



Healthcare
Improvement
Scotland

SIGN
Evidence-based
clinical guidelines

Eating disorders

A national clinical guideline

Consultation draft, May 2021

NHS
SCOTLAND

Key to evidence statements and recommendations

Levels of evidence

1 ⁺⁺	High-quality meta-analyses, systematic reviews of RCTs, or RCTs with a very low risk of bias
1 ⁺	Well-conducted meta-analyses, systematic reviews of RCTs, or RCTs with a low risk of bias
1 ⁻	Meta-analyses, systematic reviews of RCTs, or RCTs with a high risk of bias
2 ⁺⁺	High-quality systematic reviews of case-control or cohort studies High-quality case-control or cohort studies with a very low risk of confounding or bias and a high probability that the relationship is causal
2 ⁺	Well-conducted case-control or cohort studies with a low risk of confounding or bias and a moderate probability that the relationship is causal
2 ⁻	Case-control or cohort studies with a high risk of confounding or bias and a significant risk that the relationship is not causal
3	Non-analytic studies, eg case reports, case series
4	Expert opinion

Recommendations

Some recommendations can be made with more certainty than others. The wording used in the recommendations in this guideline denotes the certainty with which the recommendation is made (the 'strength' of the recommendation).

The 'strength' of a recommendation takes into account the quality (level) of the evidence. Although higher-quality evidence is more likely to be associated with strong recommendations than lower-quality evidence, a particular level of quality does not automatically lead to a particular strength of recommendation.

Other factors that are taken into account when forming recommendations include: relevance to the NHS in Scotland; applicability of published evidence to the target population; consistency of the body of evidence, and the balance of benefits and harms of the options.

R For '**strong**' recommendations on interventions that '**should**' be used, the guideline development group is confident that, for the vast **majority** of people, the intervention (or interventions) will do more good than harm. For '**strong**' recommendations on interventions that '**should not**' be used, the guideline development group is confident that, for the vast **majority** of people, the intervention (or interventions) will do more harm than good.

R For '**conditional**' recommendations on interventions that should be '**considered**', the guideline development group is confident that the intervention will do more good than harm for **most** patients. The choice of intervention is therefore more likely to vary depending on a person's values and preferences, and so the healthcare professional should spend more time discussing the options with the patient.

Good-practice points

✓ Recommended best practice based on the clinical experience of the guideline development group.

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1 Introduction

1.1 The need for a guideline

Eating disorders (EDs) are characterised by preoccupation with weight, shape and calorie balance. The name may seem misleading: not all disorders of eating are 'eating disorders' and when an ED diagnosis is made it implies that more than eating behaviour is disordered. Purging, overexercise and preoccupation with body image cause psychosocial and physical harm. The guideline includes evidence for the management of people with anorexia nervosa (AN), bulimia nervosa (BN), and binge eating disorders (BED).

Eating disorders typically begin in early to mid-adolescence, but can emerge at any age.¹⁻³ Lifetime prevalence of AN in the general population in Western countries is about 1% in women and 0.5% in men.⁴ Prevalence of eating disorders in teenage girls is as high as 12%.⁴ About 1% meet criteria for AN, the disorder with the highest mortality of any psychiatric disorder.⁴ The true prevalence may be underestimated as it has been found that half of those who meet diagnostic criteria in the community do not access treatment.⁴ Anorexia nervosa and BN are more common among female than male individuals⁵ and there are higher rates of disordered eating among sexual minorities, particularly in transgender people.⁶ A high prevalence of EDs associated with people from ethnic minorities groups was reported in a study of a community in South East London.⁷ Other UK-based studies have reported lower referral rates, and that people with minority ethnic backgrounds are less likely to seek treatment than British white people.^{8,9}

Adolescents have higher rates of full recovery and lower mortality than adults (mean mortality 2% vs 5%).¹⁰ With treatment, around 50% of people with AN achieve full functional recovery.¹⁰

The cycle of treatment, recovery and relapse can cause severe disruption to education, employment, professional development and lifetime earnings.¹¹ Caring for someone with a severe eating disorder can pose psychosocial and financial burdens on families. Within mental health services in 2015 the average annual financial cost of treating someone with an eating disorder was £8,850, but exceeded £100,000 when combined with treatment of physical consequences.¹¹

Earlier Scottish guidance on the management of eating disorders led to an expansion in the provision and quality of services in NHSScotland, however the guidance is now outdated.¹² In 2020 the Mental Welfare Commission (MWC) for Scotland undertook a themed visit of eating disorder services and identified inequalities in the provision of services, including access to psychological therapies and gaps in care during transition between services.¹³ It also showed there is wide variation in the organisation of services for people with eating disorders across Scotland. One of the recommendations from the report was for SIGN to produce a guideline on the efficacy of treatments for people with eating disorders. The MWC report was followed by a Scottish Government commissioned review of ED services, which will be implemented alongside the launch of this guideline.

This guideline draws on an evidence base, interpreted in the context of the needs of Scottish service users, and involving those with lived experience. Where appropriate, quantitative research has been supplemented with the findings of qualitative studies. Recommendations are made not only about service provision but also about ways to address the lack of agreed outcome measures and associated data collection nationally, and to direct research, paving the way for a dynamic growth in evidence and good practice.

1.1.1 Patient perspective

Patients may have different perspectives on healthcare processes and outcomes from those of healthcare professionals. The involvement of patients in guideline development is therefore important to ensure that guidelines reflect their needs and concerns and address issues that matter to them.

Common issues raised by patient groups and through research include:

- Using weight as the sole measure of illness severity and need for treatment, or of recovery, was seen as unhelpful in preventing early access to treatment. It may even provide a perverse incentive to lose more weight.
- A preference for treatment to focus on emotional and self-image concerns rather than an exclusive focus on weight gain and physical health.
- A wish for patients to have more choice about the type of treatment they receive rather than this being dictated by local protocols.
- A need for better support during transitions between child and adolescent mental health service (CAMHS) and adult services, or between health boards, for example when moving away from home to university.
- The impact comorbidities can have on eating disorders and vice versa.
- The need to adapt services and treatments to be inclusive of people from ethnic minority backgrounds, men, people who are lesbian, gay, bisexual, transgender, queer, or non-binary (LGBTQ+) and those who are not neurotypical.
- The need for awareness and treatment of eating disorders during pregnancy and parenthood.
- A concern that whilst attention is paid to eating behaviour and purging behaviour the management of healthy exercise levels is often neglected.
- The need for follow-up support by primary care, social services and the third sector after discharge from NHS eating disorder services. This includes attention to the physical problems resulting from an ED, such as fertility, dental or bone health. It may also involve signposting to self-help materials and peer-support groups.
- The importance of a positive and hopeful attitude that individuals and carers can make meaningful improvements to quality of life.

Information points, to support informed discussion with patients, their families and carers, are denoted throughout the guideline with the symbol *i*. Further information for patients, family and carers is in section 16.

1.2 Remit of the guideline

1.2.1 Overall objectives

This guideline provides recommendations based on current evidence for best practice in the management of people with eating disorders of all ages and gender groups, in any health or social care setting. Eating disorders covered are anorexia nervosa, bulimia nervosa and binge eating disorder. Advice for treating people with EDs which do not entirely meet formal diagnostic criteria is to follow guidance for the diagnosis most aligned with their difficulties. The feeding disorder avoidant/restrictive food intake disorder (ARFID) was included in the evidence review as these difficulties can be seen in a range of services, including eating disorder clinics, however no evidence was found to support advice on management of patients with this condition. It excludes, the management of obesity in the absence of a diagnosable eating disorder and prevention of eating disorders, as both of these warrant separate guidelines in their own right. This guideline does, however, include management of 'eating disordered' psychopathology occurring in the context of Type 1 diabetes mellitus.

A mixed methods approach, using quantitative and qualitative evidence was applied to key questions where it was considered that qualitative studies would provide better insight into the needs of the population addressed in the question (see *Annex 1*).

1.2.2 Comorbidities to consider when managing patients with eating disorders

Common comorbidities and coexisting health issues which have been considered when reviewing the evidence for this guideline are:

- anxiety disorders
- autism spectrum disorder (ASD) (and autistic spectrum experience which is not experienced as a disorder but as a variant of normal mental health)
- complex trauma
- personality disorders (PD)
- depressive disorders
- obsessive compulsive disorder (OCD)
- pregnancy and perinatal mental health conditions
- physical illnesses of various sorts
- post-traumatic stress disorder (PTSD)
- schizophrenia
- substance and/or alcohol misuse
- type 1 Diabetes Mellitus.

1.2.3 Definitions and treatment outcomes

Evolving considerations about the nature and classification of EDs affect the precision with which treatments can be researched. In recent years major changes have been made to the classification of eating disorders in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) and the International Classification of Diseases (ICD 11).^{14,15} Most treatments involve biological, behavioural and psychosocial elements, making it hard to dissect out effects. Clinicians recognise that failure to precisely meet listed criteria does not automatically mean that patients' symptoms could not respond to a treatment. In any case many patients' diagnoses migrate across categories during the course of their illness.

Scottish ED services specialise in those disorders sharing the core psychopathology of preoccupation with weight and shape. Thresholds for referral depend more on service availability than on diagnostic criteria, and clinicians are not obliged to ration care to those meeting formal criteria. Such criteria are commonly used to delineate research cohorts, however. DSM-5 and ICD 11 criteria discriminate between anorexia nervosa and bulimia nervosa on the basis of weight. The hallmark of AN is significant weight loss, whilst those who are not underweight are diagnosed as having BN if they purge (induce vomiting or use laxatives), but BED if they binge without purging.

The term diabulimia (not recognised in official diagnostic criteria) implies that causing calories to be excreted in the form of glycosuria and high blood glucose levels is analogous to purging. People with diabetes lose weight easily by omitting insulin rather than by diet, over-exercise and purging. Thirty to forty percent of young people with diabetes omit or reduce insulin with the intention of losing weight.¹⁶ Longitudinal studies suggest an increase in eating disorders in people with type 1 diabetes mellitus.¹⁷

There is disagreement about what constitutes recovery from EDs, with consequent variation in outcome figures. Qualitative meta-analysis finds that recovered individuals value self-acceptance, autonomy and interpersonal relationships as much as reduced ED symptomatology.¹⁸

Much of the research has been based in inpatient settings. Where this guideline refers to inpatients this indicates residential treatment in a unit that specialises in the management of eating disorders. Where the patient is treated in an acute medical hospital, a diabetic ward or a general psychiatric unit this is specified.

1.2.4 Target users of the guideline

This guideline will be of interest to primary, secondary and tertiary healthcare professionals including clinical psychologists, dietitians, endocrinologists, gastroenterologists, general practitioners (GPs), health visitors, nurses, occupational therapists, physiotherapists, perinatal mental health clinicians, psychiatrists, social workers, teachers and university staff, as well as patients and their families and carers.

1.2.5 Patient and carer versions

Patient and carer versions of this guideline are available from the SIGN website, www.sign.ac.uk [these will be available when the guideline is published]

1.2.6 Equality impact assessment

An equality impact assessment for the development of this guideline is available from the SIGN website, www.sign.ac.uk [this will be published alongside the guideline]

1.3 Statement of intent

This guideline is not intended to be construed or to serve as a standard of care. Standards of care are determined on the basis of all clinical data available for an individual case and are subject to change as scientific knowledge and technology advance and patterns of care evolve. Adherence to guideline recommendations will not ensure a successful outcome in every case, nor should they be construed as including all proper methods of care or excluding other acceptable methods of care aimed at the same results.

The ultimate judgement must be made by the appropriate healthcare professional(s) responsible for clinical decisions regarding a particular clinical procedure or treatment plan. This judgement should only be arrived at through a process of shared decision making with the patient, covering the diagnostic and treatment choices available. It is advised, however, that significant departures from the national guideline or any local guidelines derived from it should be documented in the patient's medical records at the time the relevant decision is taken.

1.3.1 Influence of financial and other interests

It has been recognised that financial or academic interests may have an influence on the interpretation of evidence from clinical studies.

It is not possible to completely eliminate any possible bias from these sources, nor even to quantify the degree of bias with any certainty. SIGN requires that all those involved in the work of guideline development should declare all financial and academic interests, whether direct or indirect, annually for as long as they are actively working with the organisation. By being explicit about the influences to which contributors are subjected, SIGN acknowledges the risk of bias and makes it possible for guideline users or reviewers to assess for themselves how likely it is that the conclusions and guideline recommendations are based on a biased interpretation of the evidence.

Signed copies of declaration of interests forms are retained by the SIGN Executive and are available on request from the SIGN Executive.

1.3.2 Prescribing of licenced medicines outwith their marketing authorisation

Recommendations within this guideline are based on the best clinical evidence. Some recommendations may be for medicines prescribed outwith the marketing authorisation (MA) also known as product licence. This is known as 'off-label' use. With the exception of fluoxetine, which is licensed for use in patients with bulimia nervosa, medications used to treat patients with eating disorders are off label.

Medicines may be prescribed 'off label' in the following circumstances:

- for an indication not specified within the marketing authorisation
- for administration via a different route
- for administration of a different dose
- for a different patient population.

An unlicensed medicine is a medicine which does not have MA for medicinal use in humans.

Generally 'off-label' prescribing of medicines becomes necessary if the clinical need cannot be met by licensed medicines within the marketing authorisation. Such use should be supported by appropriate evidence and experience.¹⁹

"Prescribing medicines outside the conditions of their marketing authorisation alters (and probably increases) the prescribers' professional responsibility and potential liability".¹⁹

The General Medical Council (GMC) recommends that when prescribing a medicine 'off label', doctors should:²⁰

- be satisfied that there is no suitably licensed medicine that will meet the patient's need.
- be satisfied that there is sufficient evidence or experience of using the medicine to show its safety and efficacy
- take responsibility for prescribing the medicine and for overseeing the patient's care, including monitoring the effects of the medicine, and any follow-up treatment, or ensure that arrangements are made for another suitable doctor to do so.
- make a clear, accurate and legible record of all medicines prescribed and, when not following common practice, the reasons for prescribing an unlicensed medicine.

Non-medical prescribers should ensure that they are familiar with the legislative framework and their own professional prescribing standards.

Prior to any prescribing, the licensing status of a medication should be checked in the summary of product characteristics (www.medicines.org.uk). The prescriber must be competent, operate within the professional code of ethics of their statutory bodies and the prescribing practices of their employers.²¹

2 Key recommendations

The following recommendations were highlighted by the guideline development group as the key clinical recommendations that should be prioritised for implementation.

[these will be published in the final version of the guideline]

2.1 Section heading

R | Rec 1

Rec 2

Rec 3

Additional comment.

R | Rec 1

Additional comment.

2.2 Section heading

R | Rec 1

Additional comment.

R | Rec 1

Additional comment.

3 Framing the journey of care

3.1 Early intervention

One hallmark of EDs is that people see them as coping strategies and are, at best, ambivalent about change. It can therefore be years before a person with an ED presents to services. Long waiting lists for services then compound the delay. Harms can accumulate during untreated disorder, particularly in AN, where prolonged starvation damages brain structure and function.²² There is no clear definition of early intervention but it is suggested that intervention in the first three years of illness provides a critical window for recovery.²³ For patients with AN, the probability of recovery is highest early after diagnosis. As the duration of the eating disorder lengthened those with BN had higher probabilities of recovery.²⁴ This translates into a practice guideline that every effort should be made to treat people with AN within three years of symptom onset, bearing in mind that symptoms are likely to have been present for many months or years before presentation at services. There is usually less urgency to treat people with normal or high-weight eating disorders, in terms of either physical risk and brain changes. Delays in treatment, however, may damage trust and motivation and paradoxically worsen the drive to lose weight.

Current NHS systems and pathways may create delays.²⁵ The First Episode and Rapid Early intervention in Eating Disorders (FREED) model has developed to provide early engagement and intervention to people who had ED symptoms of less than three years, and were aged 18–25 (later changed to 16–25). Its efficacy has been studied in 56 female patients, with two follow-up studies.²⁵⁻²⁷ All of patients offered FREED took up treatment compared to 74% in treatment as usual (TAU). Investigators suggest this may be due to the early engagement phone call (<48 hours from referral). At 12 months the FREED group had significantly improved ED psychopathology as assessed in the eating disorder examination questionnaire (EDE-Q).²⁷ In the two-year follow up, FREED patients attended more treatment sessions and had clinically relevant greater increase in body mass index (BMI).²⁶ Eating disorder psychopathology was not measured so changes at follow up could not be assessed. It appeared that FREED patients required less in-patient treatment.²⁶ Fifty-nine percent of the FREED group reached healthy weight by 12 months compared to 17% of the audit group and 70% had scores on EDE-Q at 12 months which were below the clinical cutoff.²⁷

The FREED model was established as an additional service so did not appear to affect waiting times for patients receiving TAU (ie those who were older than 25 or had longer duration of illness than three years).²⁵ This model carries considerable cost implications which should be balanced against the cost of patients becoming more entrenched in their illness and requiring longer and more intensive treatments.

R A pilot of an additional FREED service to complement existing eating disorders services may be considered. This would offer early intervention to young adults aged 16–25 with eating disorders of less than three years' duration.

3.2 Support for family and carers

Eating disorders impact the whole family and can cause significant distress. The parents of adolescent patients may be asked to participate in family-based treatments which may even increase levels of distress and conflict on a temporary basis in the interests of longer-term recovery. Adult patients are asked to be the agents of their own recovery in partnership with professional and lay supports. The support then offered to family members has a different focus.

Parents and carers have been shown to experience high levels of emotion, caregiver burden, distress and difficulties coping.^{28,29} The significant psychological impact on carers can lead to the presence of ineffective strategies for managing an ED, which may inadvertently exacerbate patient distress and, in turn, ED symptoms.³⁰

All identified studies exploring support for parents and/or carers of adults with EDs were based on the cognitive interpersonal maintenance model of EDs and associated materials, using a range of delivery formats.^{30,31} This included online delivery with low-level guidance from a clinician (Overcoming Anorexia Online (OAO)), self help consisting of written materials and videos, with and without a clinician, and/or carer coaching (Expert Carers Helping Others (ECHO)), and parent and carer workshops (Collaborative Carers Skills Workshop) over six sessions or an abbreviated two-session format.³²⁻³⁶

Overcoming Anorexia Online demonstrated greater reduction on carer distress compared to less intensive interventions. A two-session carer workshop led to greater reduction in carer burden than waiting-list controls (WLC).^{36,37} When compared to TAU or active controls, such as psychoeducation groups, the evidence for these programmes is mixed. In a pilot randomised controlled trial (RCT) comparing Collaborative Carer Workshops to a psychoeducation group, no significant difference was found in any carer outcomes.³⁵

1++

The largest body of evidence and associated longer term follow up is focused on ECHO. A pilot RCT comparing combination of ECHO and TAU to TAU only found that ECHO led to a moderate increase in carer skills and a reduction in counter-productive caring behaviours at 12 months.³³ Another RCT of ECHO (including telephone coaching) compared to TAU only, found no significant difference in carer distress but significant differences in at 6 months in caregiver burden and Expressed Emotion (EE) in favour of ECHO.³² Differences between interventions did not extend to 12- or 24-month follow up.³⁴

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Engagement with the ECHO self-help materials varied from 21% to 75% across trials.^{32,33} Two RCTs found no additional benefit to adding telephone coaching to ECHO self-help materials.^{33,38} These trials included a mixed sample of carers of adults and adolescents. No trials explored the use of this model with parents of younger children. Therefore, clinical judgement on the applicability of this model within CAMHS should be made on an individual basis. There may be some conflict between advice given to parents using this model and advice provided by family-based therapies (see section 5.1).

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R Formal carer support should be offered to all carers. This could draw on materials from ECHO self help or Collaborative Carer Workshops.

✓ Family and carer support can be provided without breaching patient confidentiality and should always be offered if carers are not involved in formal family work. Manuals are available for both clinicians and lay readers teaching the cognitive interpersonal skills used in ECHO and related models.³¹

i Encourage the patient to build a supportive network which may involve family and/or friends, while respecting the individual's right to confidentiality.

3.3 Achieving and maintaining recovery

Defining recovery from a mental disorder can be a controversial task. It is acknowledged to mean more than failure to meet diagnostic criteria, which are themselves matters for philosophical debate and development. At the same time recovery need not mean a complete absence of all symptoms. The Recovery Movement advocates for a definition of recovery which is described and owned by the individual in the context of quality of life even in the presence of enduring symptoms. It is based on connectedness, hope & optimism, identity, meaning & purpose and empowerment (CHIME).³⁹ Many patients with EDs prefer definitions of recovery which focus on quality of life and do not insist on being in the healthy weight range (see section 1.2.3). This can be problematic. The ability to accept a healthy body weight without being obliged to engage in mental and behavioural preoccupations is seen by most clinicians as a hallmark of true recovery. From both the physical and psychological point of view it is essential to provide nutrition for the brain to allow it to develop and function to live life to the full.

In the research that follows different outcome measures have been used as proxies for the concept of recovery. Where BMI is used as a convenient numerical measure it is essential that this is interpreted in the light of the patient's ability to tolerate healthy weight rather than merely reflecting other people's insistence on weight gain at any emotional cost.

Psychological and pharmacological therapies that support patients to achieve a functional recovery are addressed in sections 4–11.

3.3.1 Acute refeeding, renutrition and maintaining a healthy weight

Patients with anorexia nervosa have an extreme fear of gaining weight, in association with altered body image that makes refeeding a difficult treatment for them and sometimes for their carers. This is related to the disease itself rather than the process of the treatment. Refeeding therefore has to be carried out in association with other treatment modalities to help the patient and carers cope with the behavioural and psychological aspects of the disease. Refeeding as an acute intervention is addressed by the Management of Really Sick Patients with Anorexia Nervosa (MARSIPAN) and junior MARSIPAN guidelines, <https://www.rcpsych.ac.uk/members/your-faculties/eating-disorders-psychiatry/marsipan-national-resource>

Refeeding is a useful intervention to prevent death and achieve weight gain, and can be conducted safely by enteral nutrition or the oral route.⁴⁰⁻⁴² A higher BMI after feeding and a shorter duration of illness are associated with a lower rate of relapse.^{40,41,43,44} Patients should be re-fed to an optimised weight but no absolute criteria for BMI were noted in the studies. Treatment goals should be set on a patient-by-patient basis after a holistic assessment of the patient's general physical and psychological condition.

There is an implication that higher weight at the end of treatment and measures to prevent rapid weight loss in the immediate discharge period may produce better outcomes. An alternative explanation could also be that patients who can tolerate a higher weight at the end of treatment lose weight less rapidly and, therefore have a better prognosis, independent of the actual weight gain achieved. The current studies do not allow this to be defined further.

A systematic review and an additional small RCT concluded that, with proper management, refeeding carries few risks and is unlikely to be harmful.^{41,42}

R Refeeding to an optimised healthy weight (taking the patient's ethnicity and gender into consideration) **should be offered routinely to all patients with anorexia nervosa, both as a life saving measure and also as an adjunct to achieving an optimised weight and to reduce relapse.**

R In the acute situation the MARSIPAN and Junior MARSIPAN guidelines should be followed.

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2+

3.3.2 Physical exercise

A systematic review concluded that including supervised exercise training in the management of patients with AN is safe, as it did not result in additional weight loss and may have benefits in the areas of strength and psychological wellbeing. Exercise training was reported to improve strength and cardiovascular endurance despite no change in lean body mass. No significant impact on quality of life was reported, although, negative feelings for food and exercise were reduced. There was a reduction in anxiety and depression, improved body image, improved social behaviour, and a reduction in requirement for secret exercise.⁴⁵

An RCT found that a combination of CBT and the Loughborough exercise and activity programme (LEAP) resulted in healthier attitudes towards exercise and improvements in BMI and ED psychopathology in people with AN.⁴⁶ If the issues of dysfunctional exercise

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and negative body image are not addressed, both of which are maintaining factors of each other and of an eating disorder, then there is greater risk of chronicity and relapse.

An RCT (n=207 adolescents and adult women with AN or atypical AN) in healthy exercise behaviour (HEB), which integrates elements of exercise based therapy into a CBT approach, found that HEB resulted in significantly stronger reductions in the severity of compulsive exercise compared to the TAU group. There were no significant differences regarding weight gain, eating disorder and general psychopathology and emotional regulation.⁴⁷

1+

Introducing exercise in the management of patients with AN carries potential physical risks to bones and heart, and the risk of playing into the anorexic need to burn calories. Patients require assessment and monitoring of their medical, nutritional and psychological status.⁴⁸ This should take place in collaboration with the multidisciplinary team and the exercise programme should be supervised by a suitably qualified clinician, eg a Specialist Physiotherapist in Mental Health and Eating Disorders.⁴⁸ Including a psychoeducational component to the exercise can help patients develop healthy attitudes towards exercise and recognise when exercise is becoming problematic.⁴⁵ Further expert advice on how to manage exercise in adults with eating disorders is available in the Safe Exercise at Every Stage (SEES) guidance, <https://www.safeexerciseateverystage.com/>. [SEES also provide guidance for athletes with eating disorders.](#)

4
2++

R Specialist-supervised exercise programmes should be offered to patients with anorexia nervosa as part of a comprehensive management programme, which includes a psychoeducation component.

R Where appropriate (depending on cognitive function and patient's motivational status) the inclusion and integration of the treatment of dysfunctional exercise/activity should be considered as part of a multidisciplinary treatment programme.

R Patients with anorexia nervosa participating in an exercise programme should be managed within a multidisciplinary team.

✓ Healthcare professionals should refer to the Safe Exercise at Every Stage (SEES) guideline to support adults with anorexia participating in an exercise programme.

✓ There is increasing recognition of ED amongst athletes, dancers and participants of many sports. Labels such as female athlete triad may mask the diagnosis of a serious eating disorder. Moreover, where athletes have trained to build muscle at the expense of fat a normal BMI can mask malnutrition. In the treatment of EDs in athletes and dancers a return to high levels of physical exercise carries risks which should be acknowledged and carefully addressed and monitored. There is specific guidance from Safe Exercise at Every Stage.

3.3.3 Severe comorbid and complex eating disorders unresponsive to first-line treatments

For some patients treatments offered as first line may not be acceptable or effective for them due to underlying comorbid psychiatric conditions. For example, people with AN who have the neuropsychological features of ASD or high levels of ASD traits are associated with poorer outcome in AN and do not respond as well to traditional treatments.⁴⁹ Few trials have been identified in patients with ED and comorbidities. Trials in patients with comorbid ED and borderline personality disorder (BPD) are discussed in sections 9.3.3, 10.2.2, and 10.2.5.

1+

Around 30% of patients with an ED meet criteria for at least one PD.⁵⁰ Some features are common to both disorders, and it is possible that some are consequences of the ED or its treatment, rather than primary features of a PD. Difficulty managing relationships with different clinicians is a notorious aspect of PD presentation, so supervision and joint working are essential.

✓ Alternative choices should be offered when first line treatments are ineffective or unsuitable for those with moderate to severe comorbid psychiatric disorders. Choice of treatments should take into account therapeutic models which have an established

evidence-base in the treatment of comorbidities that have been shown to interfere with treatment outcomes in EDs (eg post-traumatic stress disorder, personality disorder, substance misuse). Assertive outreach that includes other input from psychiatric specialties and the Community Mental Health Team should be considered for those with eating disorder and severe comorbid conditions.

3.3.4 Follow up interventions

There are mixed results for the efficacy of internet or mobile phoned-based aftercare and relapse prevention for patients who are in remission.⁵¹⁻⁵³ The benefit may be dependent on the therapeutic approach rather than the method of delivery. For example, cognitive behavioural therapy delivered via internet or mobile was found to be helpful in a systematic review of 16 studies in a variety of mental disorders, four of which were in patients with ED.

1++

- ✓ Patients may relapse after functional recovery if the recovery was dependent on one main support, such as therapy or medication. Care plans therefore need to take a holistic approach to ensure patients are equipped to maintain recovery.
- i* Engage in discussions about returning to activities stopped during treatment, eg exercise. Life after treatment, and life after an eating disorder, should be considered.
- i* Ensure the patient knows how to access support programmes, when needed, as they continue through their recovery journey (*see section 16.2*).

3.4 Using the Mental Health Act to support care

The nature of eating disorders is that weight loss feels like a positive solution rather than a problem. The vast majority of patients nevertheless manage to learn other ways to cope. Sometimes the illness is simply too severe to allow this. The European Human Rights Act makes the right to life and health even more important than the right to choice in these matters. UK jurisdictions, including Scotland, therefore have protective legal codes to ensure that patients get the care they need, even when they are unable to give full consent. The Mental Health (Care & Treatment) (Scotland) Act 2003 is used to make clinicians responsible for delivering treatment on a compulsory basis, either in the community or more usually in hospital. Eating disorders are explicitly defined as mental disorders in terms of the Act, and nutrition has the statement of treatment for the disorder. The Act applies to all capacitous adults and children. The Mental Welfare Commission and mental health tribunals provide monitoring and scrutiny to ensure the Act is used with compassion and justice, and to protect against stigma.

The Mental Welfare Commission for Scotland has published a series of good practice guidelines to help clinicians caring for people with eating disorders (<https://www.mwscot.org.uk/sites/default/files/2019-06/sidma.pdf>).⁵⁴⁻⁵⁷

Use of compulsory treatment, when this is needed, had comparable outcomes in terms of weight and BMI, to informal treatment, but patients who were detained tended to have longer length of hospital stay. This may be because, where compulsory treatment was used, patients had lower weight when admitted and had more complexity and co-morbidity, with more previous admissions, not just related to the severity of the eating disorder.^{58,59}

2+
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- R** Clinicians should consider whether the Mental Health (Care and Treatment)(Scotland) Act 2003 needs to be invoked when a patient (of any age) declines treatment. There may be a responsibility to provide compulsory treatment if there is a risk to the person's life or to prevent significant deterioration to health and wellbeing.

3.5 Transition

Four main themes on transition were identified in a scoping review of a variety of study types:⁶⁰

- the importance of continuity and relationships with familiar clinicians,
- the need for provision of accurate information to patients and parents,
- the precipitous drop in attendance at mental health services after the transition at age 18, and
- the benefits of structures to guide transition including overlap and parallel provisions.

3

Two of the studies in the scoping review, which focused on people with eating disorders were qualitative. These, and three other studies from the same pool of researchers, have been appraised as moderate quality.⁶¹⁻⁶⁵

Two studies were conducted with service providers. One found that denial, coupled with ambivalence to weight restoration, interfered with transition and that transition was a difficult time for parents of young adults with eating disorders.⁶² It recommended that ongoing parental support was required to promote independence. The other suggested that there should be greater flexibility in the timing of transition, based on patients' and families' needs and readiness rather than age.⁶³

JBI
7/10

In the studies with service users it was reported that transfer procedures were inconsistent. Barriers included lack of knowledge from family doctor, actual or perceived lack of access to adult care, and inflexible treatment options. Collaborative treatment approaches are recommended during paediatric treatment to foster autonomy and independence, better communication and information provision about adult services, and the maintenance of some element of external monitoring after transfer to adult services has occurred.⁶⁵ Young people experienced uncertainty about whether they or their parent should take responsibility for managing their eating, meals, and recovery once they have left paediatric care. Young adults want ongoing parental support during transfer in the form of emotional involvement, monitoring and supporting eating and behavioural changes, and help communicating with new professionals in the adult system. The support should be collaborative not coercive and controlling.⁶¹

JBI
7/10

The participants in a UK-based study with young people and parents reported gaps in care when transitioning from CAMHS to adult services, which were unhelpful at that stage in their adolescence. Alternative suggestions were raising the age for transitions to 25, having a flexible approach dictated by need and not by age, or an integrated eating disorder service for all ages.⁶⁴

JBI
7/10

A report from the Eating Disorders Faculty of the Royal College of Psychiatrists provides recommendations for better management, summarised in the following checklist:⁶⁶

- awareness
- early identification and notification
- involve family and carers
- flexible timing
- close links between services
- transition coordinator
- provide good information
- clear protocols and pathways
- patient-centred transition plan
- multidisciplinary discharge planning meeting
- overlap period of joint working
- respect for attachments and therapeutic alliances.

4

The report recommends the following good practice:⁶⁶

R When a patient's age or geographical location necessitates a change of clinical team, the transition should be prepared, managed and followed up by clinicians in both services.

- R** | A clinician should be identified as ‘transition manager’ to supervise the process for several months before and after the move, and to communicate with all parties.
- R** | A written transition plan should be drawn up in collaboration with patient, clinicians and carers, and copied to each party.

Draft

4 Therapeutic interventions: introduction

4.1 Treatment fidelity

Issues around the definition of recovery from eating disorders and the outcome measures used is discussed in sections 1.2.3 and 3.3. Ideally treatments could be matched to the particular outcomes most important to the individual concerned. Research is not currently either consistent or discriminative enough to allow this.

All studies included in this guideline measure outcomes for specified therapies delivered by appropriately qualified, trained and supervised clinicians

- ✓ It is recommended that clinicians providing treatment for eating disorders should maximise treatment fidelity through regular ongoing training and clinical supervision, and should utilise standardised outcome measures to monitor outcomes.
- i* Discuss treatment plans with patients and allow them to share their ideas and concerns. Explain how a therapy works and why it may be appropriate for that individual.
- i* Engage in discussions about returning to activities stopped during treatment, eg exercise. Life after treatment, and life after an eating disorder, should be considered.

4.2 Delivering therapies remotely

Psychological therapies delivered via video link or internet is feasible, acceptable and may have similar efficacy as face-to-face settings in the treatment of eating disorders, including adults, children and families (see section 10.1.1).⁶⁷⁻⁶⁹ Therapeutic alliance is similar to that of face-to-face settings.⁷⁰ Video link for consultations and therapy has been widely used throughout the COVID-19 pandemic, with adaptations to therapies to support its use.^{70,71}

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1+
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- ✓ The delivery of psychological assessments and treatment via videoconferencing could be offered as an alternative to in-person sessions, especially when there are barriers to accessing in-person sessions.

5 Children and young people with anorexia nervosa

5.1 Psychological therapies

Eating disorders commonly first present in childhood or adolescence, impacting significantly on the young person as well as their family members and/or carers. Despite this, there is a relative paucity of robust evidence available to guide the treatment of those aged under 18. It is recommended that further research be undertaken to evaluate the efficacy of a variety of potential therapeutic approaches.

5.1.1 Family-based therapy

Systematic reviews identified low-quality evidence that suggests family therapy may be more effective than other treatments on rates of remission and on weight gain.^{72,73} 2++

An RCT identified in a Cochrane review compared the manualised Family Based Treatment (FBT) for patients with AN with systemic family therapy (SyFmTx).⁷² There was no statistical difference found at end of treatment or at 12 months' follow up. However, in the FBT group, rate of weight gain was superior at eight weeks ($p=0.003$), hospital admissions were lower (FBT=8.3, SyFmTx=21) and FBT cost less (FBT=\$8962, SyFmTx=\$18,005). 2++

One predictor of outcome that moderated the effect of outcome at end of treatment was OCD. Patients with higher OCD symptoms gained significantly more weight in SyFmTx than in FBT ($p=0.02$) and patients with fewer OCD symptoms gained more weight in FBT than SyFmTx.⁷² 2++

FBT was superior to adolescent-focused therapy (AFT) at 6- and 12-month follow up for full remission in one study. More participants were hospitalised in AFT (37%) than FBT (15%), however the superiority of FBT was not sustained at long term follow up.^{72,73} 2++

As clinical guidelines and practice utilise family therapy and FBT for adolescents with anorexia nervosa, trials have moved on to study augmentative approaches to FBT designed to improve outcomes and consider moderators of outcome.

A systematic review of augmentative approaches in FBT included 30 studies.⁷⁴ There was low-quality evidence for the utility of augmentative FBT approaches, in particular: separated parents/carers only session for patients from families with higher expressed emotion, longer pre-treatment illness duration or lower ED or OC symptom severity; additional parent skill and mealtime-focused sessions for patients with lower early weight gain. A multi-family therapy approach (MFT), in addition to FBT as a supplementary or standalone treatment, had superior end-of-treatment outcomes compared with those without MFT. 2++

5.1.2 Cognitive behavioural therapy

In a cohort of adolescents (age 13–17) with anorexia nervosa who were offered 40 sessions of enhanced cognitive behavioural therapy (CBT-E) over 40 weeks, 63% completed the full treatment without requiring any additional treatment, 19% did not respond to treatment and 17% stopped attending. In those who completed the treatment the mean weight gain was 8.6kg, standard deviation 4.14, 95% CI 7.03 10 10.18. There were also improvements in psychological outcomes. Improvements were maintained at 60-week follow up.⁷⁵ 2+

In another study 65.3% of the 29 adolescents who participated attained their BMI goal after 40 weeks of CBT-E.⁷⁶ 2+

Studies from an Italian research group reported adherence to treatment with 20 weeks of CBT-E (out-patient and in-patient samples) between 71–96%. Those who completed treatment had improved weight gain and psychological outcomes which were sustained at follow up (up to 60 weeks).^{75,77,78} 2+

5.1.3 Adolescent-focused therapy

In an RCT of AFT versus FBT rates of remission were higher in FBT compared with AFT (23% of AFT participants were in remission at the end of therapy compared to 40% who had FBT); superior rates of remission were maintained at 6- and 12-month follow up (23% for AFT and 49% FBT) but at longer term follow up superiority of rates of remission was not maintained. More participants were hospitalised in AFT (37%) than FBT (15%).^{79,80}

1+

5.1.4 Dialectical behaviour therapy

A small before-and-after study and a survey of participants in an RCT found improvement in symptoms and patient satisfaction with both dialectical behavior therapy (DBT) and CBT.^{81,82}

3

5.1.5 Other psychological therapies

There are a number of other psychological therapies available for children and young people with AN that require further research and investigation. Whilst some of these are delivered as standalone therapies, others are commonly offered as adjunctive parallel interventions.

There were a number of small studies of potentially-promising psychological therapies for children and young people with AN (some of which have been shown to be effective for adults) which do not yet meet criteria for inclusion according to SIGN methodology. There was a lack of robust research evidence for all of the following possible psychological therapies in the treatment of AN in children and young people: Interpersonal Therapy (IPT), Cognitive Analytical Therapy (CAT), Acceptance and Commitment Therapy (ACT), Group therapies, Supportive Specialist Clinical Management (SSCM), Schema Therapy, Radically Open Dialectical Behaviour Therapy (RO-DBT), Compassion Focussed Therapy (CFT), Cognitive Remediation Therapy. These therapies could be considered for patients with AN, as part of a clinical trial.

5.1.6 Recommendations for psychological therapies

R Family Based Treatment should be offered to young people with restricting eating disorders.

R Systemic family therapy and augmentative Family Based Treatment approaches could be considered to improve outcomes depending on the presence of factors that predict outcome.

R Enhanced cognitive behavioural therapy (CBT-E), at a dosage of 20–40 weeks, could be offered to adolescents with anorexia nervosa.

5.2 Pharmacological therapies

Evidence on the use of antidepressants in adolescents with AN was of poor quality.^{83,84} Antidepressants had no impact on weight gain and the impact on eating symptoms or psychopathology is unclear.⁸⁴ One review concluded that early intervention was associated with better outcomes.⁸³

1-4

Psychotropic medication, most often olanzapine or fluoxetine, is commonly prescribed for children and young people with EDs, usually to mitigate specific behaviours such as uncontrolled exercise, or a comorbidity.⁸⁵

3

6 Children and adolescents with bulimia nervosa

6.1 Psychological therapies

A meta-analysis of RCTs in the treatment of people with diagnosed BN concluded that psychotherapies in general, across the full age range, yielded moderate to large remission from binge eating and compensatory behaviors, and reductions in symptom severity when compared with control groups. This was mainly based on trials in CBT.⁸⁶ Within this meta-analysis there were three RCTs specific to adolescents.⁸⁷⁻⁸⁹

1++

When compared to supportive psychotherapy (SPT), family-based treatment for bulimia nervosa (FBT-BN) achieved higher binge and purge abstinence rates at end of treatment (39% versus 18% SPT). Abstinence rates for both groups dropped at 6-month follow up (29% FBT-BN versus 10% SPT), but statistically this still favoured FBT over SPT.⁸⁷ In further analysis of this RCT, no difference in treatment outcome was found between single or two-parent families.⁹⁰

1+
3

In adolescents meeting diagnosis for BN or partial BN the rate of abstinence from binge and purging episodes was significantly higher for FBT-BN (39%) compared to CBT for adolescents (CBT-A) (19%) at end of treatment and at 6-month follow up, but this difference was no longer significant at 12 month follow up.⁸⁸

1++

A further study examined CBT versus psychodynamic therapy (PDT) in girls between 14 and 20 years old with BN or partial BN. At end of treatment, a third of participants in both arms no longer met criteria for an eating disorder diagnosis and rates of remission were stable at 12-month follow up.⁸⁹

1++

R Adolescents with bulimia nervosa could be offered either cognitive behavioural therapy or family-based treatment-bulimia nervosa as first-line treatment.

R If cognitive behavioural therapy or family-based treatment are not acceptable, psychodynamic therapy could be considered for adolescents with bulimia nervosa.

6.2 Pharmacological therapies

No robust evidence was identified on pharmacological therapies in children and young people under the age of 16. This, however, should not preclude their use for comorbid conditions, such as anxiety disorders, OCD and depression.

Fluoxetine has been found to be effective in adults with bulimia nervosa (*see section 10.4*), and a SR identified evidence in 16–18 year olds that found that fluoxetine (60 mg/day) can reduce binge eating and purging behaviours and eating disorder psychopathology in the short term. Use of fluoxetine is associated with an increased risk of bleeding, and an increased risk of suicidal or self-harming thinking or aggression in under 25s, particularly on initiation.^{19,91} Fluoxetine is only licensed in 8–18 year olds for the treatment of major depression, so use in young patients with BN is unlicensed.

1+
4

R Fluoxetine 60mg may be considered in the treatment of patients with bulimia nervosa, aged 16-18, for short-term use in combination with psychological therapy, and with monitoring for suicidal, self-harming or aggressive behaviours, particularly at initiation.

7 Children and adolescents with binge eating disorder

7.1 Psychological therapies

No RCTs in any therapeutic modality conducted specifically for BED in children and adolescents were identified.^{92,93} | 1++

Cognitive behavioural therapy and IPT have been shown to be effective in adults with BED, so may be considered for treatment of adolescents (*see section 10.1*). Similarly family-based interventions have been shown to be effective for adolescents with bulimia nervosa and anorexia nervosa, so may be considered for treatment of adolescents with BED (*see sections 5.1 and 6.1*).

R | Cognitive behavioural therapy, interpersonal psychotherapy or family-based interventions could be offered to adolescents with binge eating disorder.

7.2 Pharmacological therapies

Lisdexamfetamine (LDX) has been shown to reduce binge and purge behaviours and reduce BMI in people with BED, but it also resulted in a 10% dropout due to side effects such as gastrointestinal upset, sleep disorder, nervous system arousal and headache.⁹⁴ The BNF advises caution in the use of LDX in patients with raised blood pressure or obesity, both of which are common comorbidities in patients with BED.¹⁹ There is concern around the effects of long-term use of LDX. In general, there should be caution around the prescribing of amphetamines and other stimulants for people with BED, unless in severely-affected individuals where the expected benefit outweighs the risks. | 1++

No further evidence was identified on pharmacological therapies in children and young people. Evidence in adults does not support its use in the management of patients with BED (*see section 11.4*)

R | Pharmacological therapies should not be used in the management of children and adolescents with binge eating disorder.

8 Type 1 diabetes

Eating problems are twice as common in people with type 1 diabetes than others and is usually associated with bingeing and purging. The management of insulin is used to induce hyperglycaemia to lose calories and avoid weight gain. This is associated with higher a glycated haemoglobin (HbA1c) level.⁹⁵ There are also screening tools specific for patients with diabetes and possible eating disorder, for example the Diabetes Eating Problems Survey Revised (DEPS-R) questionnaire.

- ✓ Patients with type 1 diabetes should be screened for eating disorders, as part of the psychological assessment in their routine diabetes review.
- ✓ Healthcare professionals caring for people with diabetes and/or eating disorders should be aware of the common practice of insulin reduction to avoid weight gain. A high HbA1c level, recurrent diabetic ketoacidosis (DKA), poor engagement with healthcare, infrequent/absent self-blood glucose monitoring, omission of quick-acting insulin are frequently observed in people with Type 1 Diabetes and eating disorders. DKA admissions and HbA1c are indicators of immediate and long term risks to health

8.1 Psychological therapies

A systematic review of observational studies and one RCT, all in adults, found that inpatient treatment programmes were associated with moderate improvement in HbA1c outcomes, whereas there was only a small improvement from outpatient programmes, compared to waiting list controls or treatment as usual.⁹⁵ The inpatient programmes, delivered in specialist eating disorders units, were for three to four months, and consisted of daily interventions, such as psychoeducation, CBT, family therapy and regular nurse supervision for insulin control. The outpatient trials were weekly therapy sessions for 6 weeks. Uptake for the outpatient sessions was poor. Four of the six included studies (inpatient and outpatient) reported improvement in EDI scores at follow up (ranging from one month to three years).⁹⁵

2+

R **Integrated intensive specialist care** (ie the combined involvement of diabetes professional and mental health professionals), **probably provided in a specialist inpatient eating disorders unit may be considered where there is a high risk of diabetic complications in patients with type 1 diabetes and eating disorder. Healthcare professionals should consider managing control of insulin administration alongside psychological interventions to address motivation, distress tolerance and build trusting relationships with professional and lay carers.**

- ✓ The Mental Health Act should be invoked when necessary to oblige patients to accept insulin to save life or prevent irreversible damage.

8.2 Pharmacological therapies

No evidence was identified on pharmacological therapies for children or adults with Type 1 diabetes and an eating disorder.

9 Adults with anorexia nervosa

Recovery from AN involves both physical and psychological components. The numerical nature of BMI makes it an attractive measure and full recovery from the disorder by definition involves being able to tolerate a healthy weight and healthy behaviours around maintaining this. It is more difficult to numerically measure indices of psychological and psychosocial recovery. These facets of recovery are the most important to patients and their loved ones. Validated self-report scales are helpful but at present there is little agreement on the best measures to use.

Research evidence indicates that even the most effective treatments available are limited by high attrition rates, and symptom abstinence rates of less than 50%. If first-line treatments are not effective second-line or adjunctive treatment modalities may be offered. Those therapies described below have a small evidence base. It is recommended that further research be undertaken to evaluate efficacy when offering alternative treatment models with preliminary evidence (ie less than two high-quality RCTs).

9.1 First-line psychological therapy

9.1.1 Cognitive behavioural therapy

Cognitive behavioural therapy is an established therapy to which other therapies are often compared. A review concluded that CBT led to improvements in BMI and ED symptoms using standardised measures. CBT resulted in a positive effect on depressive symptoms, self-esteem, negative thinking, interpersonal difficulties and mood, but not anxiety. It was also shown to have adequate acceptability and adherence rates. However, CBT did not demonstrate superiority over other therapies for patients with AN.⁹⁶ There is large variability in CBT format, content and administration.⁹⁶

4

When used as maintenance treatment with 88 people who recovered from AN after hospital treatment, manualised CBT (average 38 sessions over a year) resulted in no relapse in 65% of the CBT group compared to 34% in those who received TAU.⁹⁷

2+

A SR of CBT versus third wave therapies (DBT, Schema Therapy, ACT, mindfulness-based therapy, CFT), concluded that, due to the paucity of evidence for newer therapies, CBT should be considered the first choice of therapy for patients with AN.⁹⁸ Further evidence of CBT in comparison to other therapies is in sections 9.2 and 9.3.

1+

In a SR of RCTs and single-cohort pre-post-treatment studies in CBT-E there was significant improvement in patients with therapy. Patients with AN reported a large increase in weight or BMI over treatment and follow up.⁹⁹ Another SR (10 RCTs and 10 uncontrolled studies) found CBT-E to be effective for the full spectrum of EDs. This review included six of the RCTs from the earlier Dahlenburg review. Patients with all types of EDs responded well to CBT-E, including those with AN, with respect to improved BMI, reduced ED behaviours and improved core psychopathology. The six studies with a homogeneous AN sample showed that CBT-E resulted in a significant increase in BMI with large effect size.¹⁰⁰

2+

An RCT in patients with AN compared CBT-E with SSCM and with the Maudsley Model of Anorexia Treatment for Adults (MANTRA). The number of sessions was titrated according to BMI over 10 months: (BMI<16 =40 sessions, 16<17.5 =30 sessions and >17.5 =20 sessions). All therapists were experienced clinical psychologists. Completion rates were around 60% in all treatments and all resulted in improvements in weight and ED psychopathology. CBT-E was superior in helping patients achieve a healthy weight at 12 months' follow up (59% compared to 47.5% in SSCM and 44% in MANTRA). All three therapies were considered valuable treatments for AN.¹⁰¹

1++

9.2 Second-line psychological therapies

9.2.1 Interpersonal therapy and Specialist Supportive Clinical Management

An RCT for AN (BMI 14.5 to 19) comparing CBT, IPT and SSCM, (20 one-hour manual-based sessions conducted over ≥ 20 weeks) found that the different therapies had significantly different effects over time. Those in the CBT group had the most stable course. SSCM had the most immediate effect, with 75% reporting good outcome compared to 33% in the CBT group and 15% in IPT. IPT had the greater effect at long-term follow up (6.7 years), with good outcome in 64% of participants, compared to 41% in CBT and 42% in SSCM. This trial was poorly conducted, with concerns about randomisation, blinding and concealment methods.^{102,103}

1-

9.2.2 Specialist Supportive Clinical Management

The RCT, discussed in section 9.2.1, which compared CBT, IPT and Specialist Supportive Clinical Management (SSCM), showed SSCM to have the best immediate effect on the treatment of patients with AN, with good outcome for 42% at long term follow up.^{102,103}

1-

An RCT comparing CBT-E with SSCM and the MANTRA (see section 9.1.1) showed similar completion results to the other therapies (60%) and good effect over time with 47.5% of those in the SSCM group achieving a healthy weight at follow up.¹⁰¹

1++

SSCM was compared against MANTRA in the two RCTs (see section 9.2.3). Over 12 months 19% of the SSCM group achieved a BMI over 18.5 (compared to 14% in the MANTRA group). More participants in the SSCM group achieved a normal EDE score (73% compared to 59% in the MANTRA group).¹⁰⁴ In the other RCT 16.33% of the SSCM group were recovered at 12 months compared to 22.4% in the MANTRA group.¹⁰⁵ At 24-month follow up (with 79% participants) 28.3% of the SSCM group were recovered compared to 32.15% of the MANTRA group.

1++

9.2.3 Maudsley Model of Anorexia Treatment (MANTRA)

The RCT comparing CBT-E with SSCM and MANTRA in patients with AN is described in section 9.1.1. Completion rates were around 60% in all treatments and all resulted in improvements in weight and ED psychopathology. Forty-four percent of the MANTRA group achieved a health weight at 12 months' follow up compared to 59% in the CBT-E group. All therapies were considered to be valuable treatments for AN.¹⁰¹

1++

Two further RCTs of MANTRA versus SSCM were conducted at the centre where MANTRA was developed. In the first, 72 participants (BMI >16.5) had a mean duration of illness of 6.6 years and over half had had previous treatment. All patients received 20 weekly individual sessions and four monthly follow-up sessions. Two additional sessions with family members were included and a dietetic assessment as required. For lower-weight patients (BMI <15) treatment could be extended up to 30 sessions with four follow-up sessions. Treatment was provided by experienced eating disorder therapists. Patients in both arms improved significantly in terms of weight, eating disorder and other outcomes with no significant differences between them. The mean increase in weight from baseline to 12 months was 3.55kg. Over the 12 months 14% of patients in the MANTRA arm and 19% of the SSCM arm achieved a BMI >18.5 . 59% of the MANTRA arm and 73% of the SSCM achieved a normal EDE score over 12 months. The proportion of people achieving a normal BMI and normal EDE score was 14% in the MANTRA arm and 19% in the SSCM group. Patients in the MANTRA group were more likely to need additional inpatient or day care treatment ($p < 0.004$).¹⁰⁴

1++

In the second of the RCTs, 142 outpatients with AN or EDNOS had 20 weekly individual sessions and four monthly follow-up sessions. This included patients with a BMI <15 who

	<p>were given up to 30 sessions. Both treatments resulted in significant improvements in BMI, reductions in ED symptomatology and distress, and clinical improvement over time. At 12 months 22.4% of the MANTRA arm and 16.33% of the SSCM arm were recovered (BMI >18.5 and normal EDE score). The differences were not statistically significant. Subgroup analysis found a trend for patients who received MANTRA to show greater BMI increase at 6 and 12 months. At the end of 12 months MANTRA was rated as more acceptable and credible than SSCM.¹⁰⁵</p>	1++
	<p>A further study produced follow up data at 24 months, with 79% of the participants. Of these the full recovery rate was 15% (MANTRA) and 28.3% (SSCM). No patients in the study needed additional intensive treatment (inpatient or day care). Subgroup analyses continued to suggest more severely unwell patients respond better to MANTRA.¹⁰⁶</p>	2++
9.2.4	<p>Family therapy</p> <p>Two studies, including adults up to the age of 27, and rated in a Cochrane review as low quality, concluded that family therapies may be as effective as treatment as usual in the short term. Both studies had a small number of participants and potential bias. From the other six studies included, one provided insufficient evidence to offer any advantage of family therapy over educational interventions and the other five (of poor quality) did not support family therapy over other psychological therapies. There was a lack of specificity about the theoretical underpinning of the family therapy approach in a number of the trials and therefore it could not determine whether there are differences between the various types of family therapy.⁷²</p>	1++
9.2.5	<p>Focal psychodynamic therapy (FPT)</p> <p>The Anorexia Nervosa Treatment of OutPatients (ANTOP) study compared focal psychodynamic therapy (FPT) with either CBT-E or treatment as usual (structured care from a family doctor) over 10 months (averaging 40 sessions each). Outpatient treatment of AN by specialist therapy (FPT or CBT-E) or TAU lead to weight gain and reduced ED psychopathology but there were no significant differences between the groups. At 12-month follow up mean BMI in all groups had increased. The proportion of patients recovering continued to increase after the end of treatment. The group receiving FPT had higher recovery rates (35%) compared to TAU (13%) and required fewer admissions. The study had a high treatment completion rate with 70% for FPT and 81% CBT-E which was attributed to a clear framework for psychiatric and medical monitoring, brief inpatient treatment for those with a BMI <14, a brief nutrition guide and a family session. Patients within the FPT group gave positive ratings of their treatment experience.¹⁰⁷</p>	1+
9.3	<p>Other psychological therapies</p> <p>There are a number of other therapies available for people with AN that merit further research and investigation. Whilst some of these are delivered as standalone therapies, others are commonly offered as adjunctive parallel interventions.</p>	
9.3.1	<p>Compassion-focused therapy</p> <p>A study (patients with AN n=19) in the outcome of introducing CFT into a standard CBT programme for people with ED had encouraging results. Whilst this approach showed better results for patients with bulimia, 33% of those with AN were considered recovered. There were significant improvements in ED psychopathology during the treatment programme.¹⁰⁸</p>	1+

9.3.2 Cognitive-remediation therapy

Cognitive-remediation therapy (CRT) for AN was developed as an adjuvant treatment to target set shifting and central coherence in AN and to improve clinical outcome.

A systematic review found CRT for AN to be feasible across the age range and illness severity. Within the review four small RCTs (n=25–82; consisting of 8–30 group or individual sessions) demonstrated that CRT may be helpful as an adjunct to CBT or TAU. Inclusion of CRT was shown to reduce eating disorder psychopathology, reduce attrition, and improve quality of life in adults with anorexia.¹⁰⁹ It can be delivered in inpatient and outpatient settings. Individual CRT was associated with lower dropout rates than group CRT and has the potential to facilitate a stronger alliance with the therapist.¹⁰⁹ 2+

A further review looking at the same RCTs and another three more recent trials found no association with improved central coherence compared to control. Set-shifting outcomes were mixed due to the heterogeneity of measures across studies. They concluded that CRT may reduce drop out but did not report any advantage of adding CRT to TAU.¹¹⁰ An additional RCT (n=61) also concluded that CRT did not enhance the effect of TAU any more than the control.¹¹¹ 1+

9.3.3 Dialectical behaviour therapy (DBT)

A small study (N=25; 13 with AN) compared DBT and TAU, CBT in patients with ED and substance abuse found DBT to be more effective at improving behavioural and attitudinal features related to ED, substance misuse, negative mood regulation and depressive symptoms. These results were maintained at 6-month follow up.¹¹² 1-

In a pilot study of patients with ED (n=147, 18 with AN) and BPD, conducted in a naturalistic setting, DBT, was compared with CBT, both adjunctive to attendance at either outpatients or a day hospital. At end of treatment DBT, was shown to have a statistically significant effect on the symptoms of the BPD, including depression, but no significantly different effects in ED psychopathology from the CBT.¹¹³ 2-

9.4 Recommendations for psychological therapies

R Cognitive behavioural therapy-enhanced (CBT-E), or other forms of cognitive behavioural therapy should be used as first-line therapy for adults with anorexia nervosa.

R If cognitive behavioural therapy is ineffective, unsuitable or unacceptable for people with anorexia nervosa, other therapeutic approaches could be considered, such as Interpersonal Psychotherapy (IPT), the Maudsley Model of Anorexia Treatment (MANTRA), Specialist Supportive Clinical Management (SSCM), or Focal Psychodynamic Therapy (FPT).

✓ Dialectical behaviour therapy (DBT) is a transdiagnostic treatment regime showing greater validity for people with eating disorders with comorbidities including substance misuse disorder and borderline personality disorder (emotionally unstable personality disorder). Therefore this approach should be considered instead of cognitive behavioural therapy for this complex group.

✓ There are many small open studies and pilots of promising therapies such as cognitive analytical therapy, Schema therapy, mentalisation based therapy, RO-DBT which do not yet meet criteria for inclusion according to SIGN methodology. These therapies could be considered for patients with AN, as part of a clinical trial.

9.5 Pharmacological therapies

Prescribing for patients with AN always requires consideration of the starved physiology of the patient, their low body weight and abnormal electrolytes due to purging behaviours.

Psychotropic and other medication carries risks to the heart and other organs so that benefits must always be set against the very real risks, and as a result research in this field is scarce.

People with AN may need specific adjustments to medication prescribed for other conditions, both physical and psychiatric. Meanwhile the quest for medication that directly addresses ED psychopathology proceeds slowly and cautiously. It is assumed in most studies of psychotherapy for AN that patients will be taking psychotropic medications prescribed on a case-by-case basis by experienced specialists.

Expert prescribing often draws on research that is several decades old and consists of case series or small studies which do not meet criteria for SIGN methodology.

- ✓ All low-weight patients should be monitored particularly closely when psychotropic drugs are prescribed. A baseline electrocardiogram (ECG) and further monitoring can alert clinicians to avoidable dangers.

Antipsychotics

It may be a concern for patients that the rationale for using antipsychotic medication for AN is that weight gain has been reported as a side effect in people using antipsychotics for other conditions, such as schizophrenia. In practice the rationale for its use by ED specialists is the reduction of distress and obsessionality. The use of weight as a measure of its effectiveness is a proxy representing the fact that a patient needs to have acquired healthy psychological skills in order to achieve and maintain a healthier weight. For inpatients weight gain can be brought about by good nutrition and olanzapine is not prescribed to speed up this process.

Meta-analysis of seven small studies of second-generation antipsychotics (olanzapine, risperidone and quetiapine) used weight gain as a proxy for overall holistic improvement. It did not find any significant difference between treatment and placebo.¹¹⁴

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A more recent and larger RCT of olanzapine did report statistically significant weight gain in adults with AN after 16 weeks compared with placebo.¹¹⁵ No significant adverse effects were reported, and the patients on olanzapine had no metabolic adverse effects.¹¹⁵

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Cannabinoids

Use of dronabinol was associated with increased weight gain but also an increase in physical activity in one small RCT.^{116,117}

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Oxytocin

Self-administered intranasal oxytocin resulted in a reduction in anxiety levels in response to food and eating in patients at the time of refeeding, in a small RCT.¹¹⁸ Further studies into benefit from this therapy are required before a recommendation can be made.

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Testosterone

One RCT of testosterone reported a deterioration in weight in women with AN after 24 weeks of testosterone compared to those given placebo.¹¹⁹

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R Olanzapine may be offered to adults with anorexia nervosa to support recovery but should not be offered as the sole treatment.

- ✓ Once the patient is weight restored normal guidelines on the management of obsessional symptomatology and treatment for depression, anxiety and other conditions can be followed.
- ✓ Any other medication selected for the symptomatic treatment of AN and comorbid conditions should be carefully monitored and audited if possible and entered into any available research trials if the patient consents. There is no available evidence on the safest medication for rapid tranquilisation. Older antipsychotics should be avoided if possible because of potentially dangerous side effects. Olanzapine is commonly used in this situation, as it is reasonably well tolerated in patients with anorexia nervosa.

10 Adults with bulimia nervosa

Evidence indicates that even the most effective treatments are limited, with symptom abstinence rates at follow up ranging from 15–69%. If first-line treatments are not effective second-line or adjunctive treatment modalities may be offered. Those therapies described below have a small evidence base. It is recommended that further research be undertaken to evaluate efficacy when offering alternative treatment models with preliminary evidence (ie less than two high-quality RCTs).

10.1 First-line psychological therapies

10.1.1 Cognitive behavioural therapy

Most of the research identified on psychological therapies focused on CBT. It is often used as the standard comparator in trials in other therapies.

Cognitive behavioural therapy has been found to be effective in reducing symptoms of bulimia compared with TAU or WLC.¹²⁰ Network meta-analysis of studies of treatment for people with BN indicated that those most likely to achieve full remission are individual CBT (specific to EDs) (OR 3.89, 95% credible interval (CrI) 1.19 to 4.02) and guided cognitive behavioural self-help (cGSH) (OR 3.81, 95% CrI 1.51 to 10.90) compared to TAU or WLC.¹²⁰

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A 16-week, 20-session course of CBT was as effective if delivered via video link as face to face, in terms of retention rates and abstinence from binge eating and purging.⁶⁹ Reduction in binge eating was more rapid amongst those receiving face-to-face CBT. At follow up no differences were found between groups in the frequency of binge eating episodes, but purging frequency remained lower in those who had face-to-face CBT.⁶⁹

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Another study found online CBT was as effective as bibliotherapy compared with WLC in reduction of bulimic symptoms at the end of 20 weeks (abstinence from purging OR 7.2 p=0.02). The online CBT consisted of patient training materials and 25 scheduled sessions for feedback with a therapist. At one-year follow up improvements were seen in both conditions, with no statistical difference in outcomes (OR 1.0 to 1.4, p=0.99).¹²¹

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A CBT-based self-help programme delivered by the internet, and bibliotherapy, accompanied by email guidance, were equally effective in reducing binge eating and vomiting. At the end of treatment almost 20% were abstinent from both bingeing and purging symptoms. There were no significant differences between treatment conditions.¹²²

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A trial of tailored ACT-influenced internet-based CBT, with daily written interaction with a therapist, also reported improvements in eating disorder symptoms (measured with the EDE-Q) compared to the WLC, with 53.3% of the treatment group achieving clinically significant improvement compared to 23.8% in the control group.¹²³

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A further study found that an online CBT-based chat group (CBT4BN) was slower to have an impact than face-to-face CBT (CBTF2F) in reducing binge eating and purging, but improvements were seen over time so both had similar results at one year follow up. In both groups only 14 to 30% became abstinent. There was high failure to engage and high dropout rates for both.¹²⁴

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In patients with either BN (n=31) or BED (n=78), CBT, cGSH and DBT were equally effective in reducing binge eating at 6- and 12-month follow up. CBT had a more rapid effect.¹²⁵

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A small study also showed that intensive CBT had a more rapid response rate (within four weeks) to reduced bingeing behaviours and improved normalised eating behaviours than motivational interviewing.¹²⁶ There were no significant differences between the two treatments at the end of the therapy.

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After five months of treatment 15/34 patients who had CBT had stopped binge eating and purging, compared to 2/34 who had psychoanalytic psychotherapy.¹²⁷

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There were no significant differences between a 17-session outpatient course of integrated group and individual CBT and emotional and social mind training (ESM). Each therapy improved global EDE scores. Adherence rates were higher amongst the ESM group.¹²⁸

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Nineteen weeks of either CBT-E or integrative cognitive-affective therapy (ICAT) resulted in significant improvements in bulimic symptoms in both treatment groups at end of treatment and four-month follow up. There was no statistical difference between intent to treat abstinence rates for CBT-E (22.5% at end of treatment and follow-up) and ICAT (37.5% at post treatment and 32.5% at follow-up).¹²⁹

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One RCT found stepped care (starting with supervised self help) to be superior to CBT in reducing binge eating and compensatory behaviours. Results for abstinence at end of treatment were 18% for CBT and 11% for stepped care, and 18% and 26% respectively at one year. Forty percent in the CBT group and 34% in stepped care also received fluoxetine during treatment.¹²⁶

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10.2 Second-line psychological therapies

10.2.1 Interpersonal psychotherapy (IPT-BN)

Interpersonal therapy may be as efficacious as CBT, but is associated with a more rapid impact. In one RCT 44.8% of the CBT-E participants reported no binge eating, vomiting or laxative misuse at the end of treatment compared with 21.7% in the IPT-BN group (adjusted OR 6.7, 95% CI 1.9 to 23.6).¹³⁰ At 60-week follow up EDE scores continued to improve for IPT to the extent that the difference between CBT-E and IPT was no longer statistically significant (adjusted mean difference in global EDE score 0.28, 95% CI -0.74 to 0.18). Depression reduced significantly alongside ED symptoms with both therapies.¹³⁰

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10.2.2 Dialectical behavioural therapy

A study of 16 patients with BN and 46 with EDNOS, all with comorbid BPD, found that DBT delivered in a naturalistic setting improved behaviours related to BPD but did not improve dysfunctional eating.¹¹³ Two further small studies from the research group did find post treatment that DBT was more effective than the waiting list control in improving ED behaviours (binge eating and purging) and ED attitudes (EDE global scores).⁹⁸

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10.2.3 Schema therapy

In an RCT of women (n=112) with BN or BED similar efficacy was found between schema therapy, CBT and appetite-focused CBT. Each resulted in a reduction in binge frequency at the end of the 6-month weekly treatment programme and at one-year follow up. Across conditions, large effect sizes were found for improvement in binge eating, other ED symptoms and overall functioning. At end of treatment, 60% scored within one standard deviation of the community means for adult females on the EDE-12 global score, indicating clinically significant change. This was maintained at 12-month follow up with 64% of the total sample within one standard deviation of community norms. The retention levels across the three groups was 83%.¹³¹

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10.2.4 Psychoanalytical/psychodynamic therapy

A systematic review identified two RCTs that compared psychodynamic therapy with CBT in people with BN. One of the studies found improvements in both CBT and psychoanalytic conditions at end of treatment, although changes took place more rapidly in the CBT group. At two years' follow-up, 44% in the CBT group and 15% in the psychoanalytic psychotherapy group had stopped binge eating and purging (odds ratio (OR) 4.34, 95% CI 1.33 to 14.21). The authors concluded that psychoanalytic treatment may need to be strengthened with more directive behavioural interventions to increase effectiveness.¹³²

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10.2.5 Mentalisation-based therapy

An RCT in patients with unspecified eating disorder diagnoses and BPD reported a greater reduction in shape concern and weight concern in the eating disorder examination following therapy for eating disorders (MBT-ED) compared to specialist supportive clinical management (SSCM-ED). At 6, 12 and 18 months there was a decline of ED and BPD symptoms in both groups. Only 15 of the 68 participants completed the 18-month follow up.

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Adverse events were reported in 10 patients, mostly self harm.¹³³

10.2.6 Compassion-focused therapy

Modest results for the use of CFT as a treatment adjunct to CBT were reported in a naturalistic pre-post study for a subset of 26 patients with BN, within a wider study of patients with mixed diagnoses. Seventy-three percent of those with bulimia nervosa were reported to have made clinically reliable and significant improvements by the end of treatment.¹⁰⁸

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10.3 Recommendations for psychological therapies

R Cognitive behavioural therapy, preferably in the specially adapted CBT-E or CBT-BN format, should be used as first-line therapy for adults with bulimia nervosa.

R If cognitive behavioural therapy is ineffective, unsuitable or unacceptable, in adults with bulimia nervosa, other treatment options could be considered, such as, interpersonal therapy, integrative cognitive affective therapy, or schema therapy. Mentalisation-based therapy may be considered if the patient has comorbid borderline personality disorder.

✓ Adjunctive therapeutic approaches could be considered to enhance outcomes of established treatments.

✓ Alternative choices should be offered when first line treatments are ineffective or unsuitable for those with moderate to severe comorbid psychiatric disorders. Choice of treatments should take into account therapeutic models which have an established evidence base in the treatment of comorbidities that have been shown to interfere with treatment outcomes in eating disorders (eg post-traumatic stress disorder, personality disorder, substance misuse). Assertive outreach that includes Community Mental Health Team input should be considered for those with eating disorder and moderate to severe borderline personality disorder.

10.4 Pharmacological therapies

A systematic review of RCTs of medication, psychological interventions and a combination of both reported that psychological therapies had short- and long-term benefit and there was also short-term benefit (between weeks 8 and 16) from fluoxetine.¹³⁴ Fluoxetine was shown to improve behaviours such as binge eating and purging, and overvaluation of weight and shape. A dosage of 60 mg daily was more effective than 20 mg. Fluoxetine is the only licensed medication for patients with BN in the UK. A smaller number of studies also showed a reduction in symptoms of BN with trazadone, fluvoxamine, tricyclic antidepressants (TCA), monoamine oxidase inhibitors (MAOI) and the anti-epileptic medication topiramate, although further research is needed to confirm results. When compared to psychological interventions and self-help, only those which incorporated medication were associated with any side effects. Those reported are common to any use of a selective serotonin reuptake inhibitor (SSRI).¹³⁴

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In contrast, a subsequent smaller review concluded that the addition of medication to psychotherapy, primarily CBT for patients with BN did not increase the effectiveness of treatment when compared with CBT alone.¹³⁵

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A meta-analysis suggests some benefit from SSRI and TCA medication in reducing binge eating and purging symptoms, although effect sizes were small. There was an increase in remission rates with MAOIs, although dietary restrictions associated with their use may reduce acceptability and safety.¹³⁶

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In an RCT comparing the use of different SSRIs over a period of 10 weeks, fluoxetine and fluvoxamine were effective in reducing binge eating and purging symptoms in patients with BN; fluoxetine (reduction in binge 75%, purge 68%) and fluvoxamine (reduction in binge 59%, purge 62%). Both were more effective than sertraline (reduction in binge 18% purge

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0%). Despite high levels of side effects with fluoxetine, such as irritability and anxiety, there was no discontinuation from the study.¹³⁷

- R** | Antidepressant medication should be considered as a short-term treatment for patients with bulimia nervosa or as an adjunct to psychological treatments.
- R** | When considering pharmacological treatment for patients with bulimia nervosa fluoxetine, usually at a dose of 60 mg daily, should be the first choice. If selective serotonin reuptake inhibitors are contraindicated other antidepressant medications could be considered.

Draft

11 Adults with binge eating disorder

Evidence indicates that even the most effective treatments are limited. If first-line treatments are not effective second-line or adjunctive treatment modalities may be offered. The therapies described below have a small evidence base. It is recommended that further research be undertaken to evaluate efficacy when offering alternative treatment models with preliminary evidence (ie less than two high-quality RCTs).

11.1 First-line psychological therapies

The focus of CBT which is the most tested psychological therapy for BED is on eliminating dieting due to its central role in increasing risk of binge eating. Psychological therapies do not directly focus on weight loss in those with BED who are overweight and may not result in reduction of BMI. They are generally likely to be more beneficial in addressing the eating disorder. Interventions with a primary focus on BMI reduction are ineffective in their primary aim, as people tend to regain the weight they have lost over follow up.^{92,93,138} A number of studies of psychological therapies are authored by those who have formulated the therapeutic approach for BED.

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11.1.1 Cognitive behavioural therapy

Meta-analysis of studies of psychotherapies and structured self-help, most of which were CBT, reported significant post-treatment reduction of binge-eating episodes and abstinence from binge eating (pooled OR 9.9 and 8.9 respectively) compared with inactive controls (mainly waiting list). Reduction in ED psychopathology was also significant in both. Compared to WLC the dropout rate was significantly increased in both groups (OR 1.9 for psychotherapy and 2.4 for self-help treatment). The quality of the evidence was graded as very low across treatment categories and there was a lack of data on long-term efficacy.⁹⁴ The medium-term effectiveness (extending up to 12 months' follow up) has subsequently been confirmed for CBT and CBT self-help.¹³⁹

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Another meta-analysis reported benefits of CBT formats (therapist-led; partially therapist-led; structured self-help CBT; and cGSH) in reducing binge frequency and achieving abstinence compared to wait list controls. The most significant results were for therapist-led CBT (RR 4.95 for abstinence and a weekly reduction of 2.3 binges) which was rated as a high strength of evidence.⁹² CBT (in any format) has not shown significant effects for reduction in BMI.^{92,94,139} The effects for depression are mixed across meta-analyses.^{92,94,138}

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The comparative effectiveness of different levels of therapist CBT involvement have also been examined. Few differences were found when comparing therapist-led, partially-led, and structured self-help CBT, in binge-eating outcomes, based on low-quality studies.⁹² In one study therapist-led CBT was associated with significantly greater binge abstinence and reductions in binge eating frequency than CBT self help at end of treatment, but these differences were not significant at 12-month follow up.⁹³ More robust evidence is required to fully determine which mode of delivery is most effective.⁹³ Most of the studies with a therapist-led arm delivered treatment in groups rather than individually.

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An RCT which used therapists who were not experienced in eating disorders, in a population including those with binge eating and BED, found that the guided self-help group improved abstinence compared to TAU, at end of the 12-week treatment and 12-month follow up. There were also improvements in pattern of restraint, eating concern, shape concern, weight concern, depression, social adjustment, but not BMI.¹⁴⁰

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One small study compared CBT to long-acting methylphenidate. Those in the methylphenidate group had weekly support from a psychiatrist in addition to the pharmacological treatment. Following 12 weeks of treatment both groups were found to have a significant reduction in objective binge eating episodes. The number of participants who were binge free in the last four weeks of treatment did not differ. There was a reduction in BMI in the methylphenidate group but not CBT at the end of treatment. Results were maintained at three-month follow up.¹⁴¹

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11.1.2 Interpersonal psychotherapy (IPT)

Meta-analysis of two RCTs concluded modest support for IPT (group IPT versus group CBT, and individual IPT versus cGSH). IPT was found to be as effective as CBT for remission, reducing binge eating frequency and reduction in BMI at end of treatment and 12-months follow up.¹³⁸ There was insufficient data to perform meta-analysis on eating disorder psychopathology or symptoms of depression, and drop out was too high in one study to look at follow-up data beyond 12 months.

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11.2 Second-line psychological therapies

11.2.1 Dialectical behavioural therapy

A systematic review identified two small RCTs which reported benefit from DBT compared to waiting-list controls with fewer binge eating episodes, lower EDE scores and significantly greater rates of abstinence from binge eating at end of treatment.⁹⁸ In a third RCT, when compared to an active group therapy, binge eating abstinence occurred more quickly with DBT (64%) compared to therapist-led group therapy (36%), although these differences disappeared at 12-month follow up.⁹⁸ Two further studies in participants with mixed ED diagnoses were included in the systematic review, which concluded that DBT is probably an efficacious treatment.

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After 10 weeks of treatment, DBT resulted in a significant reduction in the BMI ($+3.49 \pm 1.94$ vs. $+1.93 \pm 1.22$ kg/m², $P < 0.001$), decreases in the binge eating scale (BES) and emotion regulation (measured by difficulties in emotion regulation scale (DERS)) compared to waiting list control. No follow up data was available.¹⁴²

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A small RCT reported significant reductions with large effects sizes in binge frequency with both DBT guided self-help, DBT unguided self help or an unguided self help self-esteem control at post treatment and 12 weeks follow up (Carter, 2020 #196). No differences were reported between groups.

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In patients with either BN (n=31) or BED (n=78), CBT, cGSH and DBT were equally effective in reducing binge eating at 6- and 12-month follow up. CBT achieved the quickest results. There were no notable changes in BMI from baseline to end of treatment for the participants with BED.¹²⁵

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11.2.2 Group Psychodynamic Interpersonal Psychotherapy

Comparison of therapist-led group psychodynamic interpersonal psychotherapy (GPIP) and CBT to a waiting list control found both treatments to outperform the control condition in reduction in bingeing and percentage abstinence.⁹² Both active interventions were found to be comparable and results were maintained at 12-month follow up. A stepped approach comprising 10 weeks of CBT followed by either 16 weeks of 90-minute psychodynamic interpersonal groups or no further treatment, showed that the groups conferred no extra advantage post treatment or at 6-month follow up. At 6-month follow up only 25% were abstinent from binge eating and did not differ from control. There was a significant reduction in attachment avoidance and interpersonal problems.¹⁴³

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11.2.3 Brief strategic therapy

In a small RCT comparing brief strategic therapy (BST) with CBT statistical and clinical significance was achieved for both groups in global functioning and weight decrease at 12-month follow up. There was also a reduction in binge frequency in the BST group but not CBT. Brief strategic therapy was superior in all three outcomes. The therapy was delivered by telemedicine over 7 months as an adjunct to a weight loss programme in women with BED and comorbid obesity.¹⁴⁴

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11.2.4 Schema therapy

In an RCT of traditional CBT versus “appetite-focused” CBT (additional focus on recognition and response to hunger and satiety cues) versus Schema therapy (all 6 months of weekly sessions, following by 6 months of approximately monthly sessions) there was an improvement in binge eating, other eating disorder symptoms and over all functioning across all three groups. Change in the frequency of binge eating at the end of all treatments was greater for those with BED than BN. At 12 months’ follow up no differences were found between groups in terms of binge frequency. The proportion of participants with BED or BN who met community norms on the EDE global score did not differ at the end of treatment or 12-month follow up.¹³¹

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11.2.5 Integrative cognitive-affective therapy

Integrative cognitive-affective therapy resulted in similar efficacy to cGSH in patients with BED. After 17 weeks of treatment there was a significant reduction in binge eating abstinence rates of 57.1% for ICAT and 42.9% for cGSH. At 6-month follow up rates were 46.4% for ICAT and 42.9% for cGSH (including those who dropped out of treatment). Treatment adherence was higher amongst those having ICAT, which was conducted in individual sessions (87% vs 74%).¹⁴⁵

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11.2.6 Compassion-focused therapy

Only one small pilot RCT on CFT for people with BED was identified. A 3-week self-help course with CFT or behavioural therapy reduced mean weekly binge days compared to the waiting list control.¹⁴⁶ Another small RCT in 22 participants with mixed ED diagnoses found benefit when CFT was used as an adjunct to treatment as usual.¹⁴⁷

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11.3 Recommendations for psychological therapies

R Cognitive behavioural therapy or interpersonal psychotherapy should be used for first-line therapy for adults with binge eating disorder.

R If cognitive behavioural therapy or interpersonal psychotherapy are ineffective, unsuitable or unacceptable, in adults with binge eating disorder, other treatment options could be considered, such as dialectical-based therapy, cognitive-affective therapy or schema therapy.

R People with binge eating disorder who are overweight or obese should be made aware that the focus of cognitive behavioural therapy is on eliminating dieting due to its central role in increasing risk of binge eating. Psychological therapies do not directly focus on weight loss and may not result in large reductions of BMI, but are likely to be generally more beneficial in addressing the eating disorder. Additionally, interventions with a primary focus on BMI reduction are generally ineffective in achieving this aim in the longer term.

✓ Adjunctive therapeutic approaches could be considered to enhance outcomes of established treatments.

✓ Alternative choices should be offered when first line treatments are ineffective or unsuitable for those with moderate to severe comorbid psychiatric disorders. Choice of treatments should take into account therapeutic models which have an established evidence base in the treatment of comorbidities that have been shown to interfere with treatment outcomes in eating disorders (eg post-traumatic stress disorder, personality disorder, substance misuse). Assertive outreach that includes Community Mental Health Team input should be considered for those with eating disorder and moderate to severe borderline personality disorder.

11.4 Pharmacological therapies

The majority of the identified studies of pharmacological treatments for patients with BED were conducted in North American populations. Weight loss was one of the outcome measures. The majority of the proposed medications are licensed as weight loss agents or are likely to cause weight loss, often due to stimulant and/or appetite suppressant qualities. Stimulant drugs have been associated with high levels of unwanted side effects, some serious, and with risk of misuse within individuals to whom they are prescribed or diversion and misuse within the wider community

Although sustained weight reduction may be an appropriate goal for some patients with co-morbid clinically-significant obesity, pursuit of weight loss is recognised in psychological therapy for people with ED as a powerful maintaining factor for eating disorder thinking and behaviours. This suggests a potential conflict between treatment goals of active weight loss and reduction in eating disorder psychopathology, although in practice, effective treatment for binge eating will generally result in small but meaningful weight loss. Further research into the relationship between appropriate weight management interventions in obesity and effective treatment for eating disorders is needed, with qualitative studies which explore the lived experience of BED likely to be of particular value in trying to understand how these issues may be balanced effectively and how they affect quality of life. The main outcome for this guidance on pharmacological treatment for people with BED is reduction of eating disorder thinking and behaviours.

An RCT of fluoxetine or placebo with CBT in patients with BED showed remission rates at 12-month follow up of 3.7% for fluoxetine-only, 26.9% for CBT with fluoxetine, and 35.7% for CBT with placebo, suggesting that medication alone is not effective.¹⁴⁸ Analysis of moderating factors showed that core eating disorder psychopathology of overvaluation of weight and shape was more effectively treated by CBT than fluoxetine.¹⁴⁹ Meta-analysis of antidepressants in the treatment of patients with BED found that all but one study reported short-term outcomes (8 weeks or less). The one study which reported outcomes at 16 weeks did not show ongoing benefit.¹⁵⁰

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Meta-analysis of psychological and medical treatments for patients with BED confirmed that psychological therapies were more effective than pharmacological therapies in reducing binge eating behaviours, ED psychopathology and depression. Lisdexamfetamine had a small effect on binge eating behaviours and weight reduction, but no effect on ED psychopathology or depression. There is a lack of data on the safety of long-term prescribing.⁹⁴

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In 10 out of 12 studies, adding medication to a psychotherapy, such as CBT, conferred no additional benefit in reduction of binge eating outcomes. Antiepileptic medications zonisamide and topiramate were reported as enhancing binge eating outcome reduction. No trials of LDX were included in this review.¹³⁵

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Evidence in relation to the efficacy and safety of LDX in the treatment of patients with BED is published in four RCTs carried out by the same group of researchers, and funded by the pharmaceutical company which manufactures LDX. Meta-analysis of these studies concluded that LDX at dose of 50mg and 70mg/day produced a reduction in binge eating frequency statistically significantly greater than placebo in both treatment and relapse prevention trials. There were significantly higher levels of adverse events compared with placebo. Serious adverse events occurred in 3.9% of the LDX group compared to 3.2% placebo, with many resulting in withdrawal from the study.¹⁵¹

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LDX is associated with serious physical harms, particularly to the cardiovascular system and its safety is still not ascertained for use during pregnancy.¹⁹ A limitation of reported evidence is that formal research studies screen for substance misuse, hypertension, cardiovascular disease and diabetes, psychiatric co-morbidity, and concurrent psychotropic medication. Patients with these are excluded as they could not be in routine clinical care. Furthermore, during the trial patients would be closely monitored for any adverse effects, in a manner which is unrealistic in routine care. The study samples represented only a small subgroup of the population of patients likely to present to primary and secondary care

services in Scotland for BED. This group as a whole would be particularly vulnerable to cardiovascular harms.

The longest duration of use of LDX in these studies was 38 weeks and no information was identified on longer-term safety or effectiveness of its use in this indication. Studies examining whether any reduction in binge eating symptoms was maintained after medication withdrawal showed that any gains were lost once off medication, suggesting that long-term prescribing would be required. The concern about adverse effects and misuse of medications which would potentially require long-term prescription suggests that safety data for long-term use should be available before recommendations are made.

Other studies identified were placebo controlled trials of medications either licensed for weight loss, or likely to reduce weight including:

- a novel opioid receptor antagonist,¹⁵²
- sibutramine - a stimulant drug licenced for weight loss and chemically related to amphetamines which was withdrawn due to increased risk of cerebrovascular and cardiovascular disease in people with heart disease,¹⁵³
- rimonibant, a cannabinoid receptor inverse agonist used as an appetite suppressant and weight loss medication, withdrawn due to increase risk of anxiety and depressive symptoms and some reported suicides of people taking this medication,¹⁵⁴
- orlistat, a weight-loss agent,¹⁵⁵
- a combination of the stimulant phentermine and the antiepileptic medication topiramate,¹⁵⁶
- a combination of opiate-receptor antagonist naltrexone and serotonin and noradrenaline reuptake inhibitor bupropion, which is used as an anti-obesity medication, as an antidepressant and in ADHD., and¹⁵⁷
- bupropion.¹⁵⁸

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None showed a statistically significant advantage over placebo for reduction in binge eating disorder symptoms. Orlistat and bupropion were shown to produce weight loss over the study duration only.^{155,158}

R Medication is not recommended either as an alternative or as an adjunct to psychological treatment for patients with binge eating disorder.

- ✓ In patients with binge eating disorders medication should be considered in the treatment of co-morbid conditions, with appropriate assessments of underlying risk factors, in particular cardiovascular and metabolic vulnerabilities.

12 Bone mineral density

Women with AN are likely to have an increased fracture risk of 150–300% based on significantly lower bone mineral density (BMD) values than healthy control women.¹⁵⁹ Bone mineral density is the best measure of the strength and health of bones, but there is not a direct relationship between biomarkers of bone turnover, BMD and fracture incidence, which is the outcome of concern.

Studies in people who do not have an eating disorder show that improved BMD results in increased bone strength and a reduction in fracture risk.¹⁶⁰ Achieving a healthy weight and, in women, the return of menstruation, are beneficial to bones and the strongest predictors of an increase in BMD. This is particularly important in adolescents, in helping them to achieve their full potential for bone development.¹⁶¹ Refeeding to normal weight has a low incidence of physical side effects and over time can achieve meaningful increases in BMD, whereas pharmacological interventions such as bisphosphonates and hormone replacement achieve limited improvements in the absence of weight restoration, and are associated with complex considerations around prescribing practices.¹⁶² Full nutrition should therefore be considered the primary therapy to improve bone integrity.¹⁶¹ Progress can be slow, with studies showing improvement at 16 months' follow up.¹⁶¹

One study found that male adolescents with AN who achieve weight gain but remain underweight may experience further BMD loss, unlike their weight-restored counterparts (BMI \geq 19 kg/m²), who show a significant increase in BMD and bone mineral accrual rates that double those of healthy male adolescents.¹⁶¹

No RCTs were identified addressing pharmacological therapies to increase BMD in males with AN.¹⁶² First line of management should be renutrition but, due to the enduring nature of AN, alternative therapies should be available when this is not realistic.¹⁶² For adult women, the most significant increases in BMD were from bisphosphonate therapy. No significant increase in BMD was observed following administration of oral contraceptives, transdermal testosterone or oral dehydroepiandrosterone (DHEA) alone. Conversely, 100 μ g of 17- β estradiol (with cyclic progesterone) administered transdermally did increase spinal and hip BMD in mature adolescents with AN.¹⁶²

The long-term effects of bisphosphonates are currently unknown and an inadequate number of trials exist to confirm their safety. Although bisphosphonates are effective in increasing BMD, fractures can still occur due to reduced tensile strength. Bisphosphonate use is also associated with an increased occurrence of atypical femoral fractures, osteonecrosis of the jaw, upper gastrointestinal adverse effects.¹⁶⁰ There is a potential risk to the foetus when bisphosphonates are administered to women of reproductive age.¹⁹

No correlation was found between calcium and/or vitamin D intake and BMD in patients with AN. Vitamin D and calcium supplements are not sufficient to reverse bone loss on their own, but replacement should still be regarded as important in patients with a proven deficiency, particularly if undergoing other forms of treatment.¹⁶²

A small study on the efficacy of jumping exercise to improve bone mineral density in adolescents with AN found no benefit.¹⁶³ More trials are needed before recommendations on exercise for improving BMD can be made. Advice on exercise to reduce the risk of osteoporosis in people with AN, produced by the Physiotherapy Eating Disorder Professional Network and the Royal Osteoporosis Society is available on the Chartered Physiotherapists Mental Health website:

https://cpmh.csp.org.uk/system/files/documents/2020-06/exercise_activity_osteoporosis_with_an_eating_disorder_absolutely_final_for_pdf_finally_7.pdf

R Weight restoration should be offered to patients of all genders and ages with low-weight anorexia, as part of a holistic programme of treatment, to improve bone mineral density.

R Treatment with bisphosphonates or oestrogen to prevent loss of or restore bone mineral density and so reduce fracture risk should not be considered as treatment modalities on their own, but could be used as a supportive treatment.

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1+

Benefits and risks should be discussed with the patient, and those who receive treatment should be closely monitored by experts in eating disorders and bone metabolism.

R Bisphosphonate treatment is not recommended for younger patients due to its teratogenic side effects and long half life.

- ✓ The restoration of healthy nutrition will be reflected in normal body mass index. This is essential for optimal brain development and the health of other bodily systems, such as the skeleton. Weight restoration is very difficult psychologically for patients. It is therefore essential that this is managed within a therapeutic setting ensuring that the holistic needs of the patient are met.
- ✓ Before starting any hormonal treatment for low bone mineral density in a patient with anorexia nervosa clinicians should seek advice from a paediatric, endocrinological or bone specialist and coordinate treatment with the eating disorders team.
- ✓ Men are also at risk of low bone mineral density but there is a lack of evidence on treatments other than weight restoration. Those who have persistent low bone mineral density should be referred to a bone specialist.

13 Severe and enduring eating disorders

The course of an ED is always individual and although the average time to recovery is seven years, there is huge variation. Some patients with EDs may not respond to a well-delivered course of an evidence-based treatment. However, some recoveries are reported after more than twenty years.¹⁶⁴ Around a third of people with AN and BN continue to live with their ED after this protracted time.¹⁶⁴ Poorer ED symptoms, psychological function, and work and social wellbeing, alongside more lifetime hospitalisations, are associated with people with AN >7 years' duration and a high level of reported distress, compared to those of a duration of <3 years. Fewer changes were found to occur over a 12-month period, especially in relation to work and social adjustment.¹⁶⁵

3

A recent meta-analysis, however, did not find a relationship between duration of ED and treatment outcome.¹⁶⁶ Association remained unclear due to heterogeneity across studies, so the authors advocated for continuing to offer intervention for those with a long course of ED in the context of ongoing research. This seems particularly important as there is the potential for the terms used to define longstanding EDs (eg chronic or treatment resistant) to inappropriately result in loss of hope and unsuitable discharge from all treatment, as well as increasing stigma.

2++

There is no agreed consensus on how to most appropriately define durable EDs.¹⁶⁷ In this review the term 'Severe and Enduring Eating Disorder' (SE-ED) has been used, and papers have been reviewed which primarily meet the definition 'duration of ED of at least seven years or more'. An SR identified severe and enduring as the second most common descriptive term used in studies of SE-ED (the most common being chronic, but there was concern this could be translated to mean incurable).¹⁶⁷ The SR identified that most research used duration of disorder as the sole criteria or as part of other classifications, and at least 7 years was the most common period. Although empirically-tested multidimensional criteria has recently been proposed, a limitation is that duration is defined as more than three years.^{168,169} This is a significantly shorter course than is the case for most adults with EDs.

A systematic review of treatments for people with SE-ED found only small RCTs, observational and case studies.¹⁷⁰ The studies of pharmacological therapies and brain stimulation therapies were small, making it difficult to draw meaningful conclusions.

2++

Inpatient treatments, which consisted of individual or group CBT and, in two studies, nutritional plans for weight gain, reported improvements in ED symptoms and weight gain during treatment. The largest follow-up study (n=70) reported weight increase during the two-year follow up. This study also found a decrease in binge eating behaviours during treatment, but not during follow up. Results of inpatient treatments across the studies during follow up were inconsistent. However, studies of day and outpatient treatment demonstrated improvements in symptoms both during treatment and follow up.¹⁷⁰

2++

In one RCT (n=63) of outpatient treatment patients were randomised to either adapted CBT-AN or SSCM. The therapies were modified to prioritise harm minimisation and quality of life. Patients in both groups showed overall, significant improvements on all primary outcome measures (eating disorder quality of life, depression, and social adjustment). At end of treatment, 6-month and 12-month follow up they also showed improvements in the secondary outcome measures of BMI, ED psychopathology, and readiness to recover. Retention rates for both treatments were high (87% overall). There were no differences between groups at the end of treatment on any outcome measure or health-care utilisation.¹⁷¹

1+

Further study of the sample group in the RCT reported that:

- those with AN purging subtype and poorer ED quality of life were less likely to complete treatment.¹⁷²
- weight gain and reduction in ED symptoms during treatment improved current and future quality of life.¹⁷³

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- adapted CBT-AN was more beneficial than SSCM when participants showed greater ED symptomatology, more depression, or presented with an AN binge-purge subtype.¹⁷²
- For both therapies the early formation of a strong patient-professional alliance predicted improvement in ED symptomatology, but not in weight or depressive symptoms.^{174,175}

The underlying neurological characteristics of people with enduring AN are similar to those of autistic people, so neurological traits need to be taken into account when considering appropriate treatment.⁴⁹

1+

Based on the limited evidence available people with SE-ED may respond both to traditional treatment approaches and to those specifically modified especially if they are targeted at enhancing patient engagement.^{170,171} However, there is a lack of evidence to guide clinical practice, particularly for EDs other than AN.

It may be helpful to move from active targeting of ED symptoms to a more holistic approach, concentrated on optimising and maintaining a better quality of life and wellbeing, whilst minimising the negative impact of the ED as far as possible. There is no evidence to inform when this shift should occur or exactly what form it may take.¹⁵⁵ The response to treatment is an individual matter and therefore people should be offered more than one evidence-based treatment and any available promising alternatives. In addition, neuropsychological development continues for many years into adulthood, so treatments can be tried again in the context of greater maturity.

A fluid approach to intervention may be taken, where people move in and out of periods of active treatment (which could also be adapted in its goals).¹⁷¹ At times it may be important to recognise that the ED has taken the form of a chronic disability, at least in the medium term. At any stage it could be appropriate to discuss whether symptom-focused treatment has exhausted the energies of both patient and clinician, and the approach may be changed to a broader focus as either a temporary or a longer-term option (which may be less intensive). The door for recovery should always be left open so the individual has the opportunity to change their mind, re-engage and discuss options with an appropriately trained healthcare professional.

However, it is likely that relentless imposition of therapeutic tasks (either with a symptom or broader focus) is only acceptable in a context of healthy change. Keeping people attached to services without measurable benefit might stand in the way of normal social supports and life skills. In such situations patients should be offered the opportunity to reduce the intensity of clinical input. In some cases this may become a long-term situation.

A very small number patients may request that even potentially life-saving treatment should not be imposed upon them. This is an emotionally distressing situation and requires at least one formal second opinion and medico-legal involvement. Where it has been fully agreed and documented that the patient has the capacity to take such a decision, ongoing support should be offered to individuals, their families and other carers, including after death. However, again this area is hampered by a lack of evidence to guide the provision of such care.

R Where active symptom-focused treatments have been exhausted either temporarily or in the medium-to-long term clinicians may consider offering either CBT-AN or SSCM whilst monitoring risk and quality of life outcomes.

✓ When it has been agreed that symptom-challenging treatment should stop quality-of-life treatment should be continued and support offered to the patient's family and other carers.

✓ Patients who have disengaged from therapy should have the opportunity to change their mind, re-engage and discuss the options with an appropriately trained healthcare professional.

i Individuals should be signposted to support from social services, housing, education and employment rights.

14 Pregnancy and postnatal care

14.1 Eating disorders during pregnancy and the postnatal period

Prevalence rates for eating disorders in pregnant women have been reported as 0.09% for anorexia, 0.94% for bulimia nervosa, 5% for binge eating disorder, and 0.1% for related disorders.¹⁷⁶ Screening of women attending antenatal clinics and postnatal follow up highlighted that disordered eating behaviour (assessed using the EDE-Q) during, and particularly after, pregnancy may be more common than expected, with 5.3% of prepartum and 12.8% of postpartum mothers screening positive.¹⁷⁷

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Systematic reviews assessing the impact of maternal eating disorders on dietary intake and eating patterns during pregnancy found that pregnancy is associated with overall improvements in dysfunctional eating behaviours in most women.^{178,179}

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A small study found that amongst women with current or past eating disorders, increased levels of eating disorder symptoms were present during pregnancy (compared with controls) in the first and second trimesters, although overall the severity of these symptoms reduced during the course of the pregnancy.¹⁸⁰ During the postnatal period, for women with current and past eating disorders, eating disorder symptoms again increased at eight weeks and remained higher than controls at both 8 weeks and 6 months postnatal.¹⁸⁰

2+

A further small study found that pregnancy is associated with an increase in body weight dissatisfaction in women with and without an eating disorder.¹⁸¹ Postpartum, women with a history of eating disorder tend to experience a rapid decrease in BMI. Their body weight dissatisfaction reduces to pre-pregnancy levels by three months.¹⁸¹

2-

Qualitative research on the experiences of women with eating disorders during pregnancy has identified a number of themes relating to barriers to disclosure of eating disorders by women during pregnancy. These include stigma, lack of opportunity (limited enquiry by professional), preference for self-management, improvement in ED symptomatology during pregnancy, level of knowledge about ED and acknowledgement of their symptoms.¹⁸²

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Moderate

Key themes that emerged from interviews during pregnancy included navigating a 'new' eating disorder, with pregnancy representing a time of tumultuous change with a 'battle between managing the eating disorder, the needs of the unborn child and feelings of loss of control; a new context to view the body with considerations of the safety of the child, making space for the baby, 'hiding' the eating disorder; or conversely a return to the 'old' eating disorder with an overwhelming desire to lose weight.^{183,184} Women also described pregnancy as a time of positive change in eating habits, more acceptance of their body and the desire to meet the needs of the unborn child being greater than the eating disorder.¹⁸³

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The postpartum period was experienced by some women as period of increased distress with themes relating to the loss of the pre-pregnancy body and equally loss of pregnancy identity, with increased drivers to lose weight.¹⁸⁴

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Findings from interviews with women also indicated that the pressure to relinquish the eating disorder identity, motivation and drive for change may be greater during a woman's first pregnancy compared to experiences with subsequent pregnancies.¹⁸⁴

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- R** | Healthcare professionals should sensitively enquire to determine if the woman has a current or past history of eating disorder and be aware of potential barriers for disclosure.
- R** | Healthcare professionals should discuss with women who are pregnant how their eating disorder symptoms may change during the antenatal and postnatal period.
- R** | Healthcare professionals should be aware of the risk of relapse, particularly in the postnatal period.
- ✓ | Referral to eating disorder services and/or perinatal mental health services should be considered for pregnant women with a current or past eating disorder.
- ✓ | Care planning with the extended multidisciplinary team (eg maternity staff, eating disorder service, perinatal mental health services, general practitioner, health visitor, social services) should be considered for pregnant women with a current or past history of an eating disorder relevant to their presenting needs.

14.2 Comorbidity with anxiety and depression

A systematic review found strong evidence for an association between eating disorder symptoms and depressive and anxiety symptoms during pregnancy.¹⁸⁵ Additionally it found limited evidence for an association between eating disorder symptoms and obsessive compulsive symptoms during pregnancy and between eating disorder symptoms and depressive symptoms during the postpartum period.¹⁸⁵ 2-

A large longitudinal study and a smaller study both found that at all time points during pregnancy and the postnatal period, women with an eating disorder have been found to experience higher rates of depressive symptoms than controls during the antenatal and postnatal period.^{180,186} 2+
2++

The small study also found that women who have an eating disorder are at increased risk of experiencing anxiety symptoms during pregnancy and postnatally.¹⁸⁰ 2+

- R** | Healthcare professionals providing care for women with a current or past eating disorder should consider assessing for depression and anxiety and offer evidence-based treatment as appropriate (see SIGN guideline 127¹⁸⁷), alongside management of the eating disorder

14.3 Medication use

Women with an eating disorder are more likely than women without an eating disorder to use psychotropic medication, gastrointestinal medication, such as laxatives, and analgesia during pregnancy.¹⁷⁶ Women with AN were found to be more likely to use sedative or anxiolytic medication in the postnatal period (0–6 months postpartum).¹⁷⁶ Women with BN or BED were more likely to use gastrointestinal medication during pregnancy compared to women without an eating disorder.¹⁷⁶ 2+

- ✓ | All women of childbearing age should be given appropriate counselling on the balance of risks of untreated illness and of medication exposure during the different stages of pregnancy and postnatally, taking into account breastfeeding. If possible discussions should start before conception.

14.4 Dietary intake

A systematic review, and two cohort studies found that women with a history of AN showed a significantly increased risk of iron deficiency anaemia during pregnancy.^{178,188,189}

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In general pregnant women with a history of an eating disorder achieve an adequate diet during pregnancy.¹⁷⁸ Women with lifetime AN or BN had similar patterns of nutrient intake and dietary supplements use as women without an ED.

2-

Women with BED showed higher energy and fat intakes during pregnancy.¹⁷⁸

2-

Women with BED before and during pregnancy had lower intakes of folate, potassium and vitamin C, with lower intake of fruit and juices during the second trimester.¹⁷⁸

2-

R Healthcare professionals should consider enhanced screening for iron deficiency anaemia for pregnant women who have a history of anorexia nervosa.

✓ Healthcare professionals should undertake an approximate assessment of the nutritional intake of a pregnant woman with a current or history of an eating disorder, taking into account pre-pregnancy BMI and if possible gestational weight gain. Should there be concerns about the patient's nutritional intake (either low or high), specialist eating disorder dietetic assessment, intervention and weight monitoring should be considered. Other appropriate multidisciplinary interventions (including support to manage any distress secondary to the eating disorder) should be provided if indicated.

14.5 Obstetric outcomes

A systematic review and meta-analysis found that infants of mothers with anorexia nervosa are at increased risk of being low birth weight (Solmi 2014 #21). A large population study found that women with lifetime anorexia nervosa were at higher risks of having small for gestational age, compared with controls.¹⁹⁰ Lifetime history of bulimia nervosa posed higher risks of needing a Caesarian section. The babies of women who had even sub threshold ED had higher likelihood of having a low Apgar score.¹⁹⁰

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A large cohort study found that women with all eating disorders were found to be at higher risk of preterm birth and having babies with microcephaly.¹⁸⁹ Women with anorexia nervosa were at increased risk of antepartum haemorrhage.¹⁸⁹ A further cohort study found that lifetime anorexia nervosa and bulimia nervosa were associated with restricted foetal growth and increased risk of the baby being small for gestational age. Active anorexia nervosa in the mother was associated with increased risk of the baby being small for gestational age and of preterm labour.¹⁹¹

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Anorexia nervosa prior to pregnancy was associated with smaller birth length, bulimia nervosa with induced labour, and binge eating disorder with larger birth length and large for gestational age.¹⁹² BMI before pregnancy and weight gain during pregnancy may be important factors that influence these outcomes.¹⁹²

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R Healthcare professionals should be aware that women with eating disorders may be at higher risk of obstetric complications.

✓ Women with eating disorders or a history of eating disorders with a low or high pre-pregnancy BMI or failure to gain gestational weight, may be considered for additional obstetric monitoring during pregnancy (such as foetal growth scans) to support and allow multidisciplinary intervention if indicated.

✓ Healthcare professionals may wish to consider offering preconceptual advice regarding optimising nutritional status and promoting recovery to women with eating disorders where possible prior to conception.

14.6 Infant outcomes

A systematic review found that children of mothers with eating disorders are at increased risk of difficulties in feeding and eating behaviours and higher rates of social and emotional difficulties.¹⁹³

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A small study of women with either past or current ED reported higher concerns about their infant being, or becoming overweight compared with other mothers. They also had less awareness of hunger and satiety cues.¹⁹⁴

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One small case-control study reported some associations with neurobehavioural dysregulation after the birth of infants born to mothers with current or a history of an eating disorder. Infants of mothers with a current eating disorder were found to have higher autonomic instability at eight day's postpartum using the Neonatal Brazelton Assessment Scale. Infants of mothers with a history of an eating disorder had poorer language and motor development at one year compared to other infants.¹⁹⁵

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- ✓ Healthcare professionals should consider that infants of women with eating disorders (and their care givers) may benefit from additional support with feeding, eating, social and emotional difficulties and should consider working collaboratively with health visiting staff and other parenting supports available locally.

14.7 Training and education

Healthcare professionals identified the following barriers to providing eating disorders support in the perinatal period: system constraints including lack of knowledge, role recognition (not seeing it as their role), personal attitudes, and the stigma and taboo of discussing eating disorders with pregnant and postnatal women. Lack of evidence-based knowledge and training impacts on confidence to discuss eating disorders. Other system constraints were poor continuity of care, poor communication between professionals and women and between healthcare professionals.¹⁸² Another study also highlighted the need to raise awareness and implement educational programmes and training of frontline healthcare staff.¹⁷⁷

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- ✓ Healthcare professionals working with pregnant and postnatal women should have training in identifying and appropriately managing patients with eating disorders, relevant to their role.

15 Needs of diverse communities

The majority of research into eating disorders has been conducted in young white female populations. Given the difficulties of undertaking any meaningful research in the field it is understandable that evidence is collected from the most convenient samples. There is a risk that services are then unable to offer appropriate treatments to those who do not fit their traditional profiles. No good quality quantitative evidence was identified to guide the treatment of male patients, ethnically diverse groups and LGBTQ+ people. Much of the qualitative evidence highlights obstacles and difficulties to accessing treatment rather than providing outcomes for treatment.

Further research is required in each of these areas, but also to address more general questions around identification of the disorders in non-typical groups and supporting these people to feel welcomed into services so that their treatment plans are collaboratively tailored to their specific needs. There also needs to be research into effective training programmes to enable clinicians to offer such treatments.

- ✓ Services should encourage staff diversity in terms of age, gender, ethnicity and body image to provide a welcoming environment for every patient.

15.1 Men with eating disorders

A systematic review concluded that few studies with sufficient numbers of males exist so treatment outcomes for males were inconclusive.¹⁹⁶ Men with an eating disorder are less likely to receive treatment than women.¹⁹⁷ although inpatient treatment is equally effective in males and females.¹⁹⁸ A small study that found that men had lower drive for thinness, and less body dissatisfaction than women.¹⁹⁹ Mortality in male inpatients with eating disorders was found to be relatively higher than in females.²⁰⁰

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Two systematic reviews of a total of ten qualitative studies compared treatment between men and women with ED.^{201,202} Some of the key themes did not differ from those raised by female patients and within these studies participants expressed a range of differing views about the relevance of gender in treatment. However, the following key themes emerged:

- Recognition of the eating disorder (delayed recognition, perception that it is a woman's illness, not fitting sociocultural perceptions).
- Different clinical features in males (different body image concerns, and suppression of sexual function).
- Longer delays in seeking treatment (shame/stigma, ambivalence toward the disorder, lack of knowledge and fear of subsequent rejection).
- Accessing help (difficulty accessing treatment services, minimisation/ignorance of EDs in men).
- Characteristics of services and treatments (feminised services and psychoeducation, being a minority in services, experiencing care as control, lack of a person-centred approach, availability of tailored treatments).

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15.2 LGBTQ+ people with eating disorders

Very little research, quantitative or qualitative, was identified on the specific needs of people who are LGBTQ+ to support them with treatment for an eating disorder.

A metasynthesis of nine qualitative studies on the role of gender in treatment experiences of people with eating disorders found that there was a lack of understanding about gender issues amongst healthcare professionals treating people with eating disorders. Failure to acknowledge or address gender status made people who identified as transgender more likely to disengage from the treatment. There was also concern that the issues discussed, or perceived to be the main issues for people with eating disorders were focused around women and did not address the main concerns for men or transgender people.²⁰³ The authors

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recommended that health professionals address their own unintentional biases and negative assumptions about transgender people, suggesting reflective practice in supervision as a medium for doing so.

A survey of people identifying as transgender found that eating disorders decreased after gender-confirming medical interventions improved body satisfaction.²⁰⁴

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15.3 Recommendations

- R** Gender identity and issues relating to gender should be sensitively considered by all health professionals treating people with eating disorders.
- R** Teaching and training should be offered to all healthcare professionals to allow them to identify individuals with eating disorders, and recognise potential variations in the profile of symptoms.
- R** Services should be designed so that all patients have equity of access to eating disorders services at all levels.
- R** In most outpatient services delivery of tailor-made, individualised care plans should accommodate considerations of gender or other diversity.
- ✓ Where treatment services are specifically designed for the needs of a female-dominant group (particularly inpatient services) alternative services may be considered where there are mixed or more diverse communities.
- ✓ Where male patients have to be treated within a female-dominated group alternative services may be considered where there are mixed or all-male communities.

16 Provision of information

This section reflects the issues likely to be of most concern to patients and their carers. These points are provided for use by health professionals when discussing eating disorders with patients and carers and in guiding the development of locally produced information materials.

16.1 Publications from SIGN

SIGN patient versions of guidelines are documents that ‘translate’ guideline recommendations and their rationales, originally developed for healthcare professionals, into a form that is more easily understood and used by patients and the public. They are intended to:

- help patients and carers understand what the latest evidence supports around diagnosis, treatment and self care
- empower patients to participate fully in decisions around management of their condition in discussion with healthcare professionals
- highlight for patients where there are areas of uncertainty.

A copy of the patient version of this guideline is available from www.sign.ac.uk/patient-publications.html

Other relevant SIGN patient booklets include:

- autism www.sign.ac.uk/patient-and-public-involvement/patient-publications/autism/
- diabetes www.sign.ac.uk/patient-and-public-involvement/patient-publications/diabetes/
- mood disorders during and after the birth of your baby www.sign.ac.uk/patient-and-public-involvement/patient-publications/mood-disorders-during-pregnancy-and-after-the-birth-of-your-baby/

16.2 Sources of further information

Beat

The [Beat Adult Helpline](#) is open to anyone over 18. Parents, teachers or any concerned adults should call the adult helpline.

Helpline: [0808 801 0677](tel:08088010677)

Email: help@beateatingdisorders.org.uk

Help for young people

The [Beat Youthline](#) is open to anyone under 18.

Youthline: [0808 801 0711](tel:08088010711)

Email: fyp@beateatingdisorders.org.uk

www.beateatingdisorders.org.uk/

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

CARED Scotland

www.caredscotland.co.uk

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

Mental Welfare Commission

Adviceline for personal queries: 0800 309 6809

Adviceline for professional queries: 0131 313 8777

Email: mwc.enquiries@nhs.scot

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.

NHSInform

Tel: 0800 22 44 88

www.nhsinform.scot

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

<https://www.nhsinform.scot/illnesses-and-conditions/mental-health/eating-disorders>

Scottish Association for Mental Health (SAMH)

Tel: 0344 800 0550

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.

Scottish Eating Disorders Interest Group (SEDIG)

www.sedig.org

SEDIG provides a network for information and support for healthcare professionals with an interest in eating disorders, people with eating disorders and their families and carers. It's website provides links to resources, events and lists support and services available in Scotland.

16.3 Checklist for provision of information

This section gives examples of the information patients/carers may find helpful at the key stages of the patient journey. The checklist was designed by members of the guideline development group based on their experience and their understanding of the evidence base. The checklist is neither exhaustive nor exclusive.

Initial Intervention

- Signposting and information on further support should be provided as early as possible.
- Acknowledge the difficulty of asking for help and reassure that ambivalence about recovery and seeking treatment is normal.
- Discuss reasons for seeking help, ensuring that emotional state and wellbeing is recognised beyond just physical symptoms.
- People with eating disorders may think they must become more unwell before they “deserve” help, or they are “allowed” to recover. Provide reassurance that there is no such thing as “unwell enough” and that they do deserve to get well.
- Explain diagnosis if made and discuss treatment options – include signposting to community, social and interim support such as Beat (*see section 16.2*).
- Emphasise the need for hope, that no matter how long someone has struggled with an eating disorder and how bleak they may feel about their future, things can change (for clinicians, patients, carers, family, etc).

Supporting Someone Through Treatment

- Discuss treatment plans with patients and allow them to share their ideas and concerns. Explain how a therapy works and why it may be appropriate for that individual.
- Pregnancy: encourage anyone who has, or has a history of, an eating disorder and is planning a pregnancy, to discuss their eating disorder, so support can be arranged.
- Encourage the individual to build a supportive network which may involve family and/or friends, while respecting the individual's right to confidentiality (*see section 3.2*)
- Engage in discussions about returning to activities stopped during treatment, eg exercise. Life after treatment, and life after an eating disorder, should be considered.
- Ensure the patient knows how to access support programmes, when needed, as they continue through their recovery journey (*see section 16.2*).

17 Implementing the guideline

This section provides advice on the resource implications associated with implementing the key clinical recommendations, and advice on audit as a tool to aid implementation.

17.1 Implementation strategy

Implementation of national clinical guidelines is the responsibility of each NHS board, including health and social care partnerships, and is an essential part of clinical governance. Mechanisms should be in place to review care provided against the guideline recommendations. The reasons for any differences should be assessed and addressed where appropriate. Local arrangements should then be made to implement the national guideline in individual hospitals, units and practices.

Implementation of this guideline will be encouraged and supported by SIGN. The implementation strategy for this guideline encompasses the following tools and activities.

17.2 Resource implications of key recommendations

No recommendations are considered likely to reach the £5 million threshold which warrants resource impact analysis.

17.3 Auditing current practice

A first step in implementing a clinical practice guideline is to gain an understanding of current clinical practice. Audit tools designed around guideline recommendations can assist in this process. Audit tools should be comprehensive but not time consuming to use. Successful implementation and audit of guideline recommendations requires good communication between staff and multidisciplinary team working.

The guideline development group has identified the following as key points to audit to assist with the implementation of this guideline:

- Collect appropriate, nationally-agreed baseline and outcome data (BMI, EDE-Q, DASS and CORE) on all patients.
- Any Scottish NHS Boards that implements the FREED model will automatically be included in the FREED research group and should contribute to data collection and further evaluation of the model.
- When using therapies with only preliminary evidence, collect baseline and outcome data to determine efficacy.
- Collect prescribing data in adults with AN.
- Training provided to staff on EDs.
- Whether services can provide the recommended psychological therapies and associated accredited training and supervision requirements.

18 The evidence base

18.1 Systematic literature review

The evidence base for this guideline was synthesised in accordance with SIGN methodology. A systematic review of the literature was carried out using an explicit search strategy devised by a SIGN Evidence and Information Scientist. Databases searched include Medline, Embase, Cinahl, PsycINFO and the Cochrane Library. The year range covered was 2009-2020. Internet searches were carried out on various websites for relevant guidelines. The main searches were supplemented by material identified by individual members of the development group. Each of the selected papers was evaluated by two Evidence and Information Scientists using standard SIGN methodological checklists before conclusions were considered as evidence by the guideline development group.

The search strategies are available on the SIGN website, www.sign.ac.uk

18.1.1 Literature search for qualitative studies

A SIGN evidence and information scientist conducted a literature search of Medline, Embase and Psychinfo, using a standard qualitative search filter, up to 2019. The studies were appraised and summarised by a qualitative researcher from The Scottish JBI Collaborating Centre. Qualitative studies were graded using the 10-item JBI checklist for qualitative research. It was decided *a priori* that studies scoring 8–10 (out of 10) would be considered high quality, 5–7 (out of 10) moderate quality, and 4 or below low quality, https://joannabriggs.org/sites/default/files/2019-05/JBI_Critical_Appraisal-Checklist_for_Qualitative_Research2017_0.pdf. Qualitative syntheses were graded using the 11-item JBI checklist for systematic reviews and research syntheses. It was decided *a priori* that studies scoring 9–11 (out of 11) would be considered high quality, 5–8 moderate quality, and 4 or below low quality https://jbi.global/sites/default/files/2020-08/Checklist_for_Systematic_Reviews_and_Research_Syntheses.pdf

18.1.2 Literature search for patient issues

At the start of the guideline development process, a SIGN Evidence and Information Scientist conducted a literature search for qualitative and quantitative studies that addressed patient issues of relevance to early management of patients with an eating disorder. Databases searched include Medline, Embase, Cinahl and PsycINFO, and the results were summarised by the SIGN Patient Involvement Advisor and presented to the guideline development group.

18.1.3 Literature search for cost-effectiveness evidence

The guideline development group identified key questions with potential cost-effectiveness implications, based on the following criteria, where it was judged particularly important to gain an understanding of the additional costs and benefits of different treatment strategies:

- treatments which may have a significant resource impact
- opportunities for significant disinvestment or resource release
- the potential need for significant service redesign
- cost-effectiveness evidence could aid implementation of a recommendation.

A systematic literature search for economic evidence for these questions was carried out by a SIGN Evidence and Information Scientist covering the years 2009-2020. Databases searched include Medline, Embase and NHS Economic Evaluation Database (NHS EED). Each of the selected papers was evaluated by a Health Economist, and considered for clinical relevance by guideline group members.

Interventions are considered to be cost effective if they fall below the commonly-accepted UK threshold of £20,000 per Quality-Adjusted Life Year (QALY).

18.2 Recommendations for research

There has been limited funding for eating disorder research in the UK in comparison to other mental health presentations, and physical health conditions.²⁰⁵ It has been reported that research funding for prevention, detection, the development of novel treatments and health service models in eating disorders was significantly lacking.²⁰⁵

It has been suggested that the marginalisation of eating disorders within the research community is a consequence of stigma associated with eating disorders, for example, the perception that these are transient and superficial difficulties associated with young women, perpetuating a perception that they are not as important or severe as other mental health conditions.²⁰⁶ Prevalence rates and costs of eating disorders in Europe have been severely underestimated due to the most common eating disorders, such as BED, not being counted.²⁰⁷ Both of these factors, and the associated marginalisation of eating disorder research, has potentially had an impact on the perceived need or urgency in the area by funders.

This has a direct consequence on the production of clinical guidelines. The guideline development group was not able to identify sufficient evidence to answer all of the key questions (see *Annex 1*). There was an absence of robust RCTs in EDs other than AN, especially in children and young people, despite many initial presentations occurring within this age group. Little research was identified for eating disorders in men, LGBTQ+ groups, autistic people and those experiencing more severe and prolonged presentations. Even in key questions where a number of RCTs were identified, attrition and relapse rates were high, highlighting the need for further intervention development.

There is an urgent need for a substantial increase in research funding for eating disorders in the UK to enhance and refine existing treatment protocols and support the development of novel psychological and biological interventions. To fully support these objectives funding is required for robust large scale, multicentre RCTs. It is essential that moderators of treatment are considered to support our understanding of who benefits most from different treatment modalities, to support more effective treatment pathways. Research should be co-produced with patients, families and carers.

It is also important that there is a research and data-driven ethos within clinical services in Scotland. There is a need for the agreement of standardised outcome measures and the implementation of an associated national data set across all eating disorder services. Along with robust quality improvement methodology, this will enable clinicians to work collaboratively across the country to support learning across regions in the implementation of best practice and to improve service provision. Clinicians should be supported in the robust evaluation of health service models and encouraged to develop partnerships with higher education institutions to support this process and associated dissemination of findings.

The following topics for further research have been identified:

- The nature, management and effective treatment of eating disorders in groups previously marginalised in existing research. This includes men, LGBTQ+ groups, autistic people and individuals experiencing comorbidity (particularly Type 1 diabetes, PTSD, OCD and substance use disorder). There is little research focusing the development, presentation and intervention approaches specific to eating disorders among ethnic and racial minority groups and this needs to be prioritised.
- The development of novel psychological and biological interventions via robust, large scale, multisite RCTs. Presentations where there is a lack of robust RCTs, or where RCTs exist but there are high rates of remission and relapse, should be prioritised eg ARFID across all ages, BED across all ages, BN in young people, and AN in adults.
- The definition, management and treatment of individuals with severe and enduring eating disorders, addressing quality of life as well as core eating disorder psychopathology.

- The incorporation of a holistic definition of recovery, rather than one focused on weight in isolation, and associated biological and psychological interventions that promote maintenance of recovery following active treatment.
- Clinical management of eating disorders during pregnancy and the perinatal period.
- Treatments for medical sequelae of eating disorders.
- Robust evaluation of healthcare models for eating disorders. This might include treatment provision (eg intensive treatment teams, stepped care models), methods of delivery (inclusive of digital technology), and pathways which reduce length of untreated presentations and disruptive transitions.

18.3 Review and updating

This guideline was issued in 2022 and will be considered for review in three years. The review history, and any updates to the guideline in the interim period, will be noted in the update request report, which is available in the supporting material section for this guideline on the SIGN website: www.sign.ac.uk

Comments on new evidence that would update this guideline are welcome and should be sent to the SIGN Executive, Gyle Square, 1 South Gyle Crescent, Edinburgh, EH12 9EB (email: sign@sign.ac.uk).

19 Development of the guideline

19.1 Introduction

SIGN is a collaborative network of clinicians, other healthcare professionals and patient organisations and is part of Healthcare Improvement Scotland. SIGN guidelines are developed by multidisciplinary groups of practising healthcare professionals using a standard methodology based on a systematic review of the evidence. Further details about SIGN and the guideline development methodology are contained in 'SIGN 50: A Guideline Developer's Handbook', available at www.sign.ac.uk

This guideline was developed according to the 2019 edition of SIGN 50.

19.2 The Guideline Development Group

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The membership of the guideline development group was confirmed following consultation with the member organisations of SIGN. All members of the guideline development group made declarations of interest. A register of interests is available in the supporting material

section for this guideline at www.sign.ac.uk

Guideline development and literature review expertise, support and facilitation were provided by SIGN Executive and Healthcare Improvement Scotland staff. All members of the SIGN Executive make yearly declarations of interest. A register of interests is available on the contacts page of the SIGN website www.sign.ac.uk

Kirsty Allan	Project Officer
Juliet Brown	Evidence and Information Scientist
Kelly Humphrey	Project Officer
Karen Graham	Patient and Public Involvement Advisor
Gaynor Rattray	Guideline Co-ordinator
Domenico Romano	Publications Designer

19.3 Consultation and peer review

A report of the consultation and peer review comments and responses is available in the supporting material section for this guideline on the SIGN website. All expert referees and other contributors made declarations of interest and further details of these are available on request from the SIGN Executive.

19.3.1 Specialist reviewers invited to comment on this draft or Specialist review

This guideline was also reviewed in draft form by the following independent expert referees, who were asked to comment primarily on the comprehensiveness and accuracy of interpretation of the evidence base supporting the recommendations in the guideline. The guideline group addresses every comment made by an external reviewer, and must justify any disagreement with the reviewers' comments.

SIGN is very grateful to all of these experts for their contribution to the guideline.

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19.3.2 Public consultation

The draft guideline was also available on the SIGN website for a month to allow all interested parties to comment.

19.3.3 SIGN editorial group

As a final quality control check, the guideline is reviewed by an editorial group comprising the relevant specialty representatives on SIGN Council to ensure that the specialist reviewers' comments have been addressed adequately and that any risk of bias in the guideline development process as a whole has been minimised. The editorial group for this guideline was as follows. All members of SIGN Council make yearly declarations of interest. A register of interests is available on the SIGN Council Membership page of the SIGN website www.sign.ac.uk

Dr Roberta James	<i>SIGN Programme Lead; Co-Editor</i>
Professor Angela Timoney	<i>Chair of SIGN; Co-Editor</i>

Abbreviations

ACT	acceptance and commitment therapy
AFT	adolescent focused therapy
AN	anorexia nervosa
ANTOP	Anorexia Nervosa Treatment of OutPatients
ASD	autism spectrum disorder
BED	binge eating disorder
BES	binge eating scale
BMD	bone mineral density
BMI	body mass index
BN	bulimia nervosa
BPD	borderline personality disorder
BST	brief strategic therapy
BWL	behavioural weight loss
CAMHS	child and adolescent mental health service
CBT	cognitive behavioural therapy
CBT-A	cognitive behavioural therapy adapted for adolescents
CBT-AN	cognitive behavioural therapy adapted for anorexia nervosa
CBT-BN	cognitive behavioural therapy adapted for bulimia nervosa
CBT-E	enhanced cognitive behavioural therapy
CFT	compassion-focused therapy
cGSH	guided self-help cognitive behavioural therapy
CI	confidence interval
CrI	credible interval
CRT	cognitive remediation therapy
DBT	dialectical behavior therapy
DEPS-R	diabetes eating problems survey revised
DERS	difficulties in emotion regulation scale
DHEA	dehydroepiandrosterone
DKA	diabetic ketoacidosis
DSM	Diagnostic and Statistical Manual of Mental Disorders
ECG	electrocardiogram
ECHO	Expert Carers Helping Others
ED	eating disorders
EDE-Q	eating disorder examination questionnaire
EDNOS	eating disorder not otherwise specified
EE	Expressed Emotion

ESM	emotional and social mind training
FBT	family-based treatment
FBT-BN	family-based treatment adapted for bulimia nervosa
FPT	focal psychodynamic therapy
FREED	First Episode and Rapid Early intervention in Eating Disorders
GMC	General Medical Council
GP	general practitioner
GPIP	group psychodynamic interpersonal psychotherapy
HbA1c	glycated haemoglobin
HEB	healthy exercise behaviour
ICAT	integrative cognitive-affective therapy
ICD	International Classification of Diseases
IPT	interpersonal psychotherapy
LEAP	Loughborough exercise and activity programme
LGBTQ+	lesbian, gay, bisexual, transgender, queer, or non-binary
LDX	lisdexamfetamine
MA	marketing authorisation
MANTRA	Maudsley Model of Anorexia Treatment for Adults
MAOI	monoamine oxidase inhibitors
MARSIPAN	Management of Really Sick Patients with Anorexia Nervosa
MBT	mentalisation-based therapy
MFT	multi-family therapy
MWC	Mental Welfare Commission
NICE	National Institute for Health and Care Excellence
OAQ	Overcoming Anorexia Online
OCD	obsessive-compulsive disorder
OR	odds ratio
PD	personality disorder
PDT	psychodynamic therapy
PTSD	post-traumatic stress disorder
RCT	randomised controlled trial
SEDIG	Scottish Eating Disorders Interest Group
SE-ED	severe and enduring eating disorder
SEES	Safe Exercise at Every Stage
SF-12 PCS	short-form-12 physical component score
SIGN	Scottish Intercollegiate Guidelines Network
SPT	supportive psychotherapy
SR	systematic review
SSCM	specialist supportive clinical management

SSRI	selective serotonin reuptake inhibitor
SyFmTx	systemic family therapy
TAU	treatment as usual
TCA	tricyclic antidepressant
WLC	waiting-list controls

Draft

Annex 1

Key questions addressed in this update

This guideline is based on a series of structured key questions that define the target population, the intervention, diagnostic test, or exposure under investigation, the comparison(s) used and the outcomes used to measure efficacy, effectiveness, or risk. These questions form the basis of the systematic literature search.

Guideline section

Key question

In all key questions:

Consider co-morbidities:

- personality disorder
- complex trauma
- autism spectrum disorder (ASD)
- substance misuse
- physical illness
- obsessive-compulsive disorder (OCD)
- depression
- post-traumatic stress disorder (PTSD)
- anxiety
- bipolar affective disorder
- schizophrenia

Consider setting

1. What psychological therapies are effective in the treatment of children and young people with anorexia nervosa?

Interventions:

- family therapies
- family-based treatment (FBT)
- interpersonal therapy (IPT)
- cognitive behavioural therapy (CBT)
- enhanced cognitive behavioural therapy (CBT-E)
- adolescent focused therapy (AFT)
- dialectical behavioural therapy (DBT)
- cognitive analytical therapy (CAT)
- acceptance and commitment therapy (ACT)
- group therapy
- individual therapy
- supportive specialist clinical management (SSCM)
- schema therapy
- radically open dialectical behavior therapy (RO-DBT)
- compassion-focussed therapies (CFT)
- cognitive remediation therapy (CRT)

Comparators:

- between therapies
- treatment as usual
- waiting list control

Outcomes:

- psychological Improvement (eg EDE, EDEQ, EDI)
- quality of life measures (eg Clinical Global Outcomes (CGII))

return to normal activities
 weight improvement
 weight restoration
 BMI change (in relation to age and height)

2. What psychological therapies are effective in the treatment of children and young people with bulimia nervosa or binge eating disorder?

Interventions:

- family therapies
- family-based treatment (FBT)
- interpersonal therapy (IPT)
- cognitive behavioural therapy (CBT)
- enhanced cognitive behavioural therapy (CBT-E, CBT-BN)
- adolescent focused therapy (AFT)
- dialectical behavioural therapy (DBT)
- cognitive analytical therapy (CAT)
- acceptance and Commitment Therapy (ACT)
- group therapy
- individual therapy
- supportive specialist clinical management (SSCM)
- schema therapy
- radically open dialectical behavior therapy (RO-DBT)
- compassion-focussed therapies (CFT)
- cognitive remediation therapy (CRT)
- brief strategic therapy

Comparators: See KQ1

Outcomes:

- psychological Improvement (eg EDE, EDEQ, EDI)
- quality of life measures (eg CGI)
- frequency of binge/purge behaviour
- return to normal activities
- relapse

3. What psychological therapies are effective in the treatment of children and young people with eating disorders and Type 1 diabetes?

Interventions – see KQ1

Comparators – see KQ1

Outcomes:

- psychological Improvement (eg EDE, EDEQ, EDI)
- quality of life measures (eg CGI)
- return to normal activities
- insulin compliance (HB1C levels)
- improved scores in Diabetes Eating Problems Survey revised (DEPS-R)
- general hospital admissions
- diabetic ketoacidosis episodes
- severe hypoglycaemia episodes
- weight Improvement
- weight Restoration
- BMI change (in relation to age and height)
- relapse
- remission (no longer meets diagnostic criteria)
- cost effectiveness

4. What therapies are effective in the treatment of children and young people with avoidant/restrictive food intake disorder (ARFID)?

Interventions:

- family-based treatment (FBT)
- family therapy
- adolescent focused therapy (AFT)
- cognitive behavioural therapy (CBT)
- enhanced cognitive behavioural therapy (CBT-E)
- parenting training/coaching
- dietetics

Comparators:

- between therapies
- treatment as usual
- waiting list control

Outcomes:

- psychological improvement
- quality of life measures (eg CGII)
- return to normal functioning
- nasogastric feeding rates
- hospital admissions
- BMI change (in relation to age and height)
- relapse
- remission (no longer meets diagnostic criteria)
- cost effectiveness

Consider comorbidities:

- ASD
- OCD
- PTSD
- physical comorbidities

5. What psychological therapies are effective in the treatment of adults with anorexia nervosa?

Interventions: See KQ1 (not AFT), and:

- mentalisation-based therapy (MBT)
- focal psychodynamic therapy (FPT)
- Maudsley Model of Anorexia Treatment for Adults (MANTRA)

Comparators: See KQ1

Outcomes: See KQ1

6. What psychological therapies are effective in the treatment of adults with bulimia nervosa or binge eating disorder?

Interventions: See KQ2 (not AFT), and:

- mentalisation-based therapy (MBT)
- psychodynamic Therapy

Comparators: see KQ2

Outcomes: see KQ2

7. What psychological therapies are effective in the treatment of adults with an eating disorder and Type 1 diabetes?

Interventions: Interventions: See KQ1 (not AFT), and:

- mentalisation-based therapy (MBT)
- focal psychodynamic therapy (FPT)
- Maudsley Model of Anorexia Treatment for Adults (MANTRA)

Comparators: see KQ1

Outcomes: see KQ3

8. In patients with anorexia nervosa, which factors are associated with good maintenance of recovery?

Population: Children, young people or adults with anorexia nervosa

Interventions:

- feeding to a healthy weight range
- addressing compulsive exercise

Outcomes:

- stability of weight gain
- psychological improvement (eg EDE, EDEQ, EDI)
- Clinical Global Outcomes
- return to work/education
- adverse events

9. In children and young people who have anorexia nervosa are pharmacological therapies effective in improving outcomes?

Interventions:

- antidepressants
- antipsychotic drugs
- other

Comparators:

- between pharmacological therapies
- placebo
- usual care

Outcomes:

- reduction in distress/anxiety
- remission (no longer meets diagnostic criteria)
- relapse
- mortality
- adverse effects
- weight gain
- cost effectiveness

10. In children and young people who have bulimia nervosa or binge eating disorders are pharmacological therapies effective in improving outcomes?

Interventions, comparators and outcomes: see KQ9

11. In children and young people who have an eating disorder and Type 1 diabetes are pharmacological therapies effective in improving outcomes?

Interventions and comparators: see KQ9

Outcomes:

- reduction in distress/anxiety
- relapse
- remission (no longer meets diagnostic criteria)
- mortality
- insulin compliance (HB1C levels)
- improved scores in Diabetes Eating Problems Survey revised (DEPS-R)

- general hospital admissions
 - diabetic ketoacidosis episodes
 - severe hypoglycaemia episodes
 - adverse effects
 - cost effectiveness
12. In adults who have anorexia nervosa are pharmacological therapies effective in improving outcomes?
- Interventions, comparators and outcomes: see KQ9
13. In adults who have bulimia nervosa or binge eating disorder are pharmacological therapies effective in improving outcomes?
- Interventions, comparators and outcomes: see KQ9
14. In adults who have an eating disorder and Type 1 diabetes are pharmacological therapies effective in improving outcomes?
- Interventions and comparators: see KQ9
- Outcomes: see KQ11
15. In patients who have anorexia, what is the best treatment to obtain optimal bone mineral density?
- Interventions:
- renutrition to a healthy weight
 - bisphosphonates
 - hormone preparations (oestrogen)
 - calcium and vitamin D supplements
 - exercise programmes
- Comparators:
- placebo
 - usual care
- Outcomes:
- improved bone mineral density
 - reduced fracture risk (vertebral/hip/other) at 1, 5 and 10 years
 - adverse effects
 - treatment concordance
 - cost effectiveness
16. What treatment and continuing care is required by people with severe and enduring eating disorder (SE-ED) or treatment-resistant eating disorder?
- Interventions:
- supportive psychotherapy
 - physical monitoring
 - dietetic advice
 - family support
 - occupational therapy
 - peer group support
 - modified CBT
 - SSCM
 - pharmacology
 - palliative care programmes
- Comparator: no treatment
- Outcomes:

- quality of life
- mood disorder symptoms
- social adjustment
- activities of daily living
- weight change (BMI)
- change in ED pathology
- improved motivation for change
- reduction in hospital admissions

17. What are the most effective interventions to support pregnant women who have an eating disorder?

Interventions:

- high-risk monitoring/prebirth plans
- antidepressants
- antipsychotics
- mother and baby unit (MBU) admission
- nasogastric feeding or nutritional support/supplements

Comparator: Treatment as usual

Outcomes:

- relapse
- mood (depression/anxiety)
- preterm labour
- intrauterine growth retardation
- neonatal adaptation syndrome
- small for dates
- large for dates
- cost effectiveness

18. What are the most effective postnatal interventions to support new mothers who have an eating disorder?

Interventions:

- mother-infant interventions
- CBT
- IPT
- parenting interventions
- couple counselling
- video interactive guidance (VIG)
- mentalisation
- lamotrigine
- antidepressants
- antipsychotics

Comparator: Treatment as usual

Outcomes:

- relapse prevention
- relapse
- mood disorder
- infant outcomes (growth and developmental ages and stages)
- attachment
- bonding
- recovery from ED
- cost effectiveness

19. What interventions are effective in supporting parents, siblings and carers of people with eating disorders?

Interventions: Parent/carer training/coaching (eg Maudsley, Experienced Carers Helping Others (ECHO)).

Comparator: No intervention

Outcomes:

- Reduction in anxiety/distress for parents/carers
- Improved quality of life for parents/carers
- Improved and sustained outcomes for patients with eating disorders

20. a. What are the most effective interventions for people who identify as male who have an eating disorder?

Interventions, comparators and outcomes: see KQs1–5, 16

b. What are the needs and preferences of people who identify as male when receiving treatment for an eating disorder?

Phenomena of interest: the views opinions and experiences of boys and men on treatment for EDs

21. a. What are the most effective interventions for lesbian, gay, bisexual, transgender or non-binary people who have an eating disorder?

Interventions, comparators and outcomes: see KQs1–5, 16.

b. What are the needs and preferences of lesbian, gay, bisexual, transgender or non-binary people when receiving treatment for an eating disorder?

Phenomena of interest: the views opinions and experiences of people who are LGBT on treatment for an eating disorder.

22. In people with eating disorders does early intervention improve outcome?

Intervention: early interventions models of care

Comparator: usual care

Outcome:

- quicker, more sustained recovery
- cost effectiveness

23. What are the risks and benefits of implementing the Mental Health Act for people with anorexia?

Interventions:

- application of the mental health act
- involuntary treatment

Comparators:

- waiting for/counselling to gain consent
- parental consent

Outcomes:

- patient acceptance
- parent and carer acceptance
- treatment outcomes

24. a. What are the main requirements for ensuring effective and safe transition between services for people with eating disorders?

Population: People with eating disorders and their family/carers moving from

- paediatric to adult services

- changing health board area

Intervention: models of transition

Comparators:

- between models
- no structured transition

Outcomes:

- engagement with adult services/continuity of care
- relapse rates
- patient/family/carer satisfaction
- cost effectiveness
- adverse events

b. What are the views and experiences of people with an eating disorder, their carers and healthcare providers on transition between services?

Phenomena of interest: the process and experience of transition from paediatric to adult ED services, or between services

Context:

- paediatric to adult services
- changing health board area

Outcomes:

- improved engagement with healthcare services
- improved patient/carer/family satisfaction

25. What follow up care is required to help people who have had treatment for an eating disorder to maintain their recovery?

Outcomes:

- quality of life
- maintenance of a healthy weight
- relapse

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