

## **Things I want to say to other carers of kids with eating disorders.**

This is not your fault.

It is hard for people to 'get' it. But there are other people out there who do. We really, really do.

People will try to help but might say things which seem downright unhelpful, or blaming, or simplistic. I'm sure they don't mean to. Lots of people don't really know much about eating disorders, and unfortunately that includes lots of doctors. (I am a doctor myself).

Your child will act as if they are not the child you know. Over and over I have heard people say that it is as if their child is possessed. That exact word. This is especially when you ask your child to do something that might make them better. For example, to stop exercising or eat more. So if it looks like your child has suddenly become possessed, you're probably doing something that will make them better. This is a cruel and counterintuitive illness.

No one tells you properly about the misery that the child feels. I didn't see my child smile for months. Later on someone explained it to me that to my child it is as if they are being constantly and endlessly tortured: they wanted me to take over, but at the same time were punishing me for doing so. They felt punished all the time if they tried to take the steps necessary to stay alive. An impossible situation, and an impossible situation to understand as an outsider.

I have heard more than one carer describe this as the hardest thing that they had ever been through, that included one person whose wife had died several weeks before. So be kind with yourself if you lose it. We all lose it sometimes. In my house, crockery was smashed (and I mean by \*me\*) and on at least one occasion I tried to run away. I didn't get very far as I had to make the next meal. All of this reinforces the feeling of shame, the feeling of failing at the thing you want most to succeed at.

Mostly I find it hard to remember all of it as it is a bit of a blur, and it was so hard I think I have blocked it out. You too will look back and think 'well that is a bit of a blur' as your child eats an almond croissant. We are not there yet but my child ate an almond croissant yesterday. She isn't quite there yet but there was a time when I couldn't have imagined that scenario.

Be compassionate with yourself. Find support where you can. Facebook is surprisingly helpful with thousands of carers out there who just want to share what they know. There is something about this shared trauma which brings carers together. Also listen to Eva Musby's podcasts. They also got me through.

There are lots of problems which aren't yet resolved. You may well need to take time off work. Part of this may be sick leave as you may well experience anxiety and depression. If your GP suggests you should take sick leave – then take it! Also you may have grown up, like me, unsure about your own body. We live in a society which glorifies the underweight.

There is lots else.

It does get better. It is slow, but it does.

This is NOT your fault.



*Photograph by Katharine Lazenby, taken whilst an inpatient in 2014 receiving treatment for anorexia.*

### **Things I want to say to health care professionals**

Thank you for listening to me and looking after my child. I am drowning and you are helping me keep my head above water.

I know it is so hard. I also work in the NHS and I really do know this. I am 'on your side'.

I am also terrified, and lost, and I cry when you ask me questions. I am tired because this monster has taken over my child and keeps screaming and crying; they have taken over her voice and her words and they look through her eyes which are dull and distant.

I want to know whether you have a child but I know this is not fair or right. I desperately want you to tell me what to do but also am worried you don't know what to do. I am worried my child will die. There seems no solution. She just won't eat. She said to me 'I don't care if I die - at least then I won't have to eat and I will be happy'. I want to kill this monster. My heart is breaking; it is broken.

Please tell them that I know what I am doing. My child throws my apparent incompetence in my face and says that I know nothing, that you are the expert and not me – and you are not there to say that yes, they \*do\* need to eat the rest of that sandwich.

It is so tiring, and endless, and sometimes I feel as if I am going mad. Sometimes I think I \*am\* going mad. I have lost my former identity and am now 'mum of x' – I am the mother of a child whose life I might not be able to save, who won't do the most basic thing I need to ask them to do, to stay alive. Ever since this child was born, my life has been focussed on keeping them alive, on making sure they eat enough. And now the very reason I exist, to keep my child alive, is taken away from me. It is very shaming to have a child who does not eat. It is very lonely.

Please be aware that your parents need each other, can help each other. We are being tossed in this storm together and we cling tightly, and with love. This is an illness which is about food, which is about love.

Thank you for all you do, and I am sorry if I ask too much. I think you are wonderful - I might not always show it, but I do.

Carer, Tower Hamlets