



Healthcare
Improvement
Scotland

SIGN

Eating disorders

A booklet for people living with eating disorders

PLAIN
LANGUAGE
COMMISSION
CLEAR
ENGLISH
STANDARD



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Who is this booklet for?

This booklet is for people who:

- **have been diagnosed with an eating disorder, or**
- **may be going through assessment**

Family members, friends and carers may also find the booklet helpful.

Young people might find it helpful for an adult to read this booklet alongside with them.

You can find an easy-read version of this booklet and video animations on our website <https://www.sign.ac.uk/patient-and-public-involvement/patient-publications/eating-disorders/>

Details of support organisations and other places you can find out more information are on pages 25-27.





What is this booklet about?

This booklet explains the recommendations in a guideline produced by the Scottish Intercollegiate Guidelines Network (SIGN) about the diagnosis and management of eating disorders.

The guideline is based on what we know from current research. It also gives advice based on the opinion of healthcare professionals who are trained on how best to manage your care.

On page 28 you can find out how we produce guidelines.

The booklet will cover:	The booklet will not cover:
<ul style="list-style-type: none">• What an eating disorder is• The stages of recovery• What treatments are available• Transition between services• The support available for families and carers. 	<ul style="list-style-type: none">• Avoidant restrictive food intake disorder (ARFID)• How to manage obesity separately from an eating disorder• Therapies where the evidence base is too small, such as art therapies• Gender identity, and issues relating to gender. 

There are two different types of recommendations in this booklet



**Recommendation
based on the research evidence**



**Recommendation
based on clinical experience**

The SIGN guideline is available on our website www.sign.ac.uk/our-guidelines/eating-disorders/

What are eating disorders?

Eating disorders are complex mental illnesses with a range of different causes. The eating disorders charity Beat estimates that around 1.25 million people in the UK have an eating disorder.

They affect people of any age, gender, ethnicity and social background. So it is essential that services are designed to welcome and care for individuals from all backgrounds. Eating disorders are serious, so quick access to the right treatment is important. This booklet aims to help you understand what treatment you should be offered.

There are different types of eating disorder, including these:

Anorexia nervosa

Anorexia nervosa is an eating disorder where people feel very anxious about eating, their weight, or both and may see themselves as overweight. They try to keep their weight as low as possible by restricting and controlling what they eat. They may also use other methods to control their weight such as excessive exercise or 'purging', for example by vomiting and taking laxatives and diuretics.

Bulimia nervosa

Bulimia nervosa is an eating disorder where people can feel disconnected from eating or feel out of control. This leads to episodes of eating large quantities of food (bingeing) and then trying to compensate by excessive exercise or 'purging', for example by vomiting and taking laxatives and diuretics.

Binge eating disorder

Binge eating disorder is an eating disorder where people may feel disconnected from eating or feel out of control, so they eat large amounts of food (bingeing) in a short time. However, they do not try to compensate for this with 'purging'.

Avoidant restrictive food intake disorder (ARFID)

ARFID is an eating disorder that causes people to avoid certain foods or food types, or restrict the amount of food they're eating, or both. Unlike other eating disorders it is not related to worries about weight or body image, but may arise for several reasons. Unfortunately, at this time, we do not have enough evidence to make recommendations for people with ARFID.

Other specified feeding or eating disorders (OSFED)

A lot of people may experience eating disorder symptoms that do not completely match one of the disorders described above. OSFED is just as serious as them. So you should still be offered treatment, normally based on a diagnosis that most closely matches your difficulties.



Information

For more information on the different types of eating disorder, please see the [Beats website](#) or [CARED Scotland](#).

Getting help early

If you suspect that you or the person you're caring for has an eating disorder, it's important to get help straight away. You can speak to your GP about your concerns.

The earlier you get help, the earlier you can start your recovery.

It is important to get help early as an illness like an eating disorder doesn't go away on its own.



Information

People with eating disorders sometimes think they must become more unwell before they 'deserve' to get help, or before they are 'allowed' to recover. However, there is no such thing as 'unwell enough'; everyone deserves to get well as soon as they can.



Is it possible to recover from an eating disorder?

Yes. Recovery can be difficult but with commitment from you, help from healthcare professionals, and support from family and friends, you can recover.

‘ My confidence has re-emerged and I feel much stronger. And most importantly, healthier.



Recommendation based on clinical experience

Getting involved in your recovery and actively doing things to maintain it are essential. Your healthcare professionals will work with you to make a full recovery. The plan will say what support is available at each stage of your recovery. It will also say how you can take each step when you feel ready.

What can I do to get better?

Your body needs to physically recover, so you will get support on how to improve your eating habits. You may receive help from a specialist eating disorder dietitian or another healthcare professional to help with this. It can be difficult but is necessary for your recovery.



Recommendation based on the research evidence

Weight recovery has been shown to reduce the chance of relapse and improve physical health. Your goals for weight recovery will be discussed with you and be personal to you. You will be given support and information to help you achieve your goals.

Physical activity and exercise during recovery

People with eating disorders often have a complex relationship with exercise. Taking too much exercise can be a symptom of an eating disorder.

Exercise can also help your recovery if you take it in a healthy way. Safe exercise can improve physical health and strength, as well as mental health and wellbeing.

Your healthcare provider will help you understand what 'safe exercise' means for you, and will support you to develop a healthy attitude towards exercise. They will also help you see when you are overdoing it, and how to manage this.



Recommendation based on the research evidence

Exercise programmes that are supervised by a specialist should be offered to you as part of your overall care programme.

You will be given support to help you:

- understand the effects of exercise on your body and your mental health, and
- exercise in a positive and healthy way.



Information

For more about how to include safe exercise in your recovery, see [Safe Exercise at Every Stage \(SEES\)](#).



Recommendation based on clinical experience

If you are a sports person being treated for an eating disorder and you are starting to return to your sport, your treatment team should give you a lot of support to help you safely return to exercise in stages.



Information

Your healthcare professional will talk to you about returning to activities that you stopped during treatment for an eating disorder, for example exercise. They should discuss with you life after treatment, and life after eating disorder.



Information

You can find out more about returning to sport safely from:

- [Health4Performance](#)
- [Athletes in Balance](#)
- [Safe Exercise at Every Stage \(SEES\)](#)

How will anorexia affect my bones?

When anorexia develops in childhood and adolescence, a low body weight can increase the risk of developing osteoporosis, and growth can become stunted. Osteoporosis means that bones become weaker and might be more likely to break as you get older. Regaining weight is the best way to reverse or prevent this, but medical treatments might also be offered to reduce bone loss. Unless you reach a healthy weight, these treatments may be of limited value.



Recommendation based on the research evidence

The best way to promote good bone health and prevent osteoporosis is to regain weight.

In older people, a group of medicines called bisphosphonates might be offered, but these can have risks and side effects. They are not recommended in younger people. Sometimes the female hormone oestrogen is prescribed to help protect bones.

Your healthcare professional will prescribe these treatments only after discussion with you. There will also be co-ordination between specialists in bone metabolism and eating disorders.

What if treatment isn't working for me?

Sometimes the first treatment offered does not work. An eating disorder can be severe or exist at the same time as another condition (this is called comorbidity). In these cases the usual treatments might not be suitable or successful. Your healthcare professional may need to look at other treatment options.



Recommendation based on clinical experience

If your eating disorder is severe, or if you have also been diagnosed with:

- post-traumatic stress disorder (PTSD)
- personality disorder, or
- substance misuse

then treatment for the eating disorder will be discussed with you and chosen carefully based on your specific needs.

You may also receive ongoing support from your community mental health team.

Using the Mental Health Act to support care

People with eating disorders often feel that losing weight is a solution rather than a problem. With time and treatment, most patients learn other ways to cope. However, sometimes the illness is too severe to allow normal treatment, as the person is at immediate risk. When this happens, they need to be cared for under the Mental Health Act.



Recommendation based on clinical experience

The European Human Rights Act prioritises the right to life and health over the right to choose in these matters. Healthcare professionals may need to admit people for treatment under The Mental Health (Care & Treatment) (Scotland) Act 2003, which they will provide on a compulsory basis.

What treatments are available?

Treatment usually involves psychological or 'talking therapy'.

There are different types of therapy. Your healthcare professional will explain how a therapy works and why it is appropriate for you or the person you're caring for.



Information

The healthcare professionals involved in your care will discuss treatment plans with you. You will be encouraged to share any ideas and concerns you have.



Now I have got a toolbox of strategies to help me cope in healthy ways.



Children and young people with anorexia nervosa

Many children and young people with anorexia nervosa find it helpful to have a therapy that their families can take part in too. This is known as family therapy. It involves working with a therapist to understand how anorexia has affected you and how your family can support you to get better.



Recommendation based on the research evidence

Family-based treatment (FBT) is a specific family therapy developed for treating eating disorders. If your child or adolescent's eating disorder is stopping them adequately nourishing their body, FBT should be offered to you as the best treatment option. At times this approach may need to be adjusted (for example if there are high levels of emotion, distress or conflict in the family).

In a few cases there may be other risk factors, such as obsessive compulsive disorder, or a lack of early physical improvement during FBT. If so, some additions or changes to FBT may improve the outcome of the treatment.



Children and adolescents with bulimia nervosa

Bulimia nervosa is more unusual in young children, so the evidence mainly focuses on adolescents. Healthcare professionals will be able to explain what this means for younger children.



Recommendation based on the research evidence

Adolescents with bulimia nervosa could be offered **cognitive behavioural therapy (CBT)** or family-based treatment (FBT) as their first treatment option. If you or your family don't want CBT or FBT, **psychodynamic therapy** could also be considered.

Cognitive behavioural therapy (CBT) is a talking therapy that can help you manage your problems by changing the way you think and behave. It involves working with a trained therapist who will help you challenge your thinking and behaviour.

“ I received psychological therapies, such as, CBT and schema therapy. These helped me to better understand and rationalise my thoughts.

Psychodynamic therapy explores the origins of problems that are in your past and present relationships and everyday life. It focuses on your relationship with the therapist and can help you better understand your relationships with other people.



Recommendation based on the research evidence

Healthcare professionals may consider prescribing a medication called fluoxetine for adolescents aged between 16-18 years. This would only be for short-term use and alongside one of the talking therapies described above. When you are taking this medication, it is important that you are monitored closely by your healthcare professionals for any side effects - especially when you first start taking it.

Children and adolescents with binge eating disorder

Many treatments are available to treat binge eating disorder. Your healthcare professional can explain these to you.



Recommendation based on the research evidence

Adolescents with binge eating disorder could be offered cognitive behavioural therapy, **interpersonal psychotherapy** or family-based treatment at first. Medication should not be prescribed for young people with binge eating disorder.

Interpersonal psychotherapy is when trained professionals work with you to help you understand how your relationships with others affect your emotional and mental health.



Adults with anorexia nervosa

Many psychological therapies are available to help treat adults with anorexia nervosa. Healthcare professionals will discuss the options with you.



Recommendation based on the research evidence

Cognitive behavioural therapy - enhanced (CBT-E) or another form of CBT should be offered as the first choice of psychological treatment for adults with anorexia nervosa. If this does not work, alternatives might include:

- **interpersonal therapy (IPT)** (see page 14)
- **Maudsley Model of Anorexia Treatment (MANTRA)**
- **Specialist Supportive Clinical Management (SSCM)**
- **focal psychodynamic therapy (FPT)**

These approaches are developed especially for people with eating disorders, including anorexia.

Cognitive behavioural therapy - enhanced (CBT-E) is when your therapist will work with you to help you change your thoughts and eating behaviours. The therapy follows works a specific structure over a set number of sessions.

Maudsley Model of Anorexia Treatment (MANTRA) is a specialist therapy for anorexia. It is usually provided by a therapist working from an instruction manual. It has a strong educational focus and is good for individuals with a more rigid thinking style.

What treatments are available? continued

Specialist Supportive Clinical Management (SSCM) is a psychoeducational therapy for patients with anorexia. It is time limited and involves talking to a therapist who will help you understand factors that have contributed to the development of your eating disorder. You'll learn about nutrition and how your eating habits cause your symptoms.

Focal psychodynamic therapy (FPT) aims to help you understand how your eating habits are related to what you think, and how you feel about yourself and other people in your life.

Can medication help to treat anorexia nervosa?

Prescribing medication for people with anorexia nervosa needs to be very carefully thought about. The options will be fully discussed with you.

If your body weight is low, or there are imbalances of the salts (electrolytes) in your body, it can be risky to take certain medications. Some medications can have harmful effects on organs such as your heart and kidneys. This means research on their use is limited. So, in these cases, it is especially important that you are involved in discussions about the potential risks and benefits. An **electrocardiogram (ECG)** and regular blood tests might be needed for monitoring.

Electrocardiogram (ECG) is a painless test that records your heart's rhythm and electrical activity. Electrodes are placed on your body and connected to a recording machine. The machine records your heart's pattern of activity.



Recommendation based on the research evidence

Some people with anorexia nervosa are distressed. Their symptoms are made worse by obsessional thinking. Olanzapine is a medicine that can be offered to help people with this, and there is some research to suggest it is helpful.

If your healthcare professional offers you olanzapine, they will discuss this with you first, including side effects.

Adults with bulimia nervosa

Two variations of CBT (see page 13) have been effective in treating bulimia nervosa. You may be offered cognitive behavioural therapy-enhanced (CBT-E) (see page 15) or **cognitive behavioural therapy – bulimia nervosa (CBT-BN)**. Both have been specifically developed to tackle the difficulties you face.

Cognitive behavioural therapy – bulimia nervosa (CBT-BN) is a talking therapy like other forms of CBT, but it is designed specifically to help with bulimia nervosa.



Recommendation based on the research evidence

Cognitive behavioural therapy-enhanced (CBT-E) or **cognitive behavioural therapy – bulimia nervosa (CBT-BN)** should be offered as the first choice of psychological treatment for adults with bulimia nervosa.



Recommendation based on the research evidence

If you aren't finding CBT helpful, alternatives may be considered such as: **interpersonal psychotherapy (IPT)** (see page 14), **integrative cognitive affective therapy** and **schema therapy**. **Mentalisation-based therapy** can be helpful. It may be considered if a diagnosis of bulimia nervosa and **borderline personality disorder** has been made.

Your team will work hard to find an approach which works for you and helps you recover from bulimia nervosa.

Integrative cognitive affective therapy (ICAT)

is a newer therapy looking at emotions, thoughts, behaviours and problems.

Schema therapy

is designed to address deeper, long-standing beliefs, ways of coping, and patterns in relationships.

Borderline personality disorder

is a condition that affects how you think, feel and interact with other people.

Mentalisation-based therapy focuses on improving your ability to recognise your own and others' state of mind and learning to 'step back' from your thoughts about yourself and others.

Can medication help to treat bulimia nervosa?



Recommendation based on the research evidence

You may be offered treatment with antidepressant medication, alongside psychological treatments. Fluoxetine is most commonly prescribed, at a dose of 60mg daily. There is research evidence showing that in the short term (up to 4 months) it can help with symptoms of bingeing and purging. There may be side effects such as irritability and anxiety and your healthcare professional will discuss these with you. If you cannot take fluoxetine, other antidepressant medications can be considered.

Adults with binge eating disorder



Recommendation based on the research evidence

If you have a binge eating disorder, you should be offered cognitive behavioural therapy (CBT) or interpersonal psychotherapy (IPT) first. The focus of these therapies (CBT in particular) is to stop you dieting as it increases the risk of binge eating. Psychological therapies for binge eating disorder do not directly focus on weight loss.

If these interventions are not effective or appropriate, other treatment options can be considered.

Medication is not recommended for adults with binge eating disorder.



Recommendation based on clinical experience

To increase the benefits of your initial treatment, you may be offered another treatment alongside it. Your healthcare professional will discuss this with you.

Severe and enduring eating disorders

The course of an eating disorder is individual and there is huge variation in how long people may be ill and the time it takes them to get better. Some people may not respond to initial courses of evidence-based treatment. However, people can still recover after living with eating disorders for more than twenty years.



Recommendation based on the research evidence

You should be offered more than one evidence-based treatment and any available alternatives, which may include new treatments. The structures and functions of the brain keep developing for many years into adulthood. So treatments can be tried again to reflect this.



Recommendation based on clinical experience

It may be helpful temporarily or in the medium-to-long term to move from treating your eating disorder symptoms to concentrating on maintaining a better quality of life. When doing this, your healthcare professional will try to minimise the negative impact of your eating disorder.

If you decide to stop therapy, you should have the opportunity to change your mind, re-engage and discuss your options with a suitably trained healthcare professional.



Information

If you need more support, your healthcare professional will point you towards support from social services, housing, education and employment services.

How will I be treated if I also have diabetes?

Eating problems are twice as common in people with type 1 diabetes than in others.

Problems are often linked to bingeing and purging.



Recommendation based on clinical experience

If your healthcare professional thinks you may have an eating disorder, they will talk to you about this at your routine diabetes review. To find out more, they may use a questionnaire.

If you do have type 1 diabetes and an eating disorder, the diabetes professionals involved in your care will work with mental health professionals to support you. They will consider giving you extra help to monitor and control your blood glucose. You may find it helpful to involve a family or carer in any treatments you are having for an eating disorder.

How will I be treated if I'm pregnant?

Pregnancy and the time after you give birth can be difficult times, both physically and emotionally. An eating disorder can make things more complicated.

Pregnancy may make you think about your body differently as you balance managing an eating disorder with looking after your unborn child. Your healthcare professional will be happy to discuss with you any problems you are having.



Recommendation based on the research evidence

Healthcare professionals should ask you sensitively if you have or have had an eating disorder. They should discuss and support you with such things as how your eating disorder symptoms may change during pregnancy and after the baby is born. You may need more monitoring and support on nutrition for you and your baby.



Recommendation based on clinical experience

You may need a personalised care plan to support you when preparing for pregnancy, during pregnancy and after your baby is born. This may involve a team that includes healthcare professionals from general practice, obstetrics, eating disorder services, perinatal mental health, dietetics, health visitors and midwives. They will work together to plan your care.

What if I have to move between services (transition) during treatment?

Transitions can happen in several ways, whether you are moving home, moving from child to adult services, or moving from inpatient to outpatient services. To help you with support and recovery, it's important that you get consistent care.

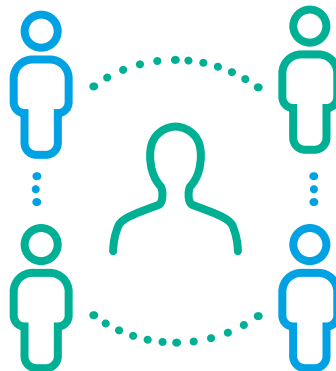
To make the move as easy as possible, your healthcare professionals from different services will work together with you and your carers to build a transition plan.



Recommendation based on the research evidence

You should be put in touch with a designated Transition Manager who will supervise the process at each stage for several months before and after transition, to make sure you have consistent support.

Healthcare professionals will work together to develop your transition plan, for example from child and adult services or from each geographical healthcare team. This will be with input from you and your carers. This makes sure that the plan is strong, and works for everyone involved. A copy of the plan will go to both healthcare teams (the one you're moving from, and the one you're moving to) to make sure everyone is aware of each step in the plan and when each change or each step will take place.



What support is available for families and carers?

Having an eating disorder can also be difficult for the people around you, such as your family, carers and friends.

Parents and carers of children or young people with eating disorders may be asked to take part in family-based treatments, which can be tough in the short term, but lead to longer-term recovery. Adults with eating disorders will guide their own recovery, but close family members are often included. It is important to have a supportive network of people you can rely on.

It is essential that families, carers and friends feel supported too, as this puts them in the best position to help you with your recovery.



Recommendation based on the research evidence

All carers should be offered support. This could be via a self-help skills book from Experienced Carers Helping Others ([ECHO](#)) or through Collaborative Carer workshops.



Recommendation based on clinical experience

Family and carer support can be given without breaching patient confidentiality. It should always be offered to help encourage the patient to build a supportive network which may involve family and/or friends.

Where can I find out more?

If you haven't found what you're looking for, here are some further sources of information. The organisations we have listed may be able to answer your questions and offer support.



National organisations

Beat

www.beateatingdisorders.org.uk

Beat is a national charity which provides support for people with eating disorders, their family and friends. It also campaigns to raise awareness and improve knowledge of eating disorders among healthcare professionals.

Help in Scotland

Beat also has a dedicated **Beat Scotland helpline**

Helpline number: 0808 801 0432

Email: scotlandhelp@beateatingdisorders.org.uk

Help for adults

The **Beat Adult Helpline** is open to anyone over 18. Parents, teachers or any concerned adults should also call this helpline.

Helpline: 0808 801 0677

Email: help@beateatingdisorders.org.uk

Help for young people

The **Beat Youthline** is open to anyone under 18.

Youthline: 0808 801 0711

Email: fyp@beateatingdisorders.org.uk

SIGN accepts no responsibility for the content of the websites listed.



National organisations continued

CARED Scotland

www.caredscotland.co.uk

A website providing information and resources for young people with eating disorders, their family and carers.

F.E.A.S.T.

www.feast-ed.org

F.E.A.S.T is a global organisation which provides information and support to parents and carers of people with eating disorders.

Mental Welfare Commission

www.mwcscot.org.uk

The Mental Welfare Commission provides advice on rights and good practice in mental health and incapacity law, and care and treatment of people with mental health conditions.

Adviceline for personal queries: 0800 309 6809

Adviceline for professional queries: 0131 313 8777

Email: mwc.enquiries@nhs.scot



National organisations continued

NHSInform

www.nhsinform.scot/illnesses-and-conditions/mental-health/eating-disorders

This is the national health and care information service for Scotland. It includes information and links to resources and to support people with eating disorders

Tel: 0800 22 44 88

Scottish Association for Mental Health (SAMH)

www.samh.org.uk

SAMH promote national mental health campaigns and work with adults and young people to provide mental health support. They provide an information service on mental health problems, self help and wellbeing, and support for carers.

Tel: 0344 800 0550

How are SIGN guidelines produced?

Our guidelines are based on the most up-to-date scientific evidence. We read research papers to find evidence for the best way to diagnose, treat and care for patients. If we cannot find this out from the research evidence, we ask healthcare professionals to use their clinical experience and judgment to suggest treatments.



1
Gather lived
experience



2
Identify the
questions



3
Search for the
evidence



4
Look at the
evidence



5
Make judgements
and
recommendations



6
Ask people for
feedback



7
Publish



8
Let everybody
know about our
guidelines

You can read more about us by visiting www.sign.ac.uk or you can phone 0131 623 4720 and ask for a copy of our booklet 'SIGN guidelines: information for patients, carers and the public'.

The Scottish Intercollegiate Guidelines Network (SIGN) writes guidelines which give advice for healthcare professionals, patients and carers about the best treatments that are available. We write these guidelines by working with healthcare professionals, other NHS staff, patients, carers and members of the public.

We are happy to consider requests for other languages or formats. Please phone 0131 623 4720 or email sign@sign.ac.uk



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