

Early referral key to better outcomes in eating disorders

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How do children and adolescents present with eating disorders?

How should patients be referred?

What are the evidence-based management approaches?



EARLY RECOGNITION, REFERRAL AND TREATMENT ARE ESSENTIAL TO ACHIEVE

good outcomes in children and adolescents with eating disorders.^{1,2,3}

Eating disorders have the highest mortality of all psychiatric conditions.⁴ They can develop at any age, but the highest risk is for adolescents aged between 13 and 17.⁵ Provided there is access to early and evidence-based treatment, the majority of patients diagnosed with an eating disorder under the age of 18 will make a full recovery.⁶ Overall, outcomes in this age group are better than in adults.⁷

Conversely, the longer eating disorders remain untreated in childhood, the harder they can be to treat.⁸ Untreated eating disorders may, in turn, irreversibly affect growth, bone and cognitive development,⁹ while also having an adverse impact on the wellbeing of parents and siblings.^{10,11}

Two documents have recently been published that emphasise the importance of early recognition and rapid intervention. The NICE guideline on eating disorders (NG69)⁵ was published in May 2017 and the Access and Waiting Time Standard for Children and Young People with an Eating Disorder (A&WT) Commissioning Guide, in July 2015.¹²

GPs can play a crucial role in the care of children and adolescents with eating disorders, and their families, see table 1, p18. Most importantly, GPs can try to ensure that they get access to appropriate treatment as early as possible.

DIAGNOSIS

DSM-V¹³ identifies eight types of eating disorder. Anorexia nervosa and bulimia nervosa are probably the two most well known. However, it is the atypical variants, termed other specified feeding and eating disorders (OSFED) and

unspecified feeding and eating disorders (UFED), respectively, that are the most common.¹⁴ In DSM-IV these conditions were previously referred to as eating disorder not otherwise specified (EDNOS). There are currently a few subtle differences in diagnostic criteria between DSM-V and ICD-10. However, ICD-10 is being revised and greater convergence between the manuals is likely in the new edition.

Eating disorders are diagnosed by the presence of characteristic thoughts and behaviours associated with evidence of distress, actual or potential harm, and impairment of function, see table 2, p18.

Anorexia and bulimia have several shared and overlapping features. Thought content primarily relates to preoccupation with weight and body shape, which then unduly influences self-evaluation. Associated behaviours seek to lose or maintain weight e.g. food intake restriction, over-exercising, »

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vomiting, bingeing and laxative use. Any of these behaviours may occur in either condition. The essential difference between the two disorders is that patients with anorexia are underweight, while those with bulimia are not. DSM-V criteria for the two conditions are shown in table 3, opposite.

Obesity is not considered an eating disorder, except in a minority of patients where it is part of a binge-eating disorder (BED) presentation. BED is a newly defined condition in DSM-V, which resembles bulimia but without compensatory purging. Binges in BED are associated with emotional distress. Another new condition is avoidant/restrictive food intake disorder (ARFID). This condition can affect people of all ages and individuals

become underweight or nutritionally compromised in the absence of weight and shape concerns. ARFID may be more common in individuals with autism spectrum disorders.¹⁵

DETERMINING UNDERWEIGHT

DSM-V no longer specifically defines the BMI at which a patient may be deemed underweight enough to receive a diagnosis of anorexia nervosa.

Body mass index (BMI) in under 18s is less useful as a metric of underweight than in adults: BMI can underestimate or overestimate weight, depending on the child's age and gender.

Percentage median BMI (%mBMI) is a better measure of underweight in children and adolescents, as it takes into account both gender and age.

%mBMI can be calculated as follows: $BMI \div mBMI$ (50th centile on Royal College of Paediatrics and Child Health BMI chart) $\times 100$. Spreadsheets and smart phone apps are also available.

A %mBMI of 70% is considered high risk.¹⁶ For many, 85% mBMI may be considered significantly underweight, however, for some constitutionally smaller individuals it may not be.

Similarly, the concept of a healthy weight can be difficult to define and depends on an individual. For females a key, but not sole criterion, is the weight at which normal menstruation can occur. For all children and adolescents a healthy weight is one that appears to enable normal growth and emotional and physical wellbeing.

EPIDEMIOLOGY

It is estimated that 1.6 per 1,000 females and 0.17 per 1,000 males aged 15-19 are newly diagnosed with an eating disorder each year in the UK.¹⁴

Incidence rates for anorexia and bulimia are approximately equal in this age group at 26/100,000/year. Rates roughly double for both conditions if only females are considered, as eating disorders are much rarer in males. Respective incidence rates for anorexia and bulimia in females are 47.5 and 46.8 per 100,000; this compares with 3.8 and 3.0 per 100,000 for anorexia and bulimia in males.

While eating disorders may be more common in females, Caucasians, and higher socioeconomic groups, these disorders affect people of all cultures, ethnicities and ages.¹⁷ Unfortunately, the majority of patients with eating disorders are not in contact with clinical services. This is especially true for bulimia and binge eating disorder because patients with these conditions may be less likely to be identified as they are not underweight. They are also less likely to seek help since these conditions are associated with high levels of secrecy, shame and stigma.¹⁸ The actual proportion of patients with eating disorders not in contact with clinical services is difficult to estimate.

It is important that GPs consider the possibility of eating disorders in males who, partly due to the combination of delayed help-seeking and under-recognition, often present for treatment at specialist services relatively late.¹⁹

PRESENTATION

Eating disorders may present with a mixture of physical, emotional and social symptoms and concerns as shown in table 4, p20.

Table 1

Role of primary care in managing children and adolescents with eating disorders

Referral

- Refer to local specialist community-based eating disorder services for children and young people (CEDS-CYP) as early as possible. Refer even when in doubt
- Unless local protocols specify otherwise, there is no need to arrange blood tests or any other investigations prior to referral
- Contact CEDS-CYP by phone/electronically as soon as a possible eating disorder is identified
- For rare high-risk/emergency cases e.g. medical instability, or intense suicidality, referral to local paediatric ward/adolescent eating disorders/psychiatric unit may be needed, before referral to CEDS-CYP. It is still important to inform CEDS-CYP immediately

Investigations

Depending on local protocols with CEDS-CYP/CAMHS, some cases may require investigations to be organised before a referral and/or after the patient has been accepted. The following investigations are likely to be the most commonly required:

- Blood tests – U&Es, LFTs, FBC, TFTs, Ca, phosphate, vitamin D, folate, B12
- ECG
- DEXA bone scan

Management

- Psychoeducation – highlight the importance of healthy nutrition for physical and emotional wellbeing growth and development; and the risks of inappropriate eating and undernutrition
- Issue repeat prescriptions for psychotropic medication, which will be initiated and monitored by CEDS-CYP
- Prescribe nutritional supplements e.g. Ensure, Fortisip, for the most severely unwell who cannot manage sufficient calorie intake through normal food and fluids

Table 2

Eating disorders: Thoughts and behaviours

Behaviours

- Food $\pm$ fluid restriction
- Over-exercising
- Self-induced vomiting after eating
- Laxative use
- Binge eating

Thoughts

- Fear of getting fat
- Preoccupation with weight and/or shape
- Preoccupation with food and/or eating
- Low self-esteem/over-evaluation of self in terms of weight and shape
- Desire for an abnormally low weight

Table 3

DSM-V criteria

Anorexia nervosa

- Persistent restriction of energy intake leading to significantly low body weight (in the context of what is minimally expected for age, sex, developmental trajectory, and physical health)
- Either an intense fear of gaining weight or of becoming fat, or persistent behaviour that interferes with weight gain (even though significantly low weight)
- Disturbance in the way one's body weight or shape is experienced, undue influence of body shape and weight on self-evaluation, or persistent lack of recognition of the seriousness of the current low body weight

Subtypes:

- Restricting type
- Binge-eating/purging type

Bulimia nervosa

- Recurrent episodes of binge eating. An episode of binge eating is characterised by both of the following:
 - Eating, in a discrete period of time (e.g. within any two-hour period), an amount of food that is definitely larger than most people would eat during a similar period of time and under similar circumstances
 - A sense of lack of control over eating during the episode (e.g. a feeling that one cannot stop eating or control what or how much one is eating)
- Recurrent inappropriate compensatory behaviour in order to prevent weight gain, such as self-induced vomiting, misuse of laxatives, diuretics, or other medications, fasting, or excessive exercise
- The binge eating and inappropriate compensatory behaviours both occur, on average, at least once a week for three months
- Self-evaluation is unduly influenced by body shape and weight
- The disturbance does not occur exclusively during episodes of anorexia nervosa

Eating disorders rarely present alone and emotional disorders such as anxiety, depression, obsessive compulsive disorder, autism spectrum disorders, and self-harm frequently co-exist.

Where there is a significant mismatch between energy intake and requirements, or starvation, these co-existing conditions may be exacerbated, or even appear to be present when in fact they are not. For example, an individual in a state of starvation may appear to be depressed or autistic, yet nutritional restoration can lead to resolution of these symptoms. Additional diagnoses are therefore usually not made until some time after nutritional balance is restored.

Initially, many children and adolescents with eating disorders may be reluctant and/or unwilling to attend primary care consultations about their eating. Many may feel a strong sense of shame, stigma or fear. This may be associated with worries about having to share information about their eating habits, beliefs about weight and shape and related behaviours such as over-exercising or purging. A minority may present with a sense of anger and indignation, convinced that they do not have an illness.

The majority will be worried about the prospect of treatment. For most, a visit to a GP will be initiated by parents and usually comes at a time when they may not be ready to make changes to their eating. They might feel especially afraid that treatment may herald uncontrolled weight gain, or an admission to hospital.

ASSESSMENT

For the reasons described above, assessment of children and adolescents with eating disorders can be challenging especially in primary care. It is important to try to be sensitive, compassionate, and pragmatic.

In primary care it is important to prioritise identification of potential physical risks and symptoms and include as much of this information as possible in the referral, see below. Ideally, this should also be combined with some brief psychosocial information, see table 4, p20. Junior MARSIPAN (Management of Really Sick Patients with Anorexia Nervosa), is a very useful guide for the evaluation of physical risk in children and adolescents with eating disorders and is available online.¹⁶

An adapted summary of the Junior MARSIPAN risk assessment guidance can be found in table 5, p21. Screening measures e.g. the SCOFF²⁰ can be useful but are not essential and should not be used on their own as a basis for diagnosis.⁵

Pre-pubertal children may not express worries about weight and shape, either explicitly or even at all, despite their behaviour showing clear attempts to avoid weight gain. An eating disorder should be considered if growth rates appear to be slowing or even stopping. This may be determined by reductions in height and growth centiles on paediatric growth charts, which without intervention, may lead to growth stunting.

If a medical condition is thought to be the most likely cause of underweight, e.g. coeliac disease, but there are still concerns of a possible eating disorder, it is advisable to refer for a specialist eating disorders assessment early rather than wait for the results of the investigations. The combination of type 1 diabetes and an eating disorder can pose particular challenges for both GPs and eating disorders services.

REFERRAL

A key recommendation from the A&WT guidance is that all children and adolescents with a possible eating disorder should be referred to their local community-based eating disorder service for children and young people (CEDS-CYP).

It is important not to use a single measure such as weight, BMI or duration of symptoms to determine if referral to CEDS-CYP is warranted. Presentations of eating disorders in children and adolescents are often atypical and with bulimia nervosa or binge eating disorder, in particular, patients can be average weight or overweight. If there is a high physical and/or mental health risk liaison with the local paediatric ward is usually required.

Key information to be included in the referral includes:

- Current height and weight
- Rate of any weight loss e.g. 3 kg in 3 weeks
- Current estimated food intake over the past week e.g. 800 kcal/day
- Presence and severity of any weight »

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losing behaviours e.g. vomiting, exercise

- Temperature, heart rate, and lying and standing blood pressure
- Phone numbers of parent(s) and/or patient especially if high risk
- GPs should contact local CEDS-CYP by phone/electronically as soon as a potential eating disorder is identified.

In 2014 new funding was committed for the development of CEDS-CYP across England to speed up access to specialist community-based treatment.

As a result new CEDS-CYP are being created throughout England and additional funding is being given to many existing CEDS-CYP. Funding is contingent on CEDS-CYP offering treatment according to the following target timescales from referral:

- Emergency 24 hours
- Urgent 7 days
- Routine 28 days

By 2020, 95% of referrals will need to be seen within these timescales.¹²

The A&WT recommends that GPs should contact the CEDS-CYP by phone or electronically following discussion with

the patient and their parents, as soon as an eating disorder is identified. Where a local CEDS-CYP service has not yet been formed then referral should be to the local CAMHS, and again contact made immediately at the point of identification. In rare cases where there is very high physical and/or psychiatric risk then GPs should arrange immediate paediatric and/or psychiatric care to manage risk via local protocols and should inform the CEDS-CYP immediately.¹²

In order to improve access CEDS-CYP have been encouraged to increase both ease and range of potential referral sources. Services are being encouraged to open dedicated self-referral routes either via phone and/or online for patients and parents. Professionals including paediatricians, CAMHS, school nurses, teachers and social workers can also refer using these routes.

Services are at different stages in improving access and it is important to check locally about current arrangements. To prevent unnecessary

delays we think it preferable to refer before organising blood tests, ECG etc.

EVIDENCE-BASED TREATMENT

The most appropriate treatment location for the majority of young people with an actual or suspected eating disorder is a CEDS-CYP.²⁰ Referral to a CEDS-CYP should be made directly from primary care or via a self-referral.

CEDS-CYP have an expert multidisciplinary team, offering a range of evidence-based interventions. Treatment should comprise a mixture of psychological interventions, nutritional support and physical monitoring. Treatment may be offered in a mixture of individual, family and group formats. Crucially CEDS-CYP enable young people to receive treatment while living at home, attending school, staying in contact with friends and engaged in hobbies and activities in so far as their physical condition allows. All these factors have been shown to be important in terms of early recovery.

A minority may, however, require

Table 4

Identifying eating disorders in children and adolescents (adapted from NICE NG69⁵)

Physical

- An unusually low or high BMI or body weight for their age
- Rapid weight loss
- Dieting or restrictive eating practices (such as dieting when they are underweight) that are worrying them, their family members or carers, or professionals
- Compensatory behaviours, including vomiting, excessive exercise, laxative or diet pill use
- Abdominal pain that is associated with vomiting or restrictions in diet, and that cannot be fully explained by a medical condition
- Menstrual disturbances, other endocrine disturbances
- Physical signs of malnutrition including: poor circulation, dizziness, palpitations, fainting, pallor
- Problems managing a chronic illness that affects diet, such as diabetes, coeliac disease or food allergies
- Unexplained electrolyte imbalance or hypoglycaemia
- Atypical dental wear (such as erosion)
- Growth reduction or stunting

Emotional

- A disproportionate concern about weight or shape (for example, concerns about weight as a side effect of contraceptive medication)
- Other mental health problems e.g. depression, anxiety, OCD
- Mood swings
- Self-harm and suicidal thoughts

Social

- Family members or carers report a change in eating behaviour
- Social withdrawal, particularly from situations that involve food
- Family arguments especially around food
- Taking part in activities associated with a high risk of eating disorders (for example, professional sport, fashion, dance, or modelling)
- Reduced interest or enjoyment in former interests e.g. swimming, meeting friends
- Decreased academic attainment/fall in school attendance
- Isolation/social withdrawal

Box 1

Psychological treatment of eating disorders, adapted from NICE NG69⁵

Anorexia nervosa

First-line

Anorexia nervosa-focused family therapy:
18-20 sessions over 1 year

Second line

a) or b) depending on which seems most suitable

- a) CBT for eating disorders:*
40 sessions over 40 weeks
- b) Adolescent-focused psychotherapy for anorexia nervosa:*

32-40 sessions over 12-18 months

*Both include 8-12 additional family sessions with the patient and their parents or carers

Bulimia nervosa

First-line

Bulimia nervosa-focused family therapy: 18-20 sessions over 6 months

Second line

CBT for eating disorders:
18 sessions over 6 months
Includes up to 4 additional sessions with parents or carers

key points

SELECTED BY

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Early recognition, referral and treatment are essential to achieve good outcomes for children and adolescents with eating disorders. Eating disorders have the highest mortality of all psychiatric conditions. However, provided there is access to early and evidence-based treatment, the majority of patients who are diagnosed with an eating disorder before the age of 18 will make a full recovery. Overall, outcomes in this age group are better than in adults.

Anorexia and bulimia have several shared and overlapping features. Thought content is dominated by weight and body shape, which then unduly influence self-evaluation. Associated behaviours such as food intake restriction, over-exercising, vomiting, bingeing or laxative use stem from the desire to lose or maintain weight, and may occur in either condition. Percentage median BMI (%mBMI) is a better measure of underweight in children and adolescents, as it takes into account both gender and age. A %mBMI below 70% is considered high risk. For many, 85% mBMI or less may be considered significantly underweight; however, for some constitutionally smaller individuals it may not be.

In the 15-19 age group, 1.6 per 1,000 females and 0.17 per 1,000 males are newly diagnosed with an eating disorder each year in the UK. Incidence rates for anorexia and bulimia are approximately equal in this age group at 26 cases/100,000/year. Although most patients are female, it is important that GPs consider the possibility of eating disorders in males, who often present for treatment at specialist services relatively late. Eating disorders rarely present alone and other mental health disorders such as anxiety, depression, obsessive compulsive disorder, autistic spectrum disorders, and self-harm frequently co-exist.

In primary care it is important to prioritise identification of risk indicators and include as much of this information as possible in the referral. Junior MARSIPAN (Management of Really Sick Patients with Anorexia Nervosa), is a very useful guide to the evaluation of physical risk in children and adolescents with eating disorders and is available online.

All children and adolescents with a possible eating disorder should be referred to their local specialist community-based eating disorder service for children and young people (CEDS-CYP) as soon as possible. Treatment is provided by a multidisciplinary team and consists of a mixture of psychological interventions, nutritional support and physical monitoring. Treatment may be offered in a mixture of individual, family and group formats. Some young people with co-existing conditions may require psychotropic medication.

admission to hospital when community treatment appears not to be working. Admissions for medical stabilisation and/or re-feeding will be to a local paediatric or adult ward and should usually be less than a week.²¹ Alternatively, or following this, there may need to be an admission to an eating disorder unit or adolescent psychiatric unit.

While admissions for eating disorders are effective in the short term, they are often exceedingly long and have high rates of relapse and readmission.^{22,23} Emerging evidence suggests that day patient services can provide more cost-effective alternatives to inpatient eating disorder unit treatment when more intensive treatment is required.²²

The A&WT guidance recommends 'that unless medical or psychiatric risk is very high, early admission should be avoided and day patient or community care offered in the first instance.'

NICE recommendations for psychological treatment of eating disorders in children and adolescents in CEDS-CYP or eating disorders units are

summarised in box 1, opposite.

Some young people with co-existing conditions may require psychotropic medication. This may include antidepressants, sleeping tablets and low-dose antipsychotics e.g. olanzapine. The latter has been found to be helpful in reducing anxiety, and the frequency and severity of eating disorders thoughts, while stimulating appetite.²⁴ Medication should never be a sole treatment for eating disorders.

ONGOING MONITORING AND MANAGEMENT IN PRIMARY CARE

Following referral, larger CEDS-CYP, especially those with close and effective links with local general hospitals, may take responsibility for organising, monitoring and managing all aspects of any necessary investigations. This may be different from arrangements with adult eating disorders services, where GPs are required to play a more active role in investigating and monitoring. Smaller and/or newer services are likely to require a shared care approach with primary care that is closer to »

Table 5

Junior MARSIPAN Risk Assessment: Adapted summary

%mBMI	Red – High risk < 70%, < 0.4th centile	Green – Moderate risk 80-85%, 2nd-9th centile
Weight loss	> 1 kg/week/2 weeks	< 0.5 kg/week/2 weeks
Abnormal eating	< 400-600 kcal/day	60-70% of calories required
Dehydration	> 10% decreased urine output, dry mouth, sunken eyes, decreased skin turgor	< 5%. Mouth may not be dry. Negative fluid balance
Exercise	> 2 hr day when malnourished	< 1 hr/day and malnourished
Temperature	< 35.5°C tympanic < 35°C axillary	Normal: 36.5-37.5°C
Heart rate (awake)	< 40 bpm	50-60 bpm
Blood pressure	Recurrent fainting + postural drop (< 20 systolic)	< 2nd centile: 98-105/40-45 mmHg
ECG	QTc > 400 boys > 460 girls	Risk factors for long QTc
Engagement/risk	Violent resistance, high risk of completed suicide	Ambivalent motivation to recover

NB: Half of risk assessment criteria can be established before examining the patient

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arrangements with adult eating disorders services (see table 1, p18).

Although most CEDS-CYP will initiate and titrate psychotropic medication e.g. antidepressants to therapeutic doses, they will need GPs to take over subsequent prescribing. The usual arrangement agreed is that the CEDS-CYP takes responsibility for monitoring mental state, level of risk, treatment response and adjusting doses as required, communicating any changes with primary care.

Similarly, CEDS-CYP also often require GPs to prescribe nutritional supplements e.g. Ensure and Fortisip, as these may not be included in outpatient formularies. Supplements are occasionally required when patients are most unwell and partially or completely refusing normal food.

Children and adolescents who have been discharged from CEDS-CYP do not need specific monitoring for their eating disorder from primary care unless specifically requested by the CEDS-CYP. Since re-referral should now be much quicker and easier following the new A&WT standards, if a patient were to relapse they can contact their CEDS-CYP or GP to seek re-referral and should be seen by a CEDS-CYP between 24 hours and 28 days.

However, there may be ongoing concerns about growth or physical wellbeing e.g. menstruation has not resumed after several months despite weight restoration and improvement in eating disorders symptoms, or a patient may have been discharged on antidepressant medication which will eventually need to be discontinued. In these cases further monitoring in primary care is required. This will usually be requested by the CEDS-CYP.

For the minority of patients who require transfer to adult eating disorders services, it is important that arrangements are made early. Local protocols should be developed to ensure that transition can be as smooth as possible.

Some services are developing all age eating disorders services to optimise transition. The relative merits of all age eating disorders services compared with CEDS-CYP have yet to be established.

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Useful information

Beat

Eating disorders information for young people, adults, parents and carers
www.b-eat.co.uk/?gclid=CLDrOL7ywtQCFRITGwod39AJ9g

NHS Choices

Eating disorders
www.nhs.uk/conditions/eating-disorders/pages/introduction.aspx

NICE

NG69. Eating disorders: Recognition and treatment
www.nice.org.uk/guidance/ng69

Junior MARSIPAN

www.rcpsych.ac.uk/usefulresources/publications/collegereports/cr/cr168.aspx

Access and Waiting Time Standards for Children and Young People with an Eating Disorder, Commissioning Guidance, July 2015

www.england.nhs.uk/wp-content/uploads/2015/07/cyp-eating-disorders-access-waiting-time-standard-comm-guide.pdf

Faculty of Eating Disorders

Royal College of Psychiatrists

www.rcpsych.ac.uk/workinpsychiatry/faculties/eatingdisorders.aspx

Maudsley Service Manual for Child and Adolescent Eating Disorders

www.national.slam.nhs.uk/wp-content/uploads/2011/11/Maudsley-Service-Manual-for-Child-and-Adolescent-Eating-Disorders-July-2016.pdf

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