

Eating disorders

Introduction

This leaflet is aimed at:

- the carers of people with an eating disorder who provide continuing help and support, without payment, to a relative, partner or friend;
- the psychiatrists and the members of the mental health team involved in the care and treatment of a person with an eating disorder.

It suggests ways of improving communication and partnerships when the person has first been diagnosed.

For the carer

About eating disorders

Eating disorder is a term used to cover disorders, such as Anorexia and Bulimia Nervosa, Binge Eating and Eating Disorder Not Otherwise Specified. These can vary in severity and there are a range of treatments available.

Changes in the person's behaviour

As a carer you may notice:

- a change in body weight
- secretive behaviour around food
- changes in mood or personality
- loss of interest in hobbies and friends
- a tendency to isolate oneself
- changes in eating patterns
- tension in relationships and general irritability
- sensitivity about body weight and shape, including excessive weighing
- smoking more, or chewing gum to keep weight down
- increased exercise.

Making a diagnosis

There are clear criteria for diagnosing each eating disorder. A diagnosis is made by talking to the person and a close relative or friend

to get an understanding of the person's history, as well as considering all other possible causes of the symptoms.

As a carer you may feel:

- scared about admitting there is a problem
- exhausted by caring and trying to ensure the person is eating
- anxious about the person's physical state
- scared that this is your fault, or that something dreadful has happened to cause this
- angry that the person is so secretive or is perhaps lying about their problems
- powerless to help
- confused about what treatments are available, and where to get them
- that you want the person to be treated immediately
- worried that the person won't accept treatment
- worried about the stigma attached to eating disorders
- worried about the risk of suicide, death or severe injury.

Tips for carers

In partnership with with your doctor and members of the health team

Good communication between a doctor, the key worker, other members of the mental health team, the person and their carer is important, but takes time and effort.

Forming a positive long-term relationship with all the staff and doctors involved in the care of the person is especially important in the treatment of Anorexia Nervosa, which can take up to five years. Treatments for other eating disorders, depending on severity and nature of the condition, can be more rapid.

Family support is particularly important as much work needs to be done outside treatment sessions.

Treatment

Treatment usually starts with the GP who will consider the patient's history, weight and height, and try to establish what the problems and behaviours are around managing food and weight. The GP may then refer the person to the Community Mental Health Team (CMHT), or sometimes to a specialist. A quick referral can often be important, as non-NHS treatment has financial implications.

A CMHT will repeat the GP assessment but in more detail, to establish if a referral to a specialist is necessary. Specialists you are likely to come across include: psychiatrists, nurses or nurse therapists, psychotherapists, occupational therapists, psychologists, dieticians

Specialist teams can offer outpatient assessment appointments. These may be carried out by one or more members of the team, and may take more than one appointment.

Questions to ask at the assessment

- What is the diagnosis?
- What treatments are available?
- Can you explain the disorder, and how long it will take for treatment to work?
- What medication is available and what may be the long-term effects?
- Are there strategies to help that can be used at home?
- How often will the patient be seen?
- How often should the carer attend consultations?



- Do you have any written materials on this disorder, if not who does?
- Are there any community facilities or groups that can help?
- Is there a local eating disorder association?
- Who is the key worker? How do I contact them?
- If the person deteriorates physically or psychologically, what is the 'out-of-hours' crisis plan?

Remember to arrange your next visit before you leave.

Aftercare programme

The carer needs to have access to an aftercare programme, including explanations about an eating plan, how to treat meal times, expected weight, gain targets and how to cope with difficult behaviour, including suicide threats.

Accepting help

Treatment for an eating disorder is most effective when the person is able to accept help. Waiting for a person to recognize the need for treatment can be a frightening and frustrating time. Ask the specialist team about strategies to help motivate the patient to accept treatment.

Advice which will help you prepare for follow up visits

- Jot down your view of how things have been, clearly listing for yourself any points of concern.
- If possible, share this with the person before you attend the appointment.
- Review all the information that you have collected since your last visit and write down your main concerns.
- Remember to talk about the things that matter.

Your concerns may include:

- questions about changes in symptoms

- side-effects of medication
- general health of the person
- your own health
- additional help needed.

It is important to agree, beforehand, with the person what they would like you to know about their treatment and what they want to keep confidential.

- Has their key worker discussed confidentiality with them?

During your visit

- If you do not understand something, ask questions. Don't be afraid to speak up.
- Ensure there is agreement between you and the team regarding care and treatment.
- Take notes during the visit. At the end, look over these and tell your doctor what you understood. This gives your doctor a chance to correct any information or repeat something that has been missed.

Further tips for carers when dealing with doctors and other health professionals

Doctors and healthcare professionals can be reluctant to discuss a person's diagnosis or treatment with the carer. There is a real duty of confidentiality between doctor and patient. Have a conversation about confidentiality at regular intervals. By continually checking what the patient is happy to share, and stating what your needs for information are as the carer, a compromise can usually be reached. (See our leaflet, '*Carers and confidentiality in mental health*').

If the doctor is unwilling to involve you as the carer, there are a number of things you can do:

- ask the person you are caring for if you can stay for part of their appointment
- talk to other carers as they may have some helpful suggestions
- contact the Eating Disorder

Association's helplines and carers' networks

- develop a relationship with your key worker.

Don't forget to take care of yourself

- Share your worries with trusted friends or family members.
- Don't bottle your feelings up – there is nothing wrong with a good cry.
- Try not to let the symptoms of the eating disorder take over your life – don't become isolated.
- If you are anxious and are unable to sleep, go and see your GP.
- Do not put your life completely on hold, and try to avoid being drawn into their world.

For the professional

As a professional working with people with an eating disorder and their carers, we hope that the following is a helpful guide to good practice.

When making an assessment, do you?

- Try to see the person and the carer separately, as well as together
- Try to see them at home first

Do you allow yourself enough time to?

- Listen, ask, listen
- Obtain a life history
- Leave time for questions and discussion
- Explain how you arrived at the diagnosis
- Talk about the prognosis

In the management of the illness, do you?

- Discuss possible treatments
- Talk about the side-effects of drugs
- Spend time asking about the carer's health – physical and emotional
- Discuss how to meet the care needs of both the

person with an eating disorder and the carer

Points to remember

- Everyone needs some respite.
- Make it clear that you will be happy to talk to other members of the family.
- Refer carers to the Eating Disorders Association or other carer organisations.
- Make it clear that someone will always be available.
- Give an 'out of hours' telephone number.
- Make sure that there is a named professional person whom the family can contact at any time.
- Make sure the patient and carer have adequate information about their care and treatment.
- When you write to the GP, consider sending a copy to the carer.
- Think about talking to the GP as well as writing.

Further help

Royal College of Psychiatrists

17 Belgrave Square, London SWX 8PG

Tel: 020 7235 2351 ext 259;

www.rcpsych.ac.uk

Produces information for the general public on common mental health problems and treatments.

Eating Disorders Association

103 Prince of Wales Road, Norwich NR1 1DW

Adult Helpline: 0845 634 1414;

Youth Helpline: 0845 634 7650;

www.edauk.com

Provides information and help on all aspects of eating disorders.

Young Minds

102-108 Clerkenwell Road, London EC1M 5SA

Parents Information Line 0800 018

2138; www.youngminds.org.uk

Provides information and advice to young people, parents and professionals.

The Princess Royal Trust for Carers

Provides information, support and advice to carers.

142 Minories, London EC3N 1LB

Tel: 020 7480 7788; www.carers.org