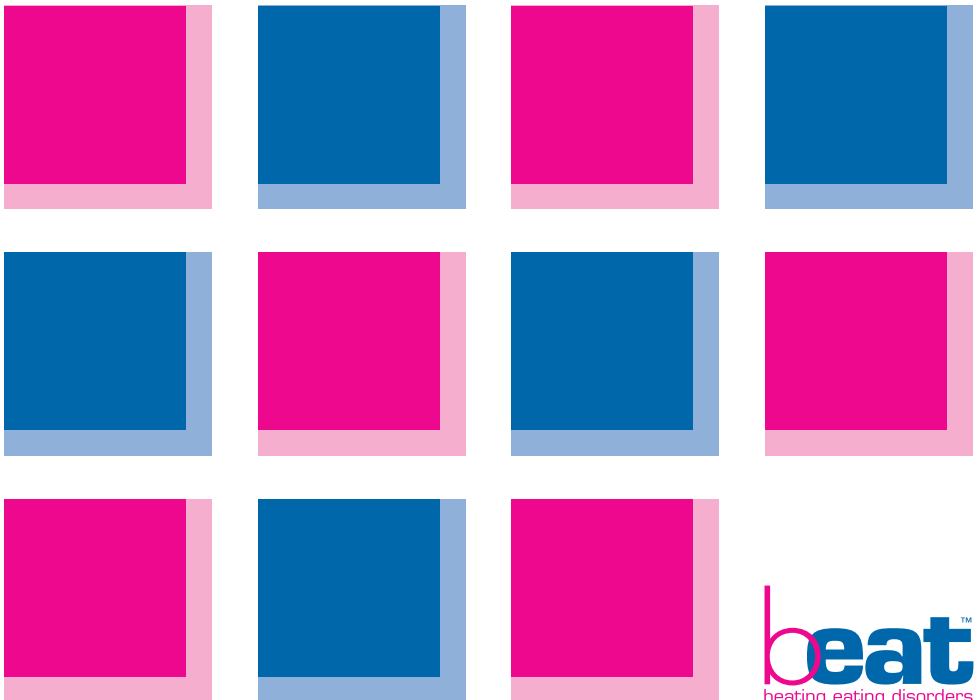




Supporting an **adult**

with an eating disorder





Introduction

Who is this booklet for?

This booklet is for anyone supporting someone over the age of 18 who is suffering from an eating disorder, whether you have only just become aware that they may have an eating disorder, or you have been supporting them for some time.

It has been designed specifically to provide carers of eating disorder sufferers with the essential information that they need: about eating disorders, appropriate treatment, and importantly, how you as a carer can best offer support, seek help for the person you care for and for yourself, and take care of yourself within and away from your caring role.

This booklet is also relevant for people who are not directly involved in the care of a person with an eating disorder – for example colleagues and tutors – who may nonetheless have concerns about them and want to know more about eating disorders and how they can help.

Am I a Carer?

By 'carer' we mean a person who provides help and support to someone with an eating disorder. You could be a parent or step-parent, child, sibling, other relative, or friend. You might be older or younger than the person you support, seeing them every day, or less often. You may or may not live with them. Nevertheless, if you provide help and support to someone with an eating disorder, this booklet is for you.

Beat's experience shows support from carers can really help someone suffering from an eating disorder towards recovery.

About Beat

Beat is the leading UK charity for people with eating disorders and their families. Beat is the working name of the Eating Disorders Association.

Eating disorders are a serious mental illness affecting at least 1.6 million people in the UK. Beat provides helplines for adults and young people, online support and a UK-wide network of self help & support groups to help people beat their eating disorder.

Beat's vision is simple: Eating Disorders will be Beaten.

Having read this booklet, you can visit the Beat Carers' Forum – www.b-eat-carers.co.uk – to access a wealth of information and message boards and online live chats just for carers.

The Beat website is also an indispensable resource: www.b-eat.co.uk. For help and support, you can contact the Beat Helplines. Contact details and opening times are printed in the 'Useful Links' section at the end of this booklet.

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What is an eating disorder?

Food is a necessary part of life. We all differ in the food we like, how much we need, and when we like to eat. Some people may develop an eating disorder, causing them to misuse food in damaging ways – dieting, bingeing or purging (getting rid of food consumed by vomiting or using laxatives).

Eating disorders can affect people of any gender, age, ethnicity, or social or economic background. Research has shown that some people are more at risk than others for developing an eating disorder. However, the exact reason why some people develop eating disorders and others do not is still not known.

Eating disorders are not just about food, they can be a way of coping with emotional distress and give the sufferer a feeling of being in control. They are not all about appearance, nor are they just a “phase” or “attention seeking”. However, eating disorders are treatable, and though the initial signs are subtle and often masked by the sufferer, early intervention is best. The sooner someone gets help, the greater the chance of them making a successful recovery.

This is not *your* fault

As you read this booklet we want you to remember that no matter what your relation to the person you care for, their eating disorder is **not your fault, but neither is it theirs**. It is important to understand, however, that eating disorders are a serious mental illness. Learning all you can about them is essential if you are to provide effective support. This booklet is a good place to begin.

Everyone who suffers from an eating disorder will experience it in a different way, respond to different types of treatment, and take different amounts of time to recover. Some people will suffer from more than one type of eating disorder in their lives.

Eating disorders can cause such drastic changes in behaviour that you may feel the person you care for has been replaced by a stranger. These changes can be shocking and upsetting, both for you and the person you support. Feelings of intense frustration are also common amongst carers, as their attempts to help and nurture the person they care for are repeatedly met with what can seem like refusal and rejection.

Whichever eating disorder the person you care for suffers from, remember they have not chosen to have this illness. No-one is to blame for their eating disorder. It is much more productive to accept that it has happened and be proactive, instead of feeling guilty or worrying about who is to blame.

Patience is hard-won, but vital; change often comes slowly. Every positive step the sufferer makes may appear tiny to the onlooker, but to the person suffering from the eating disorder, it will seem huge. With each step your help and support will be crucial. As one carer told Beat:

'I have learned to cherish and value those little steps. Then you can look back with surprise and joy at the mountain you have climbed together.'

Remember, recovery is *always* possible.

What are the different types of eating disorder?

Anorexia Nervosa literally means 'loss of appetite for nervous reasons'. However, the extreme weight loss which is often a major symptom of this eating disorder is actually caused by denial of hunger.

There are two subtypes of anorexia. Those who suffer from restricting type maintain a low body weight by restricting their food intake and sometimes by exercising. Individuals suffering from binge-eating/purging type may consume large amounts of food and then purge by making themselves vomit or using laxatives. Many will move between these subtypes during their illness.

People who suffer from anorexia focus on food in an attempt to cope with life, not to purposely starve to death. Anorexia can be fatal, so early medical intervention and treatment is fundamental for someone to make a successful recovery.

(Please note that, individually, these signs and symptoms may not signify an eating disorder. If several occur together - especially if they are worsening - they may be a cause for concern.)

Behavioural signs of anorexia:

- Intense fear of gaining weight
- Distorted perception of body shape or weight
- Inability to accept there is a problem
- Sufferer becomes aware of an 'inner voice' that challenges views on eating or exercise
- Rigid or obsessive behaviour attached to eating, such as cutting food into tiny pieces or counting calories
- Mood swings, depression, secrecy
- Restlessness or hyperactivity, difficulty sleeping
- Difficulty thinking and making decisions
- Wearing baggy clothes
- Vomiting, taking laxatives
- Excessive exercise

Physical effects of anorexia:

- Dehydration, constipation, abdominal pains
- Dizzy spells and feeling faint

- Difficulty sleeping, lethargy, inability to concentrate
- Low blood pressure
- Bloating stomach, puffy face/ankles
- Downy hair on the body; occasionally loss of hair on the head when recovering
- Poor blood circulation, feeling cold
- Dry, rough or discoloured skin
- Loss of periods or loss of interest in sex
- Loss of bone mass

Long-term effects of anorexia:

- Poor functioning of the body: specifically the brain, heart, liver and kidneys
- Difficulty conceiving, infertility
- Osteoporosis (brittle bones)

Treatment for anorexia:

Treatment for anorexia varies depending on the sufferer's symptoms. As a low weight can impair a sufferer's cognitive functioning, for those who are underweight, treatment initially focuses on weight gain. This ensures that the brain is functioning properly before psychological and behavioural issues are tackled, so that they are able to engage in therapy. Sufferers can also learn healthier ways of coping with their lives.

Overcoming Anorexia Online is a resource for carers, which helps them to understand the thoughts, feelings and behaviours of a sufferer of anorexia, and develop skills to become 'expert' carers. The eight sessions are based on Cognitive Behavioural Therapy (CBT) which helps a person change how they think ('cognitive') and how they behave as a result ('behavioural'). For details of this respected and well-researched resource, visit: www.overcominganorexiaonline.com. You should be aware that there is a fee for accessing this resource.

Bulimia Nervosa literally means 'hunger of an ox for nervous reasons', though some sufferers may at times eat very little. Bulimia is characterised by cycles of bingeing (eating a large amount of food), and then experiencing guilt, fear, or stomach pains, causing sufferers to purge. Those who suffer from the non-purging type compensate for binges by exercising or fasting.

Sufferers often hide their disorder by bingeing and purging in secret, and many stay the same weight or even put on weight, rather than drastically losing weight like those with anorexia. Consequently, their illness may go undetected for a long time. Bulimia can be fatal so early medical intervention and treatment is advised.

Behavioural signs of bulimia:

- Uncontrollable urges to eat vast amounts of food
- An obsession with food, or feeling 'out of control' around food
- Distorted perception of body weight and shape, fear of gaining weight
- Anxiety, depression, low self-esteem
- Purging behaviours – e.g. disappearing to the toilet after meals to vomit and/or use laxatives
- Fasting or excessive exercise
- Secrecy, mood swings and a reluctance to socialise (especially avoiding meals)
- Shoplifting for food, abnormal amounts of money spent on food, hoarding food from family cupboards or stealing food from housemates

Physical effects of bulimia:

- Frequent weight changes
- Heartburn, sore throat, tooth decay, bad breath, sore skin on the fingers that have been used to induce vomiting
- Dehydration, imbalance of electrolytes (essential for normal functioning of cells and organs)
- Swollen hands, feet or salivary glands; puffy cheeks
- Poor skin condition and possible hair loss
- Irregular periods or loss of interest in sex
- Lethargy and tiredness, difficulty sleeping
- Constipation or diarrhoea, intestinal problems due to laxative abuse

Long-term effects of bulimia:

- Painful swallowing, drying up of the salivary glands
- Imbalance or dangerously low levels of essential minerals in the body
- Increased risk of heart problems and problems with other internal organs
- Severe damage to the stomach, oesophagus, teeth, salivary glands and bowel

Treatment for bulimia:

Treatment of bulimia aims to disrupt the binge-purge cycle. It seeks to reduce the sufferer's urge to binge by finding healthier ways for them to deal with difficult feelings. A form of



Cognitive Behavioural Therapy – CBT-BN – can be used to treat bulimia.

Overcoming Bulimia Online allows sufferers to develop CBT skills to help understand and overcome their illness. The simplicity and accessibility of the eight-session, professionally-recognised course is noted by users, and some prefer it to face-to-face interaction with a therapist. There is a fee for using this resource. However, some GPs have licences for this resource, and can offer it free of charge. Ask your GP about availability, or visit: www.overcomingbulimiaonline.com.

Binge Eating Disorder (BED) shares some of the characteristics of bulimia; the essential difference is that the sufferer binges uncontrollably but does not purge, or compensate for consumed food in other ways, e.g. by exercising. Some sufferers say that they use food as a comfort, or to escape difficult underlying feelings.

Compulsive Overeating is a variation on binge eating. Those suffering from compulsive overeating eat when they are not hungry. Again, this is a way of coping which makes them feel better temporarily.

Signs of binge eating disorder / compulsive overeating:


- Eating much more rapidly than usual
- Eating until feeling uncomfortably full
- Eating when not hungry
- Eating alone because of embarrassment about the quantities of food consumed
- Feeling out of control around food
- Feeling very self-conscious eating in front of others
- Shame, depression, and guilt after bingeing
- Sufferer does not engage in purging or other compensatory behaviours, e.g. exercise

Long-term effects of binge eating:

- High blood pressure, high cholesterol
- Obesity, diabetes, heart disease

Treatment for BED:

Treatment for BED or compulsive overeating is similar to that for bulimia. The sufferer learns to control their urge to binge, and to recognise the difference between actual hunger and hunger triggered by anxiety and other difficult feelings. They learn new ways of dealing with their feelings. CBT-BED is a specially adapted form of Cognitive Behavioural Therapy that is used to treat binge eating disorder.



Eating Disorder Not Otherwise Specified (EDNOS) is a category of eating disorder encompassing sufferers who do not exhibit all of the symptoms required for a diagnosis of anorexia or bulimia nervosa, BED or compulsive overeating. As an example, someone with EDNOS (sometimes referred to as an Atypical Eating Disorder, or Partial Syndrome) may carry out the restricting behaviours common to anorexia, but maintain a normal weight. This type of eating disorder should not be thought of as any less serious.

Treatment for EDNOS:

There are at present no specific guidelines for the treatment of EDNOS. The NICE (National Institute for Health and Clinical Excellence) guidelines suggest that treatment of EDNOS should be appropriate to the eating disorder most comparable to the individual's eating problem.

What are the possible causes of eating disorders?

Ordinarily, when someone develops an illness, we naturally want to know the cause of it. It is important to understand and accept that there is no single cause of eating disorders.


What we do know is that certain **personality traits** are often present in those who develop eating disorders, such as perfectionism, obsessive tendencies and a hyper-sensitivity to criticism. However, just because a person exhibits one or more of these traits, or appears susceptible to any of the other influences outlined in this section, it does not mean they will necessarily develop an eating disorder.

Recent research has confirmed the influence of **genetic factors**. However, parents have no control over these and so should not believe that they are to blame. These combine with other factors:

Social factors: The influence of society and culture, which shapes our ideas of what is 'acceptable'. Narrow definitions of beauty including only specific body shapes and weights, and other people's positive reactions to weight loss may influence the development of an eating disorder.

Interpersonal factors: Our relationships with others can unintentionally cause distress, or make us doubt our self-worth or ability. Some examples of common experiences amongst those suffering from eating disorders are relationship breakdowns, and being teased about size or weight.

Significant life events such as bereavement, divorce within the family, moving house, or changing schools or colleges may also trigger the development of an eating disorder in some individuals.



All of these factors combine in unique ways in each individual; we do not know exactly why some people develop eating disorders and others do not. World-class research is underway – much of it in the UK – and our knowledge of eating disorders and their possible causes is constantly advancing.

Beat campaigns for further research and increased funding, as well as encouraging research participation. To find out more, search for 'Research' on the Beat website.

What can you do to help?

If you think someone has an eating disorder...

Approaching the topic of eating disorders with someone can be a daunting prospect. Remember that recovery is so much more difficult in an atmosphere of secrecy and denial, and the disorder will not go away by itself. Talking about it can be an essential first step.

Here are some tips for approaching someone who you think or know has an eating disorder:

- Get some help for yourself first by talking to a friend or professional about your concerns
- Prepare what you want to say, and how you're going to say it
- Choose a place where you both feel safe and won't be disturbed
- Choose a time when neither of you is angry or upset – avoid any time just before or after meals
- Have some information about eating disorders to hand – refer to them if the person seems to be listening, or leave resources behind for them to look at on their own
- Talk to them one-to-one – if other people are around, the person you are talking to may feel you're ganging up on them
- Be prepared for them to be angry and emotional, and say hurtful things
- Don't be disheartened if you're met with denial. Accept that the decision to recover has to come from the sufferer, and reflect positively on the steps you've taken - you have opened a door

Here are some tips for what to do and say when talking to someone with an eating disorder:

- Be aware that they're likely to be feeling embarrassed, ashamed and scared
- Don't label them or attempt to trick them into admitting they have an eating disorder

- Re-affirm your love for them – i.e. if they say, “I hate you”, you say, “Well I don’t hate you, I love you”
- Use “I” sentences (“I am worried as I’ve noticed you don’t seem happy”) instead of “you” sentences (“you need to get help”)
- Thinking of the eating disorder as a gremlin or monster on the shoulder of the sufferer may help you to not take things that they say or do too personally, or to blame or resent them
- If they acknowledge that they have a problem, offer to help them, e.g. by going to see the GP with them
- If they are not ready to talk about their problem, reassure them that you’ll be there when they are. Don’t leave it too long before broaching the subject again
- Remember that eating disorders are serious, potentially life-threatening illnesses; while you can’t force an adult to seek treatment, you can nevertheless draw on all of your resources to try to assist them in getting the appropriate care and support

Treatment

Perhaps the most difficult step in treatment is for the person with an eating disorder to acknowledge that eating is a problem for them. The section of this booklet entitled ‘What can you do to help?’ advises you on how to help them to do so. It is essential that as their carer you help them to take their first daunting steps towards treatment and recovery.

A GP is usually your first point of contact in the NHS healthcare system. This level of care is known as *primary care*. You may initially wish to make an appointment to see the GP on your own, so that you can openly discuss concerns which could be unduly distressing for the person you support.

Before an appointment, if you live in England or Wales it is advisable to read the NICE guidelines – a set of guidelines for the treatment of eating disorders - so that you know what the person you care for is entitled to: www.nice.org.uk. The NICE guidelines stress the importance of involving families in treatment. If you live in Scotland you can refer to ‘Eating Disorders in Scotland – A Patient’s Guide’ under ‘Findings and advice’ on the following website: www.nhshealthquality.org. This report produced by NHS Quality Improvement Scotland (NHS QIS) outlines the identification of eating disorders, appropriate treatment and support, and what the person with an eating disorder should expect from the NHS.

Offering to accompany the person you support to an appointment with the GP may help them to feel at ease. All stages of contact with healthcare professionals can be very distressing for someone suffering from an eating disorder. You could suggest that they write down what they want to say, so they can still talk and explain how they feel even if they become upset.

The GP will ask them about their lifestyle and eating habits, and examine them to check for medical problems. The GP will be able to rule out other illnesses and diagnose an eating disorder based on their symptoms. Ideally the treatment and care provided will be suited to the GP's diagnosis.

There can be long delays between initial contact with a GP and accessing appropriate treatment for the person you care for, so it is important to support them in persisting with a request for a referral.

Some doctors have more experience of treating people with eating disorders. Access to a GP who understands eating disorders and treatment options and can make an appropriate referral is essential at this first point of contact. If the GP is not sympathetic or understanding, you could help the person you support to ask to see another GP in the surgery (they don't have to give the receptionist a reason); register with another doctor's practice in the area; or seek the assistance of a mental health advocate (in England and Wales, see the details of Mind and Rethink in the 'Useful Links' section; in Scotland, contact the Scottish Independent Advocacy Alliance: www.siaa.org.uk).

The GP may decide it is necessary to refer the person you support to *secondary care*, which includes specialist treatment with a psychologist, psychiatrist, counsellor or dietician.

The main aims of any treatment for eating disorders are:

- To treat any medical problems
- To develop healthy eating behaviours and maintain a healthy weight
- To learn healthier ways of coping






The healthcare team at secondary care level will meet regularly with them, talking through their difficulties to help them to make positive changes. About 80-90% of people diagnosed with an eating disorder receive all the help they need to recover within primary and secondary care.

If they require more help they may be referred to a specialist setting such as a hospital, eating disorders unit or mental health unit. Here they may receive supported meals and snacks, therapy sessions, nutrition education, art/music therapies, and more. This may be as an inpatient at the centre full-time, a day-patient at the centre part-time, or as an outpatient. This level of care is known as *tertiary care*.

There is no specific drug treatment for eating disorders, but medication may be prescribed to aid recovery. For example, sufferers of bulimia may be offered a specific anti-depressant. Certain steps and precautions can safeguard the physical wellbeing of the person you care for, and reduce the risk of long-term effects of their illness. You can find further information by searching for general physical wellbeing recommendations on the Institute of Psychiatry website: www.iop.kcl.ac.uk.

Different treatments will work for different people, and it may take time for you to find the right treatment for the person you care for. Bear in mind that all treatment options will present unique challenges. Recovery will be long and hard, and could often involve set-backs and relapses. However, it is always possible. Remember that the person you care for needs support through treatment and recovery; reassure them that no matter how difficult things get, you love and care for them unconditionally.



'In the early stages of recovery...ideally, there needs to be some sort of solid, reliable support at this time which if not completely provided by professionals needs to be provided by the person in the caring role or by a very reliable representative for this person.'

Confidentiality and Consent

The healthcare team are legally obliged to keep detailed information confidential. You should be prepared for situations in which the healthcare professionals you deal with are not forthcoming with information regarding the treatment of the person you care for. As this can be incredibly frustrating, the information below and suggested links are included to help you to understand your rights and the rights of the person you support, and to take appropriate action if necessary.


The NICE guidelines state that respect for patient confidentiality should not be used as an excuse for not listening to or communicating with carers. You should expect to be given enough information by healthcare providers to enable you to provide effective care. Remember also that anything that you as a carer disclose should be treated confidentially.

Research with carers and mental health service users carried out by Rethink and the Government's Department of Health resulted in the following recommendations for how healthcare professionals should handle the sharing of information:

- Information should be discussed with the sufferer and carer together, if appropriate
- Possibilities acceptable to the sufferer should be explored
- The sufferer should be helped to identify aspects of their personal information that they would feel comfortable sharing
- The risks of not sharing should be assessed and discussed with the sufferer, explaining why confidentiality may have to be breached in some circumstances
- Where information cannot be shared with the carer, it should be explained why this is the case, and the carer should be signposted to alternative support
- There should be a plan for information sharing put in place when you have an assessment of your own needs, called a Carer's Assessment (see the Directgov web pages for more information, outlined in 'Useful Links' at the end of this booklet)
- Consent should be reviewed at regular intervals with the sufferer

Please note that it is not possible to give an exhaustive review of the laws and literature pertaining to issues of confidentiality within the confines of this booklet, and such information is subject to ongoing change and review. The Rethink factsheet on confidentiality and the briefing paper Carers and Confidentiality (Department of Health) are useful resources.

The Royal College of Psychiatrists website features links to further information, and examples of good practice: www.rcpsych.ac.uk.



Those living in Scotland should be aware of different legislation governing confidentiality and consent; Health Rights Information Scotland website is a comprehensive resource: www.hris.org.uk.

You may wish to share your own concerns about confidentiality and information sharing with the treatment provider, by writing to them, phoning or e-mailing them. Always let the person you care for know so that they don't feel betrayed. Focusing on the relationship that you have with them may help: if you are open, trusting and supportive, it is likely that they will open up to you.

Sectioning

If the person you care for has lost a great deal of weight, they may be in danger of starving themselves or could be developing serious complications. In these circumstances they may literally not be able to think properly and can refuse essential treatment and even life sustaining food. With the agreement of another professional and an approved mental health practitioner, your doctor may decide to admit them for specialist treatment. This is usually called being 'sectioned' because it is carried out under the rules in one of the 'sections' of the Mental Health Act.

For more information about the Mental Health Act, access to treatment and related issues, please refer to the links at the end of this booklet.

Unsatisfactory treatment

If you are concerned that the person you support is receiving unsatisfactory treatment, you may want to refer to the NICE guidelines. It may be helpful for the person you care for to take a copy to appointments to ensure that they are receiving the standard of care they are entitled to. They have the right to ask for a second opinion. Even older adults may need your support, as low self-esteem and impaired cognitive functioning could make it difficult for them to argue their case effectively.

Should you wish to make a complaint about unsatisfactory treatment, the Patient Advice and Liaison Service of the NHS (PALS) can help to ensure that your concerns are heard and action is taken (see 'Useful Links'). In **Wales**, such complaints are handled by the Community Health Council (CHC) on **0845 644 7814**; in **Scotland**, contact NHS Inform on **0800 22 44 88** or the NHS 24 Helpline on **08454 24 24 24**; and in **Northern Ireland** the Patient and Client Council should be contacted on **0800 917 0222**.

Related disorders

It is important to know that eating disorders can occur alongside other mental health issues.

These include:

- Anxiety or panic disorders
- Depression
- Obsessive Compulsive Disorder (OCD)
- Personality disorders
- Self-harming
- Alcohol or drug misuse

Some people develop other mental health issues during recovery, as they struggle to find new ways of coping without the eating disorder. If treatment for the eating disorder is to be successful, it is important that other mental health issues are recognised and treated, which may mean prioritising treatment for one problem over the other. It can be very distressing for carers when the person they support shows signs of another mental health issue, and it is important to discuss this with them, and with their healthcare provider. Early intervention and effective treatment can prevent another disorder from taking over.

More information can be found by searching under 'UK Organisations' on the Beat website.





Overcoming anorexia: Alan and Ruth's advice

Alan, a Beat service user, supported his daughter Ruth through her recovery from anorexia. Here Alan and Ruth give their own accounts of their experiences, and their advice to carers.

Alan's Story

My first encounter with an eating disorder was when my daughter Ruth, aged 18, began to show symptoms, and was diagnosed with anorexia. I had no knowledge of anorexia, so decided to educate myself on all aspects of eating disorders. It would have been only too easy to turn my back on the problem, yet I knew I had a better chance of helping my daughter overcome the disorder if I was armed with all the facts – as in the old adage, it is best to 'know your enemy'. I contacted Beat, from whom I obtained a vast amount of knowledge and support.

I have listed below points which I found beneficial in tackling this illness head-on:

- Don't assume anorexia is a feminine issue
- Educate yourself
- Get involved
- Never pass judgment
- Join a Beat self help & support group
- Never give up

Ruth's Story

I developed anorexia aged 18, yet was unaware of the on-set as it had been a gradual process. I found myself in a terrible situation, being completely taken over by the illness. My father was a source of great support throughout my hospitalisation and recovery.

Listed below are some points which I feel would be helpful from a parent's perspective when confronted by an eating disorder:

- See things from your son's / daughter's perspective
- Recognise that anorexia is not just about food
- Listen to your son / daughter
- Talk to your son / daughter
- Don't make threats (of sectioning and hospitalisation), just inform of the facts
- Don't threaten to take control out of the hands of your son / daughter



Family members and friends

When someone has an eating disorder, their behaviour will affect all those close to them. One sibling was prompted to comment poignantly: 'there is more than one sufferer.' Siblings of various ages comment about the importance of not feeling ashamed of the anger and frustration that is sometimes their response to their brother or sister's eating disorder – and of knowing it's not selfish to want to step back every once in a while and to want some attention and some 'me' time.

Parents should try not to become angry as a result of how their other children respond to their son or daughter's eating disorder. Younger siblings and relatives especially should be supported in understanding the situation, to talk about how they feel, and care should be taken to ensure that they don't feel less important than the person with an eating disorder.

If you are the friend of someone suffering from an eating disorder, there is a lot you can do to help. While you shouldn't expect to be able to make them better, being there for them can be extremely helpful; eating disorders are much harder to bear without such support. Reading this booklet and following the tips and advice is an important first step in learning all you can about eating disorders.

It is important to remember that all family members – and friends too – can all be part of a vital support network that may help the person suffering from an eating disorder towards making a full recovery. Try not to let their eating disorder dominate your relationship, and make time to do things together as you would usually. Whatever your relationship, being there for them - no matter how they behave or how hard things get - can bring them some much needed stability and support at a difficult and turbulent time – when recovery poses perhaps the greatest challenge of their life.

Please note: Beat has created a series of leaflets for siblings of all ages which can be downloaded from the Beat website. A separate booklet for partners is also available to download or purchase.

Dealing with a sufferer's emotions

For someone suffering from an eating disorder, intense emotional outbursts are common. These are commonly above and beyond the limits of acceptability. The risk of such an outburst is especially high when a person with an eating disorder feels challenged or is attempting recovery. Often the outbursts will be angry and aggressive and seemingly impossible to manage. It is important to set boundaries as to what constitutes unacceptable behaviour, discussing these with the sufferer, and other carers and family members. If you are too accommodating to the behavioural symptoms of the eating disorder, you may inadvertently encourage it.

Parents should endeavour to work together; divergent opinions and approaches can be damaging for the sufferer and further complicate difficult situations. Try to channel both your respective strengths and differing perspectives into a unified approach, rather than letting them divide you.

In a caring situation, emotions run high for all involved, so it is important to keep a check on your own behaviour too. Remember that it is always best to vent your emotions away from the sufferer. However, if you do become angry or upset, try not to feel guilty about this. Instead, try to move on, and if possible make time later to talk to the person you care for, explaining the reasons for your emotions and encouraging him or her to do the same. If you do this, bear in mind that it will probably be hard for them to open up, and they may not fully understand their own feelings.

Checklist:

- ✓ As far as possible, try to control your own emotions and vent away from the sufferer
- ✓ Set boundaries – limits on the behaviour that you will tolerate
- ✓ It may be best to walk away from an angry situation, or to agree that you will not talk about things until everyone involved has calmed down
- ✓ Listen to the sufferer's views and feelings, so you can both understand these better
- ✓ Praise them when things go well

While they may experience angry, aggressive outbursts, remember it is likely that the person with an eating disorder is having to contend with very low self-esteem, and possibly feels very insecure and fearful. It is important to tend to these emotions too, which may not be so explicit. Be sure to express your unconditional love for them, to maintain trust, closeness, and openness, and to reassure them.



Mealtimes

Mealtimes can be the most difficult time of day for someone suffering from an eating disorder. At these times they can become very anxious and can feel guilty for eating; unsurprisingly, extreme outbursts of emotion – especially aggression – may result.

It is best to enlist professional help to enable you to develop a strategy for mealtimes. This will enable you to implement some much needed control at these times, ensuring that steps are taken to encourage the person you support to eat and anticipate and alleviate potential triggers without inadvertently encouraging their eating disordered behaviours.

When you are supporting someone with an eating disorder, the aim at mealtimes is to normalise eating: to diminish the threat and dread that they associate with meals and the environments in which they take place, and to gradually get them to eat until they revert to appropriately sized, day-to-day meals at regular intervals. Re-introducing structured eating – planned meals at planned times – is crucial.

From our experience and consultation with professionals, we have put together the following list of the most useful suggestions for people who are supporting someone with an eating disorder before, during, and after mealtimes. Bear in mind that, as each case is unique, not all suggestions will work for everyone, and this list is in no way a substitute for professional help and guidance.

Before the meal

- Planning ahead can avert disaster. Consider making a meal-time agreement with the person you support – involving family members or others who will be present – to decide:
 - the time you will eat together – serving any later could prevent them eating
 - who will be present
 - the meal to be served and agreed portion sizes for the person you support. Always check you have the necessary food items for the planned meal – deviation from the agreed meal plan could cause them to panic and limit their food intake
- Don't let the person you support do the grocery shopping on their own or cook for you and others alone. By doing the grocery shopping together, you may be able to introduce new foods onto their "safe" foods list, perhaps setting a goal of one each week. You can also encourage this by cooking with them and trying new recipes together



At the table

- Aim to maintain neutral conversations, avoiding discussion of food, weight or appearance. Perhaps talk about what you have done during the day, or a specific television programme. The conversation may feel strained at times, but the focus will not be on the person with an eating disorder, and the eating disorder will not dominate
- Ensure that you and anyone else present do not focus on the person with an eating disorder unnecessarily. As far as possible, try to act as you would normally
- No matter how trying mealtimes may be, or how concerned you may be about the person you support, try to smile and appear positive and warmly supportive – worried looks from other people at the table can incite and increase their negative feelings
- Having the television or radio on can provide a welcome distraction for the person you support, diminishing their feelings of expectation and tremendous pressure to eat
- Make sure that everyone else at the table eats balanced, age-appropriate meals. Adopt a healthy approach to eating: a range of foods and sensible portion sizes. Don't shy away from fatty or unhealthy food, but don't make the mistake of over-indulging in an effort to encourage the person you support to eat

Encouraging them to eat

- Start slowly: in the beginning, be wary of pressuring the person you support to eat more than they are used to – it may take time for their stomach to re-adjust
- It may be necessary to encourage them to eat, especially if they have not started their meal after some time at the table. Be firm but nurturing – say something along the lines of, 'I know this is really difficult for you, but you need to make a start on your meal now'
- Offer further prompts if they are having difficulty continuing – it is not unheard of for a sufferer to take hours to finish a meal, so your encouragement can prevent their meal from dragging on indefinitely
- Throughout the meal, aim to be supportive, firm but relaxed – show them that mealtimes are a non-threatening, normal part of everyday life
- The person you support may feel very guilty for having eaten. Acknowledge that this is a huge effort for them, but don't patronise them, and avoid praising them for eating
- After a meal, suggest watching a film or doing something fun or creative together to help take their mind off compensatory behaviours such as over-exercising or purging
- Accept that some mealtimes will undoubtedly be disastrous. Don't worry about occasionally getting things wrong or making the odd inappropriate remark – you are only human



Holidays and Celebrations

Holiday and celebratory meals can be particularly difficult for someone suffering from an eating disorder. At these times, planning ahead can relieve stress and anxiety and the threat of eating in unfamiliar settings. By calling ahead you can find out what food will be available, so the person you support can plan what they will eat or arrange to bring “safe” foods of their own.

If the person you support gives their consent, being open about their eating disorder with family and friends can also help them to avoid excessive stress and anxiety and unwanted attention at holiday and celebratory meals.

The website www.bulimia.com features more tips and guidance for holiday meals.

Behaving sensitively

While it may seem obvious, it is important to be sensitive to how a person with an eating disorder feels. It may not always be clear just what might upset someone with an eating disorder. The following list has been included to give you some helpful pointers:

- Try to avoid engaging in conversations with them about food, calories or clothing, or body shape, size or weight
- Talk about how much you value them as a person – compliment their personality and achievements rather than physical attributes
- Continue to involve them in things they did before they were ill – even if they don’t feel like joining in, they will still appreciate being asked
- Don’t jump to conclusions – let them tell you how they are feeling and how you can best help them
- Remember that even if they look physically better, they may not feel completely better inside and may still need help and support. Someone suffering from bulimia may be far from their best or even at their worst and still look ‘okay’
- During recovery from anorexia, comments about a sufferer’s apparent weight gain may be detrimental and should be avoided
- If you are concerned that they are in immediate physical danger, call an ambulance, or take them to A&E



Going away to university

For parents especially, if the person you support is planning to go away to university, this can be a difficult time for you both. Knowing the difficulties caused by the eating disorder, the idea of them being far away where you cannot offer them day-to-day support can be a frightening prospect.


As well as the practical considerations and choices the person you support will have to make, such as where and what to study, and how far away from home they want to be, they are likely to worry about people they live with finding out about their eating disorder, and the difficulties of co-ordinating their meals around others. More information for them can be found under the 'Students' section of Beat's For Young People (FYP) website:

www.b-eat.co.uk/YoungPeople/Home.

'It was hard trying to hide the fact I was suffering all the time – feeling embarrassed by my eating habits and low weight.'

From their application to university, to providing support once they're there, carers and Beat Young Ambassadors were consulted in putting together the following useful suggestions:

- **Pre-plan:** From the outset, have a plan of action in place. Implementing each measure might help to alleviate the worry you may be experiencing, and help the person you support to feel as safe as possible as they prepare to leave home
- **Applying to university:** In applications to universities that request details of ongoing conditions, it's best to be honest about the eating disorder. It is common practice for the university to consult the sufferer's treatment team to determine how the eating disorder affects the sufferer and whether they could cope with the demands of higher education
- **Healthcare:** Encourage the person you support to register with a doctor and dentist in the area where they will be attending university. These professionals will send for their notes
- **Counselling, self help and other support:** Find out if there is support for people with eating disorders in the area where they will be studying, e.g. self help & support groups, which may be run at the university, or nearby. Accessing the Helpfinder on the Beat website can help you find these groups. Student Run Self Help (SRSRH) offers Beat-affiliated peer-to-peer support groups for students with eating disorders at various universities: www.studentrunselfhelp.weebly.com. The Student Counselling in UK Universities website outlines available counselling services: www.student.counselling.co.uk
- **Get them involved:** encourage them to socialise, join teams or clubs – not just study

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- **Tutors:** If the person you support has concerns about keeping up with the workload, ensure their tutors are informed, so they can offer support and make allowances if necessary
 - **Deferring study:** Their treatment may necessitate deferring their studies - before or after they have started university - in which case they may experience feelings of failure, shame or low self-worth which could exacerbate their eating disorder. Be prepared to offer your understanding and reassurance:

'There's no shame in taking a break if that's what you need.'

- **Staying in touch:** Once they're at university, texts, e-mails and occasional phone calls will all help to ensure that they feel supported and valued. Encouraging them to do the same might alleviate your worries too. However, don't always focus on the eating disorder:

'It can be so nice when people just have a regular conversation with you about life, and study and not your eating disorder.'

- **Visiting:** Informal, impromptu visits can show support without being intrusive or making it seem like you're 'checking up' - drop by or take them out for the day. Allowing independence is crucial for building their confidence, but try to encourage them to let you know if the eating disorder gets too much and they need your help:

'It can be really hard to find the balance between taking the eating disorder seriously, and allowing the sufferer to maintain safely some of the independence they had expected to have when going to uni.'

Finally, even if the person you support is doing well before they leave for university, don't make the mistake of thinking that there is no need for a contingency plan.

Disabled Students' Allowance:

Any student who is suffering from an eating disorder may be entitled to receive Disabled Students' Allowance. A needs assessment is carried out for individuals with ongoing health and mental health conditions; the person you support may be eligible. DSAs are paid in addition to student loans, grants and bursaries, and do not have to be paid back.

Depending on the country you live in, you can find out more by accessing the following websites:

England: www.direct.gov.uk

Northern Ireland: www.studentfinanceneni.co.uk

Scotland: www.saas.gov.uk

Wales: www.studentfinancewales.co.uk

Housemates

You may be sharing a house, halls or other shared student or professional accommodation with someone who suffers from an eating disorder. If you are reading this, then it is clear that you care about them and are keen to learn more about how you can help them. Don't be afraid to approach them at a quiet moment to ask if everything is okay, or to show your concern.

'...the fact that no one said anything made me think it can't be too big a problem and there can't really be anything wrong that I should try to get help for. I...felt alone...that no one saw me struggling, and I had to pretend everything was alright when it wasn't.'

As well as reading this leaflet, you can find further information on the Beat website or call the Beat helpline. You may want to print out some information for them, or direct them to the FYP website, on page 23.

Don't forget that living with someone with an eating disorder can be difficult, so don't be afraid to seek your own support if things get too much. It is easy to feel responsible and to worry about them, which could be especially hard for you if, for example, you have to leave them behind during the holidays. Remember you can contact the Beat Helplines for support. Alternatively, you could attend a self help & support group, or access a local counselling service.





Looking after yourself

Recognising yourself as a carer

This means more than simply recognising that you are a carer. It means acknowledging the implications of your caring role: the impact on your life, emotionally, physically, even financially, and learning what resources are available to you and how best to cope.

Taking care of yourself is crucially important to maintain your physical and emotional wellbeing; essential for you to be able to offer adequate support to the person you care for. Looking after your own health in this way may also encourage them to do the same.

Your emotions

Acknowledging your own feelings as a carer can be difficult. You may feel guilty, or that you are being selfish. It is okay to admit to the difficulties you are experiencing and seek help for yourself. Whether you discuss your emotions with your partner or your immediate family, or you choose to participate in a self help & support group or individual counselling sessions, it is crucially important that you are able to talk about your feelings, in order to maintain your own emotional wellbeing.

'I think in regards to caring...it's important to let people know that some of the emotions you feel, even if you're ashamed of them, are normal and okay.'

If you wish to talk to someone about the difficulties you are experiencing as a carer, you can receive help and support from the Beat Helplines. Contact details are printed at the end of this booklet. You will also find details of the Beat message boards – on the Carers' Forum and the Beat website – which are used by a huge number of people affected by eating disorders with whom you can share your experiences.

Other sources of help are outlined throughout this section of the booklet.

Who should I tell?

While it can be extremely difficult to open up to friends and family members who are not yet aware that the person you care for has an eating disorder, it can be very helpful to do so:

'I have been able to be very open with our family, friends and indeed new acquaintances. No-one has been critical or negative – rather, even new acquaintances are supportive and sympathetic. This has been very helpful – in some ways it has brought the family closer together, and it has certainly been a major factor in keeping the stress down in what is otherwise a very stressful situation.'



Who you choose to confide in and how much you choose to tell them is at your discretion. It is best to reach out to people who you know to be sympathetic and non-judgemental. Negative comments and judgments from others are hurtful and unhelpful. As a carer, having supportive, dependable relationships is vital.

Be honest with the person you are caring for about whom you intend to tell. Work to maintain trust between you at all times.

Overcoming Shame and Secrecy

In our society there is still a stigma surrounding eating disorders. People tend to fear what they don't understand. When somebody suffers from an eating disorder, it is easy for other people to alleviate their own fears by blaming those close to the sufferer for the illness.

'It is an illness that is hard to understand if you haven't actually had it, so it is important to break the stigma early with family and friends.'

While you will probably want to be selective about who you choose to tell about the eating disorder, it is best to be open when possible. Ignorance thrives on misunderstanding; being open can help to address this by making others aware of your situation, and of the realities of eating disorders. It can also relieve you of the exhausting need to expend time and effort keeping things hidden.

'... I made sure that my immediate family knew what was going on, so that we never had to try and hide anything when out and about.'

Remember, eating disorders thrive on secrecy; honesty and openness play a vital role in overcoming them.



Getting help from others

It should be clear by now that getting help from others is vital to ensure that not only the sufferer, but also you as a carer have the support that you need.

You may find yourself inundated with well-intentioned questions from your wider support network. If these become too much, you could nominate a friend or relative to talk to those concerned and update them. Being a carer can be isolating, so be mindful of those less close to you becoming afraid to approach you. Maintaining their 'discreet support' – encouraging occasional unobtrusive gestures like being asked how you are - can be a real boost and prevent awkwardness in these relationships.

If there are people around you who want to help but whose close involvement is not appropriate, you could still engage them positively by asking for their help with day-to-day tasks which you have less time for as a carer.

You have a right to privacy, however. If those around you persist with unwanted questions or offers of help in dealing with the eating disorder, explain that you have arranged professional treatment and what you need from them is their understanding and their continued friendship and support.

Taking time off for yourself away from your caring role

'I made certain that I went away for a long weekend every 5 weeks or so, just to recharge my batteries.'

Allowing time out for yourself away from your caring role can be vitally important in enabling you to continue to provide the necessary help and support. The benefits of getting away from an exceptionally trying environment, having the opportunity to rest and recuperate, and to put things into perspective before returning to your caring role, cannot be underestimated.

From the carers Beat has spoken to, it is clear that it is harder for some than it is for others to find the support they need in order to take a break or share caring responsibilities. Here, friends and family can help:

'My help network was excellent (dietician, therapist, family, friends & help groups). I understand that many do not have what I had... they could help at times when I wanted a break.'

If you share caring responsibilities - for example, with a partner - it may be possible to take it in turns to have a break from caring. This way you can ensure that you both have an opportunity to rest and relax. Equally, don't forget the importance of spending time together with your partner.

Should you not have anyone to share caring responsibilities with, carers' organisations may be able to help. Crossroads Care offer respite for carers, and can arrange for someone to come in and look after the person you support, for a certain number of hours each week. To find out if services are available in your area, and if you qualify, call Crossroads Care or visit their website using the contact information at the end of this booklet.

Self Help & Support Groups

'There is no substitute for talking to others in the same situation.'

A number of carers Beat has spoken to have commented that self help & support groups have been invaluable in enabling them to cope. As eating disorders are still widely misunderstood, carers often comment on the benefits of support groups where they can share similar experiences, feel understood and supported, and realise that they are not alone in what they are going through.

You can use the HelpFinder on the Beat website to find your nearest group. Alternatively, you can ask your GP or healthcare team to find out about groups in your area.

'The knowledge that other people feel just as you do, have gone through the same things... is great.'

Other forms of help and support

Aside from self help & support groups, there are additional forms of help and support available to you. There are a range of counselling and psychotherapeutic treatments available – talking therapies – which may allow you to talk about your difficulties in a confidential setting. This should not be seen as an opportunity to talk about the sufferer in their absence, but rather to deal with and alleviate your own anxiety and distress.

You can talk to your GP about the availability of NHS provided counselling in your area. Alternatively, you can search for a private counsellor on the website for the British Association for Counselling and Psychotherapy (BACP) – www.bacp.co.uk – or by telephoning the BACP on **01455 883300**. The Princess Royal Trust for Carers offers a course of free counselling sessions for carers. Contact them using the links at the end of this booklet to find out about availability in your area.

Benefits and financial issues

Being a carer for someone with an eating disorder can put a tremendous strain on your finances. You may be able to qualify for one or more of the various forms of financial assistance available. To find out more about these, to assess your eligibility and to apply, visit the Directgov website: www.direct.gov.uk.

Hopefully this booklet has helped you gain an initial understanding of eating disorders, or has furthered your existing knowledge. We hope you will feel you have an improved knowledge of how to support the person you care for, and how to alleviate the effects of your caring role. Eating disorders are such complex illnesses, many more questions are certain to arise throughout your experience of supporting the person you care for. The Useful Links section that follows may help you to answer some of these questions, and to access further information and support.



Useful Links

The Beat website features extensive information and links to other organisations, the Helpfinder, message boards, research, recommended reading and other resources: www.b-eat.co.uk

Beat Carers' Forum, a dedicated space for those supporting someone with an eating disorder:
www.b-eat-carers.co.uk

Beat services for adults (over 18):

Helpline: **0845 634 1414**

Mon-Fri 10:30am-8:30pm, Sat 1pm-4:30pm

Email: help@b-eat.co.uk

Beat services for young people (under 25):

Youthline: **0845 634 7650**

Mon-Fri 4:30pm-8:30pm, Sat 1pm-4:30pm

Email: FYP@b-eat.co.uk

Carers Direct is an NHS service for carers including a website and phone line. The website includes a Money and legal section, including details of available benefits:

Website: www.nhs.uk/CarersDirect

Phone: **0808 802 02 02**

Carers UK campaign for carers, and provide information and advice:

Website: www.carersuk.org/Home

Advice line: **0808 808 7777**

The Citizens Advice Bureau can be contacted with enquiries about legal rights, responsibilities and entitlements; benefits for carers and financial advice; as well as employment law issues.

Website: www.citizensadvice.org.uk

Admin line: **020 7833 2181**


Crossroads Care provide support to carers and have schemes in most parts of England and Wales:

Website: www.crossroads.org.uk

Phone: **0845 450 0350**

The **Directgov** website has a detailed section for carers, including information about support services, employment issues, carers' rights, carers' assessments & carers' allowance. The 'Your Rights in Health' section details the Mental Health Act, the Mental Capacity Act, and access to treatment:

Website: www.direct.gov.uk



The Institute of Psychiatry have a website featuring downloadable resources for carers, and a dedicated eating disorders research team.

Website: www.iop.kcl.ac.uk

Phone: **020 7848 1000**

Mind is a mental health charity providing information, support and services to people affected by mental health issues directly or through knowing a sufferer. They also have a legal advice service:

Website: www.mind.org.uk

Email: info@mind.org

NHS Choices gives information about conditions, treatments and local services:

Website: www.nhs.uk

The NICE Guidelines can be found on our website or at:

Website: www.nice.org.uk

Phone: **0845 003 7780**

Patient Advice and Liaison Services (PALS) explain how to complain about NHS services which you feel have failed you:

Website: www.pals.nhs.uk

Princess Royal Trust for Carers provide information, advice and support services for carers:

Website: www.carers.org

Phone: **0844 800 4361**

Email: info@carers.org

Rethink is a mental health charity aiming to help those affected by mental health issues to recover a better quality of life. Their website features Rights & laws and money, debt and benefits sections

Website: www.rethink.org

Phone: **0845 456 0455**

Email: info@rethink.org

Young Carers Net (YC Net) provide information, advice and an online community for young carers:

Website: www.youngcarers.net

Phone: **0844 800 4361**

Email: info@carers.org



Beat

Wensum House, 103 Prince of Wales Road
Norwich NR1 1DW

Admin: 0300 123 3355

Fax: 01603 664915

Email: info@b-eat.co.uk

Website: www.b-eat.co.uk

Registered charity no. 801343

Scottish charity no. SC039309

Company limited by guarantee no. 2368495

Helpline: 0845 634 1414

Email: help@b-eat.co.uk

Youthline: 0845 634 7650

Email: fyp@b-eat.co.uk

Text: 07786 201820

To become a member of Beat, call 01603 753308