

# “It’s been a journey, and hell”

## The impact of eating disorders on parents, siblings and partners



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July 2019

### Abstract

Families and other carers can play an important role in their loved one’s recovery from an eating disorder, yet they commonly report not being empowered to provide this support. This is despite the NICE guidelines for eating disorders (1) presenting a series of recommendations for carer involvement. Application of these recommendations can help minimise distress among carers, reduce feelings of isolation and improve treatment outcomes (2).

Eleven interviews with carers of someone with an existing or previous eating disorder were undertaken in order to explore the impact of the illness on the carer.

Results suggest that more must be done to ensure that carers get adequate support from NHS services, as outlined in the NICE recommendations (1). Carers’ inability to access support is leading to heightened levels of carer distress and isolation, which is likely to impact upon the wellbeing of both the carer and the sufferer. Additional areas of improvement regarding carer empowerment were also established from the interviews, thus demonstrating the need for eating disorder services to do more to support families and carers.

### Introduction

The NICE guidelines for eating disorders (1) aim to improve the care of children, young people and adults with eating disorders. Recommendations acknowledge the crucial role that carers can play in a loved one’s recovery and highlight the importance of supporting carers throughout a loved one’s period of treatment. They outline practical measures that the service should be taking to empower the carer, including the provision of information about the nature of the eating disorder and the impact it is likely to have on the carer, as well as the need to assess the carer’s own wellbeing as treatment progresses.

This research sets out to explore carers’ experiences of interacting with their eating disorder services during their loved one’s diagnosis and treatment. Carer responses are summarised and compared with the NICE recommendations.

### Methodology

In-depth investigator-based interviews were carried out via telephone with 11 carers of people who currently have or previously have had an eating disorder. The interview was designed to explore the impact of the illness on those caring for someone with an eating disorder, and the way in which carers were involved by the eating

disorder service and empowered to support their loved one. Each interview was intended to be no longer than 40 minutes. A semi-structured interview approach was used, allowing the interviewer to be flexible in their phrasing of questions.

The interviews were recorded and transcribed, before being analysed using thematic analysis as described by Braun and Clarke (3).

### Findings

When considering the impact of an eating disorder on those caring for someone with the illness, and the ways in which carers were involved by the eating disorder service and empowered to support their loved one, five main themes were identified:

- Overwhelming feelings of distress, hopelessness and exhaustion experienced by carers
- The importance of the provision of information and support by services
- The importance of good communication between the service and the carer
- The need for carers to challenge professionals to ensure their loved one receives evidence-based treatment
- The difficulties faced when a loved one experiences a transition across services

In the following analysis, a pseudonym to distinguish the interviewees has been included to distinguish their quotes from each other.

Interviewee (Pseudonym)	Gender	Relationship to sufferer
Ava	Female	Mother
Emma	Female	Mother
Sofia	Female	Mother
Chloe	Female	Sister
Robert	Male	Father
Victoria	Female	Mother
Hannah	Female	Mother
Natalie	Female	Mother
Joe	Male	Father
Ellie	Female	Mother
Mia	Female	Partner

### Overwhelming feelings of distress, hopelessness and exhaustion experienced by carers

Every carer interviewed discussed the overwhelming emotional distress that caring for someone with an eating disorder resulted in. Many described the exhaustion they felt when supporting their loved one, and the feelings of isolation:

*"We get no respite, whatsoever... I've been on pretty much, 24/7 duty, looking after her for the last four or five years, really. We have had no respite from that, whatsoever and there's nothing."* (Sofia)

*"Well, that has been quite horrendous, really because not having been in that situation before, both of us were really falling apart."* (Victoria)

*"And of course that's the hard thing when you realise that do you know what, there is nothing you can do. It's really, really tough for a parent."* (Natalie)

*"It's been a journey, and hell."* (Ava)

Five carers described needing to seek external support for themselves due to this emotional distress and the lack of support offered to them from the eating disorder service:

*"I organised myself some counselling because I at the time... I just felt like I hadn't got the strength to support the rest of my family."* (Ellie)

*"... the biggest thing that helped me was I found a charitable organisation... I used to go to their carers groups once a week and that was the thing that saved me"* (Natalie)

Often this distress was also linked to fear, with carers commonly reporting feeling scared for their loved one's life and helpless in knowing how to support them:

*"We were so scared that we were going to lose her... Her behaviour was shocking at that point. And she was screaming and ripping at her arms. And it was just horrendous"* (Emma)

*"We had a lot of very, very scary meltdowns where she would just completely lose control, threaten to kill herself, whack herself in the face, whack her head against the wall. Completely lose it."* (Sofia)

*"We could have lost him twice... It's been quite traumatic, yes."* (Victoria)

Feelings of frustration were also described. Often this frustrating was in relation to waiting for treatment, but carers also reported their anger at the illness. Multiple carers discussed feeling ill-equipped to deal with these emotions:

*"So there was a lot of waiting and a lot of frustration... I think we were both quite strained"* (Mia)

*"...it can be very frustrating and we are not saying we're angels. We've both lost our rag with him"* (Victoria)

The negative impact of the eating disorder on the sufferer's siblings was also highlighted, and concern that siblings were being overlooked due to the illness reported. This often resulted in carers reporting feeling guilty for not being able to be there for the sibling as much as they felt they would like to be:

*"And it's just like it's destroying the whole family. It's like the other two, our other two kids, they're older, and they can hardly come home ..."* (Emma)

*"Yes, it has a big effect on [the sufferer's sister], because we have to leave her. I know she is 19 but we have to leave her on her own every weekend at home and she has to fend for herself."* (Joe)

The sister of someone with an eating disorder also described her feelings of guilt at not being more able to do more to help her sister and her parents, and her desire to talk to someone about this:

*"Because we had been also closely involved, I felt because I'd left [to go to University], I wasn't helping. So more of a guilt in that sense. I wanted to talk to somebody about it."* (Chloe)

### The importance of the provision of information and support by services

Many carers described the lack of information they had received from their loved one's eating disorder service, and how unprepared this left them feeling:

*“So, we were never given any information on anything. Nothing. Nothing explaining, nothing saying what they were going to do, nothing explaining the idea of treatment or anything.” (Sofia)*

*“I mean, when she first had her major meltdowns and pretty much, psychotic episodes, which were scary, I had no idea that that was something that happened with an eating disorder because there was no information given.” (Sofia)*

*“I think more information [would have made things better] to be honest... We were told “[Your loved one] is anorexic, that’s her diagnosis... we weren’t told anything about the actual eating disorder itself, nothing about the other mental-health issues that come along with it, like the depression, OCD, or that sort of thing.” (Chloe)*

*“He was given a lot of leaflets. But not really anything about the treatment, I didn’t see any of that side of it.” (Mia)*

One carer suggested that a booklet explaining what to expect when your loved one is diagnosed would have been useful:

*“I do think the one thing that eating disorders services should do is they should have a booklet or a pamphlet or something that is pretty comprehensive that you give to parents, to just try and understand what you’re dealing with because otherwise, you are completely at sea.” (Sofia)*

The question was raised over a potential difference between how carers of children and young people are empowered, compared to those supporting adults, with one carer questioning whether this lack of information was due to her daughter being an adult:

*“I don’t remember being given any information in [my loved one’s] care, I mean she was in her 20s and I perhaps wouldn’t have been because she’s an adult. But there were definitely times when I would have appreciated the support network.” (Ellie)*

The majority of carers also raised feeling unsupported by the eating disorder service with little or no support being offered, even when they asked for it:

*“And there’s just so little support out there that we just feel like we have to do it all ourselves” (Emma)*

*“And there were no support mechanisms. I asked for help.” (Natalie)*

*“... there’s never really anything for siblings of people with eating disorders, it’s always parents of people with eating disorders.” (Chloe)*

Where carers were able to seek support, either from the eating disorder service or externally, peer support

was described as a helpful resource. Carers reported how useful talking to other carers was, and the relief in hearing that they weren’t alone in their experiences:

*“I mean, I’ve been in a couple of support groups... You gather far more and the other thing is just using a lot of resources on the internet.” (Sofia)*

*“They did have a carer’s meeting that we went to every month at [name of location] and that opened our eyes a little bit because we thought we were the only ones who that was happening to and we found out that that was the norm” (Victoria)*

## The importance of good communication between the service and the carer

Carers often reported the lack of communication they received from the service, and how unhelpful this was when supporting their loved one. They often felt helpless due to this lack of information, and like they were less equipped in their role as a carer:

*“It would have been better if they’d told us [her snacks were increasing] and then we would have at least understood why she was behaving like that.” (Ava)*

*“So, I thought, that’s ludicrous because he was in a bad way again and I was leaving messages and nobody was getting in touch with me because he’s an adult.” (Victoria)*

*“The least helpful was when she went to the eating disorder clinic at [place name]. Because were so misled... it was just not handled very well at all.” (Joe)*

A few carers did have a positive experience of communication from services and carer involvement in treatment. This emphasises how valuable empowering carers with knowledge is, and the importance of collaborative working:

*“So after every visit we speak to the main nurse and give feedback about how the weekend has gone. So we’re quite involved I think in that respect... And I think there’s been a good communication between ourselves and the hospital. So I think that, for me, has been the best bit of the process.” (Emma)*

*“I would say we were engaged, the family were engaged, but, you know, we weren’t told to get out of the room, and it wasn’t just about him, it was about all of us.” (Robert)*

*“[Name of clinician] will ring and she will text her. She has been excellent and I think we’ve been extremely lucky to get one of the people that is very good.” (Sofia)*

## The need for carers to challenge professionals to ensure their loved one receives evidence-based treatment

Seven carers described having to challenge professionals in order to ensure that their loved one received evidence-based treatment, or more intensive treatment when this was being withheld and the carer was concerned about their loved one's safety:

*"And I was horrified. So I phoned up the home team and said, what the hell is going on? Why haven't you referred my daughter back to the inpatients?... I also got my MP involved and complained about the service." (Emma)*

*"So, a lot of it is the luck of which professional you see and also if you've got the support who doesn't mind shouting a bit because I think sadly if you shout you get helped more than if you don't shout." (Ava)*

*"And I got in touch and I made it clear that, as far as I am concerned somebody needs to see my son asap. I said "I cannot wait."" (Robert)*

*"So, we came home and then, at 10 o'clock the next day, they told me they were going to discharge him. I thought, no. We've spent enough time doing this... This isn't going to happen any longer. I said, you discharge him and I will go to the top." (Victoria)*

## The difficulties faced when a loved one experiences a transition across services

Transitions, for example from Children and Adolescent Mental Health Services to adult services or when moving location, were often described by carers to be difficult and to put the sufferer at risk:

*"Her discharge was appalling, absolutely appalling. They put nothing in place for her when she was leaving. They didn't send her a discharge plan... So she was discharged home with nothing in place whatsoever. And she's becoming very ill again" (Natalie)*

*"...it must be very common for students to then move home again or for people at home to go to University, I wish that there was some sort of passport that had meant she could have continued with therapy rather than that 6 months in the middle without any during which she just spiralled down." (Ellie)*

Upcoming transitions from inpatient treatment were described to be a cause for concern for carers, as they

often worried what would happen once their loved one was out of treatment:

*"I can see how terrifying it for my parents at the moment because they know that when she comes home they have to be with her 24/7 kind of thing. And the amount of stress and strain that put on all the relationships in the house last time was ridiculous. So it's a very tense atmosphere most of the time" (Chloe)*

*"But it's just like we're feeling really worried about her coming home. Because, obviously, we want her home. But there's just this fear of, oh my God, if it happens again. And it's just like it's destroying the whole family." (Emma)*

One carer reported that her daughter had been on a waiting list to receive help for Children and Adolescent Mental Health Services, yet prior to her 18<sup>th</sup> birthday the service called to move her to the adult waiting list. Her daughter declined this help, therefore receiving no treatment for her eating disorder:

*"[CAMHS] rang me... I think it wasn't a coincidence that she was coming up to her 18th birthday ... basically what they were saying was you're now being passed over to adult services." (Hannah)*

## Discussion

The relatives and carers interviewed for this study reported experiences which vary considerably from the recommendations of good practice included in the NICE guidelines (1).

The reported absence of NICE-concordant care includes not being offered an assessment of their own needs, not being provided with support for those needs, and not being given information on topics such as the nature of eating disorders and treatment options. There is some evidence that appropriate support and information is less likely to be received by carers of adults.

Similarly, the NICE recommendations that, when appropriate, family members and carers should be involved in treatment and that an individual's care plan should be developed in collaboration with the family and carers appear not to be routinely followed.

Carers also reported not being involved in their loved one's transition from inpatient treatment to community treatment, despite recommendations to that effect in both the NICE guidelines and the Royal College of Psychiatrists' guidance for good practice (4).

## Conclusion

Although we recognise that the carers we interviewed are only a small subset of those supporting someone with an eating disorder, their accounts suggest that it is common for eating disorder services to overlook the rights and needs of carers, so exacerbating the significant distress and isolation they endure.

The experiences described here emphasise the importance of empowering carers to play the fullest role possible in the care of their loved ones. Eating disorder services should recognise the advantages of this – to the patient, the carer and the service – and take responsibility to ensure carers receive the support recommended by NICE and have avenues to express their views, be listened to and have any concerns taken seriously.

## References

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