible place. There is no other disease where you are expected to treat your child. Where it is just this constant grind of day after day after day. You are spending so much money on them. You are then, I can’t really justify spending money on another psychologist.”

Mental and physical health

Carers relayed how caring for their loved one who was experiencing an eating disorder had profound impacts on both their physical and mental health. They spoke about experiencing depression, stress, no sense of control and increased anxiety. Carers spoke about having to subjugate looking after their own physical health to looking after the person they were caring for.

“Issues with my own mental health have become more apparent and acute as my daughter’s eating disorder is heading closer to recovery. I feel that the sustained levels of stress and anxiety over the years in which she was most unwell are now having an effect, despite the relief, hope and joy of seeing recovery as a reality.”

Depression and suicidal ideation

“I got really low. I had a tree near my home. When I drove past it I would say, ‘Not today. I still have my husband and my 4 kids, not today.’ When I went to the psychologist, and they asked whether I was suicidal I’d tell her about my tree, and how I’d say to the tree ‘not today’. And she asked what if you didn’t have ‘not today’. I told her I’d probably hit it.”

Stress

"It was stressful and it built up. I was an easy-going person but now I've become, not a harder person, but I have to monitor these things. It's 9 years later and I'm stressed more easily. I'm noticing it a lot more."

Anxiety

"I was highly anxious during that time. It has stayed with me, that time. I was anxious. I would wake up in the middle of the night terrified that I was going to lose my sister."

Short tempered

"You also become fairly short tempered. I mean you get cross with the eating disorder but you end up getting cross with the person suffering too. Instead you become pretty impatient and pretty stressed and so I think those are probably the main things."

No sense of control

"You're always worrying about them, wanting to do the best you can for them. This stuff, you can't take a hammer and nails and repair it. You feel somewhat useless. It's a situation you can't control. We don't have the skills."

Impact on family/relationships

One of the most negative and the biggest impacts on the carers was on their family relationships and relationships among family members. For some, once the person was 'recovered', having been through the experience with that person – made their relationships even stronger. Carers spoke of their relationships with partners deteriorating due to stress and a lack of time together. They spoke of heightened and frequent conflict between family members and having to "walk on egg shells around the person".


"It impacted on the whole family actually – that is my husband and my son because everyone felt like they had to be walking on egg shells. It took a great toll on all of us – they all felt like they couldn't say anything to her and that it would be taken the wrong way. It was very hard for a very long time."

Some of the carers felt like they were being pushed away by the person they cared for and others were concerned about not being able to focus enough on their other children. Some spoke of losing friendships.

"There is a strong social isolation. I'm a very social person and for the last 4 years we've had little headspace or time to reach out to friends. Because it is very exhausting."

Financial and career impacts

Being a carer impacted financially as a result of both having to afford medical treatment and also as some of the carers gave up their jobs. It impacted on the working life of some of the participants and another spoke of having to give up her career. One of the carers spoke of his partner who he was caring for having to give up work as a result of her eating disorder. Another respondent mentioned that she had to sell her house.



**83% of
respondents**

**have highlighted the impact
on their mental health;
physical sleep (76%);
relationships (75%);
and social life (71%).**

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“Quit my high paying corporate role, sold my house as I’m the only parent to my daughter. This has been financially crippling after working so hard for 30 years.”

4. ADVICE FOR CARERS – WHAT THEY WISHED THEY KNEW EARLIER

Look after yourself

Carers spoke of the importance of self-care, getting professional help, disclosing to others and of maintaining relationships, hobbies and outlets. It is important for the person being cared for to see that their carer is being supported.

“You tend to think: I can fix this. And that is the thing that will almost break you. You have to be the toughest that you have ever been in your entire life. So you need to look after yourself. You must look after yourself. If you break, no one else is going to do it.”

It is not them – it is the eating disorder

Advice that came up over and over again was the importance of separating the person from their eating disorder. Not taking any negative behaviour directed towards you personally but rather being aware that it is part of their illness.

“You have just got to be really strong and realise that a lot of the things they do, all things that they do are the eating disorder and not them. So, when they are screaming out at you and saying horrible things, you can’t take offence to it. You have to be strong and stand up and know that it is the eating disorder. You really have to get a good idea of what mental illness is about.”

Giving hope is very important

Carers spoke about the value of peer support, particularly the importance of having a sense of hope and believing that your relationship with the person that you are caring for will get better.

“You need to know that they can get better and that you will have a better relationship at the end. So, you can carry on. People need to hear that. The hope. Other carers yes – but people who have recovered.”

“We do want to talk about it but we never have the opportunity to do that. All the focus is on the person with the illness, which I get. But helping us is important too.”

DISCUSSION AND CONCLUSION

While many of the carers' experiences were unique, there were also shared understandings and emotions and many of the carers wanted to connect with other carers. For those that had, many gained benefits from doing so, including feeling validated, 'not alone' and able to share advice.

A number of carers had not accessed support due to a lack of awareness about where to access support, a lack of time and finances, feeling like they did not need it, prioritising the care of the person experiencing the eating disorder, stigma, privacy and not wanting to undermine the trust of the person they were caring for.

Yet the findings illuminate the severe and far-reaching impacts of caring on the lives of many carers. This included negative impacts on their relationships particularly on family relationships; having to de-prioritise other children; severe impacts on their own mental and physical health; and impacts on their finances and careers, including study. For many carers, the experience of caring has changed their lives irrevocably and highlights the need for adequate and tailored support services for carers.

“Living with a loved one that has an eating disorder affects so much of life. It steals so much joy from us.”

thebutterflyfoundation.org.au



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Foundation for Eating Disorders

MAYDAYS
FOR EATING DISORDERS

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NEED SUPPORT NOW?

Contact the Butterfly National Helpline on 1800 334673 or thebutterflyfoundation.org.au,
8am - midnight (AEST), 7 days.