

Understanding
Eating Disorders

Contents

The path to an eating disorder	5	Physical effects	10
Anorexia Nervosa	6	Eating disorders in children	11
Binge Eating Disorder	6	Main points to watch in children and younger teenagers	11
Bulimia Nervosa	7	Some facts and figures	12
Food Avoidance	7	About recovery	13
Food Avoidance Emotional Disorder	8	Information for teachers, counsellors, health and youth workers	14
Food phobia	8	How can ABC help?	14
EDNOS	9		
Psychological effects	9		

The rate of eating disorders and problems with food and eating in the UK is rising. More and more people are becoming aware that their eating has become caught up with feelings, emotions, and even memories, leading them into cycles of behaviour which are difficult to break out of and can risk their health. At the extreme of this are the clinically recognised eating disorders – but it’s important to realise that there are many levels of disordered eating and that many sufferers do not fit exactly into any one condition.

This booklet aims to outline the main eating disorders. So, if you are worried that you, or someone you care about, may have an eating disorder it will help you to know what you should be looking for: what are the signs and symptoms of an eating disorder? It will also dispel some of the most common myths about eating disorders and help you to understand a bit more of why and how people get trapped in these sometimes hard to understand conditions.

The path to an eating disorder

Eating disorders are complex psychological conditions which produce physical complications. There isn’t a simple explanation or a single cause. Research shows that eating disorders have a genetic predisposition and are triggered by the interplay of biological, social and emotional factors, such as stress, bereavement, family break-up, physical illness, bullying or even abuse.

Whatever the eating disorder, the root is usually the same. Eating disorders usually start when someone who is already struggling with life begins to believe that maybe their life would be better if they were thinner. Often this belief has its roots in low self-esteem and poor body image – someone who is not very confident and doesn’t like themselves. They believe that controlling their intake of food would help them to get on with people and feel less alone. For others there is something very powerful about feeling in control of everything – and they feel that their weight is one very clear indicator of how in control they are. This belief can develop in someone who is a very high achiever and puts a lot of pressure on themselves in all areas of their life. Often very successful in all they do, they start to apply the same rules to their weight and appearance as they do everything else, expecting perfection –

which for them means losing weight. The key thing is that a low weight has become very significant to them, and the way that they feel about themselves is strongly linked with some very powerful emotions. Many sufferers will talk about feeling overwhelmed with hate for themselves when they are feeling low, or about hating how fat they feel they are. Of course many are not actually overweight, but the way that their emotions have become so closely associated with the way they see themselves means that even though they may be slim already, they feel overweight and are devastated by it.

The next step in developing an eating disorder comes once the sufferer decides to do something to try to lose weight. Often their weight becomes the scapegoat for everything negative they are feeling and they cling to a hope that if they can lose some weight they will not have to endure those painful feelings again. They start to follow very strict diets, aiming to drastically reduce what they eat. Some people may try to follow a diet plan, others may count calories and start to try to cut down as much as possible, still others may simply try to ‘eat healthily’ but take it too far. Often they start to put together a list of ‘forbidden’ foods – things that they aim to avoid at all costs and they feel they should never eat. These are often the very foods they love

the most – chocolate, crisps, cake, cheese... so the diet that they aim to follow is usually very limited, very restricted, and much less than their body actually needs.

The next stage of an eating disorder is where the different disorders start to become clearer.

Anorexia Nervosa

For some, a combination of practical factors and their personality means that they are able to be successful at this very strict diet. They may break it from time to time but overall they manage this drastic reduction of what they eat and as a result they start to lose weight – sometimes dramatically fast. Of course, this weight loss does not actually solve the problems they were originally struggling with, so often when they do reach their target weight they still feel the desire to lose more. As they continue to lose weight, they start to fall into **anorexia nervosa**.

Binge Eating Disorder

The second group of sufferers start with the same desire to restrict their eating and lose weight, but are not able to keep up that level of control. This may be something about their personality – for example how impulsive they are, or it may be down to lifestyle factors such as whether they have to eat with family.

Most people who have suffered with anorexia also find that eventually their control does break down. Once this happens, sufferers find themselves caught up in the way that the body reacts to starvation, craving food (especially those on the ‘forbidden’ list that they had been depriving themselves of), struggling with obsessive thoughts about food and over-eating. Many start to binge eat – where over a short period of time they will overeat the foods that they were avoiding before, all the time feeling a sense of having lost control. These binges vary in frequency but some people can find they binge several times a day. Binges are followed by extreme remorse, guilt and fear of putting on weight as a result.

For some sufferers the binges, combined with the negative feelings that accompany them, form the main part of their eating disorder. They generally gain weight, often moving from one diet to another in a desperate attempt to control their eating, but never managing to keep weight off for any length of time because of the bingeing. This is life with **binge eating disorder**, which is often related to problems with obesity and extreme weight gain.

Bulimia Nervosa

The third group of sufferers develop a final stage in the cycle of disordered eating. At some point, following a binge, the fear and guilt become overwhelming and they start to do something that they feel will stop them from absorbing the food and putting on the weight. Some may make themselves sick, others abuse laxatives or even exercise excessively. This purging stage actually makes binges worse as it means that in theory there is now something they can do after having eaten to get rid of the food – meaning that their control breaks down even further. Those suffering with **bulimia nervosa** get caught up in powerful cycles of dieting/restricting, bingeing and then purging which grow and become more dramatic, with some consuming immense amounts of food during binges which can happen several times each day. Overall, people with bulimia remain at or near a normal weight, although some do slip into a form of anorexia as they may actually take in so little nutrients and therefore lose weight.

Food Avoidance

Apart from being the first signs of an eating disorder, food avoidance (and weight loss) can signify fear or a phobia due to a physical illness or condition; therefore it's important that the sufferer sees a GP. Sufferers may avoid eating because it physically hurts to eat, and so it also produces fear and anxiety at the thought of eating. Chronic fatigue, appendicitis and cancer are examples of illnesses which can create food avoidance. You may suspect an eating disorder, but it's important to allow a doctor to rule out the possibility of a physical illness first.

Food Avoidance Emotional Disorder

This is a disorder where emotional problems such as anxiety and depression interfere with eating, so that the sufferer eats very little and loses a lot of weight. It can therefore be confused with anorexia and it can take time for the correct diagnosis to be made. FAED usually affects children between about 5 years and 16 years old. There are usually other signs of their emotional struggle that are not focused around food, and they may also exhibit problems with sleeping, phobias or extreme anxiety and other signs of depression such as tearfulness. The main factor that separates FAED from anorexia is that sufferers are generally aware that they are underweight. They often wish they could eat more and may be concerned about being too thin, for example not liking the way they look. This is very different from anorexia. Treatment for FAED therefore focuses on the emotional difficulties underlying the eating problem, and on maintaining weight within healthy levels.

Food phobia

Some sufferers avoid food, particularly certain food groups or the texture of certain foods, because they are afraid of it. People with food phobia are frightened of swallowing food because they fear choking on it or being sick or even being poisoned. As with FAED, sufferers generally do not have the body dissatisfaction associated with anorexia nervosa. This can be a difficult condition to treat, causing much anxiety just like other eating disorders. It is quite rare in adults, suggesting that children might grow out of it.

GPs will probably test swallowing since sufferers with food phobia have anxieties and problems with swallowing. Sometimes reflux may be diagnosed where the muscle between the oesophagus and the stomach is weak and therefore the stomach contents can rise which sometimes results in vomiting and a subsequent fear of vomiting. More commonly there are no physical symptoms and instead a traumatic event has occurred which has resulted in a fear of swallowing. Treatment focuses on the emotional difficulties, healthy weight and normal growth in children, and will require therapy to address the concerns and anxieties giving rise to the phobia. Speech therapy may also be recommended to help with swallowing mechanisms.

EDNOS

This stands for 'eating disorders not otherwise specified'. It is a term sometimes used to diagnose someone who has an obvious eating disorder, but does not quite fit into the criteria for any one of the disorders. It is common therefore amongst children or men, or if an eating disorder is picked up early.

Psychological effects

Many people who develop eating disorders are hard-working, intelligent, sensitive, caring people. They may not be able to communicate their mounting anxiety or struggles with life, preferring to sort things out themselves.

Most people who suffer with eating disorders are the kind of people who support lots of other people and really try not to cause anyone any bother. The eating disorder begins as a method of coping because they think it will help – but of course in the end it actually makes things much worse and can lead to things becoming really out of control instead. Along with that, the mindset and difficult emotions that an eating disorder produces are very difficult to cope with, so the eating disorder can actually make people's feelings worse and more extreme. Sufferers have to cope with feelings of despair and of being out of control and many fear that they will never be able to recover and be 'normal' again.

Meanwhile those whose weight is very low, or any sufferers who are enduring periods of self-imposed starvation, will find themselves having to deal with changes in the way they think, as well as the way they experience the world. Obsessive thought patterns are a common problem as are difficulties communicating with other people, or even keeping track of conversations in big groups. Some sufferers become very sensitive to loud noises so find being out in company very difficult. Constantly battling with your mind to keep up the control, along with those obsessive thought patterns is exhausting and sufferers often become very withdrawn and isolated as a result. Meanwhile those who have gained weight may struggle with feelings of shame, or worry about what they look like. Some hate their appearance so much that they will not go out. Others may try to cover it up with an outwardly cheerful attitude, but feel that they are dying inside.

Consequently, eating disorders are often linked with other psychological problems such as depression, anxiety and obsessive compulsive disorder. Many sufferers also struggle with bouts of self-harm or suicidal thoughts. In fact, anorexia has one of the highest suicide rates of any mental health condition. The longer an eating disorder continues, the worse these effects can get and for many this is the worst part of the eating disorder.

Physical effects

Eating disorders are dangerous, not just because of the impact they have psychologically. Extreme weight loss, and some of the behaviours involved in purging, can be very dangerous physically and many sufferers are surprised by the physical consequences their eating disorder is having on their body.

If you lose too much weight and start to become seriously underweight, you will notice some physical effects, some of which are more serious than others. For women and older girls the first sign that all is not well can be their periods becoming irregular or stopping completely. As weight gets lower, sufferers become very sensitive to the cold and may find their circulation isn't very good – leading to constantly cold fingers and toes and other problems like chilblains. A fine hair often grows all over the body, whilst meanwhile, hair gets very thin and skin becomes very dry and chapped. Additionally, being that thin is not very comfortable – sitting down for long periods may be difficult and they may need extra cushions or padding in bed at night.

While the outward signs of weight loss may be more apparent, it is the internal effects which are most dangerous. As the body goes into starvation and runs out of fuel to use, it begins to harvest its own

muscles and organs leading to the risk of weakness and ultimately organ failure. The heart is one such organ, and fairly early on sufferers may see signs that their heart is not working as well as usual – blood pressure gets very low, so standing up too fast may lead to fainting and the pulse can get very slow. Ultimately this impact on the heart can be very serious.

Another physical effect can occur even in those who are not losing weight. Taking laxatives or making yourself sick leads to the loss of a lot of water, and with it vital chemicals called electrolytes. If the levels of these get too low it can cause complications such as unusual heart rhythms (even heart attacks) and fits. Furthermore, those who do make themselves sick may notice damage to their teeth and sores on hands and fingers caused by the stomach acid. Salivary glands can also become swollen, giving the face a rounded appearance. Please remember that it is not uncommon for sufferers with anorexia to be making themselves sick and/or using laxatives or slimming pills as well as losing weight.

Of course those with binge eating disorder are not immune to physical effects, although they may be more long-term – the impact of obesity on health is well-known and has links with heart disease, cancers and many other physical problems.

Eating disorders in children

Sadly, eating disorders are also becoming more and more common in children. Anorexia nervosa in particular, can start in very young children, and some treatment centres in the UK now admit children as young as 7 years old. Bulimia and other eating disorders can also occur in younger children, although this is much less common than anorexia. Picking up eating disorders in such young children can be very difficult. Their lack of understanding of calories may lead them to eat foods that usually someone who was anorexic might refuse, such as chocolate and high calorie drinks, which can mean that it takes a long time for a diagnosis to be made. They might not admit to having a fear of putting on weight, often finding this very hard to describe. Some children do not lose weight, but instead simply fail to grow and put on weight as would be expected in a child of that age. Catching eating disorders early in this age group is essential. Young children can get very ill very quickly and the sooner they get treatment, the better the chance of recovery.

Main points to watch in children and younger teenagers:

Any weight loss in a child should be investigated as children are still growing up until about 16 years of age and should therefore be steadily gaining weight as they develop and grow.

Failure to gain weight or height at a time of expected growth (10-16 years).

Sufferers may complain of stomach aches, nausea, constipation etc, but will not admit they are avoiding food.

Obsessive and anxious attitudes towards food. This may include unusual diets in younger children.

Avoiding meals, making excuses, skipping school lunch.

Over-exercising and even the inability to stay still when seated or even refusing to sit down.

Calorie counting and reading nutritional information. Many young children have no idea of the calorific value of food. This means they may not be consistent in eating only low calorie food that may make their eating disorder hard to spot.

Laxative abuse: It is unusual for young children to have found out about laxatives and to be able to buy them. However, some younger teenagers may take laxatives, particularly if they are easily available in the home.

Behavioural changes: Many changes that will accompany an eating disorder may seem 'normal', such as an interest in appearance or cooking. If these are concerned with weight loss/failure to gain weight and with increasingly strict or limited eating habits, the possibility of an eating disorder needs to be raised.

Personality changes: depression, tearfulness, unusual clinginess, lack of interest in activities once enjoyed, low self-esteem and feelings of powerlessness may be attributed to 'normal' adolescence. However, severe or persistent problems are not normal and need attention, as they could be a signal of another problem present.

NB – children suffering with anorexia can deteriorate very quickly. If you do have concerns it is important that some action is taken and that the child does see a doctor – time may be of the essence. For advice, please ring ABC's parent helpline.

Some facts and figures

Eating disorders seem to be on the rise, and some would say that rates among some high-risk groups are reaching epidemic proportions. They usually have their roots in adolescence or early adulthood, but cases are being reported in much younger children. At ABC we support some parents of primary school children who are suffering with eating disorders, as well as many whose children are aged 11 – 18 years and beyond. Boys suffer with eating disorders as well as girls, with research showing that 25% of cases in school age are boys. Exact numbers of those suffering are hard to say as many do not come forward for help, but the number of recorded cases in children aged 10 – 19 years rose by 16% in the years 2003 – 2009. Studies among young people find that as many as 25% of girls say they have an eating disorder and many more struggle with issues of body image, self-esteem, depression, stress and anxiety.

Eating disorders are not unusual in adults (both in men as well as in women) and increasing numbers of people are now developing them for the first time in later life. Many have suffered all their life.

About recovery

The good news is that it is possible to fully recover from eating disorders, but it's important to note that recovery is a process and one that is seldom easy or fast and set-backs are to be expected. Much support from family and friends is required along with professional help and treatment. Recovery involves looking at the issues which gave rise to the eating disorder, as well as developing alternative methods of coping. Cognitive Behaviour Therapy (CBT) is often suggested, although there is a range of counselling therapies available. Counselling or psychotherapy (sometimes called psycho-education) can be found privately or accessed through the NHS Eating Disorder Service which is separated into the care for adults and the care for children and adolescents up to 18 years called CAMHS (Child and Adolescent Mental health Service).

It's very important that those with eating disorders also receive regular medical monitoring to safeguard their physical health and this is done first of all by the GP (who is the person to make the initial referral to the eating disorder services) and then by nursing staff at CAMHS or adult services. Family and friends are wise to make sure that the person they care about doesn't miss out on regular medical monitoring in terms of pulse, blood pressure and

blood tests in addition to weight loss and any worrying symptoms both physical (such as chest pains or fainting) and psychological (such as feelings of hopelessness and not being able to carry on).

If an eating disorder becomes severe, then hospital stays and inpatient care may be offered. However, not all hospitals have an eating disorder unit. Some share more specialist input from local units while other hospitals keep patients safe and on bed rest until an inpatient place can be found. Sometimes this involves a journey, although local care is aimed for.

If you are helping someone you love towards recovery then please contact us for support and some practical suggestions. Also please visit the Help Directory on our website for details of help in your local area.

Our published books are:-

First Steps Out of Eating Disorders
by Kate Middleton and Jane Smith (Lion Hudson).

The Parent's Guide to Eating Disorders
by Jane Smith (Lion Hudson).

The Parent's Guide to Self-Harm
by Jane Smith (Lion Hudson).

All these are available via the publications tab on our website or from book retailers.

Information for teachers, counsellors, health and youth workers

Eating disorders, and the related issue of dieting and disordered eating, have become issues that every professional needs to be aware of. Although eating disorders are usually thought of as something that affect older female teenagers, or adults, the truth is that more and more adults, men, boys and younger children are now becoming affected by concerns about their weight and appearance.

Studies report that children begin to worry about their weight shortly after they start school, and that more than half of girls and a quarter of boys aged between 5 and 8 want to be thinner. Even by the age of 5 years old, approximately a quarter of children know what a diet is, and that someone who is fat should go on a diet and aim to lose weight. Many children have already been on a diet themselves by the time they reach adolescence.

Of course eating disorders have complex triggers as well as genetic predispositions and are rarely about body image and dieting alone. You will notice signs of distress and look out for issues affecting those you teach or support. Getting alongside them with sensitivity and tact, allowing them to

‘open up’ to you is often the best starting point and your support can play a vital role. However, eating disorders need professional medical and therapeutic advice and treatment alongside the involvement of parents and family members. Issues of confidentiality and safeguarding also need addressing, as well as regular monitoring. We are available at ABC to answer your questions and to support you in your vital role.

How can ABC help?

ABC is a charity that has for over two decades been supporting anyone affected by eating disorders, and their families. Staffed by people who have first hand experience of eating disorders (as either sufferers or carers or both), they can help because they know what it is like to suffer – and recover. ABC can help answer questions and guide those who seek treatment, or can simply be a listening ear in difficult times.

We offer guidance and training sessions for professionals. Please see our on-line education programme by visiting our website.

For details of our full range of publications and services, please contact our office or see:

www.anorexiabulimiacare.org.uk

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