Eating disorders

This article is based on SIGN 164 (2022) and NICE eating disorders: recognition and treatment (NICE 2017, NG69, updated 2020). *It was updated in October 2023.*

Key messages

- Five eating disorder subtypes are described in this article; as soon as you suspect any of them, refer.
- Eating disorders can be present in underweight, normal weight and overweight people.
- Do not refer based on BMI alone. If your local eating disorder service has a BMI threshold, challenge this! Both NICE and SIGN are clear that patients should be able to access secondary care for eating disorders at any BMI.
- Early intervention makes a big difference, especially in anorexia nervosa.

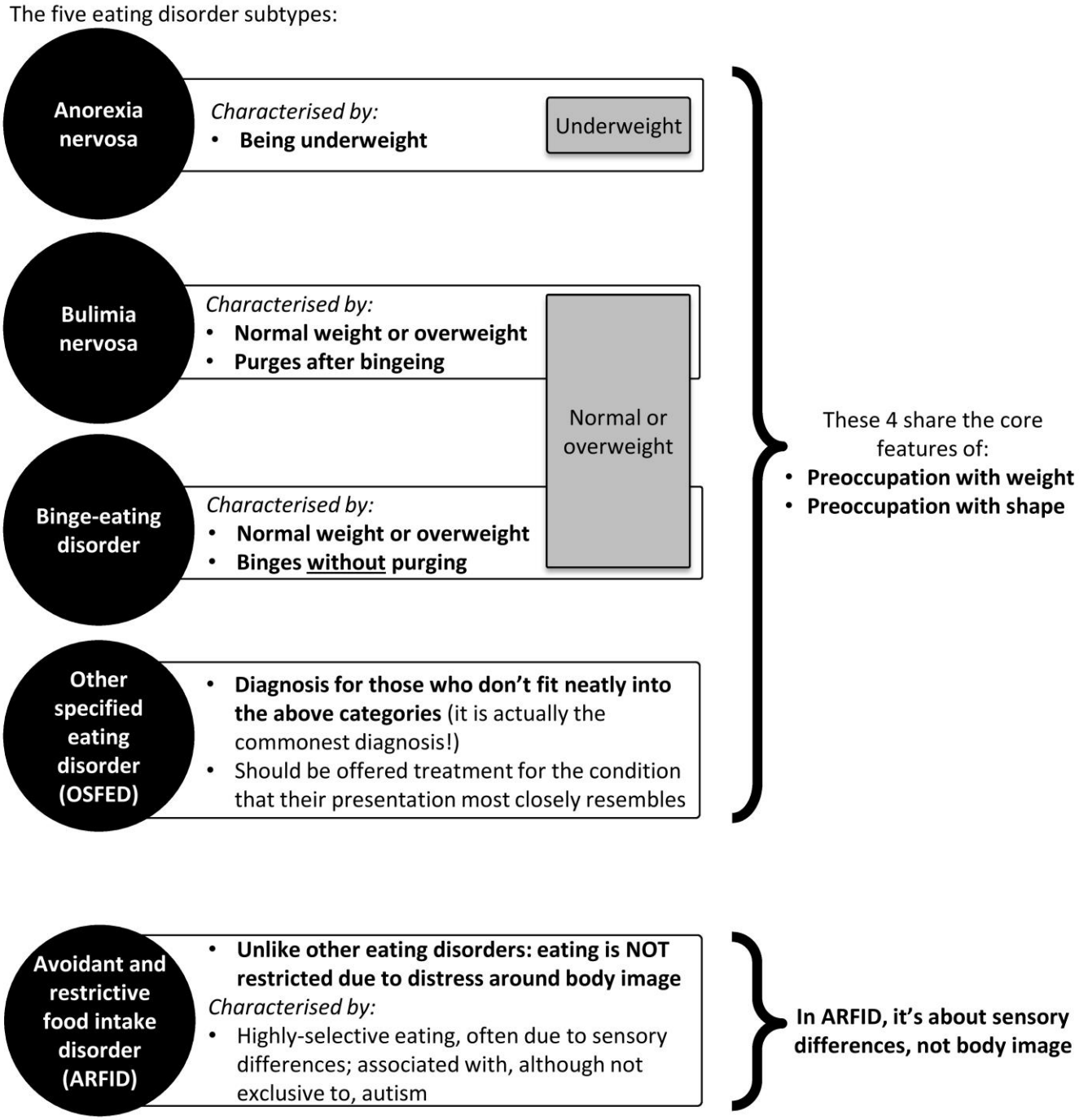
Why are eating disorders important?

All eating disorders cause significant distress and morbidity, and anorexia nervosa has the **highest mortality of any psychiatric condition**. SIGN estimates that the average care of the mental and physical health of a patient with an eating disorder costs a staggering £100 000 per year. A key role for primary care is in early recognition and referral – as there is increasing evidence that this vastly improves outcomes – but this is often a difficult task because presentation can be subtle and complex.

There also appears to have been a substantial increase in the incidence of eating disorders and self-harm among teenage girls in the UK, particularly those aged 13–16y, during the first 2 years of the COVID-19 pandemic (Lancet Child Adolesc Health 2023, volume 7, issue 8, p544-554).

Understanding eating disorders

There are five eating disorder subtypes. Four of these share the core feature of preoccupation with weight and shape. DSM-5 and ICD 11 use weight, bingeing and purging to delineate between the major three categories of anorexia nervosa, bulimia and binge-eating disorder:



Despite the name, an eating disorder diagnosis implies that much more than eating is disordered. Aetiology is complex and variable (see 'complex comorbidity' below), and patients often use food or starvation to avoid or cope with underlying distress.

Eating disorders affect all ages and genders, but peak presentation is at age 13–17y, and 75% of patients are female.

Early intervention in eating disorders

SIGN and NICE agree that **when we suspect any eating disorder, we should immediately refer** without waiting for a 'trigger' BMI or for any specific severity or duration of illness.

Harms can accumulate during an untreated eating disorder, especially in the case of anorexia nervosa. Prolonged starvation damages brain structure and function, and makes the condition less likely to respond to treatment. Because of stigma and ambivalence to change, patients have often been symptomatic for years at presentation. This means it's key that people presenting with eating disorders, particularly anorexia, receive intervention as quickly as possible after we meet them.

The FREED service model (First Episode and Rapid Early Intervention in Eating Disorders) is being implemented across multiple eating disorders services in England, and SIGN recommended a Scottish pilot in 2022. It involves patients aged 16–25y with <3y of symptoms receiving a call from secondary care within 48h of referral and a first appointment within 2 weeks. The English pilot data for this intervention is really promising: 59% of patients who were offered FREED had reached a healthy body weight by 12m follow-up compared with 17% in the 'treatment as usual' group.

Screening for and picking up eating disorders

Increasing understanding of the importance of early detection in eating disorders raises the question: should we screen for them? NICE and SIGN don't mention screening, and a US Preventive Services Task Force review into the evidence for screening for eating disorders found insufficient evidence to support its use in the general population. However, an associated JAMA editorial points out that we should still be vigilant and consider screening in high-risk groups and presentations, including those with low BMI and other relevant symptoms (JAMA 2022;327:1068 and editorial 1029.)

So, how might an eating disorder present? The JAMA article and NICE give the following examples:

- Weight:
  - Unusually low or high BMI.
  - Rapid weight change.
  - Failure to thrive in children.
  - Dieting or restricted eating, or a change in eating behaviour.
- Social factors:
  - Individual, family or friends concerned.
  - Social withdrawal, especially around food.
  - Disproportionate concerns around weight and shape.
  - High-risk professions: athletes, dance, modelling.
- Physical health:
  - Delayed puberty.
  - Menstrual problems, particularly amenorrhea.
  - Physical consequences of malnutrition, e.g. bradycardia, pallor, dizziness, electrolyte disturbance (these patients may well need acute medical admission; see the section on acutely-ill patients).
- Physical consequences of purging, e.g. laxative abuse and GI symptoms, dehydration or electrolyte disturbance; vomiting and dental problems, hypokalaemia, swollen parotids or calluses on fingers; physical sequelae of excess exercise.
- Other mental health presentations.

The SCOFF screening tool (below) can be a useful aid in screening for eating disorders, with a sensitivity and specificity of 84% and 80% respectively (JAMA 2022;327:1068), but NICE asks us not to use tools like this in isolation. One issue with SCOFF is that it's unlikely to pick up binge-eating disorder (JAMA 2022;327:1029).

The SCOFF screening tool:

Score 1 for each 'Yes': a score of ≥2 indicates possible eating disorder:

- Have you ever felt so uncomfortably full that you have had to make yourself ***Sick***?
- Do you ever worry you have lost ***Control*** over how much you eat?
- Have you recently lost or gained more than ***One*** stone in a three-month period?
- Do you believe yourself to be ***Fat*** when others say you are too thin?
- Would you say that ***Food*** dominates your life?

Risk assessment

The Royal College of Psychiatry's 'Medical Emergencies in Eating Disorders' was published in 2022 (replacing the adult and junior MARSIPAN guidance) in the wake of rapidly-rising hospital admissions for eating disorders. It emphasises that signs of severe illness in this group are easily missed, and the need for all medical professionals to be alert to this risk. In primary care, our role is to spot unwell patients and refer promptly for acute medical or paediatric admission, or urgent mental health input as appropriate. We also need to be aware that risk levels fluctuate, and patients who we've already referred to an eating disorders service may well deteriorate while they're waiting – in this case, active monitoring might be needed.

The RCPsych document includes a traffic light framework to help guide risk assessment, although it highlights that this doesn't replace clinical judgement. Below is a simplified version detailing 'red' or 'amber' parameters that would be an **acute** concern. If your patient has any of these, we would suggest you refer to the full framework (link in useful resources, below) and/or seek specialist advice around whether acute admission or other urgent input is needed – a key message for primary care is to have a low threshold to do this.

It's important to note when looking at this table that we're not just thinking about people with anorexia nervosa. People with other eating disorders and a normal or high BMI could also present in extremis – for example, those with frequent vomiting might have hypokalaemia or haematemesis.

Parameter	**Cause for <u>acute</u> concern**
Weight loss	Loss of >0.5kg/week for >2w in an undernourished person, or very rapid weight loss in anyone.
BMI	BMI <15 in over-18s (in under-18s, calculate the percentage median BMI on a BMI centile chart. Percentage median BMI <80 = below 2nd BMI centile, and is a cause for acute concern)
Heart rate	<50bpm.
Blood pressure	Hypotension, postural hypotension, postural dizziness, syncope.
Hydration	Significant fluid restriction or refusal, clinical signs of dehydration.
Temperature	<36°C.
Sit Up Squat Stand test	Difficulty with sitting up from lying, or with squatting from standing, both without using hands or arms (assessing for muscle weakness).
Blood tests	• Low phosphate, potassium, albumin, glucose, sodium, calcium, WCC or Hb. • Raised transaminases. • Rapidly-worsening diabetic control.
ECG	Prolonged QTc interval, arrhythmia.
Other clinical states	Haematemesis, confusion, DKA, significant alcohol intake, pressure sores.
Behavioural	Acute food refusal, poor engagement with treatment, dysfunctional exercise, frequent purging.
Self-harm and suicide	Any self-harm or suicidal ideation.

Where an acutely-ill person doesn't consent to admission, a Mental Health Act assessment may be appropriate. In this context, both the provision of nutrition and insulin for diabetes **can** be considered medical treatments for a mental disorder.

Family and carers

Caring for someone with an eating disorder is distressing. SIGN says that formal support should be offered to all carers by the eating disorders team, and they may need support in primary care too.

Beyond this, family-based treatment for the disorder itself is a first-line option for children and adolescents with eating disorders, with evidence for improved weight gain and reduced relapse in anorexia nervosa.

A key family therapy resource SIGN mentions is Expert Carers Helping Others (ECHO). We can signpost families to materials on implementing this approach in the community while awaiting secondary care input, including books, videos and, in some areas, telephone coaching via the charity BEAT (see useful resources at the end of this article).

Like any serious illness in children and teenagers, eating disorders in early life can delay physical and social maturity, and SIGN points out that, because of this, family involvement (with appropriate consents) may be beneficial beyond the usual age where this seems appropriate.

Treatment: SIGN recommendations

Adults

- Cognitive behavioural therapy is a first-line option for all the subtypes. Other psychological therapies may be used if this is unsuitable or ineffective, and drugs are sometimes used as an adjunct.

Eating disorder	Goals of psychological treatment	Drug therapy – to be initiated by the specialist, if appropriate
Anorexia	A key goal is refeeding to a healthy weight: this can be a challenging and distressing experience for patients.	Olanzapine may be initiated by specialist.
Bulimia	Addressing purging behaviours.	Fluoxetine may be initiated by specialist. Usually titrated up to 60mg daily.
Binge-eating disorder	Eliminating harmful behaviours such as dieting; emphasising that the therapy does not focus on weight loss, even in people with obesity.	Comorbid mental health conditions can be treated with medication but there is no evidence that any medication helps the disorder itself.

- OSFED is treated in line with whichever of the 3 subtypes listed above the disease most closely resembles.
- SIGN comments that **no** evidence exists on how to manage patients with ARFID. Often, care involves addressing factors such as sensory sensitivities around food with dietician support.

Children and adolescents

- Family therapy is usually first line.
- CBT and other psychological therapies are also sometimes offered.
- Evidence for medication use in children and teens is poor, but olanzapine and fluoxetine are sometimes used in similar contexts to those in adults. Like in adults, this is ALWAYS on specialist advice only.

Eating disorders and physical conditions

Bone mineral density (based on SIGN and NICE)	• People with anorexia nervosa have up to triple the fracture risk of the background population. • NICE suggests assessment of bone density after 1 year of underweight in children or 2 years of underweight in adults, or earlier if they have bone pain or recurrent fractures. Further scans might be appropriate as frequently as yearly if underweight persists. • Healthy weight – and the return of periods in women – are the best predictors of an increase in BMD, and achieving these is particularly important in teens. • Drugs such as bisphosphonates and oestrogens are of limited benefit in the absence of weight restoration, but can be used when this is not achievable. Bisphosphonates have the greatest effect on BMD, but their long-term safety is unknown and they're contraindicated in women 'who have the potential to become pregnant' due to teratogenicity. NICE and SIGN agree that medications in this context should only be started on the advice of secondary care. • There's a lack of evidence for treatment options in men other than weight restoration; again, we should refer.
Purging behaviours (based on NICE)	• In patients who induce vomiting, regular dental checks are needed. Avoid acid food. Avoid cleaning teeth immediately after vomiting; use a non-acid mouthwash instead. • In medication misuse, advise that laxatives, diuretics and caffeine do not help weight loss, and support reduction of these. Consider if an ECG is needed in this group.
Pregnancy and peripartum care (based on SIGN)	• SIGN suggests we refer all pregnant women with a current or past eating disorder. • Eating disorders usually improve in pregnancy, but postpartum, relapse risk is high. This group also has a higher risk of perinatal depression and anxiety. • Pregnant women with anorexia nervosa are at increased risk of iron deficiency anaemia and various adverse obstetric outcomes. Preconceptual advice is important, with optimised nutrition and mental health ideal prior to trying to conceive. • Infants in this context are at increased risk of feeding and social/emotional difficulties; health visitor support may be appropriate.
Type 1 diabetes (based on SIGN)	• Eating disorders are twice as common in those with type 1 diabetes, with **30–40% of young people** omitting or reducing insulin at times, with the intention of losing weight. • **We should consider the potential for eating disorders at routine review of these patients**. • Typically, weight loss is achieved through omitted insulin and hyperglycaemia, but carbohy-

	drate restriction is another method, and so hypoglycaemia is also a risk.
	• Factors that might raise concern include:
	  o High HbA1c.
	  o Recurrent DKA.
	  o Poor engagement with healthcare.
	  o Infrequent or absent self-glucose monitoring.
	  o Omission of quick-acting insulin.
	• An integrated approach involving the diabetes, eating disorders and primary healthcare teams may be needed.

Annual review

NICE says that GPs should offer a physical and mental health review at least annually to people with anorexia nervosa who are **not** receiving ongoing treatment for their eating disorder. The RCPsych Medical Emergencies in Eating Disorders guidance goes further and says we should review everyone with an eating disorder annually, even if they **are** under secondary care, pointing out that that their diagnosis falls under the banner of 'severe mental illness.' NICE says review should include:

- Risk assess for physical and mental health.
- Weight and BMI.
- BP and pulse.
- ECG if significant weight changes or purging.
- Assess daily functioning.
- Bloods: FBC, haematinics, glucose, renal, liver, albumin, calcium, phosphate, bicarb, CK, lipids, TFTs.
- Review bone health.
- Carer support.

Complex psychiatric comorbidity

The aetiology of eating disorders is complex, and comorbid mental health conditions and coexisting neurodivergence are common. This includes:

- Autism (autism or high autistic traits are thought to exist in about 35% of eating disorder patients; see next section).
- Personality disorder (thought to exist in at least 30% of eating disorder patients).
- Obsessive compulsive disorder.
- Depression.
- Anxiety.
- Trauma.

SIGN points out that alternative treatment approaches might be needed in those with a complex picture, highlighting dialectical behavioural therapy in particular.

Autism, avoidant restrictive food intake disorder (ARFID) and eating disorders

ARFID is unlike other eating disorders in that eating isn't restricted due to distress around body image. It's characterised by highly-selective eating due to sensory differences, and is associated with, although not exclusive to, autism. SIGN comments that it found no evidence to guide management of this condition.

More broadly, emerging data suggests that around of a third of people with an eating disorder diagnosis may also be autistic or have high autistic traits. SIGN comments that there is no robust research and no guidance as to how to best manage eating disorders in autistic people, but it does signpost to an online resource for patients and professionals named the 'Pathway for Eating disorders and Autism developed from Clinical Experience' (or PEACE pathway).

Eating disorders and gender

Men who experience eating disorders have a higher mortality risk due to increased stigma, later presentation and greater challenges to engagement with 'feminised' services.

Transgender people have a higher incidence of eating disorders than cis-gender people, and SIGN notes that failure to acknowledge gender issues or address transgender patients correctly can lead to disengagement. Research suggests

that eating disorder symptoms in transgender people decrease after gender-affirming medical interventions due to the increase in body confidence that comes with this.

Eating disorders and exercise

Engaging in **dysfunctional** exercise is one of the strongest predictors of relapse, and is often the first presenting and last remaining symptom of an eating disorder. However, **healthy** exercise improves wellbeing across all eating disorders (although in active anorexia nervosa, this needs to be under specialist care). Return to high physical activity levels in occupations such as athletics and dance is a particularly high-risk time for relapse.

Severe and enduring eating disorders

With treatment, 50% of people with anorexia nervosa fully recover, and, as focus shifts to early intervention, prognosis may get even better. But what about people with ongoing symptoms over years or decades? Recovery still happens in this group, including after 20 or more years of illness, but many patients have persistent symptoms. SIGN states that "keeping people attached to services without measurable benefit might stand in the way of normal social supports and life skills", and talks about a 'fluid' approach to intervention where patients may move in and out of treatment. Where this approach is taken, the door should always be left open to reengage, and this reengagement might well start with presentation to primary care. This may also be one of the scenarios in which an acutely physically ill patient with an eating disorder could present to primary care.

As described in the 'risk assessment' section, the Mental Health Act (and/or the Mental Capacity Act in some circumstances) can and should be used when a person with life-threatening features of an eating disorder refuses treatment, including nutrition. Very occasionally, patients with severe and enduring anorexia nervosa may request that life-saving treatment should not be imposed on them on a repeated, compulsory basis. This highly-distressing situation requires a formal second opinion and medico-legal involvement, and would be firmly in the remit of secondary care.

Eating disorders

- When an eating disorder is suspected, immediate referral is indicated. **Do not** use BMI alone or duration of illness to determine whether to offer treatment.
- Eating disorders are associated with a high mortality from easily missed physical health complications and suicide. Always assess for risk – both physical and psychiatric.
- Early intervention is key to preventing disease progression, particularly in anorexia nervosa.
- In anorexia, a key target of treatment is to reach a healthy weight. In bulimia and binge eating, the main aim of treatment is to address the behaviours rather than to reach a normal weight.
- Eating disorders can cause severe distress for families, and they should be offered support in their own right as part of the treatment. In children and teens, family therapy usually plays a key role in treatment, and we can signpost to resources which can be accessed in the community to support this.
- Treatment in adults usually involves a cognitive/cognitive behavioural approach. Medication alone is not appropriate.
- Eating disorders often exist as part of a complex mental and physical health presentation. Important potential coexisting conditions include autism, personality disorder and type 1 diabetes – in type 1 diabetes, omitting insulin to achieve weight loss is extremely common.

Useful resources:

Websites (all resources are hyperlinked for ease of use in Red Whale Knowledge)

- Peace Pathway (for autism and eating disorders)
- Royal College of Psychiatrists - medical emergencies in eating disorders (including traffic light risk assessment)

For patients and carers:

- Eating Disorders Support – links and resources (a series of links to support groups and information; includes links to the Royal College of Psychiatrists' leaflets on each eating disorder, including one for parents/families and teachers)
- Beat eating disorders (national support network)
- FEAST
- MaleVoicED (for men with eating disorders)
- SIGN patient booklet on eating disorders
- Expert Carers Helping Others resources:
  - Skills-based Caring for a Loved One with an Eating Disorder: The New Maudsley Method (book) by Janet Treasure, Grainne Smith and Anna Crane
  - Coaching via B-EAT (above)