

Eating Disorders



can Leave you in pieces...

We know because we've been
through it, and have produced
some information that might help.

www.capsadvocacy.org

This booklet has been developed and produced by people with lived experience of a wide range of eating disorders. We hope that by sharing our stories and experiences we can address some fears and worries that may prevent people from speaking out or seeking help.

What are eating disorders?

Eating disorders are a range of conditions that can affect someone physically, psychologically and socially. They are serious mental illnesses and affect over 1.6 million people in the UK.

There are many types of eating disorders, not just Anorexia Nervosa and Bulimia Nervosa. It can involve overeating, e.g. Binge Eating Disorder and OSFED, Other Specified Feeding or Eating Disorder.

Eating disorders claim more lives than any other mental illness – one in five of the most seriously affected will die prematurely from the physical consequences or suicide.

What causes eating disorders?

There is no one cause of eating disorders; it is thought to be a range of influencing factors.

"An eating disorder is like a recipe and each person's ingredients will vary."

'My eating disorder provided me with a sense of achievement as sub-consciously I felt 'not good enough' and had very low-self esteem which came from being bullied as a teenager and having two very high achieving sisters. I was struggling with identity and making relationships- the eating disorder made me feel like I was in control, provided me with routine/purpose, relieved the subconscious unhappiness I was feeling.'

'The core of my difficulties stemmed from intense fear, self-hatred, insecurity and shame...not just how I looked or what I ate. Eating, restricting, and purging became a way of coping with these intense and overwhelming emotions; a way to channel my pain.'



'I was a little bit heavier than many of my peers when I was growing up, but had a stronger emotional attachment to food as a comfort. I was extremely sensitive, shy, self-conscious, fearful and anxious. I had high expectations of myself and never felt 'good enough' despite what anyone said to suggest otherwise. I feel this made me more susceptible to focusing on what I ate and what my body was like, especially when my sense of self was so distorted.'

Who do eating disorders affect?

Stereotypes about the 'types of people' who develop eating disorders are common (e.g. that only young females are affected). These stereotypes are harmful as they can increase the likelihood that eating disorders will go unnoticed in other people who don't fit the description. They can also make it less likely that these people will seek help. Anyone can develop an eating disorder, regardless of age, gender, sexuality or cultural or racial background.

'Health care services that actively promote the inclusion of LGBTI people and other minority groups are essential in helping to break down the barriers that often keep people from seeking help from health care services.'



'For your average red-blooded male to admit to what is seen as a 'female-only' problem is not easy. It isn't macho so you hide it. You put on an act. It isn't easy for a man to say at a dinner party, 'oh, by the way, I'm on a diet.' It just doesn't wash.'

I think I have an eating disorder. Where should I go for help?

There are lots of sources of information and support if you think you have an eating disorder. You might feel like you are alone and no-one will understand what you are going through, but there are places you can go and people who can help. Your GP is usually the best person to make initial contact with. A GP can let you know about local support services and make a referral for specialist treatment. This may seem scary and something you think you cannot do, but hopefully the information in this leaflet will help to address some of your fears and concerns. Remember – you don't have to do it alone. You can bring a friend or family member with you to an appointment if it would help.

'My GP was my first point of contact and referred me straight on to outpatient services. My GP was extremely kind, never judged me and was there to help.'

'I've had a good GP over the last year that has paid attention to physical and emotional health. It made a difference to me to know someone was checking if I was okay not only physically but emotionally. She was direct about how I was harming my body and the long term implications that might have, but she was also supportive and explained what help she could refer me to.'

What is specialist treatment like?

It is usually very difficult for people with eating disorders to get better on their own. It is important that you find professional help and support as soon as possible.

Your GP will play an important part in the first step of identifying your eating disorder. Sometimes a GP might refer you straight to an eating disorder specialist or they might want you to come back to see how you are. Please don't see this as a sign that you don't deserve treatment but persevere.

Your GP will look at your weight for your age and might monitor significant weight changes, ask about concerns you have over your weight or body shape, talk about eating disorder behaviours and might also take some blood for testing. Although it might seem daunting, try to be as open with the doctor about how you are feeling and the impact your eating difficulties are having on you.

If your GP thinks you might have an eating disorder they should refer you for an assessment and possible treatment by a person or a team with specialist eating disorder knowledge.

Recommended treatment for an eating disorder differs depending on your diagnosis.

'My treatment was very psychological based and included schema therapy, CBT (Cognitive Behavioural Therapy) and eight week mindfulness based cognitive therapy course. The treatment was in my own home so it was individual to my needs and the changes made were more sustainable.'



'I saw a CPN (Community Psychiatric Nurse) who was fantastic. I definitely feel that "talking therapy" worked best for me. It allowed me to deal with things from my past which were negatively affecting me – I actually underwent treatment for PTSD (Post Traumatic Stress Disorder). I feel by dealing with the things in my head, I was then able to make positive changes to my eating disorder.'

'I Learned to eat without the obsession and fear about its effect, over a long period of time through learning to allow myself to respect my body; beginning to feel I could manage without resorting to the familiarity and extreme acts of restricting, bingeing and purging to cope. This involved practising accepting the good parts about myself, sacrificing and changing patterns of behaviours, and allowing myself to be nice to my body; instead wanting the benefits of a healthier weight.'

I am not underweight, so am I not ill enough to have a problem?

Eating disorders are first and foremost about coping with emotions not weight and appearance. Most people living with eating disorders don't look like they have an eating disorder. Many people living with an eating disorder are considered under or over weight, but most people are regarded as being of a normal weight; in all shapes and sizes. Having a BMI (Body Mass Index) in the healthy range is hardly healthy though if you are compulsively exercising, purging or restricting to maintain this. Weight can be an indicator of an eating disorder, but it certainly isn't the only one or even the best one. The most important things to consider are:

- **How much time do you spend thinking about what you eat, exercise or your weight?**
- **Are you isolating yourself from others?**
- **Do you hate yourself and/or body?**

It's when the thoughts of food and dieting overtake the rest of your life that it becomes disordered, and that can happen at any weight.

'I think that's a big misconception about eating disorders; a lot of the time people think its just about wanting to look thin and about food, but really it's a way of coping with difficult emotions and negative feelings.'

'I always felt I wasn't thin enough or ill enough to have a problem or to be deserving of help and treatment. Later on, as I started to get better I realised that it was the eating disorder thoughts that were making me feel that I wasn't ill enough to have a problem, and I was able to accept that I did need and deserve help.'



'I struggled as much being underweight as when I was of a 'normal' weight because the underlying issues (the feelings, the thoughts and beliefs) were just as dominating. I also experienced, and continue to have, many physical problems when I appear to 'look' healthier.'

Can I get treatment for an eating disorder if I have another mental health condition?

For many, eating disorders occur together with other mental illnesses, for example, anxiety, depression, obsessive compulsive disorder, personality disorders and addictions.

Eating disorders are not simply about food after all.

Some of these conditions may influence the development of an eating disorder, and some may be the trigger of them.

Eating and co-occurring disorders can reinforce each other, creating a vicious cycle so it's important to address these issues too in the process of getting better.

It is important that a person can be treated as a individual and not just seen as a 'disorder or mental health problem.'

'My unhappiness about my body was more complicated than just feeling fat. I realised that my desire to be male was interlinked with my feelings about eating and food. Finding some sense of recovery from my well established eating disorder was only going to happen if I dealt with my gender identity. At the age of 30 I sought help from my GP, a gender specialist and a transgender peer support group. Transitioning from female to male allowed me to be the 'me' I always felt I should be. This changed for the better how I relate to myself and the world around me.'

'My first psychiatrist completely changed the subject when I mentioned the food stuff. Now I get told that my eating disorder is just part of my Borderline Personality Disorder. The medications I take for this cause an increase in appetite so at times I feel my only option is to continue to restrict food. It's only in the last two years or so that I've been able to connect feelings with food and have begun to understand the eating disorder for what it is.'



'Eating disorders can definitely increase the chances and, or severity of other mental health conditions, so it's absolutely essential to get help as early as possible. Getting better is a process which doesn't just focus on thoughts about feelings and behaviour towards eating and weight. Like many sufferers of mental health conditions you learn how to accept yourself as you are, deal with painful emotions, and begin to feel good about being you, comfortable in the world... without the drive to harshly control, or hurt yourself through food.'

I overeat/binge eat. Can I get help?

If you feel compelled to eat large quantities of food over a short period of time even when you're not hungry you may be suffering from binge eating disorder (BED) or emotional overeating. This is a serious mental illness where people feel a loss of control and overeat on a regular basis, often in secret.

Self-help is often the first suggestion for treatment. Your GP might recommend helpful websites, support groups, books or self-help workbooks to look at and get involved with.

If your binge eating is persistent, your GP may refer you to see a mental health specialist. The psychological treatment that may be recommended would likely be cognitive behavioural therapy (CBT), interpersonal psychotherapy (IPT) or dialectical behaviour therapy (DBT), but these would be discussed with you.

'My binge eating disorder started when I was around 8 years old. Coming from an area of high deprivation, food was an easy and quick way to both reward and console myself. In any heightened emotional state food was used to modulate the emotions. The more food I got, the more I wanted until it consumed my night and day.'



What are the physical complications of an eating disorder?

Eating disorders are serious, potentially life-threatening conditions that affect a person's emotional and physical health. They can be fatal, with many people dying through malnutrition, heart seizures, or prematurely, due to long-term damage. Our bodies can only take so much strain. Often they are not visible or present early on, but putting such strains on our bodies can cause irreversible damage. Your brain circuitry, heart, digestive system, teeth, and all of you are affected by the abuse of an eating disorder. That's why it's so important that you get help as soon as possible.

'My periods stopped which could have made me infertile. I was also at risk of osteoporosis. My life became about hiding the behaviours and lying about what I was doing...eating, not eating, bingeing, vomiting, purge purge purge. The same whistle stop tours of fast food shops and bakeries. Alternating chemists to hide my love of laxatives. Cramps, ulcers, the insides of toilet bowls. Serious money problems. My teeth were wearing away and my malnourished body was depleted of minerals, putting my heart in danger. A strange part of me was ok with all this. It was worth it not to feel anything too much. Nothing mattered as much to me as my eating disorder.'

How else could it affect my Life?

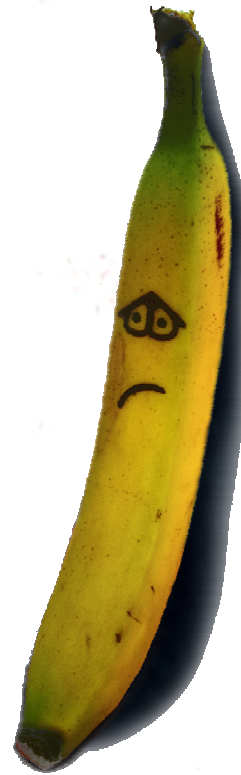
Eating disorders are not only physically demanding they also can negatively affect your social life and emotional well-being. Setting unrealistic standards or feeling depressed and lonely are common factors associated with an eating disorder. It can also lead to difficulties in concentrating, then problems in studying or at work. Eating disorders can and do affect friends and family members.



'It has affected every aspect of my life and taken away so much. It's also sadly affected those around me; my family and friends, as I retreated more into the secretive world of an eating disorder and became more disconnected from them.'

'I lost many years of my life, so much thought space; full of my obsessions about eating, numbers, shape, and worry about other people's perceptions. The rights, wrongs and never enoughs. I've spent thousands of pounds on food to escape, eat and purge, so it's been financially draining too. When I was suffering from an eating disorder I lost my curiosity and passion for my interests. It always wanted to be first, which made life feel rather empty.'

*'It dominates every waking moment of your life
– from the moment you wake
up until you go to bed all you
can think about is obeying your
eating disorder. Feeling
worthless and full of self-
hatred; walking in and out of
clothes shops but not able to
buy anything as you feel you
don't deserve it. Feeling
constantly freezing cold, no
matter how many layers you
have on. Feeling so lost, alone
and with no idea who you are
anymore. Feeling disconnected
from others, having no energy
to interact, to take part in
social situations, feeling different from others,
like you don't fit in therefore you isolate
yourself and then feel even more cut off from
life. I often just felt like I was in a dark tunnel
with no light at the end, I had no idea why I
couldn't just be carefree with food/exercise
again or how I would get back to it.'*



How might an eating disorder affect relationships ?

Often in the grips of an eating disorder our time and thoughts can revolve entirely around food and all the things we hate about ourselves.



'I have struggled with friendships and relationships throughout my life. Having an eating disorder has played a big part in this. I isolated myself, convinced that no one would want to be around me anyway. I thought that if I didn't even like myself, how could anyone else be expected to like me either? Physical relationships were out of the question. I couldn't even look at myself in the mirror, let alone let someone else see me. The thought of letting someone else get too close was a big fear too. I was terrified it would mean that I would have to give up my eating disorder which never felt like the better option. It seems crazy, but I would rather be miserable and alone if it meant that I could hold on to the eating disorder and what it meant to me.'

It is of course possible to have a relationship if you have an eating disorder, however sometimes it can be quite complicated. It's so important that you develop a good relationship with yourself first and it certainly helps to be able to trust and be honest with someone else.

'When I was at my worst the thought of someone holding me sent me into a panic which made being close to someone thoroughly difficult. When relationships work well though; when you feel you are with someone that understands and is willing to be there through the good and bad times, they can be reassuring and supportive in helping you to get better and stay well.'

'My eating issues did a lot of damage to my existing relationships, and severely disrupted my ability to make healthy ones. Secrecy is a big part of an eating disorder, I didn't want anyone to know because I was ashamed, and I went to great lengths to hide it. This worked for a while, but having and hiding such a big problem made me irritable, hostile, insecure and very lonely. I was also good at pretending to be fine, and the people closest were afraid to challenge me. They didn't know what to say and were scared of pushing me away.'

How will an eating disorder affect me during pregnancy?

When you're pregnant, it's natural and healthy to put on weight. Even so, many women don't like the idea of it. If you have an eating disorder, the idea of gaining weight during pregnancy can be much harder to accept, and can be very worrying, even frightening.

It's important that your primary care team know, so they can make sure you have the right care during and after your pregnancy. You should be referred to an obstetrician to get that specialist care. You may also be able to receive support from mental health services.

'I felt that I couldn't mention my eating disorder as I was scared that the clinicians and social workers would think I was trying to harm my unborn child. I started to have really bad problems with my teeth during this pregnancy- they literally just started to crumble which I now understand was partly due to my eating disorder in pregnancy.'



What things outside of services/ treatment could help?



'Being befriended by sufferers who are further along the path to recovery really helped me in my recovery. Now I help others who are further back along the recovery path to me and I find that a help in itself, to remind me of all the reasons I don't want to return to that life.'

'Studying child health nursing helped me in my recovery from my eating disorder. It gave me a purpose, identity and a sense of fulfilment away from my eating disorder, having supportive friends and doing 'normal' things with them.'

'Rediscovering things I used to love. As a child I did a lot of horse riding, but when I was ill I had to stop because it wasn't safe. Then I forgot about it as I got so caught up in the illness. I've started horse riding again in recent years and finding something that I really love, and being able to do it again, has given me a purpose and a new lease of life.'

"Mindfulness has helped me greatly. It helps you to be aware of staying in the moment rather than living your life worrying too much about food and weight."

Can I meet with/or speak to others who have similar issues?

While family and friends can be a huge help in providing support, you may also want to join an eating disorder support group. They provide a safe environment where you can talk freely about your eating disorder and get advice and support from people who know what you're going through. There are many types of eating disorder support groups. Some are led by professional therapists, while others are moderated by trained volunteers or people who have recovered from an eating disorder.



'Speaking to others that have experienced eating disorders or who struggle with issues like my own helps enormously. There are many great recovery orientated forums, support groups and articles online which help me to feel able to express and share difficulties in a healthier way, while supporting and inspiring willingness to keep going, working through recovery. Eating disorders can be incredibly lonely... it's difficult to talk to people who may find it difficult to imagine what it's like, so speaking with others that do understand can be invaluable and make us feel less alone in our struggles.'

Will people judge me if they find out?

Often we judge ourselves far more harshly than anyone else would, and how we think we are judged is not how we are seen at all. Usually it's much better than we think of ourselves.

'Learning to believe we are all equally important, and deserving of compassion, despite the messages we hear that contradict this, and accepting ourselves and others as they are without expectation has helped me cope much better and feel less of a drive to retreat into eating disordered behaviours. We all deserve to treat ourselves and our bodies with respect no matter what judgements others may have.'



'Over the years I have come to realise that best health care provision deals with the whole person. Care that takes account of my spirituality (identity, past and present experiences, relationships, beliefs and values or what gives my life meaning and purpose) is most effective. My mental and physical health is always better when I am able to express what matters to me without fear of judgement or discrimination.'

Can you recover from an eating disorder? Is there a cure?

Recovery is possible. Many people do and have made a full recovery, no matter how long they've endured the illness. It's a difficult path but most definitely worth it. The earlier you try to acknowledge your struggles the better. Support can make it so much easier to get through.

Everyone's recovery is unique and personal to them; it's about finding the best way and support that will help you to be able to feel better. We all need to eat, that's never going to change; and we have this body for life; so it's about finding a way that allows you to live as well as you can be in, valuing yourself and living a life suitable and worthwhile for you.

'I have discovered my own unique identity and have learnt to accept myself for who I am. I've been able to make relationships and engage with friends and family. I've been able to learn how to cope with the challenges/stresses of life in a healthy way rather than turning to my eating disorder to cope. I love waking up in the morning feeling excited to start my day rather than waking up and my thoughts being dominated around food and exercise. In the future I want to continue raising awareness about eating disorders and provide hope that you can recover.'

'I don't think I will ever fully recover from my eating disorder – it feels so deep-rooted and intrinsically part of who I am and as if it's literally in my DNA. I think I'm in the process of accepting that it's part of who I am and that's okay. My relationship with food will quite probably never be "normal" and maybe that's ok too.'



'I don't know if there is an end point to recovery. I think life is constantly changing and there's always going to be challenges, because life is so unpredictable and it's not a linear process, there's always going to be ups and downs.'

It's ok to not be ready, it doesn't mean you can't recover ever, it just means you have some work to do to figure out how to get yourself in a position to take that step. Recovery is a decision you have to make every single day and that in itself is exhausting. All I can say is that it's worth it, life after an eating disorder, and you can do it with the right support and the right attitude, don't leave it till it's too late to get help.'



What advice would you give someone currently experiencing an eating disorder?

'Speak out and seek the support you deserve. I went and saw my GP and although it was extremely scary to do so, it ended up being one of the best things I've ever done. If you do see a GP and they don't take you seriously or help you then see a different GP. Don't give up. The sooner you seek help and support the sooner you can move away from your eating disorder and get better.'

'I think this may sound a little cliché but I believe one of the most important aspects of getting well is being able to love yourself again, forgive yourself and let friends/ family love you.'



'Recovery is very challenging, there will be lots of ups and downs but it is a journey and a process of discovery that can lead to freedom.'

You can recover from an eating disorder and there is life away from an eating disorder. Although it may seem like things will never be any different or get better, it honestly does. Believe in yourself.'

What next?

An eating disorder is serious regardless of your weight. If you feel it is having a detrimental effect on you or someone you love there is good help available and it's important to seek it out.

Resources and more information

This leaflet is also available to access online through the CAPS website – www.capsadvocacy.org

Other resources that people with lived experience have found useful include:

BEAT - www.b-eat.co.uk

SEED – www.seedeatingdisorders.org.uk

NCED - www.eating-disorders.org.uk

MGEDT - www.mengetedstoo.co.uk

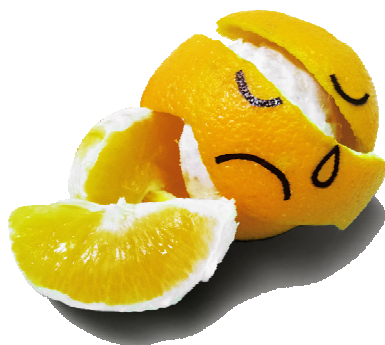
ABC - www.anorexiabulimiare.org.uk

MIND – www.mind.org.uk/information-support/types-of.../eating-problems

Edinburgh Crisis Centre - <http://www.edinburghcrisiscentre.org.uk>

The *EDSPACE*, *MIDSPACE*, *EASTSPACE* and *WESTSPACE* websites signpost people to appropriate mental health and wellbeing services in their local areas.

We hope that this booklet has addressed some fears or worries you may have in relation to yourself or someone you know. It's ok to be scared, to not know if you want to recover or restore weight, to be ambivalent, all of that is to be expected but there are people that can help you work through those feelings. The best thing you can do is to be open and honest and talk about it, to reach out and tell someone, anyone, to get support. **After all, the most deadly symptom of an eating disorder is silence.**



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You are not alone.

It can get better, you can get better.

Your thoughts do not have to be so harsh, the internal critic does not need to be so strong, your life does not need to be controlled by fear. You can be free of the hold of the eating disorder, you can get help to let it go.

You deserve help and treatment, you are worthy of it, you do not need to feel guilt for accepting it. You may not believe these words, but know that they are true.

The eating disorder may feel safe, it may seem strong whilst you are weak, but you are infinitely more powerful. It may seem like it is all you have – that too much time is gone and you have lost too much – but there is always time and there is always hope.

It may seem that this is impossible, that these words are meaningless – and at one time I would have thought exactly the same – but I have been there, experienced it, taken one step forward and two steps back, thought there was no way out, faltered and fallen but have made it through to the other side.

I'm not saying it's going to be easy, it may be the most difficult thing you ever have to do, but you have to – for you. Not all by yourself, but with the support and treatment of those who are willing to help.

You are not alone.