

Carer to carer: tips and advice

Becoming a carer

Recognise that you are a carer; until you do you won't recognise the importance and difficulty of what you're doing, and you can't get help that may be available to you, whether financial, work or health related. You don't have to be a parent to be a carer; you might be a partner or friend or another supportive person in your loved one's life.

Others may not understand the enormity of what you are dealing with. This isn't surprising, you probably didn't know much about eating disorders before you embarked on this journey. They are complex mental health disorders and most people don't understand the difficulties until they experience it first-hand. Try to help family members and other key people to better understand, and if you can, attend classes and groups together. Be a team. Also recognise that some people will never understand, and it will be better to keep those people at arm's length.

Acknowledge that this is not an easy ride and equip yourself as best you can. Learn about eating disorders, engage with the help that is available to you and be flexible during the journey. Eating disorders can morph, change, and develop, as do the treatments on offer and the person themselves. Eating disorders are not generally short illnesses, and if the person you are supporting is a teenager or young adult then they are already in the middle of monumental growth, so inevitably they will change during the course of this journey as well.

Join eating disorder support groups and skill up (my recommendations include EDSUK on Facebook, BEAT resources and training courses, Jenny Langley's training courses and resources at the New Maudsley Carers, Eva Musby's website, FEAST's insightful "First 30 Days" daily newsletter). Take what you can from the help and resources available. You may not agree with everything, but there is huge value in learning from, and talking, to others, especially your peers. It's so helpful to know that you are not alone, that it's really tough and that we are all learning and doing our best.

Your loved one

Try to understand and empathise with your loved one's situation. They didn't choose to have an eating disorder and they feel powerless to overcome it. Part of them may feel like they want to continue to do this thing that makes them feel safer in the world and they can't see the terrible impact it is having on their health, or they see it as a price worth paying. It serves them in some way.

If the healthy side and the eating disorder side of your loved one are in direct conflict, then they are in the midst of a very frightening battle and they need your support to get through it. Many eating disorder sufferers also experience "anosognosia" (common in many mental health conditions), which means that they literally don't know or believe they are ill. They are convinced they are fine and cannot understand why people

around them are concerned. This must be such a difficult place to be – “*why are my parents trying to make me get treatment for something I don’t have?*”

Adjust your thinking if you’re caring for a young adult. Your loved one is maturing and developing their independence at the same time as battling a serious mental health condition. Their independence may be key to their recovery and as a young adult they need to be helped to take ownership of the illness and their own recovery from it. This can be hard as a parent or carer, when you have been used to stepping in and solving issues, especially of a sick child. It’s worth reading up on co-dependency, to understand a little about your role in your loved one’s recovery and whether intense daily intervention is actually helping them as they grow up. Depriving them of their chance to grow might actually make things worse, so when the time is right, trust them and let them lead the way, all the while having their back. Ask “what can I do to help?” instead of saying “I think you need to do this”.

Help your loved one to remember life beyond the eating disorder; what they were like before and what life can be like again. Young people struggle to understand that difficulties they are having will pass; help them to understand that and reassure them that they are still loved. Always. Try to do things together that are non-eating disorder related and if your loved one lives away from home don’t make every phonecall about eating and illness; they are not their eating disorder.



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

Working with healthcare professionals

Engage with your loved one’s caregivers and medical team, provided you have their permission (if they are an adult) to do so. It may not be easy; there is a certain reluctance to avoid engaging with carers, even with permission in place, but when your loved one is so ill they may need you to advocate for them, ask questions and to speak up on their behalf, keep an eye on treatment plans and push for the help they need. Work with the treatment team and encourage them to work with you. Ultimately, they want your loved one to be well again, just as you do. Find out what resources exist in your area to treat the person you are caring for. Do not be afraid to ask questions – knowledge is power.

Understand that many healthcare staff are not highly trained, if at all, in eating disorders, including many GPs. They are also under huge pressure. They want to

help, but they may not be equipped to do so and may also be stressed by the lack of suitable help they can offer. Push for support for your loved ones, from specialist staff and units and work with the care team as much as possible. There is no simple one-size-fits-all 'cure' for an eating disorder unfortunately, and there is a lot more research to be done into these complex conditions, so treatments are developing and changing all the time, albeit slowly. If you are unhappy with care provided or not provided, it is your right to complain, to try and get better care for your loved one. You will also be helping those who come behind you if you speak up when things go wrong. On the other hand, don't beat yourself up if you can't. You are human and we all have limits.

Know that eating disorders should not be assessed on weight loss or gain. It is perfectly possible to have an eating disorder and be a 'healthy' weight. Recovery should be about "state not weight". Weight restoration is important of course, but it's also about restoring good mental health and brain health. This takes time.

Be ready for an emergency. If the person you are supporting is seriously sick you may need to take them to A&E. Have a printed copy of the MARSIPAN guidelines to take to the hospital and ensure that staff carry out the full range of tests. If you feel that you can't keep your loved one safe then you need to say so, loud and clear, and the hospital have a duty of care to respond.

Self-care

Look after yourself as best you can. This is not an easy thing to go through (to put it mildly), in fact it will probably be one of the hardest things you ever do, and you need to have the resources to keep going through the tough times. When things are just too much, ask for help. Speak to your GP, find out what local resources there are to support you, speak to trusted friends and family and however difficult it may seem, find time for yourself. Guard that time fiercely, it will help you, your loved one and other close people impacted by the condition such as siblings. Everyone will be in better shape.

Trust your own judgement. You know your loved one well; if you're their parent or partner you probably know them better than anyone else, so don't be afraid to trust your instincts and to speak out when necessary.

Know that it's okay to be scared, overwhelmed and lost. We have all felt these feelings. Often. This is an enormous challenge to face and it's not one you wanted or expected. It can be truly shocking, but like emotions in other situations, this feeling will eventually pass. Take yourself out of the immediate situation if you can, catch your breath and be kind to yourself.

Remember that it is NOT YOUR FAULT. You did not cause this. It may take a while to untangle the cause or that may never become clear, but **it isn't your fault.** Holding onto guilt is supremely unhelpful as it can make you ill and it also stops you from helping your loved one. Let go of the guilt; you have done your best and you will continue to do so, what you need to focus on is how to support your loved one.

Focus on the good things around you and the little pleasures; see the good and really acknowledge it. We tend to focus on the negative generally, and when things

are hard that can be overwhelming. It's so important to try and balance that with good things, however tiny they may be. Treasure them.

Recognise that you will make mistakes and you won't always be able to be calm and supportive in a storm. It's okay, you're human. An eating disorder can make the patient behave very destructively; deceit is common, tempers fly and your loved one might well blame you for it all. This is the eating disorder speaking. Deep down your loved one is sick and needs you. Just do your best and try to see them as separate from their eating disorder. Don't take it personally. I have seen many letters written by recovering or extremely sick eating disorder patients, thanking their parents for sticking close when things were really bad, and acknowledging the pain they've caused. At the time they couldn't help it and sometimes that very fight might be essential and a key part of their development and their journey to recovery.

Know that this is not a straightforward journey. The journey from point A when the illness begins, to point B where there is recovery, is convoluted and messy. There will be false dawns, cul-de-sacs and real lows, but try to hold on to the fact that with each of these experiences you are slowly moving towards point B. Sometimes things have to get worse before they get better and sometimes the lowest point can create positive change.

Hold onto hope ALWAYS. Many, many people do fully recover from their eating disorder and still more learn to live a full life despite their eating disorder. We hear most about the people who have not made it, the terrible tragedies that occur. These are heart-breaking and terrifying to hear, but they are not the norm. Hold onto hope and remember that just as in your own life, most things pass; things that seem terrible now will be tomorrow's history and things will most probably get better.



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

*"Hope" is the thing with feathers -
That perches in the soul -
And sings the tune without the words -
And never stops - at all -
- Emily Dickinson*

My own daughter is now in recovery. It feels such a joy to be able to write that. We aren't out of the woods yet and there have been times when we didn't know when, or if, things would ever improve, but amazingly they are. She is in her second term at uni and despite challenges in the first term, she went back this time more positive and

confident than I have seen for years. There isn't one single intervention that has enabled her recovery, but pieces have gradually fallen into place, and she is growing up. I think her eating disorder was a huge red flag; she needed serious help to navigate the world and now she is out there in it, enjoying life again, believing in herself more, trying hard to get her eating on track and slowly recognising that life is better without her eating disorder.

Clare, Tower Hamlets,
Parent to a twenty-one year old daughter who is in recovery from anorexia.