Eating disorders: core interventions in the treatment and management of anorexia nervosa, bulimia nervosa, and related eating disorders

A guide for people with eating disorders, their advocates and carers, and the public

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About this information

This information describes the guidance that the National Institute for Clinical Excellence (called NICE for short) has issued to the NHS on eating disorders. It is based on *Eating disorders: core interventions in the treatment and management of anorexia nervosa, bulimia nervosa, and related eating disorders*, which is a clinical guideline produced by NICE for healthcare professionals working in the NHS in England and Wales. Although the information in this booklet has been written chiefly for people with eating disorders, it may also be useful for family members, those who care for people with eating disorders, advocates for people with eating disorders, and anyone with an interest in eating disorders or in healthcare in general.

Clinical guidelines

Clinical guidelines are about improving the care and treatment provided in the health service. The guidelines produced by NICE are prepared by groups of healthcare professionals, people who have personal experience or knowledge of the condition, patient representatives, and scientists. The groups look at the evidence available on the best way of treating conditions and make recommendations based on this evidence.

What the recommendations cover

NICE clinical guidelines can look at different areas of diagnosis, treatment, care, self-help or a combination of these. The recommendations in *Eating disorders: core interventions in the treatment and management of anorexia nervosa, bulimia nervosa, and related eating disorders* cover physical and psychological treatments, treatment with medicines, and what kind of services best help people with eating disorders. The guideline looks at eating disorders for children aged 8 years through to adults and it covers anorexia nervosa, bulimia nervosa, and related eating disorders, in particular, binge eating disorder. It does not look at

obesity, or how to diagnose or treat an eating problem that is a symptom of another physical or mental disorder.

The information that follows tells you about the content of the NICE guideline on eating disorders. A glossary describing some of the more unfamiliar words and phrases is included at the end.

This document doesn't explain eating disorders or describe the treatments in detail. If you want to find out more about eating disorders, ask your doctor or another member of your health team. Alternatively, NHS Direct may be a good starting point. You can call NHS Direct on 0845 46 47 or view the NHS Direct website at (www.nhsdirect.nhs.uk).

How guidelines are used in the NHS

In general, healthcare professionals working in the NHS are expected to follow NICE's clinical guidelines. But there will be times when the treatments recommended will not be suitable for some people for reasons including their specific medical condition, their general health, their wishes or a combination of these. If you think that the treatment or care that you (or someone you care for) receive does not match the treatment or care described in the pages that follow, you should discuss your concerns with the healthcare professional involved in your care, your GP, advocate or other members of your health team.

If you want to read the other versions of this guideline

The guideline used by NHS professionals is called *Eating disorders: core interventions in the treatment and management of anorexia nervosa, bulimia nervosa, and related eating disorders* and it is available from the NICE website (www.nice.org.uk). The full guideline was produced by the National Collaborating Centre for Mental Health and is available from [details to be confirmed]. It contains all the details of the guideline recommendations and how they were developed.

About eating disorders

This guideline covers anorexia nervosa, bulimia nervosa, and atypical eating disorders, mainly binge eating disorder. Most people with atypical eating disorders are not suffering from anorexia nervosa, bulimia nervosa or binge eating disorder but their eating disorder is often very similar to anorexia nervosa or bulimia nervosa and therefore it would be treated in much the same way.

Anorexia nervosa is an illness in which low weight is maintained as a result of a preoccupation with body weight that stems from a fear of being fat or from wanting to be thin. Because of rigid dieting or vomiting, weight falls to 15% below normal or lower. This weight loss can be seen as a positive achievement that can help increase confidence and self-esteem, and can contribute to a feeling of gaining control over body, weight, and shape. The seriousness of the physical and emotional consequences of the condition is often not acknowledged or recognised and people with anorexia nervosa often do not seek help. Other changes, such as withdrawing from family and friends, not carrying out educational or employment plans, or physical health problems often occur. There can also be physical problems due to the effects of starvation on the body. This can lead to loss of muscle strength, reduced bone strength and loss of menstruation.

Bulimia nervosa is an illness in which a person, moves between binge eating of excessive quantities of food and then, in order to prevent weight gain, does things such as vomiting, taking laxatives, fasting, or excessive exercising. Usually this behaviour is hidden from others.

Atypical eating disorders including binge eating disorder. Many people with eating disorders, perhaps more than 50%, have symptoms that fall between anorexia nervosa and bulimia nervosa, or they move from one set of problems to another over time. These are referred to as atypical eating disorders. Although people with atypical eating disorders may well have anorexic or bulimic

symptoms, such as dieting, binge eating, vomiting, and a preoccupation with food, they do not quite meet the diagnostic criteria for either anorexia or bulimia. Of the atypical eating disorders most is known about the treatment of binge eating disorder (BED). With BED, people have episodes of binge eating, but do not deal with this by vomiting.

Acknowledging the condition: People who suspect they might have an eating disorder may find it difficult or embarrassing to acknowledge the problem, seek help or talk about their symptoms to a healthcare professional. They may fear they will be criticised or treated unsympathetically. They may have heard about the negative treatment experiences of others or fear compulsory treatment.

For carers of someone with an eating disorder

When a family member has an eating disorder, this can be difficult for all other members of the family. As a family member or carer, you might need help from a healthcare professional or support group in order to help the person with an eating disorder accept that there is a problem and understand what role you might play in their care and treatment. You should be provided with appropriate information about treatment approaches and how to communicate this information to the person with the eating disorder. You should also receive support as family in order to best understand and cope with the problems **not because** you or your family may have caused or contributed to the development of the problem. As well as local support groups you can find useful information about the important role that carers provide for people with a range of mental health problems from the following website www.carers.gov.uk.

What you can expect if you have an eating disorder

Your GP and other members of the primary care team will often play an important part in first identifying your problems and will continue to be involved in your treatment and care. If you are referred to a specialist service the team may

include a number of healthcare professionals including psychiatrists, psychologists, nurses, occupational therapist, dieticians, social workers, family therapists and other professionals.

Good information and mutual support.

Whatever the nature of your eating problem, it is very important that you develop a supportive and caring relationship with the professionals that work with you. You should be provided with information and support that can help you, your family or carers understand your problems better. Many people with eating disorders have concerns about getting help and this can sometimes make treatment difficult. Healthcare professionals will normally be aware of these problems and may want to discuss them with you. Besides providing information about eating disorders and the treatments available, healthcare professionals should also inform you and your family about self-help groups and support groups for people with eating disorders.

Comment: Should we not take this out as it is just a repetition of what was above in previous para take out

When you are offered any treatment, you should be given information about the illness and the treatment **before** the treatment s[illegible]s.

Confidentiality

People with eating disorders can be concerned that the involvement of their relatives may breach their rights of confidentiality. Consultations between people with eating disorders and healthcare professionals are bound by rules regarding confidentiality and you should know that these will only be breached if you or others are at significant risk and where informing a family member or carer is likely to reduce that risk. You should be informed if confidentiality has been breeched, but issues of good practice with regard to confidentiality should not be accepted as an excuse for not listening to or communicating effectively with carers. Carers should be given enough information by medical and mental health services so that they can readily understand, in order to help them provide care

effectively. Information from carers is also subject to the same rules of confidentiality as those applied to the individual with an eating disorder.

Support from your GP

Your GP is often the first person in the health service you will see about your eating problems. This first contact can be very difficult as it may be hard for you to talk about your eating problems. Your GP may be able to help by asking a few simple questions. The signs of an eating disorder that your GP will look for include:

- a low weight for your age, or recent significant loss of weight
- excessive concern about your weight
- if your are a women, problems with your periods
- vomiting that has no obvious other explanation.

Your GP may also do some blood tests.

If your GP thinks you may have an eating disorder, the first step will often be an assessment and possible treatment by a person with special experience of eating disorders. This should include a comprehensive assessment of your medical, psychological, and social needs, any psychological or physical risks that you may be facing and whether any urgent action is needed. Sometimes it can be difficult for your GP to be sure if you have an eating disorder and if this is the case your GP or the healthcare professional may ask to see you again.

Usually your GP will coordinate your care with other specialists as necessary. As you progress through treatment, your GP should continue to monitor your medical and psychological needs. If your GP is involving other healthcare professionals in your treatment, there should be a written agreement that says who is responsible for monitoring the various aspects of your health and

Comment: Looks like Rachel or Simon wanted this deleted, but it's actually a recommendation 1.1.1.2 – I'd need to check the emails to see the rationale for this. – rationale – not realy for GP so OK with me

progress. You, and if appropriate your family, should be given a copy of this agreement.

Support and treatment if you have anorexia nervosa

This section deals with anorexia nervosa. It explains what you can expect from treatment in general, whether you are treated as an outpatient, as an inpatient in a hospital or in a day unit. It also covers what to expect after being discharged from hospital and the treatment that should be available for children and adolescents with anorexia.

General treatment for anorexia nervosa

Psychological treatments

Psychological treatments involve a series of meetings in which a healthcare professional works with a patient, group of patients or a family to help deal with the eating problem. There are a number of different kinds of psychological treatments for anorexia nervosa that include cognitive analytic therapy, cognitive behaviour therapy, interpersonal therapy, focal psychodynamic therapy and family therapy. (Further information about these approaches is given in the glossary.) The aims of psychological treatment are to encourage weight gain and healthy eating, to reduce other symptoms related to the eating disorder and to help psychological recovery. Your preferences should be a key factor in choosing a treatment.

Monitoring your physical health.

You can become very physically unwell with anorexia nervosa, particularly if your weight is very low. The healthcare professional responsible for your care should discuss the risks with you and monitor your health. If you have anorexia nervosa and are losing more than 1 kg a week you are at a high risk of becoming seriously ill and you should be told about this risk. Sometimes it will be necessary

to involve a specialist, such as a physician or paediatrician, and you may need extra tests and treatment. Also if you are pregnant and have, or have had, anorexia you may also need extra physical health checks.

One aim of treatment for anorexia is to increase your weight. If you are being treated in a hospital or unit, you should aim to put on an average 0.5 kg to 1 kg a week. If you are at home, you should be aiming for an average of 0.5 kg a week.

Taking medication

You might be prescribed medication to help with your anorexia nervosa, but this should not usually be the only or main treatment that you get. Indeed some of the problems that medication can help with in other conditions, for example depression or obsessive symptoms, may get better without specific drug treatment as your eating problems improve. You should also be informed about the side effects of any medication and a note should be placed in your records about the possibility of such side effects. People with anorexia nervosa can be more at risk of certain kinds of heart disease and you might need a test of your heart's functioning, called an electrocardiograph (or ECG). This is particularly important when medication is used because there are some medications that should be avoided or only used with great care in anorexia nervosa because of the side effects they may cause. These include antipsychotic medication, some types of antidepressant medication (particularly tricyclic antidepressants), and some types of antibiotics and antihistamines. (These are the general names for groups of medicines – ask your doctor if you want more information about a specific medicine.)

Care as an outpatient

You should expect that most of your treatment will be as an outpatient. The psychological treatment (of the kind described above) you get as an outpatient should normally last for at least 6 months. The person you see for treatment should be competent and experienced in giving this type of treatment.

Counselling just about your diet and food is not an effective treatment for anorexia nervosa when used on its own and this should not be the only treatment you are offered.

If you are not getting better or if your condition is getting worse, you might change treatment or try more intensive treatments, such treatment could be on your own or with your family. If it is thought that there is very serious risk to your mental or physical health you might be asked to consider day or inpatient care.

Care as an inpatient

Inpatient treatment may be recommended if your physical health is very poor or if you are felt to be at risk of harming yourself in some way. You might also be asked to consider going to hospital if you have not improved or are getting worse despite a good deal of treatment. If you have inpatient treatment, you should be treated in a unit that has experience and expertise of the treatment of eating disorders.

If you become so physically ill that there is a serious and immediate risk that you might die, you could be fed against your will. This happens very rarely and is an action of last resort. If your doctor decides that this is necessary for you, you will be told about your legal rights. This treatment should only be carried out in centres where staff have specialist knowledge and experience of this procedure

Care after being in hospital

Once you are well enough to leave hospital, you should be offered psychological treatment that again focuses on your eating behaviour, attitudes to weight and shape, and wider psychological and social issues. This treatment should usually last for at least 12 months.

Children and adolescents and their families

If you are a child or adolescent with an eating disorder, involving your family members in your treatment can be helpful. You and your family should be offered meetings with healthcare professionals. As a child or adolescent you should also be offered your own meetings with a healthcare professional. Your family should normally also be told about your progress in treatment.

Once you have returned to a healthy weight, you will need to have a diet that provides the extra energy necessary for you to grow and develop through childhood and adolescence. If you are female and your weight is low, you are at risk of losing bone strength. The best way to deal with this is by healthy eating and not hormone supplements, which may possibly do harm. Family members should also be included in education about diet and discussions about meal planning. Having anorexia nervosa can seriously disrupt your education and social life; the healthcare professionals responsible for your treatment will need to balance your educational and social needs with making sure you get the best treatment.

If, as a young person with anorexia nervosa, you refuse treatment that is considered to be essential, it may be necessary for your parents or those with parental responsibility to override your refusal, or to use the Mental Health Act (1983). If the issue of consent to treatment comes up, healthcare professionals should consider seeking a second opinion from a colleague. Doctors should try to avoid relying on the consent just from your parents where treatment is continuing over a long period of time. The legal basis for such treatment against your wishes should be recorded in your medical notes. If both you and your family refuse treatment that your doctor considers to be essential, he or she will probably seek legal advice on whether he or she can give treatment under the Children Act 1989.

Support and treatment if you have bulimia nervosa

This section deals with bulimia nervosa. It explains what you can expect about treatment in general, if you are treated as an outpatient, an inpatient, and after being discharged from hospital. It describes the psychological treatment, medicines, and medical care you can expect. It also explains to carers and family members the treatment they can expect for young people with bulimia nervosa.

General treatment for bulimia nervosa

Psychological treatment

Psychological treatment (see the Glossary for an explanation of these treatments) and self-help programmes are key elements in the treatment of bulimia nervosa. As a possible first step, a healthcare professional may recommend that you try a self-help programme based on research evidence that has been designed for people with bulimia, and he or she may give you some support in following this programme. For some people with bulimia nervosa, particularly if you are not binge eating and purging a great deal, this may be all the treatment that you need.

Most people with bulimia nervosa who have not benefited from self-help should be offered cognitive behaviour therapy that has been designed specifically for bulimia nervosa (called cognitive behaviour therapy – bulimia nervosa or CBT-BN). This should normally last for 16 to 20 sessions over 4 to 5 months. If you have not improved or do not want CBT-BN, your healthcare professional will consider other psychological treatments. Interpersonal psychotherapy (IPT) is an alternative, although it does take longer than CBT to achieve comparable results. People with additional problems, such as serious drug or alcohol misuse, are less likely to get better by just following a standard treatment and the healthcare professional might need to adapt the treatment if you also have this kind of problem.

If you are an adolescent you might be offered CBT-BN, if this is the case it should be adapted to suit your age, circumstances and understanding of your problem.

Taking medication

Antidepressants can help in bulimia nervosa. Your doctor might prescribe antidepressants on their own, as an alternative to a self-help programme, or in combination with a psychological treatment to increase the likelihood of you responding to the psychological treatment. The medicines known as SSRIs (specifically fluoxetine) are the ones most often chosen for treating bulimia nervosa. On their own, antidepressants are most likely to reduce the frequency of binge-eating and purging and this will happen soon after you have started taking them but their long-term effects on your eating problems are not known.

No medicines other than antidepressants are recommended for the treatment of bulimia nervosa.

Monitoring your health

For a small but significant number of people, bulimia nervosa can lead to serious physical problems, such as dehydration and changes in the chemical balance in your body that can result in heart and other physical problems. It can be especially serious when laxatives or vomiting are used excessively to remove food from the body. Laxatives do not stop the body absorbing food and you should gradually reduce their use and increase food that is high in fibre. If you have serious problems with your body's chemical balance you might have to take a special supplement. If you are pregnant and have bulimia nervosa or if you have diabetes and bulimia nervosa your risks of health problems increases and you may need to have more regular health checks.

Reducing dental problems

If you are vomiting regularly you can seriously damage your teeth and gums. You should be advised about dental hygiene; this should cover avoiding brushing

after vomiting, rinsing with a non-acid mouthwash after vomiting and trying to eat foods which reduce acidity in the mouth.

Care as an inpatient

The vast majority of people with bulimia nervosa do not need hospital treatment. But if you are at serious risk of suicide or harming yourself physically, your healthcare professional might suggest that you to go into hospital for a time or that you have more intensive outpatient care. If you are admitted to hospital, then it should be to a unit with experience of treating people with bulimia nervosa.

Support and treatment if you have an atypical eating disorder, including binge eating disorder

There is some evidence to guide the treatment of binge eating disorder but for most people with an atypical eating disorder, (that is an eating disorder that is not easily categorised as anorexia nervosa or bulimia nervosa), your healthcare professional should follow the advice for the eating problem that it is most similar to the one you are suffering from. The rest of this section explains the psychological treatments and medicines for binge eating disorder.

Psychological treatments

As a possible first step, your doctor may recommend that you try a self-help programme that is based on research evidence that has been designed for people with binge eating disorder, and he or she may give you some support in following this programme. For some people with binge eating disorder, this is all the treatment that you may need

If you have persistent binge eating disorder, your GP or other healthcare professional might suggest psychological treatments such as cognitive behaviour therapy for –binge eating disorder, interpersonal psychotherapy for binge eating disorder or modified dialectical behaviour therapy (see Glossary for a definition

Comment: Cathy – these need spelling out in full

of these treatments). They should tell you that all psychological treatments for binge eating disorder have a limited effect on body weight and if appropriate, they should offer you a programme on treating obesity at the same time as the psychological treatment.

An adolescent with a persistent binge-eating disorder should be offered a psychological treatment adapted for his or her age group.

Taking medication

As an alternative or additional first step to using a self-help programme or a behavioural weight control programme, your doctor may offer you a trial of a selective serotonin reuptake inhibitor (SSRI) antidepressant (see Glossary). Although an SSRI can reduce binge eating, the long-term effects are unknown. An antidepressant on its own may be sufficient treatment for some individuals.

Questions you might want to ask about your care and treatment

This guide gives you a general introduction to the kind of support and treatment you can expect if you or a family member has an eating disorder. Having read those parts of the guide relevant to your problems, you may find it helpful to ask the healthcare professional responsible for your care for more detailed information, in order to be fully informed and better able to make decisions about your care and treatment.

It is very understandable if you get anxious when talking to a health professional, and easy to forget to ask important questions about your care. The section that follows gives some examples of the kind of questions you could ask. It can help to write them down and take with you to your consultations.

Information about your condition

You may not understand the type of eating disorder you have, and how it could affect your health. If that is the case, you could ask:

- What kind of eating disorder have I got?

or

- What does it mean for my health?

or

- I don't really understand what the problem is, can you explain it to me again, or in a different way?

Information about your treatment or care

For most eating disorders there is a range of effective psychological treatments and medications. This guideline is about making sure you get the best treatment available for you. This means that you should be properly informed about the kind of treatments you are being offered. You might want to consider asking the healthcare professional:

- What kind of treatment do you think will best help me with my problem?

If you are offered a particular treatment you might want to know more about it and so you could ask:

- Can you tell me in more detail what the treatment will involve?

or

- Can you tell me why you have decided to offer me this type of treatment?

If you feel that the treatment is not working as you had expected you might want to raise this with the healthcare professional providing the treatment. You might want to consider this question:

- I am not getting better as I expected, can we review the type of treatment that I am getting?

Some medications for a range of physical and psychological problems can have side effects, which are particularly important if your physical health is seriously affected by your eating disorder. You should know about these side effects, if you are unsure you might consider asking the following question:

- Does this medication have any side effects that could affect my physical health in any way?

Questions for families and carers

Families and other carers can play a key role in helping and supporting people with eating disorders, especially children and adolescents. In order to do this they need to be well informed and supported. If, as a family member or carer, you are unsure about either of these issues consider asking the following questions:

- What role can we have in helping (person with eating disorder) with their problem?

or

- Can you please let us know how the treatment of (person with eating disorder) is progressing?

or

- Can you advise us on the kind of support that you think we might benefit from as a family?

Further information

You have the right to be fully informed and to share in decision-making about your healthcare. If you need further information about any aspects of your eating

disorder or treatment, please ask your specialist, GP or a relevant member of your health team. You can discuss this guideline with them if you wish.

There is more about NICE and the way that the NICE guidelines are developed on the NICE website (www.nice.org.uk). You can download the booklet *The Guideline Development Process – Information for the Public and the NHS* from the website, or you can order a copy by phoning 0870 1555 455 and quoting reference number N0038.

Glossary [– to be completed]

Antidepressants: medicines used to relieve the symptoms of depression. These drugs also may be used to treat other conditions, such as obsessive–compulsive disorder, premenstrual syndrome, chronic pain, and eating disorders.

Antihistamines: medicines that relieve or prevent the symptoms of hayfever and other kinds of allergy.

Antipsychotics: medicines used in the treatment of psychosis.

Cognitive behaviour therapy [CBT]: A form of therapy that is designed to help people to establish links between their thoughts, feelings or actions and their current or past symptoms and to re-evaluate their perceptions, beliefs or reasoning about the symptoms. CBT should involve at least one of the following: (1) monitoring thoughts, feelings or behaviour about the symptom; (2) being helped to use different ways of coping with the symptom; (3) reducing stress.

Cognitive behaviour therapy for binge eating disorder [CBT-BED]. A form of cognitive behaviour therapy especially designed for patients with binge eating disorder.

Cognitive behaviour therapy for bulimia nervosa (CBT-BN): A form of cognitive behaviour therapy especially designed for patients with bulimia nervosa. A course of CBT-bulimia nervosa usually involves 16-20 hour-long one-to-one treatment sessions over 4 to 5 months. It focuses on helping patients change their eating habits and addressing the ways of thinking (most especially the over-evaluation of shape and weight) that maintains their eating habits.

Compulsory treatment: treatment that is carried out using the legal powers available under the Mental Health Act 1983, the Children Act 1989, or the authority of the court. Treatment usually involves inpatient treatment of anorexia nervosa in adults, children and adolescents. In the case of children and

adolescents compulsory treatment can take place on an outpatient basis under the parents' authority,

Dialectical behaviour therapy (DBT): A complex and intensive psychological treatment originally designed for patients with borderline personality disorder. A simplified and shortened form of the treatment has been modified for patients with bulimia nervosa or binge eating disorder. It primarily focuses on enhancing patients' emotion regulation skills and involves 20 2-hour group sessions once a week.

Electrocardiograph: A test that records the electrical activity of the heart. It can measure the rate and regularity of the heartbeats, the presence of any damage to the heart, or the effects of drugs used to regulate the heart.

Family therapy: sessions with a family and a healthcare professional that provide support. The treatment is based on psychological principles. With eating disorders, the focus is on the eating disorder and how this affects family relationships. In the early stages of treatment, it emphasises the necessity for parents to take a central role in supporting their child's efforts to eat.

Interpersonal psychotherapy (IPT): A specific form of psychotherapy that is designed to help patients identify and address current interpersonal problems. It was originally developed for the treatment of depression, and it has been adapted for the treatment of bulimia nervosa. In this treatment, there is no emphasis on directly modifying eating habits; rather, it is expected that they will change as interpersonal functioning improves. It usually involves 16–20 hour-long one-to-one treatment sessions over 4 to 5 months.

Macrolide antibiotics: antibiotics are medicines that work by killing bacteria or inhibiting their growth. Macrolide antibiotics are a type of antibiotic that share the same derivation and a certain type of chemical reaction in the body. They are generally used for the treatment of the upper and lower respiratory tract, skin and soft tissue infections of mild to moderate severity.

Sectioned: If a person has been sectioned under the Mental Health Act, they have been detained for assessment and/or treatment against their wishes. A patient who has been sectioned can expect as much care and help as anyone else, and that time will be taken to explain what is happening.

Selective serotonin reuptake inhibitors (SSRIs): medicines that target specific chemical messengers in the brain. These drugs work by increasing the level of the chemical serotonin in the brain, which helps to alleviate the symptoms of depression.