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National Institute for
Clinical Excellence

Eating disorders: anorexia nervosa, bulimia nervosa and related eating disorders

Understanding NICE guidance: a guide for people with eating disorders, their advocates and carers, and the public

January 2004

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Eating disorders: anorexia nervosa, bulimia nervosa and related eating disorders
Understanding NICE guidance: a guide for people with eating disorders, their advocates and carers, and the public

Issue date: January 2004

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Copies of this booklet can be ordered from the NHS Response Line; telephone 0870 1555 455 and quote reference number N0407. A version in English and Welsh is also available, reference number N0408. Mae fersiwn yn Gymraeg ac yn Saesneg ar gael hefyd, rhif cyfeirnod N0408. The NICE clinical guideline on which this information is based, *Eating Disorders: Core Interventions in the Treatment and Management of Anorexia Nervosa, Bulimia Nervosa and Related Eating Disorders*, is available from the NICE website (www.nice.org.uk/CG009NICEguideline). A quick reference guide for healthcare professionals is also available from the website (www.nice.org.uk/CG009quickrefguide), and from the NHS Response Line, reference number N0406.

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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* (NICE Clinical Guideline no. 9), 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. 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 has been caused by 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 healthcare 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 receive (or someone you care for receives) 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 healthcare team.

If you want to read the other versions of this guideline

There are four versions of this guideline:

- this one
- the NICE guideline, *Eating Disorders: Core Interventions in the Treatment and Management of Anorexia Nervosa, Bulimia Nervosa and Related Eating Disorders*

- the quick reference guide, which is a summary of the main recommendations in the NICE guideline; NICE has sent copies of the quick reference guide to doctors and other healthcare professionals working in the NHS
- the full guideline, which contains all the details of the guideline recommendations, how they were developed and information about the evidence on which they were based.

All versions of the guideline are available from the NICE website (www.nice.org.uk). This version and the quick reference guide are also available from the NHS Response Line – phone 0870 1555 455 and give the reference number(s) of the booklets you want (N0407 for this version, N0408 for this version in English and Welsh, and N0406 for the quick reference guide).

About eating disorders

This guideline covers the care of people with anorexia nervosa, bulimia nervosa, or other related (or 'atypical') eating disorders (mainly binge eating disorder). In general, eating disorders develop over time, sometimes over years, and often at a point when life brings fear and insecurity.

Anorexia nervosa is an illness in which people keep their body weight low by dieting, vomiting, or excessively exercising. The illness is caused by an anxiety about body shape and weight that originates from a fear of being fat or from wanting to be thin. How people with anorexia nervosa see themselves is often at odds with how they are seen by others, and they will usually challenge the idea that they should gain weight. People with anorexia nervosa can see their weight loss as a positive achievement that can help increase their confidence and self-esteem. It can also contribute to a feeling of gaining control over body weight and shape.

Anorexia nervosa is, however, a serious condition that can cause severe physical problems because of the effects of starvation on the body. This can lead to loss of muscle strength and reduced bone strength in women and girls; in older girls and women their periods often stop. Men can suffer from a lack of interest in sex or impotency.

The illness can affect people's relationship with family and friends, causing them to withdraw; it can also have an impact on how they perform at school or in the workplace. 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.

Anorexia nervosa in children and young people is similar to that in adults in terms of its psychological characteristics. But children and young people might, in addition to being of low weight, also be smaller than other people their age, and slower to develop.

Bulimia nervosa is an illness in which people feel that they have lost control over their eating. As in anorexia nervosa, they evaluate themselves according to their body shape and weight. Indeed in some instances (although not all), bulimia nervosa develops out of anorexia nervosa. People with bulimia nervosa are caught in a cycle of eating large quantities of food (called 'binge eating'), and then vomiting, taking laxatives and diuretics (called 'purging'), or excessive exercising and fasting, in order to prevent gaining weight. This behaviour can dominate daily life, and lead to difficulties in relationships and social situations. Usually people hide this behaviour from others, and their weight is often normal. People with bulimia nervosa tend not to seek help or support very readily.

People with bulimia nervosa can experience swings in their mood, and feel anxious and tense. They may also have very low self-esteem, and might try to hurt themselves by scratching or cutting. They may experience symptoms such as tiredness, feeling bloated, constipation,

abdominal pain, irregular periods, or occasional swelling of the hands and feet. Excessive vomiting can cause problems with the teeth, while laxative misuse can seriously affect the heart.

Bulimia nervosa in children and young people is rare, although young people may have some of the symptoms of the condition.

Atypical eating disorders including binge eating disorder may affect more than half of people with an eating disorder. These conditions are called 'atypical' eating disorders because they do not exactly fit the description of either anorexia nervosa or bulimia nervosa. People might have some of the symptoms of anorexia nervosa and bulimia nervosa (such as dieting, binge eating, vomiting, and a preoccupation with food), but not all; or they might have symptoms that fall between anorexia nervosa and bulimia nervosa; or they might move from one set of problems to another over time. Many people with an atypical eating disorder have suffered with anorexia nervosa or bulimia nervosa in the past.

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 try to control their weight by purging. A person with BED may feel anxious

and tense, and their condition might have an effect on their social life and relationships.

Atypical eating disorders in children and young people are thought to be quite common, although little is known about binge eating disorder in this age group.

For carers of someone with an eating disorder

When someone has an eating disorder, this can be difficult for all other members of his or her family and immediate circle. As a family member, partner or carer, you might consider asking for help from a healthcare professional or support group. You can be advised how 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 given information about treatments and how to talk about this information to the person with the eating disorder. You should also receive support as a family to help you understand and cope with the problems – not because you or your family may have caused or contributed to the development of the problem, but because you are all a key part of the recovery process. 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 from the NHS if you have an eating disorder

Your GP and other community-based healthcare professionals such as your practice nurse (also known as 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 different professionals who will be involved in different aspects of your care.

Good information and support

Whatever the nature of your eating problem, it is very important that a supportive and caring relationship between you and the professionals that work with you is developed. You should be given information and support that can help you, and 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 tell you and your family about self-help groups and support groups for people with eating disorders and how to contact them.

When you are offered any treatment, you should be given information about the illness and the treatment **before** the treatment starts.

Confidentiality

People with eating disorders can be concerned that the involvement of their relatives may breach their rights to confidentiality. Rules of confidentiality apply in consultations between people with eating disorders and healthcare professionals, and you should be told 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 told if confidentiality has been breached. Children and young people have the same right to confidentiality as adults.

Carers should be given enough information by medical and mental health services to help them

provide care effectively. Respecting the patient's confidentiality should not be accepted as an excuse for not listening to or communicating with carers. Information from carers is also subject to the same rules of confidentiality as those applied to the person 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 condition. 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:

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

Your GP may also do some blood tests.

Recognising eating disorders

People who suspect they might have an eating disorder may find it difficult or embarrassing to admit to 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 other people's bad experiences of treatment, or be afraid of being treated against their will. Your GP should understand and be sensitive to these problems and may want to discuss them with you.

Getting help early

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 caring for people with eating disorders. This should happen at the earliest opportunity and 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.

Monitoring your health

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 checking on the various aspects of your health and progress. You, and if appropriate your family,

should be given a copy of this agreement. This section covers advice that people with any type of eating disorder should receive.

Diabetes and eating disorders

You should have intensive and regular health checks if you have diabetes and an eating disorder, because you are at high risk of problems with your eyes and other serious complications.

Pregnancy and eating disorders

If you are pregnant and have an eating disorder, you should be carefully monitored throughout your pregnancy and after giving birth.

Osteoporosis and eating disorders

If you have an eating disorder and osteoporosis or other bone disorder, healthcare professionals should advise you to avoid physical activities that might lead to falls.

Use of laxatives

If you are taking excessive amounts of laxatives, you should be advised to gradually reduce your use of them. You should be told that using laxatives does not significantly decrease the number of calories that your body absorbs.

Reducing dental problems

If you are vomiting regularly you can seriously damage your teeth and gums. Your healthcare

professional should discuss dental hygiene with you, and advise you to:

- avoid brushing your teeth after vomiting
- rinse with a non-acid mouthwash after vomiting
- avoid acidic foods such as fruit, fruit juice, carbonated drinks, pickled products, yoghurt, and some alcoholic drinks
- visit your dentist regularly.

General considerations for children and young people

If you are a child or young person with an eating disorder, your growth and development will be closely monitored. The doctor looking after you may ask the advice of another doctor if, after treatment, you are not growing and developing properly.

Members of your family, including your brothers and sisters if you have them, will usually be told about any treatments that you are having.

Support and treatment if you have anorexia nervosa

This section explains what treatment you can expect 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 young people with anorexia nervosa.

Psychological treatments

Psychological treatments involve a series of meetings in which a healthcare professional works with a patient on their own, with a group of other patients with similar conditions, or together with their family to help deal with the eating problem. There are a number of different kinds of psychological treatments adapted for anorexia nervosa, which include:

- cognitive analytic therapy (CAT)
- cognitive behaviour therapy (CBT)
- interpersonal therapy (IPT)
- focal psychodynamic therapy
- family therapy.

Further information about these approaches is given in the glossary. Your preferences should be a key factor in choosing a treatment.

The aims of psychological treatment are to reduce the risk of harm from the illness, to encourage weight gain and healthy eating, to reduce other symptoms related to the eating

disorder, and to help psychological recovery. If you are being treated in this way your physical health should also be monitored.

Monitoring your physical health

You can become very physically unwell with anorexia nervosa, particularly if your weight is very low and/or you are rapidly losing weight. The healthcare professional responsible for your care should discuss the risks with you and monitor your health. Sometimes you may need to see a specialist, such as a physician or paediatrician, and you may need extra tests and treatment. If you are pregnant and have, or have had, anorexia nervosa you may also need extra physical health checks.

One aim of treatment for anorexia nervosa is to increase your weight. If you are being treated in a hospital or eating disorders unit, you should aim to put on an average of 0.5 kg to 1 kg a week. (See below for further information about inpatient care.) If you are at home, you should be aiming for an average of 0.5 kg a week. You may also be treated with multivitamin or multimineral supplement tablets while in inpatient or outpatient care.

Taking medication

You might be prescribed medication to help with your anorexia nervosa, but this should not be the only or main treatment that you receive. You should also be informed about the side effects of any medication, and a note should be placed in your medical records about the possibility of such side effects. If you have an eating disorder together with depression or a condition called obsessive–compulsive disorder, you may find that these other conditions get better as your eating problems improve.

People with anorexia nervosa can be more at risk of certain kinds of heart disease and you might need an electrocardiograph (usually shortened to ECG) to test that your heart is working as it should. This is particularly important when you are taking medication. Some drugs should be avoided or only used with great care in people with anorexia nervosa because of the side effects they may cause. These include antipsychotic drugs, some drugs used to treat depression (particularly a type called 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. There is also further information in the glossary.)

Care as an outpatient

You should expect that most of your treatment will be as an outpatient. Any psychological treatment that you receive as an outpatient (of the kind described above) should last for at least 6 months. The person who treats you should be competent and experienced in giving this type of treatment. Advice that is 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 be offered different or more intensive treatments. Such treatment could be on your own or with your family.

If you have had anorexia nervosa for a long time, but are not under the care of a hospital service for people with anorexia nervosa, you should be offered an annual physical and psychological check-up by your GP.

If it is thought that there is 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 as expected or are getting worse despite a good deal of treatment. If you have inpatient treatment, you should be cared for in a unit that has experience and expertise of caring for people with eating disorders. You should expect to receive inpatient treatment within reasonable travelling distance of where you live.

If you are severely ill and refuse treatment that is considered essential, you may be admitted to a hospital for compulsory treatment. This is commonly known as being 'sectioned' under the Mental Health Act (1983). (See the glossary for further information.)

You should be admitted to a unit that is skilled in increasing people's levels of nutrients. You should be closely monitored in the first few days while this is happening. Inpatient treatment for anorexia nervosa should also consist of a structured psychological treatment that will help you to gain weight. This should focus on your eating habits, your attitudes to your weight and shape, and your feelings about gaining weight.

Your physical health will be closely monitored as well.

Feeding you against your will

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 will take place only as a last resort. If your doctor decides that this is necessary for you, you will be told about your legal rights under the Mental Health Act (1983) or Children Act (1989). Because this treatment is highly specialised, it should only be carried out in units 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 young people and their families

If you are a child or young person with an eating disorder, involving your family members in your

treatment can be helpful. You and your family together should be offered meetings with healthcare professionals. You should also be offered your own private meetings with a healthcare professional. Your family should normally also be told about your progress in treatment.

If you are very ill it may be necessary for you to be treated in a hospital. If you are admitted to a hospital, then it should be in a unit with experience of treating people of your age group. You should expect to receive treatment in a hospital close to where you live.

Once you have returned to a healthy weight, your doctor should make sure that you have a diet that provides the extra energy you need, to grow and develop through childhood and adolescence. If you are a young girl and your weight is low, you are at risk of losing strength in your bones. The best way to deal with this is by eating healthily, not by taking hormone supplements, which may do harm. Your family members should also be included in any discussions or advice about diet and planning meals. Having anorexia nervosa can seriously disrupt your education and social life; the healthcare professionals looking after you should not neglect your educational and social needs while making sure you get the best treatment.

In some situations consent is needed for treatment to start. This means that you and your parents, or guardians, have to agree to treatments being given to you. If you are being treated over a long period of time, your doctor may consult another doctor about your care. If you do not wish to receive certain treatments, your doctor should write them down in your notes.

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 your guardians, to overrule your decision. If the situation is thought to be very serious, your family or those taking care of you can have you treated against your will under the Mental Health Act. If both you **and** your family refuse treatment that your doctor considers to be essential, he or she may apply to the courts to give you treatment under the Children Act.

Support and treatment if you have bulimia nervosa

This explains what you can expect from the general treatment you will receive, either as an outpatient or as an inpatient. 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.

Psychological treatment

Psychological treatments involve a series of meetings in which a healthcare professional works with a patient on their own, with a group of other patients with similar conditions, or together with their family to help deal with the eating problem. There are a number of different kinds of psychological treatments adapted for bulimia nervosa listed below:

Self-help may be recommended by your healthcare professional as a first step in your treatment, and this may involve some relevant reading. He or she may give you 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.

Cognitive behaviour therapy for bulimia nervosa (CBT-BN) may be offered to you if you have not benefited from self-help. Treatment should normally last for 16 to 20 sessions over 4 to 5 months.

CBT-BN can be provided to both adults and adolescents.

Interpersonal therapy (IPT) may be offered to you if you have not improved after CBT-BN or do not want CBT-BN. IPT can take longer than CBT to achieve comparable results.

Further information about these treatment approaches is given in the glossary. Your personal preferences should be a key factor in choosing a treatment.

Taking medication

As an alternative or in addition to a self-help programme, your doctor may offer you a trial of antidepressant medication.

The antidepressants known as selective serotonin reuptake inhibitors (SSRIs) – and in particular one called fluoxetine – are the ones most often chosen for treating bulimia nervosa. Antidepressants can help to reduce the number of times you are binge eating and purging, and this will probably happen soon after you have started taking the medication. Their long-term effects on your eating problems, however, 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. If you are vomiting often, or taking large quantities of laxatives, your doctor should do a blood test to check your fluid levels and chemical balance.

Care as an outpatient

You should expect that most of your treatment will be as an outpatient. Any psychological treatment that you receive as an outpatient (of the kind described above) should last for at least 6 months.

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.

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 harming yourself physically, your healthcare professional might suggest that you 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.

Children and young people and their families

If you are a child or a young person with this condition, healthcare professionals should offer you the same kind of treatment as adults with bulimia nervosa. They should, however, take into account your age, circumstances and level of development.

Involving your family members in your treatment can be helpful. You and your family together should be offered meetings with healthcare professionals. As a child or young person you should also be offered your own meetings with a healthcare professional. Your family should normally also be told about your progress in treatment.

Young people and psychological treatment

If you are a young person with bulimia nervosa you might be offered cognitive behaviour therapy for bulimia nervosa (CBT-BN). (See the glossary for details of this treatment.) If this is the case it should be adapted to suit your age, and what you know about your problem. This form of treatment may include your family if appropriate.

Support and treatment if you have another type of eating disorder, including binge eating disorder

If you have an eating disorder that is not easily categorised as anorexia nervosa or bulimia nervosa (often called an atypical eating disorder), your healthcare professional should usually follow the guidance for the eating problem that is most similar to the one from which you are suffering.

There has been, however, some research into the treatment of one type of atypical eating disorder, called binge eating disorder. The rest of this section explains the psychological treatments and medicines for binge eating disorder.

Psychological treatments

Psychological treatments involve a series of meetings in which a healthcare professional works with a patient on their own, with a group of other patients with similar conditions, or together with their family to help deal with the eating problem. There are a number of different kinds of psychological treatments adapted for binge eating disorder listed below.

Self-help may be recommended to you as a possible first step. Your GP or other healthcare professional may give you support in following it. For some people with binge eating disorder, this may be all the treatment that you need.

If you have a persistent binge eating disorder, your GP or other healthcare professional might suggest the following psychological treatments:

- cognitive behaviour therapy for binge eating disorder (CBT-BED)
- interpersonal psychotherapy (IPT)
- modified dialectical behaviour therapy (DBT).

Further information about these treatment approaches is given in the glossary. Your personal preference should be a key factor in choosing a treatment.

Your healthcare professional should tell you that all psychological treatments for binge eating disorder have a limited effect on body weight.

Taking medication

As an alternative or additional first step to using a self-help programme or a programme to help manage your weight, your doctor may suggest that you try a drug that is usually used to treat depression. This will usually be of a type called a selective serotonin reuptake inhibitor (SSRI), such as fluoxetine (see the glossary). Although SSRIs can reduce binge eating, it is not known how well they work in the long term. An antidepressant on its own may be the only treatment some people with binge eating disorder need.

Care as an outpatient

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

Care as an inpatient

The majority of people with binge eating disorder are treated as outpatients, but you may be asked

to attend a specialist day unit where you can be advised about planning and eating meals.

Children and young people and their families

If you are a child or a young person with this condition, healthcare professionals should offer you the same kind of treatment as adults with an atypical eating disorder, or binge eating disorder. They should take into account your age, and what you know about your eating disorder.

Involving your family members in your treatment can be helpful. You and your family together should be offered meetings with healthcare professionals. As a child or young person you should also be offered your own meetings with a healthcare professional. Your family should normally also be told about your progress in treatment.

Children and young people and psychological treatment

If you are a young person with a persistent binge-eating disorder, you should be offered a psychological treatment that is suitable for people of your age.

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. 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 understandable if you get anxious when talking to a health professional, and it is 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 then take them with you to your consultations, or you could take this booklet along with you.

Information about your condition

You may not be sure what type of eating disorder you have, and how it could affect you. If that is the case, you could ask:

- **What kind of eating disorder do I have?**
  or
- **What does it mean for my health, daily life, work or schooling?**
  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 treatment that is best 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?**
  or
- **Are there other treatments that might suit me better?**

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 medication can have side effects, and these may be 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 questions:

- **Does this medication have any side effects that could affect my physical health in any way?**
- **What should I do if I get any of these side effects?**

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 young people. 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 the person with the eating disorder with their problem?**
  or
- **Can you please let us know how the treatment of the person with the 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 healthcare 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: explanation of medical and technical words

Antibiotics: a type of medicine used to treat infections with bacteria.

Antidepressants: medicines used to relieve the symptoms of depression. They work by increasing the activity and levels of certain chemicals in the brain that help to elevate your mood. These medicines 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 hay fever and other kinds of allergy.

Antipsychotics: medicines used in the treatment of psychosis, which help to control delusions and hallucinations.

Atypical eating disorder: an eating disorder that may have some of the characteristics of anorexia nervosa and bulimia nervosa but not all. These conditions may also be called 'eating disorders not otherwise specified'.

Children Act (1989): one of the provisions of this Act of Parliament enables parents and guardians to give their consent for a young person under 16 years of age to be treated for illnesses against their will.

Cognitive analytic therapy (CAT): a psychological treatment in which a therapist works with a person to help them to make positive changes in their lives, and to build a future. This can require understanding what has prevented them from making changes in the past and improving the ways they cope with problems. CAT is 'analytic' in the sense that it explores unconscious motivations.

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-BN 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 the ways of thinking (most especially the over-evaluation of shape and weight) that maintain 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. In the case of eating disorders, compulsory treatment usually involves inpatient treatment of anorexia nervosa in adults, children and young people. In the case of children and

young people 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 group sessions lasting 2 hours once a week.

Dietitian: a healthcare professional who can advise you about nutrition and health, and how to manage your weight. They can also explain how eating disorders can cause damage to physical health.

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 who provides support. The treatment is based on psychological principles and is most commonly used with families where a child or adolescent has an

eating disorder. 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.

Focal psychodynamic therapy: this works at identifying and focusing on a central conflict or difficulty in a person's early life that is having an impact on that person's current problems.

Inpatient: a person who is having tests or treatment while staying in hospital.

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 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.

Mental Health Act (1983): When a healthcare professional believes that a person is so ill that he or she is unable to make a decision about treatment, or if a person who is ill refuses

treatment, the healthcare professional can treat the person under the Mental Health Act of 1983. This treatment, against the will of the patient, or without their consent, is called being ‘sectioned’. If you are treated under the Mental Health Act you will receive your care in an inpatient unit. The people in charge of your care will make sure you understand what is happening to you and your legal rights.

Outpatient: a person who has appointments at a hospital clinic but does not need to stay overnight.

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): antidepressant 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.

Tricyclic antidepressants: antidepressant medicines that work in a similar way to SSRIs (see above) but may have more side effects.

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