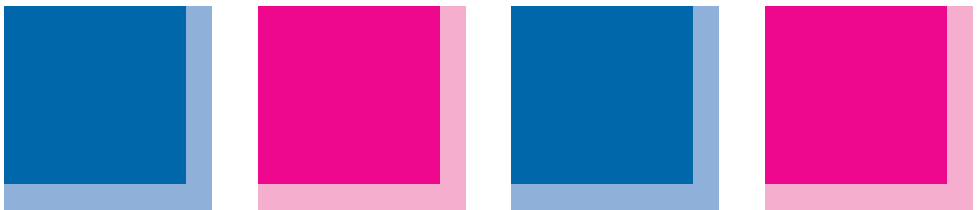




Supporting a **partner**

with an eating disorder





Introduction

Who is this booklet for?

This booklet is intended for anyone whose girlfriend, boyfriend, wife or husband suffers from an eating disorder.

Whether you have just become aware that they have an eating disorder, or you have been supporting them for some time, this booklet has been designed to provide the essential information you need: about the different types of eating disorders, appropriate treatment, and how you can best support them and take care of yourself too.

Partners as ‘Carers’

In this booklet, the word ‘partner’ has been used to denote the boyfriend, girlfriend, husband or wife of someone who suffers from an eating disorder. Beat recognises partners do not see themselves as ‘carers’, as one individual has exemplified:

‘I would never consider myself a carer, as this...brings connotations of it being a profession and also not a desire. I’m a boyfriend and my girlfriend is...someone who struggles with her own self-image, confidence, beliefs.’

As far as possible, within this booklet the term ‘carer’ has been avoided, and ‘partner’ has been used instead. However, it is important to get used to thinking of yourself as a ‘carer’ and being thought of or addressed as such; you may otherwise find that you ignore information and services which could be of use to you, or which you qualify for.

Within the healthcare profession and the field of mental health, any persons providing support to an individual receiving treatment are often referred to by the blanket term ‘carer’. As such, this term has been used in the ‘Treatment’ and ‘Confidentiality and Consent’ sections of this booklet.

The importance of recognising yourself as a carer is made abundantly clear in the final section of this booklet, entitled ‘Looking after yourself’.

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 and 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, message boards and online live chats specifically 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).

It may come as a shock to learn that the person you are starting a relationship with, or with whom you have had a relationship for some time, has an eating disorder. Many people don't know a great deal about eating disorders, so this can be frightening and hard to understand.

'To hear of this type of illness was hard to put into perspective... How could something so easy to the majority – eating – create such a fearful, lonely and desperate place for some?'

Finding out more about eating disorders can be a daunting prospect: there's so much to learn. However, arming yourself with useful information is vital if you're to provide the best possible support for your partner, and accompany them on their journey towards recovery.

This booklet is a good place to begin. It is a comprehensive resource which will provide you with all the basic information you need, and tell you where you can look for further information and answers to the many questions that you will no doubt have.

While eating disorders can affect people of any gender, age, ethnicity or social or economic background, the exact reason why some people develop eating disorders and others do not is not known. The risk factors that have been identified are discussed further on in this booklet.

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.

Your partner's behaviour may be so drastically changed by the eating disorder you may at times feel that you don't recognise them. The changes can be shocking and upsetting for you both, and those around you. What's more, it can be immensely frustrating if your attempts to help are spurned.

Whichever type of eating disorder your partner 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.

Eating disorders can be a way of coping with emotional distress and can give the sufferer a feeling of being in control. They are not all about appearance and are not a "phase" or "attention seeking". They are serious mental illnesses. However, they are treatable. While the initial signs can be subtle and are often masked by the person suffering, early intervention is best. Recovery is always possible: the sooner your partner gets help, the greater the chance they will fully recover from their eating disorder.

'It is the hardest thing for a sufferer to tell someone, but once you know you can make choices that make their life so much easier and less stressful, allowing them to concentrate on recovery and not just concealment.'

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:

- In children and teenagers, poor or inadequate weight gain in relation to their growth, and/or substantial weight loss
- 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
- Delayed puberty, or puberty halted once it has begun
- 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)
- Stunted growth

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 should be sought.

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, or hoarding food

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?

First steps: If you think your partner 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 broaching the subject of your partner's eating disorder with them:

- 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 your partner 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, your partner 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 your partner, and reflect positively on the steps you've taken – you have opened a door

'The best thing you can do is be a listener... Gaining their trust is a must and trying to do things too quick[ly] does not work.'

Here are some tips for what to do and say when talking to your partner:

- 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 your partner’s shoulder 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
- Get young sufferers into treatment. There is every chance they will protest; don’t give in and don’t wait until they are ready



Your relationship

Openness and establishing a dialogue

Your partner is likely to be forever contending with difficult emotions, such as guilt and shame. Secrecy also plays a big part in eating disordered behaviour; unless your partner is able to open up - unless you are able to establish a dialogue with them – this will only be perpetuated. Early on, you need to ensure that your partner feels they can open up to you with even their darkest thoughts. Only then can you move on together.



It is important to really listen to your partner, to let them tell you what's going on for them. Don't try to rely on a 'manual', or on generic conceptions, such as 'this sign must mean this or that'. Focus on your partner as an individual, letting them tell you how they're experiencing things.

'When you start a relationship with someone with anorexia nervosa, you're taking on that eating disorder. You can't get around it, you can't brush it away, there are no quick fixes. The only thing you can do, if you're serious about the relationship, is to understand everything you can about the eating disorder – and you won't get that from just reading about it. You've got to make a massive effort to find out from your partner, and you can only do that by being open and understanding, by talking and listening.'

This openness is equally important for you: it's crucial not to get into a situation where either of you feels that you can't talk things out. After all, there are two of you in your relationship. You need to be able to talk about your feelings too. Remember always to be clear about how you are feeling and to explain what you mean, as someone suffering from an eating disorder may be inclined to 'read the worst understanding of what you've said'.

'I realised that I could say what I thought but would always explain it as there is nothing more dangerous than allowing someone with an eating disorder to decide what you mean for you.'

If they misunderstand you, your partner may feel bad as a result and may revert back to secrecy. If this happens, try not to beat yourself up. Learn from your mistakes and remember that under the scrutiny of your partner's eating disorder, you can't get everything right all of the time.

Your partner may show a complete awareness of the irrationality of some of their thoughts, but at the same time be overwhelmed by their desire to carry on with their eating disordered behaviours. You need to be the sensible, rational voice.

Keep talking – keep the dialogue open all the time.

Dealing with difficult emotions

Your attempts to listen, to help and understand are likely to be repeatedly refused by your partner, who may experience your efforts as threatening. They may become angry at you, shout and call you names: this is most likely the voice of their eating disorder. It can be very hard not to retaliate when you are attacked or insulted verbally, but to react in kind can simply confirm your partner's insecurities and encourage more of the same behaviour.

'If the person snaps at you, the best response (in my opinion) isn't to snap back and get petty, but to reassure them, to stay close and understanding so that if part of them tries to push you away, you don't provide an excuse for the other part to push as well.'



While this is arguably the best approach, it is far from easy:

'There are huge elements of self-control which need to be used by the partner... as the end goal is to get the sufferer to feel good and change their beliefs but by doing that you need to hold your tongue or realise that sometimes you just can't understand, and that it isn't a bad thing to admit it.'

You will likely find that your partner experiences intense emotional outbursts, which can be angry and aggressive and seemingly impossible to manage. The risk of these outbursts is especially high when a person with an eating disorder feels challenged or is attempting recovery. It is important to work out a way of setting boundaries – limits on the behaviour you will tolerate.

Try to walk away from angry, unmanageable situations, and talk again when things have calmed down. Similarly, while it is always best to vent your own emotions away from your partner, try not to feel guilty if you become angry or upset. If possible, make time to discuss your feelings with your partner later. Explain the reasons for your behaviour and encourage your partner to do the same.

What can I say?

It can be hard to know just what to say around someone with an eating disorder. You may sometimes feel that you're walking on eggshells when you're with your partner. Conversations about food can trigger the strongest emotions. You need to walk a fine line, as far as possible shying away from discussions that centre on food, calories, clothing or body shape, size or weight, while not avoiding mention of weight, eating, etc. altogether – otherwise you might encourage more secrecy.

Within a relationship, compliments are a natural way to express your appreciation of your partner. It can be awkward and uncomfortable not knowing what to say, or fearing that a compliment will trigger a negative response from your partner. Again, the best approach is to avoid comments about your partner's weight, body shape or size. If your partner is in recovery, you could comment on their energy levels, or how healthy they look. A comment such as 'You're full of energy' safely affirms that their health is improving without mention of their body.

'Commenting on non-weight related things such as her hair was particularly nice that day or how I love her laugh or smile...boosted her self-confidence.'

Keep in mind the following points too – they may be very helpful:

- Talk to your partner about how much you value them as a person – compliment their personality and achievements rather than physical attributes
- Don't jump to conclusions – let your partner tell you how they are feeling and how you can best help them
- Remember that even if your partner looks 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 your partner's apparent weight gain may be detrimental and should be avoided
- If you are concerned that your partner is in immediate danger, call an ambulance, or take them to A&E





Intimacy and coping with feelings of rejection

There is little doubt that you will find yourself rejected by your partner. Relationships are founded on intimacy, closeness with another: emotionally, physically. With your partner's eating disorder dominating their thinking, this will simply not be possible for them. Inevitably, when you find yourself repeatedly rejected by them, your self-confidence is going to suffer.

Try to imagine things from your partner's point of view: they're likely to be lacking in self-esteem, feeling ugly or unworthy, or they may imagine that they're unlovable – and that intimacy with you will only confirm this belief. Then acknowledge your own feelings too – and be sure to talk about them with your partner:

'You will be and you will feel rejected. You're going to be bombarded with that sometimes. For your own self-confidence, you need to have that dialogue because you're going to feel very unwanted. If you can get to the bottom of the problem and realise it's not you, your relationship is going to be better for it.'

Maintaining 'normality' and taking time out

'Time to yourself to let go and be "normal" is critical to keep you focused.'


Continuing to live life as normal, involving your partner in things that you enjoy doing together, can maintain a healthy relationship which isn't ruled by your partner's eating disorder. So too can continuing with your own hobbies or spending time with your friends. This can help you to occasionally find some much-needed space away from your relationship, allowing you time to relax and ensuring that you can continue to support your partner.

'...I feel that any relationship is about giving and receiving...I think you should try and remain balanced and not let the relationship become dominated by the disorder, so for myself I do things with [my partner] just like anyone else would...go to stand up, cinema, walks, TV together. I'll also do as I would otherwise, like golf with the guys, go on nights out, etc.'

Moving forward in your relationship

Positive steps forward in your relationship and your commitment to each other, such as moving in together, may not bring about the response you might expect from your partner.

This new level of intimacy, such as sharing a living space and being around each other more often than you were previously, could bring about a negative reaction from your partner, as they may find they can no longer so easily engage in eating disordered behaviours. Remember, changes such as this – which ordinarily bring great happiness for many couples – can feel invasive and



frightening to someone with an eating disorder, and they may appear resistant to the change. Again, it will be important for you to be able to share your feelings with one another, to talk about how the changes affect each of you, to adapt to your new situation and move forward together.

Finally, move on – but don't close the door entirely

It is important to remember that recovery is always a case of small steps – not great leaps. It's not finite: it's a journey, not a destination.

When your partner starts to get beyond his or her eating disorder, understandably you may want to try to forget about it, put it in the past, and move on.

Be very wary of doing so. If you try to close the door completely, your partner may feel unable to talk about their problems if something once again triggers their negative thoughts or eating disordered behaviours. If you both adopt a rigid attitude that your partner is 'recovered', they might dismiss these signs, feel that they can't share them with you, and not get the help they need. Aim to keep communication open between you. About everything. Always.

Rob & Helen's story

Rob & Helen met in 1996. After a short time together it came to light that Helen was suffering from anorexia. What developed was a strong team of family and professionals who openly communicated and worked together with Helen to help her overcome this illness. Rob says that advising close friends and family of the illness meant there was no need to try and cover anything up – they could concentrate on recovery and keep things as "normal" as possible.

Helen wanted so much to get better for their wedding in August 1998 that every effort was focused on this goal. The wedding came and went, but unfortunately Helen rapidly deteriorated soon after. The couple had learnt that trying to beat this illness quickly was not going to work.

After Helen hit rock bottom, late in 1998, there was slow and steady progress, often taking steps backwards to gain some forwards. There was also the added frustration of OCD entering the frame as Helen started to recover. Helen's self-esteem and self-worth were lower than they had been throughout the illness. Again the team pulled together and co-ordinated a plan to push Helen forward, always encouraging, always listening and always being there for any issues – however small.

Different stages of the illness required different approaches, guided by treatment professionals – crucially, Helen's dietician and psychotherapist. Helen went from strength to strength at a pace that worked for her, although it did take time to get the right results. Caring for a partner was hard, but Rob ensured the couple remained focused on dreams and goals for the future, to keep Helen fighting.

Following "sign off" in 2002, Rob and Helen now enjoy a busy family life with two beautiful girls, Chloe & Sophie, both rewards for their hard work and positive way in which they confronted and beat this illness. Helen is now a more positive and confident person because of what she has been through and knows that she never wants to be back there. Life is better without an eating disorder and these two people are proof that it can be beaten.



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. Acknowledging a problem can be especially hard for younger sufferers. As their partner, it is essential that you support them in taking 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 your partner.

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 your partner is entitled to: www.nice.org.uk. 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 your partner to an appointment with the GP may help them to feel at ease, and with younger sufferers it is encouraged. All stages of contact with healthcare professionals can be very distressing for someone suffering from an eating disorder. It may help them if they write down what they want to say, so they can still talk and explain how they feel even if they become upset. Likewise, if they have consented to you being at the appointment, it may be easier for you to retain some of the essential information, which you can then both discuss later.

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 your partner, so it is important to be persistent with your 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 your partner to ask to see another GP in the surgery (you don't have to give the receptionist a reason); register with another doctor's practice in the area; 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); or call the Beat Helplines for advice.

The GP may decide it is necessary to refer your partner to *secondary care*, which includes specialist treatment with a psychologist, psychiatrist, counsellor or dietician. At this level, you may hear the term CAMHS (Child and Adolescent Mental Health Services) – NHS provided mental health care services for children and adolescents in the UK

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 your partner's physical wellbeing, 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 to find the right treatment for your partner. 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 your partner needs support through treatment and recovery and reassure them that no matter how difficult things get, you love and care for them unconditionally.



Confidentiality and Consent

The healthcare team are legally obliged to keep detailed information confidential. Continuing to work on trust, openness and honesty between you will be particularly beneficial here, as in most instances you will find that you do not have any right to access information about their treatment or medical records unless your partner gives their consent.

If children under 16 are deemed to have the capacity and understanding to enable them to make decisions about their treatment, then they are further entitled to make decisions about the use and disclosure of information that they have provided in confidence.

Young people of 16 and 17 are entitled to the same duty of confidentiality as adults, as they are deemed to be competent for the purposes of consent to treatment. However, if a competent child refuses treatment for a life-threatening illness, the Department of Health imposes a duty of care requiring confidentiality to be breached, to the extent that those with parental responsibility for the child may be informed.

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; the Health Rights Information Scotland website is a comprehensive resource: www.hris.org.uk.

Sectioning

If your partner 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 your partner is receiving unsatisfactory treatment, you may want to refer to the NICE guidelines. It may be helpful for your partner 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. It is likely that they will 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 if your partner 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.





Eating disorders, your family and friends

If you and your partner have children, you naturally may have concerns about how they will be affected by and respond to your partner's eating disorder. However, you needn't automatically assume that your children will be negatively affected.

You, your partner or both of you may feel tempted to keep your partner's eating disorder from your child or children, in an effort to protect them. Remember that with children, very little goes unnoticed; while you may think you're getting things past them, your attempts at secrecy may actually be easily spotted by keen-eyed and inquisitive children denied a sufficient explanation or understanding of what they have witnessed. This lack of understanding in a confusing atmosphere of secrecy can lead them to feel guilt or anxiety.

Depending on the age of your children and whether or not it is possible to do so, the best approach is to involve them, explaining the situation for them in age-appropriate terms, offering them reassurance and encouraging them to ask questions and talk about how they feel.

While you may feel pressured or burdened, it is worth remembering that if your partner is struggling with an eating disorder, the effect on your children can be alleviated by you taking control of the situation, sticking to your strengths, and modelling healthy eating behaviours that your children - at an impressionable time of their lives - can learn from.

Your partner's behaviour, especially when it is aggressive and angry, may be difficult for your children. However, as one partner pointed out:


'Children will be able to understand some of the things that are going on. If there's one thing children understand, it's tantrums. Demonstrating to your child a range of emotions is no bad thing – it's not an adult's job to be somebody who's totally in control all the time.'

Again, if appropriate, try to ensure your children have an opportunity to talk about how they feel. They may experience the same grief and stress as you, avoid the situation altogether or become too heavily involved, adopting an inappropriate caring role. Encourage them to be open.

They may want to talk to someone outside of the situation, in which case you could suggest that they call Beat's Youthline. Youth Access provide a directory of free young people's services, including counselling: www.youthaccess.org.uk.

Although supporting your partner can be extremely demanding, and physically and mentally exhausting, try to find time for your children, and try not to become angry with them if they misbehave or act out in response to the difficult situation facing you all.

With your attention understandably focused on your partner, it can be easy for children to feel ignored and unloved. Try to maintain normality as much as possible: talk to your children, love



and care for them as you would normally and make time to do things together as a family. You could fix a time when discussion of the eating disorder is banned. You may also be able to call on relatives who can spend time with your children, or support your partner at times when you want to be able to give your children more focused time and attention.

Who you choose to tell about your partner's eating disorder and involve in your support network should be a joint decision (there is more about this in the 'Looking after yourself' section at the end of this booklet). However, be wary of explicitly promising to keep anything secret; this may come back at you if your partner discovers it has been inadvertently disclosed to someone else, potentially unsettling your partner and compromising the trust you have worked so hard to establish.

For both of you, maintaining close friendships can prevent harmful social isolation, maintain normality, and provide you both with greater stability at a difficult and turbulent time. Friends and relatives alike can also be called upon to offer their help and support when you most need it.

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 your partner to eat and anticipate and alleviate potential triggers without inadvertently encouraging their eating disordered behaviours.

When you are caring for 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 your partner – 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 your partner. 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


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- Don't let the person you care for 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 your partner, 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 your partner, 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 your partner to eat

Encouraging them to eat

- Start slowly: in the beginning, be wary of pressurising your partner 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
- Your partner 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

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- 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 your partner can plan what they will eat or arrange to bring “safe” foods of their own.

If your partner 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.

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 for your partner. 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 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 your partner 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.

If applicable, including amongst your support network the appropriate persons at the school or college your partner attends can be very helpful. This can help to ensure consistent support, and raise awareness of the sensitivities of the situation and potential triggers that should be avoided.


Be honest with your partner 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

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'



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 care for, 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 your partner 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 the 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 better prepared to support your partner. Eating disorders are such complex illnesses, many more questions are certain to arise. The Useful Links section that follows may help you to answer some of these questions, and to access further information and support.

Each individual case will be different. While resources such as this booklet can help you to understand and improve your situation, there will be unique challenges for you both, and it may take some time to figure out what works best for you and your partner and the way you relate to one another. Remember, trust, openness and understanding are key:

'There are similarities in every single experience I've read about but no single one of them has been hugely close to mine, simply because we are all different. I want to know different things about a different person and have a different way of dealing with them. This is hugely frustrating when you are trying to read up and get answers, but when you accept that the solution will take a long time, and that the best solutions will need time to build (building trust around the issues and accepting the good with the bad) it instantly gets easier to deal with.'



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 and laws and Money, debt & 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



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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