

# CARING FOR SOMEONE WITH AN EATING DISORDER



This leaflet has been written collaboratively by the service users and staff of Sheffield Eating Disorders Day Service, as an aid to understanding and supporting communication between sufferers and carers.



# Introduction

Eating Disorders cover Anorexia Nervosa, Bulimia Nervosa, Binge Eating Disorder and EDNOS (Atypical Eating Disorder). Eating Disorders can begin for a variety of reasons, often unrelated to a preoccupation with shape and weight. However, as the eating disorder develops, preoccupation with food, weight and shape often becomes a core feature.

Eating disorders develop in different ways for different people but generally both physical and mental health are affected. The majority of sufferers can and do recover provided they receive effective help and support.

## ***A glimpse into the experience:***

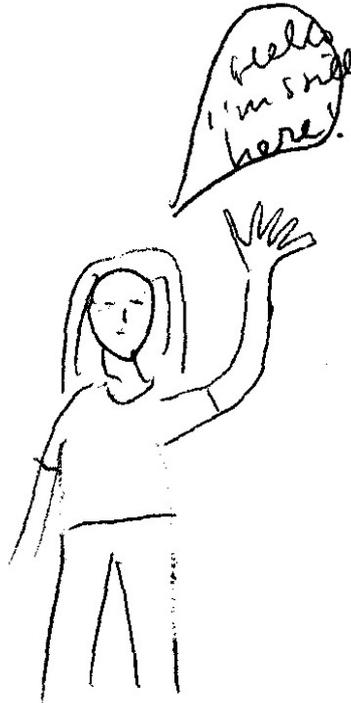
“Eating disorders are hard to understand unless you’ve suffered from one yourself. Someone who was once your child, friend or partner may seem to change dramatically – not just physically, but in terms of their personality and emotions as well.

The sufferer is still the same person, they still love you and they’re still human; but the constant tormenting thoughts arising from an eating disorder causes such severe anxiety, guilt and other difficult emotions, that it can be hard, as a carer, to know how to respond.

Having an eating disorder is like having your mind taken over by a bullying presence; being constantly reminded by this inner voice that you are worthless and guilty, fat and ugly. Eating disorders are not logical or rational and they are not a reflection of intelligence. An eating disorder is separate from the person and gradually takes over body and mind.



When we suffer from an eating disorder, our brains become malnourished and we may find it hard to concentrate, make decisions, respond to situations rationally or regulate our emotions. We may seem like an empty shell, subdued or erratic, exhausted or eager to exercise. Remember we're still here, we are still your child, friend or partner."



## Understanding the Eating Disorder

It may appear that an eating disorder is centred around food and weight but actually there are often underlying issues underpinning an eating disorder such as low self-esteem, perceived self-control or thinking distortions.

Understanding an eating disorder can be extremely difficult for a carer but on the following pages are some tips that might help you and your loved one support one another. Your loved one is as aware of impacting on you as you will be of impacting on them.



Understand that...

- The person is separate from their illness;
- Eating disorders are very individual to the sufferer and therefore it is essential to maintain communication. It may seem easier to avoid talking about “the elephant in the room” but this makes it harder for you both in the long run;
- Realise that changing behaviour takes time. Patience and sensitivity are essential;
- It takes a lot of courage for a person to accept and admit to having an eating disorder; the sufferer may be in denial and isolating themselves from others;
- It would help to try and keep the needs of the sufferer in mind, as they are likely to be neglecting themselves and their own feelings as their eating disorder takes over;
- Be aware that people with an eating disorder are often not good at asking for support or accepting it;
- The eating disorder is irrational and, therefore, it is hard for carers / family to get it right. It would be unrealistic to ‘get it right’ all the time;
- We are grateful for support from carers and recognise how difficult it can be to do the right thing all the time;
- Remember it is just as important for the carer to look after their own emotional needs and take time out. You cannot help the person recover if you are suffering yourself.



# Helpful/ Unhelpful Comments

## Helpful

- Communication is key. Don't be secretive, involve me in conversations;
- It would be helpful to open up conversations proactively about where I'm at;
- Give me time to talk and encourage me to talk about my feelings. Ask questions like "perhaps you could tell me what's going on for you now?";
- Lead by example e.g. have a snack or say "I might stop for my snack now".

## Unhelpful

- A Bulldozer effect can make things more difficult. For example, saying "just eat", repeatedly suggesting or reminding me about different things to eat;
- It's not what you say but how you say it. Being 'accusing' is not helpful;
- Avoid commenting on portion sizes / appetite – especially at meal times or while eating. For example if having a special meal don't say "I've barely eaten all day to prepare for this" or "I'm stuffed. I can't finish this, it's a huge portion";
- Avoid discussing diets, weight loss, calories and nutrition in front of me;
- Avoid talking about body shape or size;
- Don't pretend it will all just go away.

*This advice is still relevant and important no matter what stage the person is at and regardless of weight.*



# What to do

- Initially when you first notice something's wrong and suspect I may have an eating disorder, try to talk to me. If I'm defensive and you hit a brick wall (e.g. I say "I'm fine"), then consider seeking professional help as soon as possible;
- Be patient. Recognise how hard recovery is for me. Cut me some slack;
- Try to understand me. I am not my eating disorder;
- Offer practical support. Most people find it helpful to have someone eat with them and to establish regular meal times. Routine helps wherever possible;
- In the early stages it can be helpful to support the sufferer with decision making and control our portion sizes and food choices. However, in later stages when the eating disorder is less powerful, it may be more helpful to allow the person to make their own choices;
- Try and be gentle, firm, patient and tactful;
- Offer encouragement with keeping on with my goals;
- Help plan for difficult situations such as time spent alone or going out for meals;
- Work together and communicate – remember you are working towards a shared goal. As parents or carers, try to be consistent in your approach.



## What to avoid

- Please avoid making assumptions about my eating disorder. For example, certain decisions around food might be genuine likes and dislikes, unrelated to the eating disorder. However in the early stages this can be difficult to identify;
- Try not to pre-empt what the sufferer will or will not want to eat. Instead encourage them to make their own choices;
- Realise that at some point I am going to have to take responsibility for eating and exercise choices. Don't 'fuss';
- Don't push me to do a certain thing if I'm not comfortable, but suggest ideas every so often;
- It can be unhelpful to make jokes or sarcastic comments about me or my eating disorder. For example, "you make me look like a whale";
- It can be easy to let emotions get the better of you when you reach boiling point and this is often when the most unhelpful things are said. In these situations it is better to say "things are getting too heated, I think we should talk later";
- Often this scenario can lead to finding someone to blame and often carers blame themselves, but this makes us feel worse as if we are a burden.

Please see Chapter 3 ("Don't Waste Time on 'Why'?") in 'Help Your Teenager Beat an Eating Disorder' by James Lock and Daniel Le Grange



## Available Support:

- Sheffield Eating Disorders Service is one of the specialist services provided by Sheffield Health and Social Care Trust. The Eating Disorders Service offers out and day patient services to sufferers with a severe eating disorder and also provides information and support for carers. Access to the Service is via referral from your GP or a health professional.

Sheffield Eating Disorders Service,  
St George's Community Health Centre,  
Winter Street, Sheffield S3 7ND.  
Tel (0114) 2716938 Fax (0114) 226 2223

- SYEDA (South Yorkshire Eating Disorder Association) offers a range of support and services for people with an eating disorder and carers including a course specifically for carers 'Treading on Eggshells'. Further information is available from SYEDA. Access to the service is via a self-referral, which can be done on-line, over the phone or in person.

South Yorkshire Eating Disorders Association  
26-28 Bedford Street, Sheffield S6 3BT  
Telephone: 0114 2728822. Website: [www.syeda.org.uk](http://www.syeda.org.uk)

### Useful books:

- Help your Teenager Beat an Eating Disorder – James Lock and Daniel Le Grange (Guilford Press)
- Anorexia Nervosa: A Survival Guide for Families, Friends and Sufferers – Janet Treasure (Routledge)
- Skills-Based Learning for Caring for a Loved One with an Eating Disorder – Janet Treasure, Grainne Smith and Anna Crane (Routledge)
- Cold Hands, Warm Heart: A Memoir – Grace and Liz Nicholas (available from SYEDA)

