

Medical Emergencies in Eating Disorders: Guidance on Recognition and Management

(Replacing MARSIPAN and Junior MARSIPAN)

May 2022 (Updated October 2023)

COLLEGE REPORT CR233

Endorsement statement

The Royal College of Psychiatrists' Medical Emergencies in Eating Disorders: Guidance on Recognition and Management has been endorsed by the Council of the Academy of Medical Royal Colleges, which represents all the Medical Royal Colleges and Faculties in the UK.

In endorsing the document, the Council recognised the importance of having guidance across health care settings and the need for clinicians in all specialties to understand how to recognise and manage medical emergencies in eating disorders.

The Academy welcomes the guidance and encourages its use throughout the NHS.

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This report was developed with support and advice from an independent expert reference group established by the Royal College of Psychiatrists

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Forewords

1: Patient perspective

The voices of patients and carers have been central to the development of these guidelines. Our many and varied lived experiences of emergencies with eating disorders demonstrate the importance of managing them well – this can, and does, save lives like ours.

But that does not mean this subject is without difficulty, despite everyone's best efforts. These guidelines are to simply heighten awareness around the treatment of a person with an eating disorder and hopefully broaden knowledge on how best to deal with someone who presents with signs of an eating disorder. From spotting eating disorders and signs of emergencies when they may not be obviously present, to supporting patients who may be frightened at the prospect of receiving any intervention – there are many challenges in an emergency which are faced by clinicians, patients and families alike. The provision and acceptability of good care is therefore a shared endeavour, and so the human and relational basis of healthcare should never be forgotten. Even in a crisis, understanding how we feel and creating an alliance when you talk to us, can remove barriers to lifesaving care.

The clinical need for guidance on recognising and managing emergencies arising from eating disorders, across presentations and populations, is without question. The demand for knowledge among healthcare professionals is also evident. There is nothing worse than feeling ill-equipped in the face of an emergency when, in fact, there is much that can be done using this guidance as a base.

As patients and carers, we need clinicians to be proactive in considering eating disorders in the first place, thus reducing the chances of a situation becoming an emergency. They must then be equipped with the knowledge and skills to manage emergencies wherever and however they show up in healthcare systems. We hope these guidelines can contribute to a cultural shift whereby healthcare professionals no longer see eating disorder emergencies as the sole responsibility of specialist workforces. Eating disorders are everyone's business.

Most of all, these guidelines need to be shared and used. As beneficiaries of lifesaving care, we are indebted to those who have helped manage our emergencies effectively. Because of this care, we have a voice in these guidelines when so many can tragically no longer be heard. Deaths from eating disorders result from a lack of care, and can be prevented.

James Downs and Ben Robinson, Patient Representatives

2: College and NHSE perspective

We are very pleased to see the launch of this exceptionally timely and important report addressing the management of medical emergencies in eating disorders. Alongside welcome investment in and development of services for people with eating disorders, the past few years have seen eating disorders spotlighted through untimely deaths of young people with anorexia nervosa. Failings were found in the care that each of these young people received, across all sectors of healthcare. Eating disorders are common, and through the COVID-19 pandemic we have seen an unprecedented increase in clinical presentations of people with severe eating disorders warranting urgent care across healthcare settings. The skills to recognise and manage eating disorders when they become a medical emergency are a necessity.

We are particularly pleased to see this report published with endorsement from the Academy of Medical Royal Colleges, as the findings have relevance for clinicians from many professional backgrounds. The team behind the report reflects the intended multi-professional readership, with an authorship and editorial team spanning the breadth of clinical expertise likely to encounter patients with eating disorders, working alongside patients and carers with lived experience of severe eating disorders, all underpinned by the well-established processes of the NCCMH for rigorous scientific review and achieving professional consensus.

A key objective of this report is for all clinicians likely to encounter such patients, from primary through to intensive care to have practical tools at their fingertips to guide care in an emergency. Perhaps more importantly however, the report highlights the need for all services to be prepared for such emergencies and to anticipate the challenges our health care structures can create for people with simultaneous mental and physical health care needs. Commissioners and managers are as much the intended audience for this report as clinicians themselves.

The challenge for all reports is to make sure they result in better care. The NHS, General Medical Council and Academy of Medical Royal Colleges are already deeply embedded in development of training, clinical audit and quality improvement initiatives to improve the care of patients with eating disorders. The contents of this report form the basis of a core element of that work, namely competence in management of medical emergencies in eating disorders, across all ages, all types of eating disorders and all health care settings. Our hope is that all the stakeholder organisations involved in its development will also support dissemination of its contents.

Dr Adrian James, President of the Royal College of Psychiatrists and Professor Tim Kendall, National Clinical Director for Mental Health, NHS England

Executive summary and recommendations

Eating disorders are common and affect people irrespective of age, ethnicity, social class and geography. They can arise in all settings, from major cities to remote and rural areas, including locations that do not have formal eating disorder services (EDSs). During the COVID-19 pandemic, many people found they could carry out their work remotely, including delivery of many types of mental health care. This approach may have helped people who live in places with little access to specialised treatment,¹ but remote consultation restricts physical monitoring and presents challenges compared with in-person treatment.^{2,3,4} Referrals to children and young people's community EDSs in England increased significantly during the pandemic, and paediatricians reported large increases in admissions of young people with restrictive eating disorders,⁵ reflecting increased acuity of cases. National data for adults are not so readily available, but what data there are tell a similar story.⁶ This paints an alarming picture in which all clinicians are increasingly likely to encounter patients with eating disorders in their daily practice.

The aim of this guidance is to make preventable deaths due to eating disorders a thing of the past. It is not a comprehensive textbook on eating disorders; rather, it addresses eating disorder presentations likely to lead the patient to an emergency department or a medical/paediatric ward. The emphasis is on medical management, meaning both physical and psychiatric care. The working group that produced this guidance is the fourth group to address these issues, which succeeds the Management of Really Sick Patients with Anorexia Nervosa (MARSIPAN) and Junior MARSIPAN guidance.

The project first arose out of concerns that patients with severe anorexia nervosa⁷ were being admitted to general medical units and, in some cases, deteriorating and dying. Reasons for this included non-adherence

¹ <u>http://www.imj.ie/wp-content/uploads/2021/01/Eating-Disorders-During-the-COVID-19-Pandemic.pdf</u> ² <u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7323318/</u>

³ https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7550882/

⁴ <u>https://onlinelibrary.wiley.com/doi/full/10.1002/eat.23289</u>

⁵ https://www.rcpch.ac.uk/news-events/news/paediatricians-warn-parents-be-alert-signs-eating-

disorders-over-holidays ⁶ https://pubmed.ncbi.nlm.nih.gov/34486966/

⁷ ICD-11 definitions of eating disorders (anorexia nervosa, avoidant/restrictive food intake disorder [ARFID], binge eating disorder and bulimia nervosa) are given in the <u>Glossary</u>, along with abbreviations used in this guidance.

to nutritional treatment, and complications of treatment, such as refeeding syndrome, as well as underfeeding.

In this guidance, we have:

- reviewed and synthesised the evidence on which the guidance is based, including a comparison with international guidance on medical management in eating disorders
- provided advice on the assessment and management of all eating disorders that can lead patients to present as a clinical emergency
- provided an eating disorders risk assessment tool (<u>Table 1</u>) using the 'traffic light' approach that can be applied to all ages
- developed a series of summary sheets (Annexe 1) written for the different target clinical groups (including physicians, psychiatrists, dietitians, GPs and nurses, as well as people with eating disorders, families and managers). These are intended to be quick reference guides that also signpost to key areas in the main guidance
- updated practice guidance on the physical, nutritional and psychiatric management of patients with severe eating disorders in medical units, including the appropriate use of mental health legislation
- provided advice for commissioners on required services for this group of very ill patients

Recommendations

- Medical and psychiatric ward staff need to be aware that patients with eating disorders being admitted to a medical or paediatric ward may be at high risk despite appearing well and having normal blood parameters. (EB+C⁸)
- 2. The role of the primary care team is to monitor patients with eating disorders, refer them early and provide monitoring after discharge, in collaboration with medical services and EDSs (including community EDSs). Eating disorders are covered, in England, by the term severe mental illness⁹ and physical checks in primary care should be performed,¹⁰ even if under specialist outpatient care. Patients with eating disorders not presenting in an emergency may nevertheless require urgent referral. (C)
- 3. Physical risk assessment in primary and secondary settings should include nutritional status (including current intake), disordered eating behaviours, physical examination, blood tests and electrocardiography. (EB+C)
- Assessment measures (such as body mass index [BMI] or blood pressure [BP]) for patients under 18 years must be age-adjusted. (EB)
- 5. Where specialist eating disorder unit (SEDU) beds are not available, general psychiatric units should be supported to provide specialist eating disorder care. This will require input from liaison psychiatry and EDSs, so that patients can be transferred safely without delay when discharge from a medical bed is appropriate. (C)
- 6. Patients who require admission to medical or paediatric wards should be treated by a team with experience of treating eating disorders and involving their carers, using protocols developed in collaboration with eating disorder specialists, and having staff trained to implement them. (EB+C)
- 7. The inpatient team on the medical/paediatric unit should include (at least) a lead physician/paediatrician, a dietitian with specialist knowledge of eating disorders and a lead nurse. An eating disorders or liaison psychiatry service should provide sufficient support and training to medical/paediatric wards to allow them to manage

⁹ www.birmingham.ac.uk/Documents/college-mds/haps/projects/HCNA/HCNAVol2chap13sh6L.pdf

⁸These letters indicate whether the recommendation was formed from the evidence base (EB) or by consensus of the Expert Reference Group (C), or both.

¹⁰ <u>https://www.england.nhs.uk/statistics/statistical-work-areas/serious-mental-illness-smi/</u>

eating disorder patients. Around this core team for each individual patient, key professionals should be added who are involved with or knowledgeable about a patient and their illnesses, needs and community care plans (e.g. nurses, therapists or psychiatrists from EDSs or community mental health teams, or diabetes team professionals), forming a multi-agency group to guide the admission and subsequent care. (C)

- 8. Responsibilities of the inpatient teams are:
 - Medical team:
 - safely refeed the patient
 - o avoid refeeding syndrome caused by too rapid refeeding
 - avoid underfeeding syndrome caused by too cautious refeeding
 - manage fluid and electrolyte problems, often caused by purging behaviours
 - arrange discharge, in agreement with the mental health team and commissioners, to eating disorders community care or intensive treatment (e.g. day care or specialist inpatient care) as soon as possible once such treatment is safe and indicated
 - for patients with complex mental health problems, consult with psychiatric experts to decide on further management.
 - Mental health team:
 - manage, in collaboration with the medical team, the behavioural problems common in patients with eating disorders
 - occasionally assess and treat patients under compulsion using relevant mental health legislation
 - address family concerns and involve both patients and their families in discussions about treatment
 - advise on appropriate onward care following medical stabilisation. (C)
- 9. Health commissioners (clinical commissioning groups and national commissioners) should:
 - be aware of the local provision for severely ill patients with eating disorders
 - ensure that robust plans are in place, including adequately trained and resourced medical, nursing and dietetic staff on the acute services, and specialist eating disorders staff in mental health services

- support the establishment of intensive community treatment, including outpatient and day patient services for both young people and adults. (C)
- 10. Job plans for consultants in eating disorders and liaison psychiatry should allow a session for training professionals in paediatric and medical wards. (C)
- 11. Units treating patients with eating disorders join peer review networks and participate in audit and quality improvement activity. (C)
- 12. Knowledge and training about the content of this guidance should be required for all frontline staff. (C)

1. Introduction

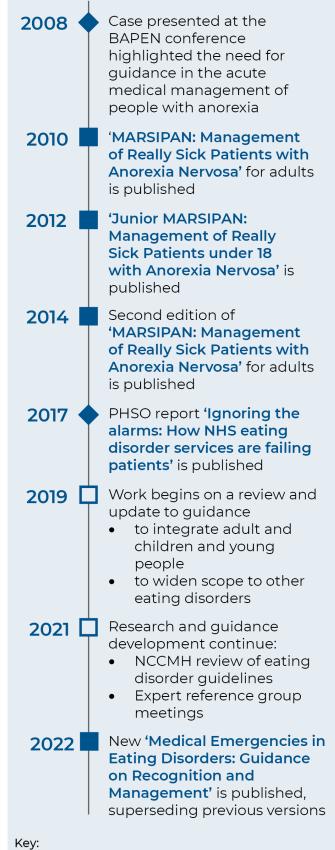
a. History of the project

This project began in 2008 when the very tragic case of a young woman with anorexia nervosa, who died in a medical ward, was presented at an annual British Association for Parenteral and Enteral Nutrition (BAPEN) conference. It was clear that the medical team involved did not have the close support of eating disorder specialists. Following the presentation at the conference, a psychiatrist (Paul Robinson) and a physician (Tim Bowling) met and decided to try and improve that unsatisfactory situation. A large number of physicians and psychiatrists, and a smaller number of other people including a GP. a pharmacist, dietitians, a psychologist, self-help professionals and carers, were then invited to collaborate in the production of the first guidance in 2010. A revision of the adult version was published in 2014. A separate 'Junior' version of the guidance (led by Dasha Nicholls) was successful in its aim of reaching and engaging paediatricians in the care of children and adolescents¹¹ with eating disorders in acute settings.

b. What has happened since?

i. Has the guidance been taken up?

In 2018, a national survey of MARSIPAN guidance utilisation by professionals (see <u>Annexe 2</u>) was sent to 562 clinicians across the UK, of which 214 (38%) responded. The aim was to assess awareness among non-eating disorder specialists in acute hospital settings. The response rate for



BAPEN = British Association for Parenteral and Enteral Nutrition NCCMH = National Collaborating Centre for Mental Health PHSO = Parliamentary and Health Service Ombudsman professional groups differed: adult physician/gastroenterologists 23%, paediatricians 37%, adult EDS clinicians 56%, and CAMHS eating disorder clinicians 65%. Of the clinicians who responded, 92.5% (n=198) had heard of MARSIPAN and 96.5% (n=192) used Junior or Adult MARSIPAN guidance in their workplace.

The guidance has reached academic and public awareness in the UK and beyond, including reference in the NICE guideline on eating disorders.¹² A book, *Critical Care for Anorexia Nervosa*, co-edited by Robinson and Nicholls, was published in 2015¹³ and had over 11,000 chapter downloads by November 2021.

A Junior MARSIPAN app for Android and iOS¹⁴ has been widely used among clinicians. An all-age app is being developed to accompany this edition of the guidance.

ii. Is there evidence that problems continue?

In 2017, the Parliamentary Health Services Ombudsman (PHSO) produced a hardhitting report entitled 'Ignoring the alarms: How NHS EDSs are failing patients'.In the PHSO report, three tragic cases are reviewed. One of these is that of 19-year-old Averil Hart. Averil developed anorexia nervosa, for which she was treated as an inpatient in a specialist eating disorders service. After discharge in 2012, she went to university, which she had been very keen to do. In Averil's first term, her anorexia nervosa worsened and she was treated in a local eating disorders service. Sadly, she continued to deteriorate and lose weight. She was discovered by her cleaner very unwell, and an ambulance was called. Averil was admitted to a medical ward where she continued to lose weight and she was transferred to another medical unit where she died, having had severe hypoglycaemia.¹⁵ The Ombudsman's comment was:

We found that all the NHS organisations involved in Averil's care and treatment between her discharge from hospital on 2 August 2012 and her tragic death five months later on 15 December failed her in some way. We found her deterioration and death were avoidable."

The PHSO recommended the following:

- 1. The General Medical Council should conduct a review of training for all junior doctors on eating disorders to improve understanding of these complex mental health conditions.
- 2. Health Education England should review how its current education and training can address the gaps in provision of eating disorder specialists. If necessary, Health Education England should consider how the existing workforce can be further trained and used more innovatively to improve

¹¹The World Health Organization (WHO) defines 'adolescents' as individuals in the 10–19 years age group' and young people as the 15–24 years age group. We use have used 'child' to mean ages 12 and under.

¹² http://www.nice.org.uk/guidance/ng69

¹³ <u>https://www.springer.com/gp/book/9783319081731</u>

¹⁴ <u>http://www.marsipan.org.uk/</u>

¹⁵ https://www.judiciary.uk/wp-content/uploads/2021/03/Averil-Hart-2021-0058-Redacted.pdf

capacity. It should also look at how future workforce planning might support the increased provision of specialists in this field.

- **3.** The Department of Health and National Health Service (NHS) England should review the existing quality and availability of adult EDSs to achieve parity with child and adolescent services.
- 4. The National Institute for Clinical Excellence (NICE) should consider including coordination in its new Quality Standard for eating disorders to help bring about urgent improvements in this area.
- 5. Both NHS Improvement and NHS England and equivalent organisations in other UK countries have a leadership role to play in supporting local NHS providers and commissioners to conduct and learn from serious incident investigations. They should use the forthcoming Serious Incident Framework review to clarify their respective oversight roles in relation to serious incident investigations. They should also set out what their role would be in circumstances where local NHS organisations are failing to work together to establish what has happened and why, so that lessons can be learnt.

A working group was established to address these recommendations, led by NHS England and with participation of arm's length bodies including the Royal College of Psychiatrists, reporting to the PHSO.¹⁶ Meanwhile other coroner's inquests into deaths from anorexia nervosa have taken place, and headlines such as 'Eating disorders: 12 deaths in seven years led to coroner warnings'¹⁷ continue to appear.

Anorexia nervosa is known to be a potentially fatal disease, with a high standardised mortality ratio,¹⁸ particularly if comorbidity is present. Not all deaths are avoidable, but our view is that psychiatric and medical services for patients with eating disorders must do more to improve the care that severely ill patients receive so that patients such as Averil Hart can be successfully treated. We therefore strongly endorse all of the PHSO's recommendations, and with it the acknowledgement that all eating disorders, not solely anorexia nervosa, can result in high, and often preventable, mortality.

iii. This revision

This updated version of the guidance is significantly different from previous versions, having undergone a number of major changes with the purpose of improving its clinical and scientific value, including reach of the guidance. The guidance is across the age range and the evidence base for recommendations, when available, is clear. Nonetheless, too many of the recommendations are based on expert opinion rather than empirical research and further research is needed.

¹⁶<u>https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/824522/pa</u> <u>cac-inquiry-into-eating-disorders-government-response-print-ready.pdf</u>

¹⁷ <u>https://www.theguardian.com/society/2020/jan/19/eating-disorders-12-deaths-in-seven-years-led-to-coroner-warnings</u>

¹⁸ <u>https://pubmed.ncbi.nlm.nih.gov/21727255/</u>

1. Contributors

The Royal College of Psychiatrists (RCPsych) commissioned the NCCMH¹⁹, based on their experience of producing NICE guidelines, to work with the team. The project group comprised nine members: three clinicians (Dasha Nicholls, Chair; Paul Robinson, Clinical Advisor; Agnes Ayton, Eating Disorders Faculty Chair) and six NCCMH team members. An Expert Reference Group (ERG) was established, comprising professional leads from among the guidance authorship and three patient representatives/experts by experience. A consultation group with 34 further members mainly comprised clinicians, with two commissioners and the chief executive of Beat, the UK eating disorder charity. Most members of the consultation group were nominated by their professional organisation, and the experts by experience were nominated by RCPsych. See the <u>list of contributors</u> for full details.

2. Scope

While anorexia nervosa was the main focus of MARSIPAN, as prompted by the initial cases, other eating disorders can also be very dangerous.

In this updated guidance, more emphasis has been placed on the risks posed by other eating disorders, including bulimia nervosa (which results in an estimated 22 deaths per year in the UK⁶), avoidant restrictive food intake disorder (ARFID, which carries risks due to weight loss and nutritional deficiencies) and binge eating disorder (which also has significant dangers, although data on mortality are sparse). There is also a significant risk of suicidal thoughts and self-harm in eating disorders, with one in five deaths of people with anorexia nervosa being due to suicide²⁰, and very high rates of self-harm and comorbid depression across eating disorder diagnoses, including 'other specific feeding and eating disorders' (OSFED) and 'unspecified feeding or eating disorders' (UFED) in which people have key symptoms of an eating disorder but do not meet full diagnostic criteria, such as purging disorder. A supplement on eating disorders and type 1 diabetes mellitus accompanies this guidance (see Annexe 3). Scientific knowledge about the risks posed by dietary restriction when BMI is normal or high is limited, although there are anecdotal accounts of, for example, severe malnutrition that can develop after bariatric surgery for obesity.²¹ Moreover, serious medical consequences can arise for people with ARFID who are within the normal weight range²² as well as at low weight.

In this guidance, discussion of feeding and eating disorders, including ARFID, will be restricted to circumstances in which a medical emergency can be expected. We have used the term 'restrictive disorder' to refer to anorexia nervosa and ARFID, as well as some atypical eating disorders defined by the terms OSFED and UFED. In the absence of research, risks in atypical eating disorders should be based on symptoms, such as purging behaviour, low weight or self-harm.

¹⁹ https://www.rcpsych.ac.uk/improving-care/nccmh

²⁰ <u>https://pubmed.ncbi.nlm.nih.gov/21727255/</u>

²¹ https://pubmed.ncbi.nlm.nih.gov/23192683/

Who this guidance is for

The guidance is primarily designed to support all clinicians likely to encounter patients with severe eating disorders, such as:

- Medical doctors (including trainees):
 - general practitioners
 - emergency and acute physicians
 - paediatricians
 - psychiatrists (including liaison psychiatrists)
- Allied healthcare professionals:
 - emergency department staff
 - dietitians
 - general and mental health nurses
 - physiotherapists
 - psychologists and therapists
- It also offers value to other professions and groups, including:
- managers and commissioners coordinating care
- people with eating disorders
- relatives and carers of people with eating disorders.

<u>Annexe 1</u> contains a summary sheet of advice for each of these groups.

Guidance for all ages

For this revision, the decision was made to combine the adult and child and adolescent versions into guidance for all ages, to reduce confusion around transition ages and redress potential disparities in approach. Each chapter starts with issues that affect all ages, then issues affecting under-18s mainly, and, lastly, issues affecting over-18s mainly. In fact, most issues affect all ages. The risk assessment framework first developed in the Junior MARSIPAN guidance has been developed into an all-age framework (Table 1).

MARSIPAN

The acronym MARSIPAN has been dropped from the title following feedback by patient and carer groups, and to capture the changed scope of medical risk for all eating disorders, not only anorexia nervosa. The focus on medical emergencies is reflected in the new title:

Medical Emergencies in Eating Disorders: Guidance on Recognition and Management.

Rather than a bibliography at the end of the document, hyperlinks to cited sources are provided in footnotes so that they can be accessed directly.

3. Method

Development of this guidance was led from within the RCPsych Eating Disorders Faculty. It included authors of the previous edition of the guidance and other clinicians known to actively contribute to the field, representing the professional groups most likely to encounter a patient in a medical setting.

The authorship was divided into teams with a lead, each team drafting a chapter. Drafts were then reviewed by Paul Robinson and Dasha Nicholls for further editing and combined into draft guidance. The resulting draft was then reviewed by the NCCMH team and Agnes Ayton representing the Faculty of Eating Disorders prior to circulation to the ERG. Comments and suggestions were either incorporated in the draft or referred to the ERG for discussion. The guidance was then circulated to the full authorship for comment, reviewed again by the project team, and matters where consensus was needed were taken to the ERG for discussion.

The Royal College of Psychiatrists will review this guidance in 2025, to ensure it remains current, as per their framework for guidelines.

Stakeholder consultation

The draft documents were circulated to stakeholder organisations that had been identified by the authorship and those who registered interest in commenting on the guidance. The public stakeholder consultation ran for 2 months from August to October 2021. Comments on the draft guidance and supporting documents were received from stakeholder organisations, a list of which can be found in <u>Appendix 1</u>. Stakeholder comments were reviewed by the project group, consulting the ERG where necessary, and incorporated into the guidance as appropriate to produce the final report. The documents were amended based on the consultation feedback and all comments were responded to. The consultation process was based on that of NICE.

Forming the recommendations

In developing the guidance, the NCCMH used processes that they had previously used for the development of NICE mental health clinical guidelines. Where possible, recommendations (found in the <u>Executive summary and recommendations</u>) were based on the evidence that was reviewed. Where conclusive high-quality research evidence was not available, informal consensus was used to develop recommendations. Informal consensus was reached through discussion with the Expert Reference Group, drawing on members expert knowledge and experience, and incorporating the feedback from the stakeholder consultation. Where consensus was not immediately possible, additional expertise was sought (for example, a cardiologist was consulted regarding aspects of ECG findings). In all cases, additional information enabled consensus to be reached.

NCCMH involvement

The NCCMH contributed to the development and validation of the guidance in four main areas.

- 1. Research and development tasks, including:
 - a. Reviewing the guidance and the quality of the systematic reviews already included
 - **b.** Where there was uncertainty in the evidence, carrying out additional research including systematic reviews

- 2. Project management support, including:
 - a. Convening the ERG and organising ERG meetings
 - b. Establishing and delivering a timeline for completion of the guidance
 - c. Communicating and coordinating processes required to complete the guidance
- 3. Supported the stakeholder engagement and endorsement process by:
 - a. Coordinating and delivering the engagement and consultation process to ensure endorsement from relevant organisations and wider stakeholders
 - **b.** Carrying out consultation on the guidance, collating comments and feedback, and supporting the main authors to address comments
 - c. Ensuring that the guidance met standards for sign-off/endorsement from relevant organisations
- **4.** Undertaking editing tasks and providing support to deliver the final guidance by:
 - **a.** Providing editorial support to the main authors to improve readability, functionality, and accessibility of the guidance for the target audience
 - b. Providing infographics and design elements.

The additional research that the NCCMH carried out included:

- A comparison of the assessment and determination of risk of serious complications in current evidence-based guidelines for eating disorders: A systematic review.
- A review of patients' experiences and perceptions of compulsory treatment for eating disorders: Results of a scoping search
- A review of a systematic review looking at differences in clinical outcomes for those who experience compulsory treatment for eating disorder and those who do not.

A summary of these evidence reviews can be found in <u>Appendix 2</u>. The body of evidence supporting this guidance is limited. Consequently, as in the NICE guidance on eating disorders, many of the recommendations are based on expert consensus. Where evidence is available, this is made explicit.

4. Improving reach of the guidance

This guidance is intended for all clinicians with patients with eating disorders who need urgent attention but needs to be useful for doctors in the emergency department, physicians on medical wards and other stakeholders whose patients need urgent attention.

Two-page (single sheet) advice aimed at various professional groups, including physicians and paediatricians, emergency staff, general practitioners, nurses, other ward staff, psychiatrists, patients and relatives (see <u>Annexe 1</u>) has been included for quick reference. There is also a checklist for frontline staff (<u>Appendix 3</u>). The

information in this document can also be found on websites, in apps and in training materials.

Experts in primary care, mental health, eating disorders, acute and emergency medicine/paediatrics, and dietetics need to work together with the patient and family so that each of their skills is optimally utilised. The GP or school-based health staff may be the first professional to see and assess the patient. They play a critical role in engaging the patient, initiating treatment and referring for specialist care. Specialist EDS multidisciplinary teams include experts on eating-disordered pathology (physical medical state, mental state, nutritional status and needs, thresholds for compulsory admission, capacity and insight, social and psychological factors influencing the expression of eating-disordered behaviours and their required nursing). With time and training, each professional can enhance their knowledge and skills in other areas, and regular multidisciplinary meeting can greatly enhance mutual learning.

The emergency situation is the remit of the present guidance. A brief and useful guide to medical management of eating disorders published by the Academy for Eating Disorders^{23,} goes beyond the emergency situation covered in this guidance.

²³ https://www.aedweb.org/publications/medical-care-standards

2. Risk assessment: evaluating the impending risk to life due to the patient's illness

a. Introduction

Eating disorders can present with life-threatening emergencies often in the emergency department,²⁴ although such presentations are also seen in primary care, medical and paediatric wards, and mental health treatment settings. Most medical problems arise from undernutrition and/or compensatory behaviours, such as bingeing, purging, and other associated behaviours. Presentations may be triggered by concerns from parents/carers, or from schools/universities or employers, and adequate support must be given to those caring for people in non-medical settings.

In primary care, in-person consultation may be necessary for patients presenting with eating disorder symptoms in order to complete a risk assessment.

See <u>Appendix 3</u> for an eating disorder risk checklist for emergencies.

i. Balancing risks

Risk assessment in eating disorders is multidimensional; the clinician must balance risks in physical, psychological and social domains while paying attention to matters of insight, motivation, consent and the legal framework for intervention. Some challenges to accurate and meaningful risk assessment have been listed in <u>Box 1</u>. Parent/carer accounts of risk behaviours as well as their ability to manage their child's/loved one's eating disorder are key elements of risk assessment. We advise that the risk assessment should be used to inform rather than dictate clinical management.

Note:

In this guidance, you will see that some text has been shaded with different colours. This is to highlight the ages that are being discussed.

Children and/or young people

Adults

ii. Risk in different populations

Weight loss in **children and adolescents** is often more acute than in adults, due to lower body fat stores, thus medical compromise occurs relatively frequently, and typical features (e.g. amenorrhoea) may not be present. Working with children and young people and their parents/carers during paediatric admissions to plan, with the community EDS and primary care team, for care on discharge is vital (see <u>Chapter 3</u>).

Adults with more long-standing eating disorders may run higher levels of risk and reach care later and can thus be very unwell on admission with severely depleted intracellular electrolyte levels, such as potassium, that are not reflected in serum levels. Thus, caution is advised, regardless of blood parameters. Patients with bulimia

²⁴ Also known as an accident and emergency department (A&E).

nervosa can present with severe electrolyte disturbances, and gastrointestinal complications, even when at a normal weight or overweight.

Males should be asked specifically about excess training and exercise and misuse of anabolic or androgenic steroids. Males and some females who overtrain may have extremely low body fat levels and larger than average muscles. Use of anabolic steroids and Vitamin D injections can lead to increased physical risk at higher levels of BMI (and age-adjusted BMI) than those quoted.²⁵

Box 1: Potential challenges to accurate risk assessment

• Patients can appear well and this can falsely reassure the clinician



- Consider parent/carer information when assessing risk
- Patients may have an extremely powerful drive to exercise (including microexercise, discussed in <u>Chapter 6.b</u>) that can override their lack of nutritional reserve, so that they appear very energetic right up to a physical collapse. Increased rather than reduced energy and activity levels is one of the features that distinguishes anorexia nervosa from starvation syndrome.²⁶
- Suicidal ideation is common in people with eating disorders. Suicide accounts for the cause of death for 20% of all deaths among adults with anorexia nervosa. Among both young people and adults with bulimia nervosa, and binge eating disorder, the risk of self-harm and suicide is increased.²⁷
- Blood parameters that fall within laboratory reference ranges are frequently seen in advanced uncomplicated malnutrition and should not be taken as cause for reassurance.
- Do not reassure the patient that their risk is low. That will compound the dismissive nature of their eating disorder cognitions and increase perception that change is not necessary. Emphasise the severity of the problem and the lack of precision in risk assessment while making sure to conduct the necessary physiological and psychological examinations.
- Due to the nature of eating disorder cognitions and associated distress, a patient's fear of weight restoration may limit their capacity to provide an accurate account of their presentation. This can falsely reassure the clinician about the assessment of risk.

²⁵ https://pubmed.ncbi.nlm.nih.gov/31585781/

²⁶ <u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6265370/</u>

²⁷ https://pubmed.ncbi.nlm.nih.gov/25070478/

b. An all-age risk assessment framework for assessing impending risk to life

There have been several attempts to produce a physical risk assessment schedule, which in the UK include the first NICE guideline on eating disorders (2004) and the Royal College of Psychiatrists guideline on nutrition in anorexia nervosa (2005). The most recent NICE guideline on eating disorders advocated the use of MARSIPAN and Junior MARSIPAN guidance to assess risk.²⁸

The all-age risk assessment framework below (<u>Table 1</u>) has been adapted from the framework in Junior MARSIPAN, which has been adopted and used extensively since its publication.

The risk assessment framework combines clinical assessment with investigations, assessment of motivation and engagement with treatment plans, and particularly for younger patients, assessment of parent/carer support. It can help clinicians determine the risk of serious complications to a patient of any age, including serious illness (acute pancreatitis or gastrointestinal rupture) or death (from suicide, sudden death, infection or cardiovascular complications²⁹), as well risk for refeeding complications.

Each domain in <u>Table 1</u> is rated with a traffic light system, indicating the risk to life. Green indicates low impending risk to life, F indicates for the clinician to be alert to high concern for impending risk to life, and red indicates high impending risk to life. It is important to note that patients with bulimia nervosa who are not underweight can also present in life-threatening emergencies, due to electrolyte disturbances, and gastrointestinal complications.

The framework is intended to guide level of concern and requires clinical judgement for its interpretation. Nonetheless, it is based on the best available evidence and international consensus guidance, where available (see <u>Appendix 2</u>). No single parameter is, in and of itself, an adequate indicator of overall level of risk or illness. Moreover a 'red' score in one realm (e.g. electrolytes) may not be equivalent to a 'red' score in another area (e.g. temperature). The traffic light system is more useful for comparing within rather than between domains. Detailed advice on diagnosis and treatment of eating disorders in acute settings is available if needed.^{30,31}

The risk assessment tool is designed to aid decisions on emergency management, such as admission for monitoring and refeeding. If any items score 'amber' or 'red', please consult <u>Table 2</u>, which contains guidance on management of clinical findings, for advice on what to measure, what to look for, when to be concerned and what to do. However, decisions always depend on clinical judgement; the risk assessment framework should only be an aid in that process. All patients with eating disorders should be offered NICE approved psychological treatment at the earliest opportunity.

²⁸ <u>https://www.nice.org.uk/guidance/ng69 para 1.11.3</u>

²⁹ https://pubmed.ncbi.nlm.nih.gov/30173377/

³⁰ https://www.amazon.co.uk/Multidisciplinary-Management-Eating-Disorders-Morris/dp/3319641301

³¹ https://www.springer.com/gp/book/9783319081731

<u>Appendix 3</u> contains an eating disorder checklist for frontline staff to use in emergencies.

It is important to note that risk parameters for adults cannot be applied to children and young people without adjustment for age and gender.

This is a guide to risk assessment and cannot replace proper clinical evaluation. However, a patient with one or more red ratings or two or more amber ratings should probably be considered high risk.

Table 1: Risk assessment framework for assessing impending risk to life

| | Red: High impending risk to life | Amber: Alert to high concern for impending risk to life | Green: Low impending risk to life |
|-------------------|---|--|--|
| Medical history | and examination | | |
| Weight loss | Recent loss of weight of ≥1kg/week for 2 weeks (consecutive) in an undernourished patient ³² Rapid weight loss at any weight, e.g. in obesity or ARFID | Recent loss of weight of 500–999g/week for 2 consecutive weeks in an undernourished patient ¹²⁶ | Recent weight loss of <500g/week or fluctuating weight |
| BMI and weight | Under 18 years: %mBMI³³ <70% Over 18: BMI <13 | Under 18: %m BMI 70-80% Over 18: BMI 13-14.9 | Under 18: %mBMI >80%³⁴ Over 18: BMI >15 |
| HR (awake) | <40 | 40–50 | >50 |

³² Patients losing weight at higher BMI should be assessed for other signs of medical instability and weight loss strategies to determine risk.

³³ Also known as weight for height percentage. %mBMI is calculated by: current BMI divided by BMI on the 50th centile for age and gender, multiplied by 100.

³⁴ Note these do not denote a healthy weight but rather a weight above which other parameters in this risk framework may better reflect risk.

| | Red: High impending risk to life | Amber: Alert to high concern for impending risk to life | Green: Low impending risk to life |
|---|---|---|---|
| Cardio- vascular health ^{35 36} | Standing systolic BP below 0.4th centile for age or less than 90 if 18+, associated with recurrent syncope and postural drop in systolic BP of >20mmHg or increase in HR of over 30bpm (35bpm in <16 years) | Standing systolic BP <0.4th centile or <90 if 18+ associated with occasional syncope; postural drop in systolic BP of >15mmHg or increase in HR of up to 30bpm (35bpm in <16 years) | Normal standing systolic BP for age and gender with reference to centile charts Normal orthostatic cardiovascular changes Normal heart rhythm |
| Assessment of hydration status | Fluid refusal Severe dehydration (10%): reduced urine output, dry mouth, postural BP drop (see above), decreased skin turgor, sunken eyes, tachypnoea, tachycardia | Severe fluid restriction Moderate dehydration (5–10%): reduced urine output, dry mouth, postural BP drop (see above), normal skin turgor, some tachypnoea, some tachycardia, peripheral oedema | Minimal fluid restriction No more than mild dehydration (<5%): may have dry mouth or concerns about risk of dehydration with negative fluid balance |
| Temperature | <35.5°C tympanic or 35.0°C axillary | <36°C | >36°C |
| Muscular function ³⁷ : SUSS Test | Unable to sit up from lying flat, or to get up from squat at all or only by using upper limbs to help (Score 0 or 1) | Unable to sit up or stand from squat without noticeable difficulty (Score 2) | Able to sit up from lying flat and stand from squat with no difficulty (Score 3) |

- ³⁵ <u>https://pubmed.ncbi.nlm.nih.gov/24067349/</u>
 ³⁶ <u>https://www.nhlbi.nih.gov/files/docs/guidelines/child_tbl.pdf</u>
 ³⁷ No muscle function test has been researched in patients <18 years.

2. Risk assessment: evaluating the impending risk to life due to the patient's illness

| | Red: High impending risk to life | Amber: Alert to high concern for impending risk to life | Green: Low impending risk to life |
|--|---|---|---|
| Muscular function: Hand grip strength ³⁸ | Male <30.5kg, Female <17.5kg (3rd percentile) | Male <38kg, Female <23kg (5th percentile) | Male >38kg, Female >23kg |
| Muscular function: MUAC ³⁹ | <18cm (approx. BMI<13) | 18–20cm (approx. BMI<15.5) | >20cm (approx. BMI >15.5) |
| Other clinical state | Life-threatening medical condition, e.g. severe haematemesis, acute confusion, severe cognitive slowing, diabetic ketoacidosis, upper gastrointestinal perforation, significant alcohol consumption | Non-life-threatening physical compromise, e.g. mild haematemesis, pressure sores | Evidence of physical compromise, e.g. poor cognitive flexibility, poor concentration |
| ECG abnormalities | <18 years: QTc >460ms (female), 450ms (male) 18+ years: QTc >450ms (females), 430ms (males) Or any other significant ECG abnormality | <18 years: QTc >460ms (female), 450ms (male) 18+ years: QTc >450ms (females), >430ms (males). And no other ECG anomaly Taking medication known to prolong QTc interval | <18 years: QTc <460ms (female), 450ms (male) 18+ years: QTc <450ms (females), <430ms (males) |

³⁸ <u>https://pubmed.ncbi.nlm.nih.gov/19129352/</u>
 ³⁹ <u>https://pubmed.ncbi.nlm.nih.gov/12765671/</u>

| | Red: High impending risk to life | Amber: Alert to high concern for impending risk to life | Green: Low impending risk to life |
|---|---|--|---|
| Biochemical abnormalities ⁴⁰ | Hypophosphataemi a and falling phosphate Hypokalaemia (<2.5mmol/L) Hypoalbuminaemia Hypoglycaemia (<3mmol/L) Hyponatraemia Hypocalcaemia Transaminases >3x normal range Inpatients with diabetes mellitus: HbA1C >10% (86mmol/mol) | | |
| Haematology | Low white cell count Haemoglobin <10g/L | | |
| Disordered eating behaviours | Acute food refusal or estimated calorie intake <500kcal/day for 2+ days | | |

⁴⁰ <u>https://www.rcpch.ac.uk/sites/default/files/rcpch/HTWQ/Reference%20ranges%20Jan%2018.pdf</u>

2. Risk assessment: evaluating the impending risk to life due to the patient's illness

| | Red: High impending risk to life | Amber: Alert to high concern for impending risk to life | Green: Low impending risk to life |
|--|--|---|---|
| Engagement with management plan | Physical struggles with staff or parents/carers over nutrition or reduction of exercise Harm to self Poor insight or motivation Fear leading to resistance to weight gain Staff or parents/carers unable to implement meal plan prescribed | Poor insight or motivation Resistance to weight gain Staff or parents/carers unable to implement meal plan prescribed Some insight and motivation to tackle eating problems Fear leading to some ambivalence but not actively resisting | Some insight and motivation to tackle eating problems May be ambivalent but not actively resisting |
| Activity and exercise | High levels of dysfunctional exercise in the context of malnutrition (>2h/day) | Moderate levels of dysfunctional exercise in the context of malnutrition (>1h/day) | Mild levels of or no dysfunctional exercise in the context of malnutrition (<1h/day) |
| Purging behaviours | Multiple daily episodes of vomiting and/or laxative abuse | Regular (=>3x per week) vomiting and/or laxative abuse | |
| Self-harm and suicide | Self-poisoning, suicidal ideas with moderate to high risk of completed suicide | Cutting or similar behaviours, suicidal ideas with low risk of completed suicide | |

Key:

°C = degrees Celsius; ARFID = avoidant restrictive food intake disorder; BMI = body mass index; BP = blood pressure; bpm = beats per minute; cm = centimetre; ECG = electrocardiogram; g = grams; h = hour; HR = heart rate; kcal = kilocalories; kg = kilogram; L = litre; mmHg = millimetres of mercury; mmol = millimole; mol = mole; ms = millisecond; QTc = corrected QT interval; SUSS Test = Sit Up-Stand–Squat Test.

c. Differential diagnosis

Eating disorders can present challenges in recognition and diagnosis, in part because consultant psychiatrists, physicians, paediatricians and other health care professionals have limited training and expertise in the field.⁴¹ Almost all the parameters outlined in the risk assessment framework have multiple aetiologies, and there is a need to consider and exclude potential organic causes. For example, the haematological changes commonly found in anorexia nervosa can be found in primary haematological conditions such as leukaemia and lymphoma, and can present with pancytopaenia and weight loss, as can infection that is either acute (e.g. sepsis) or chronic (e.g. tuberculosis).

i. Principles of differential diagnosis and eating disorders

A few principles may be helpful here. First, eating disorders are relatively common, whereas most of the syndromes that might otherwise account for these findings are not. Second, delay in diagnosis and treatment could lead to a continued weight loss, which would increase risk and so should not divert the physician's attention from the need to provide nutrition. It may be helpful to distinguish between baseline screening investigation to exclude organic cause/comorbidity and assessing and monitoring risks. For example, raised liver enzymes occur regularly in patients with severe malnutrition, probably as a result of hepatocellular autophagy.⁴² Abnormal transaminase levels may be found during acute starvation⁴³ as well as refeeding.⁴⁴ Liver enzymes should be monitored to ensure that they decrease as nutrition is provided, and should only be investigated if they persist despite weight restoration – in which case an acute liver disease screen should include a viral hepatitis screen.

All patients should have a history taken and a thorough clinical examination with basic tests (e.g. TTg IgA for coeliac disease, blood film, CRP⁴⁵) and more involved tests if necessary. When the diagnosis is uncertain, offering food can elicit calorie-avoiding behaviour in those with a drive for thinness and fear of weight gain. Some patients may present with concurrent eating disorders and other pathology; these are complex patients to manage, and specialist advice should be sought.

It would be reasonable to refer for specialist assessment any patient in whom an eating disorder is considered as part of the differential diagnosis and to withdraw the referral if an alternative diagnosis is confirmed. Most importantly, the search for a diagnosis should never delay nutritional therapy in an undernourished patient.

⁴¹ https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6646967/

⁴² https://pubmed.ncbi.nlm.nih.gov/23280717/

⁴³<u>https://pubmed.ncbi.nlm.nih.gov/25250330/</u>

⁴⁴ https://pubmed.ncbi.nlm.nih.gov/23280717/

⁴⁵ A normal CRP (C-reactive protein) and ESR (erythrocyte sedimentation rate) suggests the absence of an inflammatory condition, and both are usually low in people with anorexia nervosa. However, for a CRP of >40mg/dL the false negative rate is around 20% and the false positive rate around 60%. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3740117/pdf/nihms337827.pdf

d. Assessing different domains of acute risk

| Check for/ measure | What to look for | When to be concerned | Specific management |
|--|--|---|---|
| HR | Bradycardia, postural tachycardia | <40bpm awake, or symptomatic postural tachycardia | Nutrition, monitor ECG |
| ECG (especially if bradycardic or any other cardiovascular system complication) | Other cause for bradycardia (e.g. heart block), arrhythmia, check QTc interval, check electrolytes, drugs | Prolonged QTc (males >450ms, females > 460ms), HR <40bpm, arrhythmia associated with malnutrition and/or electrolyte disturbances | Nutrition and correct electrolyte abnormalities, increased QTc – bed rest, discuss with cardiologist; medication for arrhythmia or bradycardia likely to be unhelpful |
| BP | See <u>Table 1, Risk</u> <u>Assessment</u> <u>Framework</u> | Systolic BP<90 or <0.4th percentile. Syncope | Nutrition and rest until postural hypotension improved; echocardiogram likely to be abnormal while malnourished |
| Hypothermia | Core temperature | <35.5°C | Nutrition, blankets, may need space blanket |
| Dehydration | Hypotension and bradycardia usually due to undernutrition | Fluid refusal, signs of dehydration | Oral rehydration solution orally or via a nasogastric tube unless there is hypovolaemia; beware of giving fluid boluses unless in hypovolaemia – cardiac compromise or hyponatraemia may occur; check |

Table 2: Guidance on management of clinical findings

| Check for/ measure | What to look for | When to be concerned | Specific management |
|--|---|--|--|
| | | | electrolytes and renal function |
| Hypovolaemia | Tachycardia or inappropriate normal HR in undernourished person, hypotension and prolonged capillary refill time | | Senior medical/paediatric review. Normal saline 10ml/kg bolus, then review. If IV fluids are used then these should usually be normal saline with added KCI, with added electrolytes, e.g. phosphate, as required; consider other factors, e.g. intercurrent sepsis, as contributors |
| Other features of severe malnutrition | Skin breakdown and/or pressure sores | | Nutrition. If skin breakdown or pressure sores present, seek specialist wound care advice. Avoid prolonged bed rest. Use special mattress and cushion. |
| Evidence of vomiting or laxative abuse | Low potassium, metabolic alkalosis or acidosis, enamel erosion, swollen parotid glands, calluses on fingers | Hypokalaemia as below, uncontrolled vomiting with risk of oesophageal and other visceral tears | Specialist nursing support and supervision to prevent vomiting |
| Hypokalaemia | Likely to be due to purging. Note: normal electrolyte level does not exclude medical compromise | <3.0mmol/L obtain medical/paediatri c opinion, consider admission and | Correction; Consider IV initially if <2.5mmol/L (oral supplements may still be vomited); Beware |

| Check for/ measure | What to look for | When to be concerned | Specific management |
|---|---|--|---|
| | | cardiac monitoring | hyperkalaemia. Monitor ECG |
| Hyponatraemia | Consider water- loading, medications, such as SSRIs, and diuretics. Check urine osmolality | Consider admission, obtain medical/ paediatric opinion, | Specialist nursing supervision to prevent water- loading. IV correction, proceed with caution. Review medication if needed. |
| Other electrolyte abnormalities | Check phosphate, magnesium, calcium. Consider refeeding syndrome | Follow refeeding guidelines | See <u>Figure 4:</u> <u>Refeeding decision</u> <u>tree</u> |
| Hypoglycaemia | Blood glucose by finger-prick and venous sample. Urine or blood ketones. | Occurs in very severe emaciation due to low glycogen stores, Usually accompanied by ketones. | Check for additional (e.g. sepsis) or alternative (Addison's disease, insulin abuse) diagnoses. If symptomatic, e.g. coma, give IV glucose. Otherwise, give food or complex carbohydrate preparations |
| Mental health risk or safeguarding/fam ily | Suicidality, evidence of self- harm, family not coping | Urgent psychosocial evaluation. For <18s, may need admission for protection and assessment | If emotionally unstable personality disorder is suspected, avoid admission if possible and refer for urgent psychological treatment |

Key: BP = blood pressure; bpm = beats per minute; IV = intravenous; ECG = electrocardiogram; HR = heart rate; KCI = potassium chloride; kg = kilogram; mmol/L = micromole per litre; ms = millisecond; QTc = corrected QT interval; SSRIs = selective serotonin reuptake inhibitors

i. Risks discernible while taking the patient's history

1. Who to ask for information

A multi-informant perspective (collecting collateral information from multiple sources) is helpful to assess the risk. Parents/carers will often notice symptoms and behaviours they find worrying, which can expedite consultation with the GP or a visit to the emergency department. Young people are sometimes identified by their school teachers and nurses as having problems, avoiding mealtimes and self-isolating.

Children and young people should be provided with developmentally appropriate healthcare and offered time for independent consultation. They should be reassured about confidentiality, but informed of its limits, and given appropriate psychosocial assessment. At all ages, it is often highly informative to obtain the perspective of parents/caregivers who may witness and experience eating-disordered behaviours and have concerns about the impact of the eating disorder on the individual and others. Anyone living independently is less likely to have their symptoms and behaviours noticed by people around them: for example, symptoms can go unnoticed in students away at university.⁴⁶

2. Signs and symptoms

Symptoms that should give rise to the suspicion of an eating disorder include unexplained changes in weight, restriction of diet (sometimes apparently for health reasons), binge eating, menstrual irregularity, vomiting, muscle weakness, abdominal symptoms, and changes in mood (irritability, anxiety or depression). Once an eating disorder has been raised in the mind of a GP or emergency department doctor, the checklist in <u>Table 3</u> should be followed so that a risk assessment can be performed. Collateral history from parents, caregivers and friends, at times in the patient's absence, and from electronic health records or the GP, are essential. Patients with eating disorders can be deeply ashamed of their difficulties, while for others denial can be strong. They may also be extremely scared about the consequences of sharing information about their difficulties – the thought of changing could feel too overwhelming or terrifying. Past response(s) to treatment may help to inform treatment options.

| Realm of enquiry | Finding | Notes |
|------------------|--------------------|--|
| History | Rapid weight loss | >1kg per week for 2 consecutive weeks ⁴⁷ |
| | Acute food refusal | Seek expert advice if >24 hours |

Table 3: Checklist of 'lightbulb' signs indicating increased severity of presentation

⁴⁶ <u>https://www.ombudsman.org.uk/publications/ignoring-alarms-how-nhs-eating-disorder-services-are-failing-patients</u>

⁴⁷ Higher rates have been reported after bariatric surgery, although over 1.5kg per week may predispose to gallstones (<u>https://pubmed.ncbi.nlm.nih.gov/7847427/</u>).

| Realm of enquiry | Finding | Notes | |
|------------------|--|---|--|
| | Frequent vomiting | Can lead to hypokalaemic alkalosis | |
| | Muscle weakness | E.g. difficulty climbing stairs TC Can accompany cardio-respiratory malfunction Can mean renal shut-down | |
| | Faints, chest pain, short of breath | | |
| | Little urine output | | |
| | Intractable constipation | Can mean colonic atony | |
| | Suicidal thoughts | Can lead to suicidal behaviour | |
| Examination | BMI <13, or %mBMI <70 in <18 years | Also depends on rate of weight loss | |
| | Pulse <40, postural hypotension with recurrent syncope | Both are Red on <u>Risk assessment</u> | |
| | Core temp <35.5° | Red on <u>Risk assessment</u> | |
| | Muscle weakness (SUSS, HGS, MUAC tests) | SUSS score 0–1 Red on <u>Risk</u> assessment | |
| Investigations | Any significant ECG abnormality | Red on <u>Risk assessment</u> | |
| | Hypokalaemia | <2.5mmol/L Red on <u>Risk assessment</u> | |
| | Hyponatraemia | Can mean water-loading | |
| | Urine SG <1.010 | Can mean water-loading | |
| | Low phosphate | If patient is being refed or has recently binged, this can mean refeeding syndrome | |
| | Raised transaminases | Usually due to malnutrition; monitor and only investigate if there is a continued rise | |
| | Hypoglycaemia Glucose <3mmol/L | Can occur in extreme starvation often with exercise; patient usually ketotic | |
| | HbA1C >10% | Patient has type 1 diabetes mellitus and eating disorder | |

Key: BMI = body mass index; %mBMI = median percentage BMI; ECG = electrocardiograph; HbA1C = glycosylated haemoglobin A1C; HGS = hand grip strength; MUAC = mid upper arm circumference; SG = specific gravity; SUSS = Sit Up-Squat–Stand test

ii. Risks associated with abnormal physical examination

Physical examination can yield findings which may be subtle and hence provide potential pitfalls in risk assessment. For an adequate risk assessment, the following should be covered.

1. Anthropometry

BMI is an important but imprecise measure of health risk. A person of any age who has been at a higher weight for many years and then loses weight rapidly may have many of the symptoms and signs of malnutrition, even though their weight is still in, or close to, the normal range. At present, fewer data are available to interpret the risk of death and serious injury associated with rapid recent weight loss when weight is in or close to the normal range. Low weight is not necessary for a diagnosis of anorexia nervosa if all other criteria are met.⁴⁸

Interpretation of weight or BMI in assessing malnutrition in young people requires particular care owing to the changes in weight, height and BMI during growth in childhood and through puberty.^{49,50} The World Health Organization (WHO) recommend that the severity of wasting be assessed by BMI for age in those 10–18 years old⁴⁸. Studies have shown that age-adjusted BMI (median percentage BMI [%mBMI] for age and gender) of <70%, or Z-score <-3 predicts a high risk of mortality. The presence of bilateral (nutritional) oedema improves predictability of increased risk of mortality and independently, low serum albumin. However, normal serum albumin should not reassure the clinician.

%mBMI for a given age can be read from BMI centile charts,⁵¹ or there are programmes and apps⁵² that use the UK BMI reference data. Note that the reference data are not ethnically sensitive. However, while there is some individual variation, overall, there is synergy across countries.⁵³ Clinician judgement is needed to assess and interpret individual BMI relative to familial and population BMI.

BMI in under 18s

In line with this, we have defined risk in people under the age of 18 as follows:

- Low immediate risk to life: %mBMI >80%
- Medium risk: %mBMI 70–80%
- High risk of life-threatening malnutrition: %mBMI <70%

BMI in older adolescents

A question sometimes arises in older adolescents as to whether to use the criteria for children and young people or the criteria for adults. In line with WHO,⁴⁸ we recommend using %mBMI up to the age of 18. BMI 13 equates to less than 65% %mBMI in a 17-year-old girl, with BMI 15 equating to around 70% %mBMI. As yet, there are no empirical data supporting a low- versus high-threshold approach to hospitalisation for medical risk and a conservative approach is justifiable. For patients

⁴⁸ https://icd.who.int/browsell/l-m/en#/http%3a%2f%2fid.who.int%2ficd%2fentity%2f263852475

⁴⁹ <u>https://pubmed.ncbi.nlm.nih.gov/16077053/</u>

⁵⁰ https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6138903/

⁵¹ https://www.rcpch.ac.uk/sites/default/files/2018-03/boys_and_girls_bmi_chart.pdf

⁵² https://apps.apple.com/gb/app/junior-marsipan/id951888106

⁵³ https://www.bmj.com/content/335/7612/194

who have lost height because of osteoporosis, their past maximum adult height should be used.

The above notwithstanding, rate of weight loss at any BMI and with any eating disorder can give rise to increased risk. For example, severe protein malnutrition is common after bariatric surgery⁵⁴ when the patient may still be overweight. Hudson *et al.* (2012)⁵⁵ found in adolescents with early anorexia nervosa that rate of weight loss was associated with medical instability, although many still had a %mBMI of >80%. However, if other symptoms (e.g. potassium or suicidality) indicate a particular level of risk, the risk should not be assessed any lower purely because of BMI and no patient should be denied a higher level of care purely because their BMI is in the normal or high range. In general, we recommend avoiding discussion of risk levels and BMI with patients as this can exacerbate symptoms.

BMI in adults

There are few studies in adults to guide determination of the BMI at which risks increase and, therefore, no overall consensus. In a study of mortality in patients with anorexia nervosa, the mean lowest BMI of the nine patients who died of anorexia nervosa (as opposed to suicide or other causes) was 10.69 (range 9.1–12.4).⁵⁶ This gives some rationale for a high-risk range being defined as BMI <13 for adults. *The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*⁵⁷ uses a BMI <15kg/m2 to connote 'extreme' anorexia nervosa. However, several studies have questioned the validity of this conservative approach.^{58,59,60} The Royal Australian and New Zealand College of Psychiatrists (2014)⁶¹ suggest BMI <14 for a psychiatric admission and <12 for a medical admission in adults; the British Columbia Eating Disorders Clinical Practice Guidelines (2010)⁶² suggest using BMI 13–15 for medium risk and <13 for high risk. In addition, according to ICD 11 (WHO) diagnostic criteria 6B80, anorexia nervosa with dangerously low body weight is defined as BMI under 14.0 kg/m² in adults or under the 0.3rd percentile for BMI-for-age in children and adolescents.⁶³

Factoring in the current sparsity of data and lack of consensus, we considered what the appropriate thresholds to advise and propose the ranges for risk, as outlined in the first edition of MARSIPAN for adults, namely:

- Low immediate risk to life: BMI 15–17.5
- Medium risk: BMI 13–15

⁵⁴ <u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5700383/</u>

⁵⁵ <u>https://adc.bmj.com/content/97/9/779</u>

⁵⁶ <u>https://pubmed.ncbi.nlm.nih.gov/21472749/</u>

⁵⁷ https://www.psychiatry.org/psychiatrists/practice/dsm

⁵⁸ <u>https://pubmed.ncbi.nlm.nih.gov/28402070/</u>

⁵⁹ https://pubmed.ncbi.nlm.nih.gov/28623853/

⁶⁰ https://pubmed.ncbi.nlm.nih.gov/28593630/

⁶¹ https://www.ranzcp.org/files/resources/college_statements/clinician/cpg/eating-disorders-cpg.aspx

⁶²https://insideoutinstitute.org.au/assets/clinical%20practice%20guidelines%20for%20the%20british%20columbia%20eating%20disorder%20continuum%20of%20services.pdf

⁶³ https://icd.who.int/browse11/I-m/en#/http://id.who.int/icd/entity/647582417

High risk of life-threatening malnutrition: BMI <13.2. Cardiovascular findings

Bradycardia is very common and well-documented in patients with anorexia nervosa. An awake heart rate (HR) of <50 beats per minute (bpm) should raise concern, and a consistent HR of <40bpm is grounds for assessment by a paediatrician or physician. Such an assessment would include lying and standing blood pressure (BP) and HR, blood tests (to ensure that there are no electrolyte disturbances which could impact further on cardiovascular status) and an ECG. Bradycardia associated with anorexia nervosa and other restrictive eating disorders will improve with adequate nutritional intake, cessation of weight loss and a degree of weight restoration.

An equally worrying sign is when the pulse rate is normal or high despite very low weight⁶⁴ or with low BP, which could indicate infection or dehydration. Bradycardia associated with anorexia nervosa and other restrictive eating disorders should not usually be treated with atropine or other cardioaccelerants.

There may or may not be pulse rate variability with the person standing or when under stress. HR may drop during sleep and recover with waking, but consistently low HR even in sleep is a concern because it can be a precursor of potentially lethal arrhythmia and 'represents an ominous sign for cardiac sudden death'.⁶⁵ The ECG should be checked for heart block as an alternative cause. Patients with severe bradycardia associated with low weight are at risk of junctional escape rhythms.⁶⁶

BP in **children and young people** must be compared with age- and gender-based normal values.⁶⁷ The criteria in the risk assessment framework are based on data from healthy UK children, young people and adults up to age 24. Low weight children and young people are particularly likely to have serious medical complications of eating disorders.⁶⁸

Syncope and pre-syncopal symptoms are common in people suffering from undernutrition who have an eating disorder. The concern, at least in adults, is that syncope may be a marker of cardiovascular instability and may reflect a predisposition to sudden unexpected cardiovascular death in this group⁶⁹. Frequent syncopal events merit assessment by a physician or paediatrician.

Orthostatic hypotension⁷⁰ is seen in undernourished people and those with rapid weight loss and is a marker of disruption of the normal homeostatic physiological cardiovascular mechanisms which control BP with change in posture. A postural drop of more than 20mmHg (systolic) or 10mmHg (diastolic), or to below 0.4–2 centiles for age, or systolic 96–102 in adult females are also indicators of medical instability. Moreover, a significant increase in HR on standing is an indicator of cardiovascular instability. It is likely that excessive exercise adds to cardiovascular risk in vulnerable individuals.

⁶⁴ https://pubmed.ncbi.nlm.nih.gov/20558930/

⁶⁵ <u>https://pubmed.ncbi.nlm.nih.gov/24436590/</u>

⁶⁶ <u>https://onlinelibrary.wiley.com/doi/abs/10.1002/eat.22481</u>

⁶⁷ <u>https://adc.bmj.com/content/92/4/298</u>

⁶⁸ <u>https://pubmed.ncbi.nlm.nih.gov/3162764/</u>

⁶⁹ <u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5728985/</u>

⁷⁰ <u>https://eatingdisordersreview.com/orthostatic-hypotension-and-tachycardia-in-adolescent-patients-with-anorexia-nervosa-a-marker-of-illness-severity/</u>

Poor peripheral perfusion, suggested by cold hands, pale or blue peripheries and prolonged capillary refill time, is a common observation in patients with anorexia nervosa. The importance of this finding in determining physical risk is unknown. However, it can lead to misdiagnosis, e.g. Raynaud's disease. Chest pain, palpitations and breathlessness can also indicate cardiovascular decompensation.

Resources for monitoring cardiac risk

Resources required to monitor cardiac risk include:

- 1. A sphygmomanometer and appropriate range of cuff sizes. Note that some patients find this measure intrusive and triggering of 'body-checking' thoughts.
- 2. A 12-lead ECG machine.
- **3.** Corrected QT interval (QTc) measurement (machine-measured is 98% accurate).⁷¹
- 4. Cardiac monitoring equipment.
- 5. Appropriate adjustable bed.
- 6. Resuscitation equipment.

All people with eating disorders who are medically compromised should have a 12lead ECG performed. A discussion with a paediatrician or physician with expertise in cardiology should be arranged if there is a significant abnormality, particularly if the QTc is prolonged or heart block is noted on the ECG.

3. Hypothermia

Hypothermia is found in 32% of adolescents with anorexia nervosa (<35.6°C)⁷² and 22% of adult outpatients (<36°C),⁷³ likely due to loss of body fat combined with slower metabolic rate. Data from adults^{74Error! Bookmark not defined.} suggest the following symptoms may occur:

- 34–36°C: Patient feels cold and moves around more. They may become withdrawn or aggressive.
- 33–34°C: Patient may stagger and become confused and drowsy. Paradoxical undressing may occur because the person thinks they are warm or it may occur deliberately to increase energy expenditure.
- 26–32°C: Coma may occur.
- <26°C: Death may occur, sometimes following ventricular fibrillation.

⁷¹ academic.oup.com/eurheartj/article/38/suppl_1/ehx493.P5514/4086874

⁷² https://pubmed.ncbi.nlm.nih.gov/30747833/

⁷³ <u>https://pubmed.ncbi.nlm.nih.gov/15767533/</u>

⁷⁴ <u>https://oxfordmedicine.com/view/10.1093/med/9780199204854.001.1/med-9780199204854</u>

4. Under- and over-hydration

Dehydration

Hydration status is notoriously difficult to assess in the context of malnutrition. Examining mucous membranes, eyes (whether sunken or not), skin turgor, pulse, BP, postural hypotension, capillary refill time and urine output are all important but unreliable. Serum urea, electrolytes and haematocrit may be abnormal. Weight loss can be secondary to dehydration. Young people with eating disorders who are undernourished usually have baseline bradycardia. In this context, HR within the normal range or elevated or a significant postural drop in blood pressure (>20mm Hg) may be signs of hypovolaemia. However, no single sign of hypovolaemia is reliable and requires the assessment of a range of clinical parameters. Caution must be taken in treating hypovolaemia intravenously in the context of malnutrition at all ages to avoid precipitating heart failure. Smaller aliquots (e.g. 10ml/kg IV) administered in stages are safer. Moreover, 5% dextrose might contribute to refeeding syndrome and should be given with caution. In general, fluid replacement should be oral or via nasogastric tube (NGT) and the intravenous route avoided.

Over-hydration (and oedema)

Hypoalbuminaemia in the absence of other conditions is very rare in anorexia nervosa.⁷⁵ It must therefore be assessed carefully, particularly if associated with oedema, which, in the context of an eating disorder, may be the result of refeeding, sudden cessation of laxatives or vomiting,⁷⁶ or occasionally congestive cardiac failure.

A low albumin level in a patient with an eating disorder should prompt assessment for infection or other inflammatory causes.

In assessing hydration status, if the clinician is uncertain the assistance of a renal physician can be very helpful. Over-hydration can be due to excess water consumption and, whatever the cause, can increase risk by making true weight and BMI very difficult to determine. This affects risk assessment and prescription of feeding regimes.

5. Muscle weakness

This can be detected in the history (e.g, unable to manage stairs) or on examination. Two tests that have been evaluated are the Sit Up-Squat–Stand (SUSS) Test and Hand Grip Strength (HGS)⁷⁷ and both have been found to be useful in evaluating muscle power in anorexia nervosa.

Hand grip strength test

Hand grip strength can be measured using a relatively inexpensive meter (e.g. a digital hand-grip-strength meter/dyanometer⁷⁸) with excellent face validity and test-retest and inter-rater reliability in the cited study. For healthy women aged 18–24, the 50th percentile HGS is 28.4kg and for men it is 47.8kg.⁷⁹ In the cited study, below BMI

⁷⁵ https://jandonline.org/article/S2212-2672(17)30444-6/pdf

⁷⁶ https://pubmed.ncbi.nlm.nih.gov/21344464/

⁷⁷ https://onlinelibrary.wiley.com/doi/pdf/10.1002/erv.2839

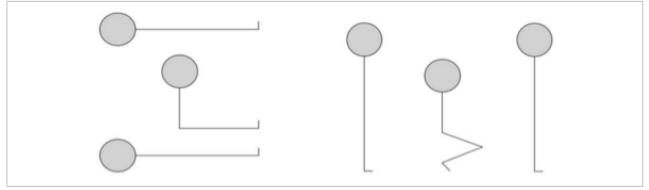
⁷⁸ <u>https://www.amazon.co.uk/Digital-Dynamometer-Strength-Measurement-Capturing/dp/B00A8K4L84</u>

⁷⁹ <u>https://pubmed.ncbi.nlm.nih.gov/29792107/</u>

14, most female patients had HGS of <20kg and males HGS of <33.7kg, and we suggest these levels as indicating 'Concern' in risk assessment. The mid-upper arm circumference (MUAC) has been evaluated in anorexia nervosa⁸⁰ and is a third test of muscle function available to clinicians, if weight and height are not easy to obtain (e.g. the patient is unconscious). A value lower than 18 suggests that BMI is <13.

Sit-Up–Squat–Stand (SUSS) Test

The SUSS Test is described below. However, clinical experience suggests that adolescents frequently 'pass' this test, especially if they are athletic. Performing poorly is therefore a concern, but it is important not to be falsely reassured if the person performs well. The SUSS Test has two parts (see <u>Figure 1</u>):



1. Sit Up: patient lies down flat on a firm surface such as the floor and sits up without, if possible, using their hands

Scoring (for Sit Up and Squat-Stand tests separately)

- 1. 0: Unable
- **2.** 1: Able only using hands to help
- **3.** 2: Able with noticeable difficulty
- **4.** 3: Able with no difficulty

Figure 1: The SUSS (Sit-Up–Squat–Stand) Test

6. Other clinical conditions including diabetes

Other conditions that can complicate eating disorders include type I diabetes mellitus (see <u>Chapter 9</u> and <u>Annexe 3</u>), and conditions such as infectious mononucleosis, inflammatory bowel disease and malignant disease, such as pituitary tumours, in which weight loss due to the medical condition may have triggered the eating disorder in a vulnerable person.

iii. Risks associated with abnormal physical investigations

1. ECG abnormalities

There are a number of possible causes of arrhythmia in people with eating disorders, including undernourishment, congenital prolonged QTc, electrolyte disturbances and medications. Heart block may also be detected, possibly unrelated to the eating disorder. If prolonged QTc is detected, this should be promptly investigated for causes such as medication, electrolyte imbalance or a genetic long QT syndrome, because

2. Squat-Stand: patient is asked to squat down on their haunches then rise to standing without, if possible, using their hands or arms as levers

Performing and scoring the SUSS Test are demonstrated in an online video: <u>https://youtu.be/mOuHb4Nh4NM</u>

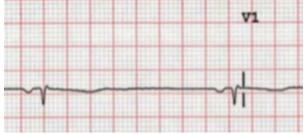
⁸⁰ <u>https://pubmed.ncbi.nlm.nih.gov/12765671/</u>

prolonged QT can be associated with ventricular arrhythmias and sudden death. It has been suggested⁸¹ that malnutrition could result in prolonged QTc and that QTc increases with undernourishment. However, this has been recently challenged⁸² and the matter is still uncertain. Congenital prolonged QTc is frequently found with T-wave abnormalities, in contrast to prolonged QTc in the context of undernutrition.

Arrhythmias causing or likely to cause cardiovascular decompensation should be treated promptly and cardiovascular monitoring instituted and maintained until definitive treatment is provided or the risk of sudden death or cardiovascular collapse is reduced.

In **children and young people**, a prolonged QTc for age and gender requires further assessment and should be discussed with local cardiology experts. However, sinus arrhythmia, where the HR varies with breathing, is a common finding in children and young people and is not in itself a cause for concern.

In established anorexia nervosa, ECG changes are common.⁸³ Two examples are given below in <u>Figure 2</u>.

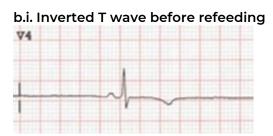


a. Bradycardia

⁸¹ <u>https://pubmed.ncbi.nlm.nih.gov/8068473/</u>

⁸² https://pubmed.ncbi.nlm.nih.gov/29929679/

⁸³<u>https://pubmed.ncbi.nlm.nih.gov/30173377/</u>



b. ii. T wave corrected 2 days after starting refeeding



Figure 2: (a.) Sinus bradycardia, and (b.i.) inverted T-wave before and (b.ii.) 2 days after starting refeeding in the same patient

Sudden cardiac death does occur in anorexia nervosa. In Rosling *et al.*'s (2011)⁸⁴ study, one in 23 deaths was due to cardiac arrest and one to cardiovascular collapse. In a study of out-of-hospital deaths of young adults in Australia, Deasey *et al.* (2011)⁸⁵ reported that three in 572 were attributed to anorexia nervosa.

2. Abnormal electrolytes

Patients with eating disorders can be extremely medically unwell and still have normal blood tests. Normal electrolytes are therefore not a cause for reassurance, although abnormal ones are a cause for concern.⁸⁶

Potassium

Both low and high potassium levels can occur in people with eating disorders. Hypokalaemia is most likely to be secondary to self-induced vomiting or laxative misuse, sometimes in conjunction with poor nutrition, and may be associated with a metabolic alkalosis, confirmed on venous blood gas and raised venous serum bicarbonate. Hypokalaemia and acidosis suggest the possibility of laxative misuse. A potassium level of less than 3mmol/l⁸⁷ should be discussed urgently with a physician or paediatrician to determine the most appropriate care. Low potassium suggests chronic intracellular hypokalaemia because of long-term purging. Moreover, a small study demonstrated low total body potassium in three out of four patients with anorexia nervosa and normal serum potassium.⁸⁸ Chronic hypokalaemia is thought to predispose to end-stage renal failure.^{89, 90}

⁸⁴ https://pubmed.ncbi.nlm.nih.gov/21472749/

⁸⁵ <u>https://pubmed.ncbi.nlm.nih.gov/21783315/</u>

⁸⁶ <u>https://pubmed.ncbi.nlm.nih.gov/32582446/</u>

⁸⁷ <u>https://pubmed.ncbi.nlm.nih.gov/33023762/</u>

⁸⁸ <u>https://pubmed.ncbi.nlm.nih.gov/8556023/</u>

⁸⁹ <u>https://pubmed.ncbi.nlm.nih.gov/16231363/</u>

⁹⁰ https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6224672/pdf/main.pdf

Sodium

Hyponatraemia can be caused by water-loading to hide body mass loss. Urine specific gravity can be used as a rapid check (e.g. in primary care or outpatients) for water overload. A urine specific gravity below 1.010 can be a sign of water-loading. Low sodium (normal range 135–145mmol/L0 may also be an indicator of underlying sepsis, syndrome of inappropriate antidiuretic hormone hypersecretion (which has many causes, including respiratory infections and drugs such as carbamazepine), or excessive sodium loss due to diarrhoea/vomiting. Patients with very severe eating disorders can experience 'sick cell syndrome', which is associated with low sodium due to membrane pump malfunction.⁹¹ The patient generally recovers with nutritional treatment and does not usually require sodium supplementation. In general, however, plasma sodium is a poor indicator of total body sodium, and urinary electrolytes should be checked. Hyponatraemia in the context of dehydration/hypovolaemia may be associated with hypokalaemia. It may also be caused⁹² by medications, such as SSRIs or diuretics.

Calcium

Both hypocalcaemia, perhaps related to low Vitamin D levels and phosphate treatment, and hypomagnesaemia, which is related to laxative abuse, are not uncommon and increase the risk of arrhythmia. Hypocalcaemia <1.1mmol/l can lead to tetany, stridor, seizures, weakness, atrioventricular block, prolonged QTc, arrhythmias and a risk of sudden unexpected death.

Phosphate

Phosphate is important in cellular energy and transport pathways throughout the body. Hypophosphataemia (defined as a phosphate level <1mmol/L (adolescents)⁹³ and <0.8mmol/L (adults),⁹⁴ may occur secondary to starvation. In addition, refeeding syndrome (see <u>Chapter 4</u>) is associated with a low serum phosphate level.

Serum creatinine and urea

Serum creatinine and urea need careful interpretation. Severe malnutrition can result in low creatinine, because of reduced muscle mass. Urea may be low because of poor protein intake, and as a result a 'normal' urea or creatinine level can reflect renal insufficiency, and the glomerular filtration rate should be checked. Sustained renal dysfunction with a raised creatinine and urea that does not correct quickly with careful rehydration is a significant sign and requires careful assessment, and a search for other renal causes and concomitant medical conditions. Estimated glomerular filtration rate is unreliable in undernourished patients of any age and should not be used to evaluate renal function.⁹⁵

⁹¹ <u>https://www.ncbi.nlm.nih.gov/pubmed/16125161</u>

⁹² https://cks.nice.org.uk/topics/hyponatraemia/#:~:text=Hyponatraemia%3A%20Summary-

^{.&}lt;u>Hyponatraemia%20is%20defined%20as%20a%20serum%20sodium%20concentration%20of%20less,130%E2%80</u> %93135%20mmol%2FL.

⁹³ https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6159900/

⁹⁴ https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3319220/

⁹⁵ <u>https://onlinelibrary-wiley-com.libproxy.ucl.ac.uk/doi/epdf/10.1002/eat.20813</u>

3. Abnormal liver tests

Raised liver enzymes may be caused by autolysis of hepatocytes, perhaps as a way of releasing energy in a person who is starving, or hepatic steatosis. Mild elevation of transaminase levels is common in patients with anorexia nervosa and sometimes appears during the course of refeeding. Raised alanine aminotransferase (ALT) is common in undernourishment and will usually recover with weight restoration. In general, ALT >100 should be given balanced consideration. If other tests of liver dysfunction (hypoalbuminaemia, altered coagulation tests, jaundice or any features of encephalopathy) are present another cause for raised LFTs should be sought.

There are reports of severe liver dysfunction and, very rarely, death with refeeding, but substantial rises in liver enzymes should always prompt a search for other causes, such as sepsis, viral or ischaemic hepatitis, therapeutic drugs, (including paracetamol overdose), recreational drugs and alcohol misuse.

Paracetamol toxicity

Note that in a patient weighing 30kg, 7.5g of paracetamol over 24 hours may lead to serious toxicity⁹⁶. It has been reported⁹⁷ that the following combination is a good predictor of acute liver failure in drug induced hepatotoxicity:

• AST 17.3x ULN, Total Bilirubin 6.6 x ULN and AST/ALT ratio >1.5.

4. Abnormal haematological parameters

Abnormalities in haematological parameters may occur in any person with malnutrition, including those with eating disorders, although they will usually resolve with weight restoration and improved nutritional intake.^{98, 99} Changes can involve a number of cell lines, including leucopoenia, especially neutropaenia, and some thrombocytopaenia. If more than two cell lines are affected, consider other differential diagnoses (e.g. leukaemia).

Deficiencies

Anaemia can occur, but because there is often a degree of dehydration this is less commonly noted and is rare in young people. Low serum and ferritin indicate iron deficiency. Ferritin is typically high in undernourished people in response to stress. Low serum B12 can be associated with a macrocytic or normocytic anaemia due to poor vitamin intake, not uncommon in those on a vegan diet. Folate deficiency can occur, although levels may be increased.¹⁰⁰ Bone marrow aspirates can show hypocellular morphology (gelatinous transformation of the bone marrow^{101, 102}) which recovers with refeeding.

⁹⁶ <u>https://www.toxbase.org</u>

⁹⁷ <u>https://pubmed.ncbi.nlm.nih.gov/24704526/</u>

⁹⁸ <u>https://pubmed.ncbi.nlm.nih.gov/19445758/</u>

⁹⁹ <u>https://pubmed.ncbi.nlm.nih.gov/27811940/</u>

¹⁰⁰ https://pubmed.ncbi.nlm.nih.gov/29026589/

¹⁰¹ <u>https://pubmed.ncbi.nlm.nih.gov/19040272/</u>

¹⁰² https://onlinelibrary.wiley.com/doi/abs/10.1002/%28SICI%291099-

^{0968%28200003%298%3}A2%3C158%3A%3AAID-ERV337%3E3.0.CO%3B2-F

Sepsis

Although the immune system is affected in many ways in anorexia nervosa, whether malnourished patients (including those with lower white cell counts) are at a greater risk of infection is unclear, and there is a paucity of information on children and young people. In the context of fever and neutropenia, sepsis should be considered, but this is rare and usually has other clinical features.

Coeliac disease

Coeliac disease is associated with functional hyposplenism and white cell anomalies. Coeliac disease is a common condition with a prevalence of 1–2% at all ages in Western populations and often manifests as functional gastrointestinal symptoms with weight loss and iron and folate deficiency. The anti-TTg IgA (tissue transglutaminase immunoglobulin A) antibody test will pick up over 90% of cases and this condition should be checked for if there is any concern. The refeeding of an underweight patient should not be delayed by the search for alternative diagnoses.

White blood cell count

In one well-designed randomised controlled trial, a low white blood cell count was associated with an increased risk of refeeding hypophosphataemia.¹⁰³ The presence of a low white cell count should therefore be considered when establishing a safe refeeding plan. It is important to be aware that normal white cell count in a severely malnourished patient may indicate infection, as the immune response is suppressed.

Thrombocyte count:

Thrombocytopenia occurs in 10–25% of patients with anorexia nervosa¹⁰⁴ due to malnutrition related bone marrow suppression. If it does not improve with weight restoration, haematological opinion should be sought. Relative or absolute thrombocytosis should raise the possibility of inflammatory disease, such as inflammatory bowel disease, which can be associated with eating disorders. Faecal calprotectin is a non-invasive tool that can help with differential diagnosis.

5. Compensatory behaviours

Compensatory behaviours occur in bulimia nervosa, purging disorder and anorexia nervosa, and can give rise to substantial risks.¹⁰⁵ Purging behaviours include self-induced vomiting, laxative abuse and diuretic abuse. Some biochemistry laboratories will measure laxatives and Furosemide (diuretic) in urine.

Dysfunctional exercise

This is a form of compensatory behaviour that tends not to interfere with electrolytes, although it can lead to hypoglycaemia¹⁰⁶ and raised creatine kinase¹⁰⁷ (CK) levels.

¹⁰³ <u>https://pubmed.ncbi.nlm.nih.gov/26869609/</u>

¹⁰⁴ <u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5107965/</u>

¹⁰⁵ https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4803618/pdf/nihms746587.pdf

¹⁰⁶ https://pubmed.ncbi.nlm.nih.gov/3071324/

¹⁰⁷ https://pubmed.ncbi.nlm.nih.gov/27721832/

Abuse of amphetamines and other appetite suppressant drugs do not usually affect electrolytes.

Self-induced vomiting

Repeated self-induced vomiting can deplete potassium from the body, at least in part by causing alkalosis due to loss of acid from the stomach leading to increased renal potassium excretion. The most life-threatening consequence of the resulting hypokalaemia is sudden death due to cardiac arrhythmia. ST depression, T-wave inversion and U waves are among the changes observed on ECG.¹⁰⁸

Hypokalaemia due to vomiting has been treated with Lanzoprazole,¹⁰⁹ which blocks acid secretion in the stomach and so prevents alkalosis from developing. Other serious complications of vomiting are oesophagitis due to reflux and haematemesis due to Mallory–Weiss syndrome. Rarely, purging can lead to oesophageal rupture, with persisting chest pain and signs of systemic illness.

Functional gastrointestinal symptoms

These include bloating (sometimes related to delayed gastric emptying and slow bowel transit, related to malnutrition and laxative abuse), and are very common in patients with eating disorders. They rarely reflect physical risk but can be distressing to the patient, and difficult to interpret. Consider referral to a paediatrician or physician with appropriate expertise who can advise and guide any further assessment or investigation. Such a referral should not delay refeeding.

Laxative misuse

Taking laxatives to try to avoid weight gain occurs in anorexia nervosa, bulimia nervosa and OSFED (purging disorder). The number of tablets taken can escalate, probably because they become less effective. The resulting diarrhoea causes loss of electrolytes, resulting in hypokalaemia, hypomagnesaemia and dehydration¹¹⁰. Prolonged laxative abuse can cause colonic atony due to progressive weakness of the colonic muscle, and chronic constipation and rectal prolapse can follow, sometimes requiring colectomy.

Laxative abuse is rare in **children** under the age of 15 years (0–1.8%) and reflects the general population level from 15–18 years (3.2–5.5%).¹¹¹ It is found in 4.18% of the general population and 15–70% of people with eating disorders.

Diuretic misuse

In eating disorders, diuretics may be used to lower weight, although, as in laxative abuse, the reduction is illusory as it is due to loss of water from the body. They cause dehydration, hyponatraemia, hypokalaemia, and the reduced plasma volume may lead to an elevation in serum aldosterone levels.¹¹² Thus, when the diuretics are stopped, the patient can experience severe oedema, which can cause enormous anxiety in the context of intense body image concerns. The diuretic spironolactone has been suggested to aid the treatment of oedema associated with laxative

¹⁰⁸ <u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3383164/</u>

¹⁰⁹ https://pubmed.ncbi.nlm.nih.gov/11784888/

¹¹⁰ <u>https://gut.bmj.com/content/gutjnl/15/9/758.full.pdf</u>

https://pubmed.ncbi.nlm.nih.gov/20687617/

¹¹² https://pubmed.ncbi.nlm.nih.gov/20186716/

withdrawal if severe oedema occurs, especially in patients of normal weight or higher, because it antagonises aldosterone which may be driving the oedema.¹¹³

6. Other biochemical and endocrine abnormalities

Thyroid function

Sick euthyroid syndrome (abnormal thyroid function tests without pre-existing thyroid or pituitary disease) may occur in anorexia nervosa with lowered triiodothyronine levels, low thyroxine levels, and elevated reverse T3^{114, 115.} The important differential diagnosis is secondary hypothyroidism due to a thyroid tumour. Occasionally thyroxine levels can be elevated due to thyroxine, obtained medically or via the internet, being consumed as a weight-loss aid. A careful history and examination and assessment of other hormones in the pituitary should be undertaken. Referral to a paediatrician or endocrinologist should be considered.

Hypoglycaemia

Patients with severe anorexia nervosa have limited fat stores, and if their dietary intake is minimal, ketones will be produced by beta-oxidation of fats and to a smaller extent from lipogenic amino acids released mainly from muscle protein. It should be borne in mind that prolonged ketosis may contribute to reduction in bone mineral density¹¹⁶. In practice, most patients with anorexia nervosa are carrying enough glycogen to maintain blood glucose.¹¹⁷ However, in a severely malnourished patient who has used up all glycogen and fat stores, fatal hypoglycaemia becomes a possibility¹¹⁸ although it can also result from other conditions (e.g. Addison's disease) and, if persistent despite feeding, needs to be investigated. Hypoglycaemia can occur in extreme malnutrition,^{119,120,121} particularly in adults, and can lead to death if not treated. It represents extreme depletion of glycogen stores. Importantly, ketotic hypoglycaemia should not be treated with rapid-acting carbohydrate (e.g. GlucoGel) but rather with more complex carbohydrates (e.g. food).

It is important to check ketones (using urine or capillary test strips) at the time of hypoglycaemia.

Nonketotic hypoglycaemia is always pathological and rare. It is most commonly seen in insulin overdose, where insulin excess prevents ketogenesis and leads to neuroglycopaenic (drowsiness/mood change) and adrenergic symptoms. It is helpful to get a hypoglycaemia diagnostic screen before treating if possible.

Insulin restriction/omission in patients with an eating disorder and type I diabetes presents particular risks and is addressed in <u>Annexe 3</u>.

¹¹⁵ https://abstracts.eurospe.org/hrp/0082/hrp0082p3-d1-980.htm

¹¹³ <u>https://eatingdisordersreview.com/causes-and-management-of-edema-in-patients-with-eating-disorders/</u>

¹¹⁴ <u>https://www.jahonline.org/article/S1054-139X(03)00265-9/fulltext</u>

¹¹⁶ <u>https://pubmed.ncbi.nlm.nih.gov/28778055/</u>

¹¹⁷ With thanks to Professor George Grimble for this contribution.

https://pubmed.ncbi.nlm.nih.gov/4048325/

https://pubmed.ncbi.nlm.nih.gov/31059162/

¹²⁰ https://jeatdisord.biomedcentral.com/articles/10.1186/s40337-020-00303-6

¹²¹ https://www.clinicalnutritionjournal.com/article/S0261-5614(20)30467-2/abstract

In bulimia nervosa, and in the binge/purge form of anorexia nervosa and OSFED, most biochemical abnormalities are related to purging (i.e. self-induced vomiting and laxative abuse), which can lead to renal impairment. Hypoglycaemia can also occur^{122,123}, possibly related to binge-related insulin surges.

Creatine kinase

CK is an enzyme contained in muscle cells and released when the muscle is damaged. In eating disorders, the two most common causes of raised CK are muscle autophagy (i.e. the body metabolising muscle as a source of nutrition) and over-exercising, which can result in very high CK levels in undernourished patients who exercise.^{124, 125} Increased CK is used in the diagnosis of myocardial infarction, in which selective increase in the cardiac iso-enzymes (CK-MB) in contrast to the skeletal muscle isoenzymes (CK-MM). In one reported case report of a patient with anorexia nervosa,¹²⁶ CK was greatly raised at 2,580 iu/L and 3.5% was found to be CK-MB, i.e. 90 iu/L, which is nearly four times the upper limit of normal, suggesting cardiac involvement in muscle damage. However, it has been reported that exercising athletes may have an abnormally raised serum level of CK-MB¹²⁷ which may have relevance for patients with eating disorders who suffer with dysfunctional exercise.

Micronutrients

Vitamin deficiencies can give rise to abnormal blood tests, for example vitamin C deficiency causing anaemia, and low calcium and phosphate in vitamin D deficiency. Thiamine deficiency, associated with a low level of red-cell transketolase, is found in beriberi and Wernicke–Korsakoff syndrome (a neurological disease caused by thiamine deficiency characterised by ataxia, visual changes and memory impairment), as well as 38% of patients with anorexia nervosa.¹²⁸ Most adult units give thiamine routinely during refeeding (see <u>Chapter 4</u>) because of the potential risk of inducing Wernicke–Korsakoff syndrome. Other vitamin deficiencies, including B12 or folate deficiency can cause serious consequences. Scurvy may occur in ARFID, if the patient avoids fruit and vegetables for long periods of time. Lastly, low levels of vitamin K may lead to impairment of blood clotting and elevated prothrombin time.

iv. Risks associated with psychological symptoms

Assessment

A thorough assessment of the patient's mental state is an essential part of the risk assessment. Patients presenting as an emergency are often highly distressed, and those with eating disorders have an increased risk of self-harm and suicide.¹²⁹ Other common psychological symptoms include obsessions and compulsions, depression, autistic traits, anxiety and emotional dysregulation. They may also have cognitive

¹²² https://pubmed.ncbi.nlm.nih.gov/8032348/

¹²³ https://www.bmj.com/content/bmj/372/bmj.m4569.full.pdf

¹²⁴ https://downloads.hindawi.com/journals/crim/2016/8194160.pdf

¹²⁵ <u>https://neurologyindia.com/article.asp?issn=0028-</u>

^{3886;}year=2020;volume=68;issue=2;spage=495;epage=496;aulast=Papadopoulos;type=3#ref2

¹²⁶ https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2398865/pdf/postmedj00077-0051.pdf

¹²⁷ https://pubmed.ncbi.nlm.nih.gov/6686133/

¹²⁸ <u>https://pubmed.ncbi.nlm.nih.gov/11054793/</u>

¹²⁹ <u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8058850/pdf/S2056472421000235a.pdf</u>

impairment. A compassionate and empathetic approach helps to put the person at ease.

It is important to include questions about weight and shape, dietary restriction and compensatory behaviours, suicidality, mood, sleep disturbance and specific fears – especially food-related ones. The psychiatric interview helps to establish if the patient has a mental disorder and whether they have capacity, which are essential for decision-making about treatment options. However, with very young patients, be particularly careful to ask open questions to avoid suggesting specific behaviours or cognitions. Only become specific if responses to open questions raise concern. Table 4 presents some psychological symptoms that can affect the patient's response to treatment.

Medication and restraint

If patients are finding eating extremely challenging, they may react against attempts to encourage food intake. Some might even become aggressive towards staff who are trying to help them, due to high level of anxiety and distress. In such an extreme situation, patients may need additional measures such as medication or even restraint, to support the process of refeeding. This can further exacerbate distress, perhaps increasing the risk of self-harm and suicide, and it is important to seek advice from a consultant psychiatrist specialising in eating disorders to help devise a safe treatment plan. In contrast, some patients may appear extremely cooperative while remaining terrified of change and consequently negating efforts at nutritional rehabilitation. Avoid prolonged negotiations. Patients value clinicians responding with compassion to the distressing thoughts underpinning their fears, while delivering a clear message that adequate nutrition and reduction in any eating disorder compensatory behaviours is essential. Clinicians are advised to monitor whether interactions between staff and patient improve the latter's behaviour or the reverse and modify the approach of staff accordingly.

Neurological examination

Poor attention and concentration are common in malnourished patients and can be due to purging or treatment for diabetes. Confusion and delirium are rarer, but extremely worrying; they may reflect refeeding syndrome (see <u>Chapter 4</u>), Wernicke's encephalopathy, or be evidence of other infectious, metabolic or neoplastic pathology. A neurological examination and a computed tomography/magnetic resonance imaging scan may be indicated in such situations, particularly if the presentation is at all atypical for an eating disorder or associated with neurological abnormalities on examination.

| Symptom | Possible origin | Possible consequences |
|----------------------------------|--|--|
| Body image disturbance | Eating disorder | Rejection of help to gain weight |
| Anxiety | Fear of weight gain | Feeling of panic, or panic attacks |
| Depression | Eating disorder, family, social issues | Self-harm, suicide, fear of stigma |
| Dietary restriction | Eating disorder, feeling of reward for weight loss | Dysfunctional exercise, disposing of food |
| Thoughts of self-harm | Depression, distress | Self-harm, suicide |
| Poor attention, concentration | Depression, anxiety, purging, low glucose | Poor understanding of treatment plan |
| Memory disturbance | Thiamine deficiency | Wernicke-Korsakov |
| Compensatory behaviours | Eating disorder | Hypokalaemia, (vomiting, laxatives), weight loss, (dysfunctional exercise) |

Table 4: Some psychological symptoms that can affect treatment response

Working collaboratively with the patient

Examination of the patient's mental state can reveal the degree of body image disturbance, urge to exercise and motivation to recover. This gives clinicians an indication of the patient's attitude to treatment, which can manifest in firmly held wishes to lose weight or maintain a low weight. However, equally, there may be lack of trust in the system and the staff, which can lead to a lack of adherence to treatment, including weight restoration. Staff need to recognise this ambivalence, avoid confrontation, gain trust and work collaboratively with the patient, their family members and carers, and other members of the team, to help the patient through the illness. Input from mental health nurses or other staff who have been trained to support mealtimes can facilitate patients managing their meals on paediatric or medical wards.

In approaching a patient with eating disorder behaviours, the interviewer should assume that it is a sensitive and difficult area. Many dietitians and nurses are expert at this type of negotiation. Try to elicit the patient's confidence to begin with and ask open questions. Here is an example conversation:

"The nurses have told me that you are not that happy to go along with the meal plan. Can you explain that to me a bit?"

"You're just trying to make me fat."

"OK, I understand this is a really difficult area for you. Is there a way we could make it just a little more acceptable?" "Well, you could cut out the ice-cream for a start."

"OK, we can replace that with a banana and work from there."

Negotiating a little in this way can be helpful, although in time the patient will need to accept the need for weight gain, which can be a big hurdle.

Patients with eating disorders (especially young people) can reach a critically ill state quickly, with rapid weight loss, or (more in adults) slowly with weight loss over months or years. With long-standing low weight, it can be hard to know how to apply the risk parameters. This is particularly the case in patients with ARFID, whose low weight may be lifelong and who appear to have a physiologically accommodated to being low weight. Patients with eating disorders may find the increase in nutrition required for weight restoration very difficult to manage, so respecting these difficulties and forging an alliance with the patient with the help and support of their family and carers is important.

v. Risks associated with eating disorders comorbid with other psychiatric disorders

Patients with severe eating disorders have high rates of psychiatric comorbidities. When significant comorbidity is present, managing distress becomes challenging and may require the expertise of a specialist eating disorder service or a liaison psychiatrist team.

The MEED guidelines are pertinent to patients requiring emergency treatment in medical settings when they are severely malnourished or have other potentially life-threatening physical complications. These consequences can impact metabolic brain function, leading to significant behavioural and emotional changes, and heightened anxiety.

Given these factors, caution is advised when diagnosing other psychiatric disorders, especially during the acute phase of the illness or in individuals with chronic malnutrition.

Successful management of the patient involves the clinician establishing a personalised formulation of maintaining factors – taking differential diagnoses into account – and using a non-judgmental and collaborative approach. Clinicians need to be aware that comorbid psychiatric conditions increase the risk of mortality, either by increasing the risk of suicide or by physical complications (e.g., alcohol or substance misuse).

Management protocol for care setting

Co-occurring psychiatric disorders (such as alcohol and substance misuse, PTSD, EUPD, depression and OCD) increase the mortality risk associated with eating disorders.¹³⁰

¹³⁰Hambleton A, Pepin G, Le A *et al* (2022) Psychiatric and medical comorbidities of eating disorders: findings from a rapid review of the literature, *Journal of Eating Disorders*, 10:132 <u>https://.doi.org/10.1186/s40337-022-00654-2</u>

It is crucial to recognise that acute food refusal can manifest in a variety of psychiatric conditions other than an eating disorder. To prevent unintentional harm and prolonged hospitalisations, the medical and psychiatric teams must work closely together to optimally manage these patients.

We suggest the following management protocol:

- **1.** Assess the risk factors for both eating disorders and any comorbid psychiatric disorders.
- 2. If a risk factor is present (as outlined in MEED or acute risk of suicide) that would lead to a recommendation for admission, the patient should be admitted until they can be safely discharged.
- 3. Whenever possible, patients with eating disorders should receive outpatient or day patient management, utilising evidence-based therapies such as CBT-ED in accordance with NICE guidelines.
- 4. If admission is necessary, evidence-based treatment should be provided for both the eating disorder and any comorbid conditions.

vi. Risks associated with eating disorders comorbid with autism spectrum disorder

The prevalence of autism spectrum disorder (ASD) and eating disorders is higher than in the population as a whole,¹³¹ and the presence of autistic traits may have an impact on treatment response and outcome.¹³²

In autistic people, it may be difficult to discern whether symptoms, such as inflexibility and detail focus, or stimming are attributable to the eating disorder, and therefore whether they are best challenged or accommodated.

Managing high levels of distress in patients with significant comorbidities will require the support of professionals who specialise in autism. Many hospitals now have autism consultancy/liaison teams who can advise on this.

Management protocol for care setting

Because evidence suggests that autistic people struggle more than neurotypical people during hospital stays, reducing the number of autistic people in inpatient care is a government policy priority (e.g., The NHS Long Term Plan 136). It is important to note, however, that this approach, and the supporting evidence, focus on avoidable admissions rather than medical emergencies.

In some cases, the risk of not admitting a person outweighs the risk of admitting them. As a result, it is critical to assess risk on an individual basis – medical emergencies must be safely managed.

We suggest the following management protocol:

- **1.** Assess the risk factors for both eating disorders and autism.
- 2. If a risk factor is present (as outlined in MEED or acute risk of suicide) that

¹³¹ <u>https://pubmed.ncbi.nlm.nih.gov/28540593/</u>

¹³² <u>https://pubmed.ncbi.nlm.nih.gov/25774282/</u>

would lead to a recommendation for admission, the patient should be admitted until they can be safely discharged.

- **3.** As far as possible, autistic patients with eating disorders should be managed as outpatients or day patients, using evidence-based therapies such as CBT-ED for eating disorder as per NICE guidelines.
- 4. During any admissions, implement reasonable adjustments, if necessary (e.g., to take account of sensory needs profile) and use evidence-based methods (such as the <u>PEACE pathway</u>).

3. Location of care and transfer between services

a. Where should treatment take place?

When the decision has been made to admit a patient to hospital, the referrer's actions will be informed by many factors, not all clinical. Nonetheless, decisions about location of care should be made with the patient's best interests foremost. The options usually are:

- Medical/paediatric bed
- Specialist eating disorders bed (SEDB): this is a general psychiatric bed that has all services that would be provided in a SEDU
- Specialist eating disorders unit (SEDU) bed, which may be in the NHS sector, or the independent sector commissioned by the NHS.

The decision rests on the clinical state of the patient, as well as the services available locally (as part of a network of care for people with eating disorders) and, where possible, on patient, parental/carer or clinician choice. We recommend that units treating patients with eating disorders are members of one of the quality networks described below.

When people with eating disorders are admitted a long distance away from home, consideration must be given as to how to support them to maintain links with their family and friends, and with their school or work (although this must not compromise clinical care). Proximity to family is particularly important for children and young adolescents, so that separation anxiety does not exacerbate an already distressing experience. Consideration should be given to investigating such distant transfers as significant incidents.

The patient will have a number of needs, all of which must be met. They include treatment for nutritional and other medical problems, and management of behaviours that may compromise treatment. Decisions on accepting a patient for a SEDU or a SEDB should be made by SEDU or SEDB outreach staff, usually a consultant psychiatrist, and this should be part of the doctor's agreed job description in NHS or private units. However, the patient may be so physically ill that admission to such a unit may not be appropriate (see <u>Table 5</u>) or there may be no specialist bed in the locality. In such cases, the options will be:

- 1. A medical or paediatric bed, or
- 2. Treatment in a SEDS using intensive day and outreach care.

See item 3 in <u>Box 2</u> for a description of care when a SEDU is not available.

Table 5: Services that a specialist eating disorders inpatient service should be able to offer and services they are unlikely to offer

| SEDUs and SEDBs will normally be able to offer | SEDUs and SEDBs will not usually offer |
|---|--|
| Nasogastric tube feeding (insertions may be performed off-site) | Intravenous infusion |
| Daily biochemical tests and ECG | Artificial ventilation |
| Frequent nursing observations | Cardiac monitoring |
| Management of compensatory behaviours (water drinking, absconding, exercising, etc.) | Central venous pressure lines |
| Detection, prevention and management of refeeding syndrome | Total parenteral nutrition |
| Sedation or restraint of a highly distressed patient | Cardiac resuscitation ('crash') team |
| Use and management of mental health legislation and safeguarding frameworks | Treatment of serious medical complications |
| Treatment of pressure sores | 24-hour immediate medical availability |
| Immediate cardiac resuscitation without presence of cardiac resuscitation ('crash') team | |
| Access to advice from physicians/paediatricians and dietitians in a timely and flexibly responsive manner, ideally in the form of a MEED group | |

Key:

ECG = electrocardiogram; MEED = Medical Emergencies in Eating Disorders (formerly MARSIPAN); SEDB/U = specialist eating disorders bed/unit

See <u>Box 2</u> for guidance on location of care for children and young people, adults, what to do if a SEDU bed is unavailable, and NGT feeding is required.



Box 2: Guidance on location of care

For **children and young people** requiring hospitalisation, 3 weeks has been suggested for a structured admission to a paediatric setting for restrictive eating disorders¹³³, although in practice the duration will depend on the severity of presentation and an assessment of community support and parent/carer needs. Most patients discharged from paediatric wards will be managed by a specialist community EDS, with a minority requiring further treatment in an SEDU or SEDB. In the latter scenario, if there is difficulty obtaining access to an SEDB or SEDU, this should be escalated to local NHS management. Adult patients with severe eating disorders requiring admission should be cared for by a specialist EDS (in either inpatient or community settings) unless they need medical services that the EDS cannot provide. If they have psychiatric symptoms such as severe self-harm which might be exacerbated in an inpatient setting, assessment by appropriate psychiatric experts should be arranged and a care planning meeting convened in order to recommend the most appropriate management. We suggest that patients with pre-existing electrolyte or renal abnormalities or comorbidity that increase the risk of refeeding syndrome, such as significant infection, should be admitted to a medical ward or a psychiatric unit with excellent medical support, for cautious introduction of feeds with quick-turnaround biochemical monitoring more than once daily.

- 2. If a SEDU or SEDB is indicated but unavailable, the choice is between a medical and a general psychiatric bed without SEDB services. Factors such as the quality of liaison between medical/paediatric team and the EDS, the experience of the general psychiatric unit of managing malnutrition, as well as the clinical condition of the patient and requirements for monitoring, will influence the decision. In many areas there will be a EDS responsible for the population or a liaison team at a nearby hospital. We suggest that a senior member of the EDS or liaison team consult with medical/paediatric and psychiatric colleagues to develop a local strategy to address this problem. This should include training of the general psychiatry or CAMHS team, including consultant psychiatrist input. If a patient is admitted to a medical hospital, we recommend obtaining support from an EDS or a liaison psychiatry service near or in the hospital. A general psychiatric unit should also obtain specialist support and be equipped to offer nasogastric feeding if required.^{134, 135}
- 3. NGT feeding can usually be managed in a SEDS or a SEDB. It would be reasonable for a SEDU/SEDB to ask that a patient's NGT be placed and position verified in a medical/paediatric unit, and that the initial few days of feeding be provided there, until the danger of refeeding syndrome (see <u>Chapter 4</u>) has reduced. However, EDS with substantial experience may be able to care for the patient from the outset and, as elsewhere in this guidance, local solutions must be generated to match local provision.

b. Quality of inpatient care

The quality of health care in the UK is subject to regulation and is overseen by the Care Quality Commission in England, the Care Inspectorates in Wales and Scotland and the Regulation and Quality Improvement Authority in Northern Ireland. To

¹³⁴ <u>https://www.whittington.nhs.uk/document.ashx?id=6128</u>

¹³⁵ <u>https://www.cntw.nhs.uk/content/uploads/2020/10/CNTWC61-Nasogastric-Tube-Feeding-at-Ferndene-and-Ward-31A-V01.1-Mar-2021.pdf</u>

¹³³ https://pubmed.ncbi.nlm.nih.gov/27169764/

support units in developing and maintaining high-quality care, the College Centre for Quality Improvement at RCPsych develop and host Quality Networks.¹³⁶ The networks use a process of regular peer review and self-review against service standards to promote high-quality care. The standards to which these networks encourage members to adhere are developed by clinicians and experts by experience, overseen by multidisciplinary steering groups. The oldest and best-established of these is the Quality Network for Inpatient CAMHS (QNIC), which has a subsection of quality standards for inpatient units treating children and young people with eating disorders. A network for adult inpatient eating disorders units and a network for community EDSs have now been added, comprising the Quality Network for Eating Disorders.¹³⁷ We recommend that inpatient units routinely admitting patients with eating disorders should adhere to these standards and participate in peer review accreditation visits.

c. Transfer between services

Several patient's deaths and other near-miss incidents have occurred following transfer between services at all levels (transfer between CAMHS and adult services, between two inpatient units, between medical units and specialist inpatient services, between primary and secondary care). There are a number of reasons for this. The risk is higher if the patient does not find the receiving unit acceptable, the explanation for which may relate to the receiving unit (inadequate resources, lack of appropriate staff, or that it is new and unknown), or it may be the patient who is unable to accept help because of the nature and severity of their disorder. Lack of consent for such a transfer needs careful consideration, with assessment of capacity and risk, and consultation with family members. Transitions occur in many ways and here discussion is confined to those transitions which can give rise to medical emergencies. Refer to reports by NICE¹³⁸, and the Royal College of Psychiatrists¹³⁹ for a broader discussion.

i. Primary to secondary care

In primary care, because severe anorexia nervosa is seen relatively rarely, there can be a risk of a delay in recognition.¹⁴⁰ Moreover, normal blood tests and relatively preserved energy levels can be falsely reassuring. Any patient with a severe eating disorder can deteriorate rapidly, and should be referred without delay. We recommend that the GP discuss any patient of concern with an eating disorders or liaison psychiatry clinician, the local CAMHS service or a paediatrician/physician, providing as much information from the risk assessment as possible. In primary care, regular weight measurement and repeating any even mildly abnormal test will improve the accuracy of risk assessment, and hence inform how urgently the patient should be assessed. Moreover, when the patient is deemed well enough to return

¹³⁶ <u>https://www.rcpsych.ac.uk/improving-care/ccqi/quality-networks-accreditation/eating-disorders-</u> <u>qed/resources</u>

¹³⁷ https://www.rcpsych.ac.uk/improving-care/ccqi/quality-networks-accreditation/eating-disorders-ged

¹³⁸ <u>https://www.nice.org.uk/guidance/qs175/chapter/Quality-statement-6-Risk-assessment-when-moving-between-services</u>

¹³⁹ <u>https://www.rcpsych.ac.uk/improving-care/campaigning-for-better-mental-health-policy/college-</u>

reports/2017-college-reports/managing-transitions-when-the-patient-has-an-eating-disorder-cr208-nov-2017 ¹⁴⁰ <u>https://www.beateatingdisorders.org.uk/uploads/documents/2017/11/delaying-for-years-denied-for-</u>

<u>months.pdf</u>

home, contact between the secondary provider and primary care must be made with a clear management plan and requirements for monitoring as well as contingency plans if these do not go well. The patient must participate in this process and have a chance to pose questions.

ii. Transferring from one unit to another

Patients transferring between psychiatric, eating disorder and medical units face particular risks. It is the responsibility of the unit arranging the transfer to make sure that it is carried out safely and efficiently. Patients should be stabilised prior to transfer. Patients are usually in a very frail condition, therefore, for their own safety care should be taken to ensure they cannot tamper with their treatment. Use of the Mental Health Act or Mental Capacity Act or equivalent legislation and combined medical treatment, psychiatric monitoring and restraint may be required. Occasional high-dependency care should be available, funded separately by the local NHS commissioners, to provide intensive medical and psychiatric care for such patients if needed.

The choice of transport will depend on local circumstances and geography. Transfer by air ambulance may be the quickest method but can expose the patient to cold and other stresses. A longer transfer by a road ambulance may sometimes be safer, and the potential risks and benefits need to be assessed carefully.

Units should be aware of what is available for patients in nearby areas and have had discussions about where things go wrong. Paediatric/medical units will usually be more worried about nursing care and behavioural management; psychiatric units about medical risk, so understanding what is lacking in each setting is important in improving working together in the interests of patients. If there is no clear shared-care arrangement, it is possible that there will be false expectations around the responsibilities of the teams involved. Staff in an acute hospital may not feel confident to start refeeding if the patient does not cooperate or is in distress, and may expect the psychiatric team to take responsibility, whereas the psychiatric team may assume that the patient will be physically stabilised before transition takes place. As a result, the patient can get worse in the medical/paediatric setting, and may even be too unwell to be transferred to a psychiatric unit once a bed becomes available.

Young people aged 16–18 are particularly at risk if they fall between paediatric and adult services. We advocate specific discussion with local providers about patients in this age group, in which many 'paediatric' issues such as impaired growth and development are still prominent and need of paediatric expertise. Moreover, at any age, discussions about physical, psychiatric, dietetic and nursing management should take place between members of those professional groups in both locations, with written handovers. In any setting, it is essential that, if the patient's needs exceed the capability of ward staff, help, support and advice is requested from the appropriate service.

iii. Transfers between CAMHS and adult services

Although it is recognised that transition from CAMHS to adult EDS is an important¹⁴¹ time of heightened risk, research in this area is limited. The TRACK (Transition from CAMHS to Adult Mental Health Services) study found that 'Optimal transition, defined as adequate transition planning, good information transfer across teams, joint working between teams and continuity of care following transition, was experienced by less than 5% of those who made a transition.'¹⁴² Often there is a significant cultural and resource difference between CAMHS and adult services, with young people's EDS mindful of the responsibilities of the parents/carers and adult EDS focusing on individual responsibility. Differences in culture around responsibility are reflected, for example, in responses to patient non-attendance.

Transfers between CAMHS and adult services need careful planning, making sure that the young person is capable of taking responsibility or their capacity to make decisions about treatment is clarified. Capacity is assumed from the age of 16 until proven otherwise, but it can be difficult to assess in the context of eating disorders (see <u>Chapter 8</u>). Without a careful transition, a sudden change of approach can cause confusion and dissatisfaction at best and tragedy at worst. Both services should take advantage of the knowledge of the patient and family in the long term that can be provided by the primary care team. The GP can be an important bridge, providing support to the patient and their family during transfer between CAMHS and adult services. Transition issues also occur when a young person leaves home to go to a distant institution for higher education and training, and all health care services, primary and secondary, under- and over-18s, should communicate with counterparts in the new location so that patients with eating disorders do not fall through the net. Both the Royal College of Psychiatrists¹⁴³ and, more recently, the NHS Long Term Plan¹⁴⁴ envisage mental health services from birth to 25 years in the expectation that this will address some of the problems of transition we have described. However, in some areas, admission of someone aged 16-18 can raise difficulties: "16- and 17-yearolds may be managed in either [adult or paediatric wards], with no consistency across services, and sometimes there are 'end of the bed' arguments over which service is responsible for the care of a [young adult or adolescent]".¹⁴⁵

iv. Summary

Transitions between different health providers provide substantial challenges and much can go wrong. A structured handover template/agreement as per NICE guidelines¹⁴⁶ and agreed protocols¹⁴⁷ between services can help to ensure safe transfer and optimal transition of people with severe eating disorders between services. <u>Appendix 4</u> contains a template for a handover from one clinical area to another for

¹⁴¹ https://pubmed.ncbi.nlm.nih.gov/16260812/

¹⁴² https://pubmed.ncbi.nlm.nih.gov/18573214/

¹⁴³ <u>https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr208.pdf?sfvrsn=ace4d5db_2</u>

¹⁴⁴ <u>https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf</u>

 ¹⁴⁵ <u>https://www.rcplondon.ac.uk/projects/outputs/why-young-adults-and-adolescents-need-better-healthcare</u>
 ¹⁴⁶ <u>https://www.nice.org.uk/guidance/ng94/documents/draft-guideline-32</u>

¹⁴⁷ <u>https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-reports/college-report-cr208.pdf?sfvrsn=ace4d5db_2</u>

eating disorders. <u>Box 3</u> offers a checklist of the key stages in transfers. As a minimum, when a person is transferred from one service to another, there should be a properly conducted and recorded meeting between representatives of the two services, usually including the patient and family, so that it is clear what will happen during and after the transfer of care, and who is responsible for what. Parent/carer concerns should form part of the risk assessment on transfer. Such meetings should be continued until transfer is satisfactorily achieved. Safe care pathways and joint working between different organisations should be supported by commissioners.

Box 3: Checklist of key stages to address around transfer

From Royal College of Psychiatrists report CR208¹⁴⁸:

- □ Awareness of possible problems including lack of capacity
- $\hfill\square$ Early identification of need to transfer and notification
- $\hfill\square$ Involve family and carers
- □ Flexible timing
- $\hfill\square$ Good communication between services, patient and family
- □ Transition coordinator appointed
- □ Provide comprehensive information
- $\hfill\square$ Both sending and receiving units to have clear protocols and pathways
- Patient-centred transition plan
- Multidisciplinary discharge planning meeting with both units represented
- Overlap period of joint working
- $\hfill\square$ Respect for patient's attachments and the rapeutic alliances
- □ Follow RCPsych CR208 standards for transfer and QED standards for EDSs¹⁴⁹

¹⁴⁸ <u>https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-reports/college-report-cr208.pdf?sfvrsn=ace4d5db_2</u>

¹⁴⁹ <u>https://www.rcpsych.ac.uk/improving-care/ccqi/quality-networks-accreditation/eating-disorders-</u> <u>qed/resources</u>

4. Safe refeeding of malnourished patients with restrictive eating disorders

a. Introduction

This section contains recommendations which are at the core of this guidance and is designed to facilitate physicians, paediatricians, dietitians, nurses and psychiatrists and other health professionals working together with the patient to improve outcomes in eating disorders in paediatric or medical settings. However, other services, including specialist eating disorders services, should find the guidance useful. In this chapter, refeeding and how to achieve it safely is discussed. As elsewhere, allage advice is provided when appropriate, separating into age groups when the content or evidence demands. The emphasis is on treatment of anorexia nervosa, although rapid weight loss and the need for careful nutritional treatment can occur in all eating disorders at any BMI. The evidence for refeeding in ARFID and atypical anorexia nervosa is currently lacking, however. Figure 3 provides a decision tree on how to approach the management of a severe eating disorder, which can begin in primary care. Figure 4 provides guidance on the refeeding process and in Table 6, the process of refeeding and its challenges are listed, together with management advice.

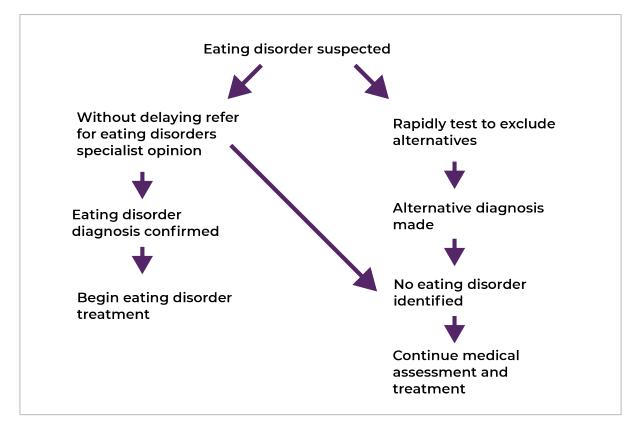
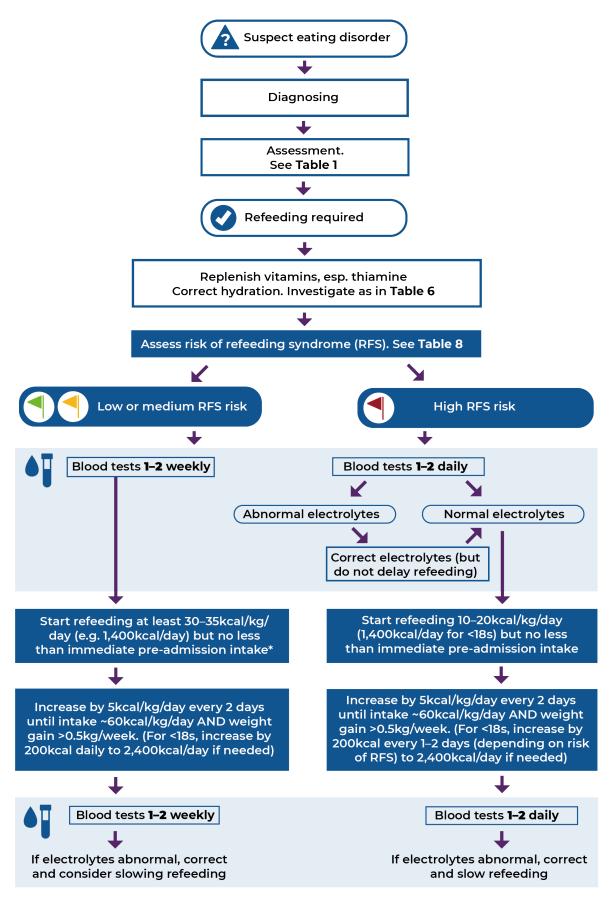


Figure 3: Decision tree for non-specialists in eating disorders (including in primary care)



* In adolescents, an initial rate of 1,400–2,000 kcal per day is safe for most patients.

Figure 4: Refeeding decision tree

Table 6: Clinical management of refeeding of severe anorexia nervosa and other eating disorders with high risk to health and safety

| Area of concern | Findings | Treatment | Notes |
|---|--|--|---|
| Risk assessment | Red ratings on <u>Risk Assessment</u> <u>Framework</u> | Consider management of each risk factor | Consider employment of 1:1 specialist nurse |
| Diagnosis in doubt | Non eating disorder possibilities | Investigate to confirm or rule out alternatives | Do not delay nutrition Alternative diagnosis may be in addition to eating disorder |
| Mobility | Excessive exercise | Restrict exercise | • Provide distraction and alternative activities to reduce distress |
| | Risk of faints and falls | Time limited bed rest and/or wheelchair use | Mobilise as soon as safe Prophylaxis re: pressure sores and DVT |
| | Wants to leave ward | No unaccompanied ward leave | May leave if indicated, with staff or carer |
| Self-care | Washes and showers | Assist and supervise if risk of water loading | |
| | Toilet | • Assist if weak | |
| | | May require supervision if risk of self-induced vomiting or exercise | |
| Physical observations | TPRBP | 4x daily | |
| | GlucoseBM machine | Before meals (depending on severity) | |
| | Weight (kg) | 2x weekly | Patient may not wish to know weight |
| Supportive behavioural observations | Falsifying weight (e.g. water loading) | Consider 1:1 support by trained staff | Consult with psychiatric/EDS staff |
| | Inadequate dietary intake | | |

| Area of concern | Findings | Treatment | Notes |
|-----------------|---|---|--|
| | Self-harm | Consult with psychiatric staff | Consider discharge to community care/ or transfer to mental health setting if medically safe |
| | Other mental health symptoms | Consult with psychiatric staff | |
| Blood tests | Electrolytes: Na K Cl HCO ₃ P Mg Ca | Correct abnormalities | May need to repeat 1–2x per day for first 7–10 days Do not delay refeeding |
| | СК | Increase may suggest dysfunctional exercise | |
| | TransaminaseBilirubin levels | If liver failure predicted (see <u>Risk Assessment</u> <u>Framework</u>) look for other cause | Specialist medical review |
| ECG | Any serious abnormality | Consider cardiac monitoring | Do not delay refeeding |
| Urine | Reduced osmolality | Suggests water loading | |
| Vitamins | Risk of vitamin deficiency | Thiamine 50mg qds (4 x daily). Consider intravenous thiamine, e.g. Pabrinex Replace vitamins, e.g. Forceval or Centrum Advance 1 daily | Continue thiamine for 7–10 days |
| Nutrition | Not consenting or lacks capacity to consent | Psychiatric assessment of consent and capacity | Refer for Mental Health Legislation assessment for compulsory treatment |
| | Tolerates oral intake | If high risk of refeeding syndrome (see <u>Table 7</u>) start at 20kcal/kg/day food and/or supplements Increase by 5kcal/kg every 2 days to ~60kcal/kg/day or more | Monitor electrolytes every 12–24 hours for 5 days to detect refeeding syndrome (low P, K, Mg) Intensive nursing support may be |

| Area of concern | Findings | Treatment | Notes |
|--------------------|---|--|---|
| | | until weight increases by 500g per week or more | necessary at mealtimes to help manage the distress and ensure completion of diet |
| | | If not high risk for refeeding syndrome, start at 30– 35kcal/kg/day food and/or supplements Increase as above | Monitor electrolytes 3x per week |
| | Not tolerating oral food and/or supplements | Pass NG tube Feed as above, using NG feed Rate depends on refeeding syndrome risk | If not consenting, obtain psychiatric opinion regarding compulsory treatment as above |
| Common problems | Hypokalaemia | Suggests vomiting/laxatives or refeeding syndrome | |
| | Hyponatraemia | Suggests water loading | Check urine osmolality |
| | Hypophosphataemia | Suggests refeeding syndrome | |
| | Failure to gain weight | Suggests hiding or disposing of food/feed or excessive exercise | |

b. Refeeding and 'underfeeding' syndromes: recognition, avoidance and management

Refeeding syndrome is a potentially fatal condition¹⁵⁰ that occurs when patients whose food intake has been severely restricted are given nutrition via oral, enteral or parenteral routes. Sudden reversal of prolonged starvation by the reintroduction of food leads to rapid shifts of electrolytes back into cells from which they had, during starvation, been leached out. Phosphate, potassium and magnesium levels can fall very rapidly within the first week of refeeding, with neurological and cardiovascular consequences: this is known as the refeeding syndrome. The resulting effects, most notably cardiac compromise, can be fatal. Respiratory failure, liver dysfunction, central nervous system abnormalities, myopathy and rhabdomyolysis are also recognised complications and patients are at risk of vitamin deficiencies. Refeeding syndrome usually occurs within 72 hours of beginning refeeding, with a range of 1–5 days,¹⁵¹ but bear in mind that it can occur late (in one study, up to 18 days) in the most malnourished. Hence patients discharged before 20 days should be followed up to check electrolytes and detect late appearing refeeding syndrome.

Definitions of refeeding syndrome are highly heterogeneous among studies, with some studies only relying on electrolyte disturbances with different cut-offs, and others also integrating clinical parameters. The definitions by Mariks¹⁵² and Rio *et al.*¹⁵³ are the most commonly used (see <u>Table 7</u>). While refeeding syndrome is an important threat to patients with anorexia nervosa and other restrictive eating disorders, there have been more reported deaths in anorexia nervosa from underfeeding, which sometimes occurs because staff fear inducing refeeding syndrome.¹⁵⁴

Table 7: Clinical and laboratory features of refeeding syndrome (adapted from Rio *et al.*, 2013¹⁵⁵)

Clinical and laboratory features of established refeeding syndrome

Note: Not all features need to be present.

1. Severely low electrolyte concentrations:

- Potassium <2.5mmol/l
- Phosphate <0.32mmol/l
- Magnesium <0.5mmol/l
- 2. Peripheral oedema or acute circulatory fluid overload
- 3. Disturbance to organ function including respiratory failure, cardiac failure or pulmonary oedema, raised liver transaminases

¹⁵⁰ <u>https://www.who.int/bulletin/volumes/94/9/15-162867/en/</u>

¹⁵¹ <u>https://journals.lww.com/md-</u>

journal/fulltext/2020/01030/refeeding_syndrome_is_associated_with_increased.22.asp

¹⁵² https://jamanetwork.com/journals/jamasurgery/article-abstract/596636

¹⁵³ https://bmjopen.bmj.com/content/3/1/e002173

¹⁵⁴ MARSIPAN and Junior MARSIPAN, available from the senior author of this guideline.

¹⁵⁵ <u>https://bmjopen.bmj.com/content/3/1/e002173</u>

Symptoms of refeeding syndrome can occur in inpatients or outpatients. Monitoring for hypophosphataemia is essential, because it is one of the earliest clinical indicators that heralds onset of refeeding syndrome and is easily treatable. Hypophosphataemia is defined as a phosphate level <1mmol/L (adolescents)¹⁵⁶ and <0.8mmol/L (adults).¹⁵⁷ The incidence of hypophosphataemia during refeeding varies, but is typically reported in 8–18% in adolescents admitted with anorexia nervosa for refeeding.^{158,159}



Case study 1: A patient with a BMI of 14.5 had been eating almost nothing. His psychiatrist told him that unless he could reverse the weight loss, he might find himself in hospital. Terrified by this prospect, he began to overeat (binge) to restore weight. Within 3 days, his serum phosphate level had fallen to 0.6mmol/L and he required oral phosphate supplements to correct this abnormality.

Traditionally, refeeding syndrome has been managed by hypocaloric feeding with slow introduction of calories^{160, 161} This approach seems to be appropriate for patients with malnutrition due to medical illness, in whom a coexistent inflammatory response is often present, which may increase the likelihood of refeeding syndrome. Patients in which an acute inflammatory response is present usually have significant underlying medical conditions and should be treated as high risk and managed in a medical setting. Patients with uncomplicated anorexia nervosa do not usually have an acute inflammatory response and typically have normal plasma albumin, urea and CRP.

However, the cautious approach advocated for those with medical conditions can result in underfeeding in some patients with anorexia nervosa. Underfeeding occurs when clinicians are overly concerned about the risk of refeeding syndrome or follow guidance intended for medically compromised patients. Underfeeding can inadvertently prolong the acute risk of potentially life-threatening undernutrition.¹⁶²



Case study 2: An adolescent girl was transferred from the adolescent psychiatric unit to the paediatric setting because she was losing weight and had become medically unstable. On the paediatric ward, refeeding via NGT was instituted at a cautious rate following nutritional guidelines. She lost a further 6kg on the paediatric ward before a specialist opinion was sought.

There are several studies, including three randomised controlled trials, published since 2013 reflecting increased awareness of refeeding syndrome and demonstrating that, with higher-calorie approaches and electrolyte supplementation, refeeding syndrome is manageable^{163, 164} at least in adolescents. Together with the literature on

¹⁵⁶ <u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6159900/</u>

¹⁵⁷ https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3319220/

¹⁵⁸ <u>https://europepmc.org/article/med/25151056</u>

¹⁵⁹ <u>https://pubmed.ncbi.nlm.nih.gov/25625572/</u>

¹⁶⁰ https://pubmed.ncbi.nlm.nih.gov/18583681/

¹⁶¹ <u>https://www.nice.org.uk/guidance/cg32</u>

¹⁶² https://pubmed.ncbi.nlm.nih.gov/23241095/

¹⁶³ <u>https://pubmed.ncbi.nlm.nih.gov/26661289/</u>

¹⁶⁴ https://jamanetwork.com/journals/jamapediatrics/article-abstract/2771984

refeeding syndrome (see <u>Chapter 4.b</u>), and clinical experience, this suggests that for most patients, an overly cautious approach to refeeding is not necessary, but close monitoring is required. Garber *et al.*'s study¹⁶⁵ concludes that higher calorie refeeding beginning at 2000kcal/day from the outset increasing by 200kcal/day is safe for most patients. However, in patients at high risk, a more careful approach may be needed.

i. Indicators of higher risk for refeeding syndrome

Predictors for the development of refeeding hypophosphataemia include low white blood cell count¹⁶⁶ and higher haemoglobin level.¹⁶⁷ Patients at the highest risk of refeeding syndrome are those with very low weight, minimal or no nutritional intake for more than 3–4 days, weight loss of over 15% in the past 3 months, and with abnormal electrolytes and medical comorbidities such as pneumonia or other serious infections, cardiac dysfunction or disease and liver damage (e.g. due to alcohol dependence) before refeeding (<u>Table 8</u>).

Any patient at high risk of refeeding syndrome should be managed in an acute medical environment with high-dependency facilities available if needed. In the majority, this will be an acute medical/paediatric unit but could be a SEDU if it is colocated on an acute hospital site with high dependency (HDU) facilities should they be required or unless there is an extenuating clinical circumstance which suggests another care environment is more appropriate as determined by the multidisciplinary team.

| Clinical feature | High risk level | Management |
|---|--|---|
| Extremely low weight | %mBMI <70% BMI <13 ¹⁶⁸ | Cautious refeeding |
| Prolonged low intake | Little or no intake for >4 days | Cautious refeeding |
| Deranged baseline electrolytes | Low potassium, phosphorus, magnesium | Measure levels up to twice per day initially and supplement as needed |
| Low white blood cell count | <3.8 | Monitor |
| At risk for low thiamine The precise requirement for thiamine is not known. | Low thiamine and other vitamins | Pabrinex, oral thiamine. and multivitamins. |
| Medical comorbidities and/or complications | Infection, e.g. pneumonia, cardiac disease liver disease, alcohol misuse, other serious disease | Should be discussed with an acute medical unit and HDU/ICU considered if the patient has a serious comorbidity. Refeed cautiously |

Table 8: Factors associated with the risk of refeeding syndrome

¹⁶⁵ <u>https://pubmed.ncbi.nlm.nih.gov/33074282/</u>

¹⁶⁶ https://pubmed.ncbi.nlm.nih.gov/26869609/

¹⁶⁷ https://pubmed.ncbi.nlm.nih.gov/25846384/

¹⁶⁸ <u>https://pubmed.ncbi.nlm.nih.gov/31584711/</u>

Although the risk of refeeding syndrome is greatest in the first few days of refeeding, the syndrome may develop later¹⁶⁹ and biochemical monitoring should continue until electrolyte parameters are stable and extend to 2 weeks to detect late developing RFS.¹⁷⁰

c. Guidance for refeeding

See <u>Table 6</u> for clinical management of refeeding patients with severe anorexia nervosa and other eating disorders who are at high risk.

i. Initial approach

Initiating nutritional treatment can be very frightening for a severely ill patient, and staff must recognise the possible trauma that the patient is experiencing. Supporting a patient with these anxieties is key to effective treatment and is a skill that all staff working with patients with eating disorders should aspire to. Empathy and compassion are foremost, coupled with an understanding of treatment needs. This can work best when mealtimes are time limited with, for example, 20 minutes allocated for food to be eaten and if this is not managed an oral supplement can be offered for a further 10 minutes. If neither are managed, NGT feeding may be required.

Guidelines on initiation rates for refeeding patients with anorexia nervosa vary significantly and is an area of ongoing academic and clinical debate. Suggested caloric intakes range from 5–10kcal/kg¹⁷¹ in high-risk patients, 25–35kcal/kg/day for adults and 50kcal/kg/day for 15- to 18-year-olds¹⁷² and up to 60kcal/kg/day for 11- to 14-year-olds.¹⁷³ We agree with the British Dietetic Association (BDA) guidelines,¹⁷⁴ who recommend that refeeding starts at 30–35kcal/kg/day (less if the patient is of very low weight and clinically unstable) and increases by 200–300kcal/day every 2–3 days, so that weight is starting to increase by the seventh day (although this may be delayed if purging, tampering with feed, or other behaviours driven by fear of weight restoration continuing). Also advised are the provision of intravenous B vitamins (Pabrinex) and phosphate supplementation at the onset of refeeding for low weight patients. These latter recommendations align with the higher caloric recommendations in the NICE guidance on nutrition support for adults¹⁷⁵ for people who are not severely ill or injured, nor at risk of refeeding syndrome.

In a systematic review, O'Connor *et al.*¹⁷⁶ concluded that severity of malnutrition appeared to be a more relevant predictor of refeeding syndrome than the rate of

¹⁶⁹ https://pubmed.ncbi.nlm.nih.gov/31584711/

¹⁷⁰ https://pubmed.ncbi.nlm.nih.gov/12507806/

¹⁷¹ https://www.nice.org.uk/guidance/cg32/resources/nutrition-support-for-adults-oral-nutrition-support-enteraltube-feeding-and-parenteral-nutrition-pdf-975383198917

¹⁷² <u>https://pdfslide.net/download/link/refeeding-syndrome-guidelines-cape-town-syndrome-guidelines-cape-</u> town-metropole.html

¹⁷³ https://pubmed.ncbi.nlm.nih.gov/12468372/

¹⁷⁴ British Dietetic Association, 2018/2020, Practical guidelines for refeeding adult patients with anorexia nervosa. Available on request from the BDA.

¹⁷⁵ https://www.nice.org.uk/guidance/cg32

¹⁷⁶ https://pubmed.ncbi.nlm.nih.gov/23459608/

calories provided. The Parenteral and Enteral Nutrition Group of the BDA have produced a useful guide to managing and avoiding refeeding syndrome.¹⁷⁷

Refeeding: Summary of research in adolescents

The evidence to guide refeeding is stronger in **adolescents** than in adults. Whitelaw *et al.* (2010),¹⁷⁸ in a sample of 29 adolescents in Australia, with a mean body weight of 72.9%, found that, starting at 1,900kcal or higher in the majority of the sample, 37% of patients developed mild hypophosphataemia and no one developed moderate or severe hypophosphataemia. This equates to about 42kcal/kg/day for a 45kg adolescent or 47.5kcal/kg/day for a 40kg adolescent. However, four adolescents were considered at sufficiently high risk to start with lower regimes or on rehydration alone. Low body weight was associated with the subsequent development of hypophosphataemia. Madden *et al.* (2015),¹⁷⁹ also in Australia, studied a rapid refeeding protocol, starting at 2,400kcal/day with a combination of low carbohydrate NGT and oral feeds, and weaning onto full oral diet of 2,400–3,000kcal/day over 2 weeks. They found no indicators of refeeding syndrome in 78 patients aged 12–18 years with a mean %mBMI of 78%.

O'Connor *et al.* (2016)¹⁸⁰ carried out the first multicentre, single-blind, randomised controlled trial of 36 patients with anorexia nervosa, aged 10–16 years, in UK paediatric settings. Mean %mBMI was lower in this study, at 70%, with all patients under 78%. Participants were randomised to start refeeding at 500kcal/day (control group, mean calories 16kcal/kg/day) or at 1,200kcal/day (intervention group, mean calories 38kcal/kg/day), with both groups increasing by 200kcal/day. Refeeding at the higher rate had no adverse effect on QTc interval or HR and no significant increase in the incidence or severity of hypophosphataemia.

A more recent trial¹⁸¹ used an even higher caloric regime, comparing outcomes from higher-calorie refeeding, beginning at 2,000kcal/d and increasing by 200kcal/d, versus lower-calorie refeeding, beginning at 1,400kcal and increasing by 200kcal every other day in 120 adolescents. Short-term outcomes found that the higher-calorie refeeding restored medical stability significantly earlier than lower-calorie refeeding (hazard ratio, 1.67 [95% CI, 1.10–2.53]; P=.01), that electrolyte abnormalities and other adverse events did not differ by group, and that hospital stay was 4.0 days shorter among the group receiving higher-calorie refeeding resulting in significant cost savings. A 1-year follow-up of this study found no difference in clinical outcomes and health care utilisation in the high and lower-calorie refeeding groups.¹⁸²

In summary, the most up-to-date evidence suggests that for adolescents, starting at 1,400–2,000kcal/day, and increasing by at least 200kcal/day up to around 2,400kcal/day (some patients require higher calorie intakes to gain weight), is safe for all except patients at highest risk, provided that medical parameters are closely monitored (see <u>Table 7</u>). A key consideration is that no patient should be started on a

¹⁷⁷ https://www.peng.org.uk/pdfs/presentations/2017/rhys-white.pdf

¹⁷⁸ https://pubmed.ncbi.nlm.nih.gov/20472215/

¹⁷⁹ <u>https://pubmed.ncbi.nlm.nih.gov/25017941/</u>

¹⁸⁰ <u>https://pubmed.ncbi.nlm.nih.gov/26869609/</u>

¹⁸¹ <u>https://pubmed.ncbi.nlm.nih.gov/33074282/</u>

¹⁸² https://pediatrics.aappublications.org/content/pediatrics/early/2021/03/18/peds.2020-037135.full.pdf

lower-calorie amount than they were eating prior to admission, provided that there is confidence in self-reported intakes. An expectation is set that there will be a steady calorie increase until weight restoration of 0.5–1kg/week¹⁸³ is achieved. Higher rates of weight gain, up to 2kg/week, are thought to be safe as long as there is close psycho-physical monitoring. In one inpatient study¹⁸⁴ the mean optimal rate of weight gain was 2.1kg/week and 5% of the series gained over 3.3kg per week. Higher-calorie refeeding seems to be well tolerated, provided that the patient is closely monitored with electrolyte replacement.¹⁸⁵ No study of higher-calorie feeding since 2010 has reported a case of refeeding syndrome.

Refeeding: Summary of research in adults

In **adults,** the evidence base is much weaker and opinion is divided between SEDUs, in which higher calories are provided from the outset, and medical units, in which, undoubtedly, more unwell patients are seen and where practice is more conservative. There is an urgent need for a study of refeeding adults with anorexia nervosa in order to establish an evidence base for practice. In the absence of large prospective studies we offer the following guidance:

- First, identify any medical comorbidities that make the patients at high risk of refeeding syndrome. Examples are diabetes mellitus and occult sepsis, which is often missed. (See <u>Table 1, Risk Assessment Framework</u> and <u>Table 2, guidance</u> <u>on management of clinical findings</u>)
- 2. The patient should not be started on fewer calories than they were consuming prior to admission; because feeding is the life-saving treatment that needs to be administered, this should be the clinical priority. If intake is uncertain, start as per point 3 or 4 (below) depending on risk.
- 3. Patients with anorexia nervosa with evidence of an acute inflammatory response (i.e. raised CRP), low albumin, deranged electrolytes or raised WCC should be regarded as at high risk of refeeding syndrome and other potential complications and managed accordingly.
- 4. If the patient has a BMI<13 in addition to the clinical features suggesting additional physical risk described in point 3 (above), then start feeding at around 10kcals/kg/day increasing daily. It is rarely necessary to delay daily increases in calories due to refeeding syndrome or pending electrolyte correction. Similarly, it is not necessary to delay starting feeding to correct electrolytes. If electrolytes are significantly deranged on presentation, an HDU may be the most appropriate care area for correction while feeding is established.
- 5. In the absence of other medical comorbidities, feeding can be safely started at a higher level than in patients who are malnourished for other reasons.

¹⁸³ This range reflects an expert consensus rather than having a clear evidence base.

¹⁸⁴ <u>https://pubmed.ncbi.nlm.nih.gov/28186654/</u>

¹⁸⁵ <u>https://pubmed.ncbi.nlm.nih.gov/29656932/</u>

Although there is a dearth of published data in adults, the total number of adults reported in case studies and five case series^{186, 187, 188, 189, 190} is at least 296. While refeeding hypophosphataemia is reported (up to 45% in the most severely ill patients), no case of refeeding syndrome or death is reported from this five-case series. However, the frequency with which refeeding hypophosphataemia occurs does point to the risk of refeeding syndrome which, although rare, can be fatal. Patients admitted to medical units may well be more unwell and have lower BMI than those admitted to SEDUs, and also may have coexisting complications such as sepsis, electrolyte imbalance and cardiac failure, and the combination of such factors will influence the risk of refeeding syndrome and complicate treatment.

We regard assessing the risk of refeeding syndrome against the risk of underfeeding syndrome, which has been associated with a number of deaths as overly cautious. Published recommendations such as those from the American Society for Parenteral and Enteral Nutrition¹⁹¹ in which "10–20kcal/kg for the first 24 hours, advance by 33% of goal every 1 to 2 days" is recommended for all patients with anorexia nervosa with BMI <16. Similarly, BAPEN¹⁹² recommend a maximum of 10kcal/kg per day, which we regard as too conservative in uncomplicated patients at lower risk of refeeding syndrome. In adults with anorexia nervosa with no features of an acute medical condition or inflammatory response, and with a BMI <13, the limited data suggest that higher rates of feeding can be used safely, provided the patient is monitored carefully and appropriate action taken if refeeding syndrome develops.

In summary, adult patients with evidence of active medical comorbidities, particularly if acutely ill, or with a BMI <13 should be refed cautiously, ideally in a unit with experience in refeeding critically ill patients. There is a consensus among eating disorder specialists contributing to this document that for patients admitted to EDSs (SEDUs, SEDBs) and those without features suggesting increased risk, refeeding can proceed more rapidly, as recommended by the BDA. In all cases, patients must be monitored frequently, given vitamins, especially thiamine, and underfeeding avoided.

ii. Initiating nutrition during refeeding

The process of improving nutrition in someone who has been eating very little can be difficult for the patient. At the same time, the staff are tasked with getting quite a technical process right, and as long as they do, the patient will get better and hopefully will be able to take over responsibility for their nutrition in time. A patient who is fully involved in decision-making, understands the process and is kept fully informed, is more likely to work with the team to improve health.

In the case of young people, the responsibility for accepting or rejecting treatment is shared with carers to a greater or lesser extent. Parents should be offered the chance to feed their child in hospital where that is appropriate.

¹⁸⁶ https://pubmed.ncbi.nlm.nih.gov/29656932/

¹⁸⁷ <u>https://pubmed.ncbi.nlm.nih.gov/19169075/</u>

¹⁸⁸ https://pubmed.ncbi.nlm.nih.gov/17499892/

¹⁸⁹ https://pubmed.ncbi.nlm.nih.gov/25625572/

¹⁹⁰ <u>https://pubmed.ncbi.nlm.nih.gov/22170021/</u>

¹⁹¹ <u>https://pubmed.ncbi.nlm.nih.gov/32115791/</u>

¹⁹² https://www.bapen.org.uk/nutrition-support/assessment-and-planning/nutritional-assessment?start=2

1. Feeding rates

Among the technical issues that the team needs to get right are how much food (or feed) to offer and how rapidly. In the UK, most specialist services offer three main meals and three snacks, although international practices vary. Regular small meals can be helpful to prevent hypoglycaemia and may also be easier to manage for the patient than smaller number of larger meals. Severely unwell patients usually need one-to-one nursing support during mealtimes. Feeding rates should increase incrementally, e.g. every 1–2 days until the patient is consistently restoring weight. Slower, lower rates of refeeding may be appropriate for patients with unstable clinical features, such as infection.¹⁹³ If lower-calorie intakes are prescribed, this, and the reasons behind it, must be carefully explained to the patient, the feeding regimen must be reviewed frequently (e.g. every 12 hours) and the regimen increased as soon as there is no clinical reason to continue the lower-calorie intake. It is usually unwise for staff to discuss specific calorie provision with a patient of any age. If phosphate levels fall, intake should remain static, not reduce, until it stabilises.

2. Blood monitoring

Typically, blood tests are done daily during the at-risk period, usually days 2–5, in those who are being re-fed through an NGT or who have risk factors for refeeding syndrome. In those with electrolyte disturbances, the tests may need to be repeated every 12. This usually requires acute hospital admission. The reasoning behind frequency of testing should be explained to the patient. Repeating blood electrolytes after 7–10 days is recommended because of the risk of late refeeding syndrome.

For those who are re-fed orally without additional risk factors or who are being managed as outpatients, and where the risk of refeeding is judged to be low, the frequency of blood monitoring will be part of an individualised management plan. For most patients, the aim is to reach full nutritional requirements for steady weight restoration to begin in 5–7 days. The outcome of inpatient treatment is best predicted by early improvement in symptoms.¹⁹⁴

3. Refeeding at home

If refeeding is being undertaken at home, a staged approach through portion size (rather than calorie counting) is advocated, starting at quarter portions, increasing to half portions, full portions, extra portions, with 3 meals, 3 snacks and adequate fluids. Blood tests should be performed at least twice weekly. Once the initial refeeding risk has passed, usually after the first week, meal plans should be altered to ensure continued weight restoration. This requires relatively reliable weight measurement, which can be challenging. It is important that reliance on weight measurement does not take precedence over common sense. There is little evidence to guide such an approach, and if in doubt, the inpatient approach outlined above should be followed.

¹⁹³ <u>https://pubmed.ncbi.nlm.nih.gov/26661289/</u>

¹⁹⁴ https://pubmed.ncbi.nlm.nih.gov/26171853/

4. Weight monitoring

Weight is best monitored no more than twice a week in both inpatient and outpatient contexts, preferably before breakfast, after toilet and in underwear for inpatients, and in light clothing, without shoes for outpatients. Staff, parents and carers need to remain vigilant about food disposal, exercising, vomiting, water-loading and other concealed weights, all of which can explain unexpected changes in weight. Weight trends are more important than individual weight measurements. Access to scales may need to be restricted to decrease the likelihood of frequent weighing by the patient. We suggest that staff consider keeping documentation of weight away from the patient bedside and avoid openly discussing a patient's weight or change in weight during ward rounds and other meetings near the patient. It should be decided by the clinical team whether the weight is shared with a patient.

5. Carbohydrate and phosphate intake

Avoidance of refeeding syndrome, which is insulin-mediated, can also be encouraged by limiting carbohydrate calories¹⁹⁵ and increasing dietary phosphate. A diet that incorporates foods high in phosphate (e.g. milk) may be helpful. If refeeding is by NGT or nutritional supplements, those higher in concentration (e.g. 2kcal/ml) have higher levels of carbohydrate and may therefore be more likely to produce refeeding syndrome. A randomised trial of refeeding with different levels of carbohydrate¹⁹⁶ is under way in Australia and results will be available in due course.

iii. Micronutrients

Many guidelines advocate prescribing electrolyte, vitamin and mineral supplementation, as medically necessary, immediately prior to initiating feeding and for the first 10 days of refeeding or until medically stable. Some guidance on micronutrient replacement is provided in <u>Table 9</u>, but local trusts may use different preparations and parameters. Please refer to local trust/pharmacy guidelines.

| Supplementation | Administration |
|------------------------------------|---|
| Pabrinex | Ampoules 1+2 by infusion ¹⁹⁷ over 30 minutes or Intramuscular ¹⁹⁸ administration |
| Thiamine (NICE 2006) | 50mg qds (four times daily) |
| Vitamin B Co-Strong (NICE 2006) | 1–2 tablets, three times daily |

| Table 9: Micronutrient replacement in severe anorexia nervosa and other restrictive eating |
|--|
| disorders |

¹⁹⁵ <u>https://pubmed.ncbi.nlm.nih.gov/33236366/</u>

¹⁹⁶ https://bmjopen.bmj.com/content/10/10/e038242

¹⁹⁷ https://www.medicines.org.uk/emc/product/1427/smpc

¹⁹⁸ <u>https://www.medicines.org.uk/emc/product/1426/smpc#gref</u>

| Balanced Multivitamin/Trace Element Preparation (e.g. Forceval) (NICE, 2004) | One capsule daily |
|--|---|
| Phosphate | 500mg twice daily orally/via NGT (see text for <18s advice) |

Prescribing a complete multivitamin and mineral supplement (e.g. Forceval[®]) for malnourished young people is logical and carries minimal risk. For older adolescents and those with chronic illness, following adult guidelines on prescription of thiamine and phosphate is justifiable and prescription of a supplement, such as Forceval[®] or Centrum Advance[®], is advised given the multiple deficiencies found in patients with eating disorders¹⁹⁹. In general, micronutrient deficiencies are more likely the longer the duration of the restriction and the severity of undernutrition.

There is no evidence to support routine phosphate supplementation to prevent refeeding hypophosphataemia in young people unless the phosphate level is falling, at which point Phosphate Sandoz (effervescent sodium acid phosphate), 2–3mmol/kg/day, should be given in two divided doses and adjusted based on phosphate levels. Note that there are differences in normal phosphate level by age, e.g. 3–10 years, 1.2–1.8mmol/L; 10–15 years, 1.1–1.75mmol/L; >15 years, 0.8–1.45mmol/L.

In **adults**, phosphate (500mg [16.1mmol] twice daily) may be provided prophylactically to support refeeding, particularly in cases at high risk of refeeding syndrome. Blood levels need to be monitored regularly and treatment is not usually needed for longer than a few days. It may cause side effects²⁰⁰ including diarrhoea, and symptoms of hypocalcaemia,²⁰¹ which should lead to review and possible reduction in dose.

For adult patients with severe hypophosphataemia, use of intravenous supplementation at a dose of 20–30mg/kg/day, in divided doses is recommended, usually infused over 6 hours^{202, 203, 204}

There are no accepted guidelines for adolescents with refeeding hypophosphataemia, but published advice²⁰⁵ is:

- 1. For moderate hypophosphataemia (e.g. 1.1–3.0mg/dL [0.36–0.97mmol/L], exact range will depend on the patient's age, as above) oral supplementation at a starting dose of 30–60mg/kg/day, divided three to four times per day, adjusted based on repeated serum phosphate measurements.
- 2. Intravenous phosphate replacement should be considered for severe hypophosphataemia (e.g. <1.0mg/dL, 0.25mmol/L), and requires close monitoring and frequently a higher level of care (e.g. HDU/ICU, depending on local policy) due to risks of cardiac arrhythmia when intravenous phosphate is infused. A dose of 20–30mg/kg/d in divided doses usually infused over 6 hours

¹⁹⁹ https://pubmed.ncbi.nlm.nih.gov/22349551/

²⁰⁰ <u>https://bnf.nice.org.uk/drug/phosphate.html#sideEffects</u>

²⁰¹ <u>https://pubmed.ncbi.nlm.nih.gov/7351810/</u>

²⁰² <u>https://pubmed.ncbi.nlm.nih.gov/12507806/</u>

²⁰³ https://pubmed.ncbi.nlm.nih.gov/25846384/

²⁰⁴ <u>https://pubmed.ncbi.nlm.nih.gov/25830024/</u>

²⁰⁵ https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6159900/

has been recommended. Locally developed protocols may use different thresholds and, if that is the case, local policy should be followed.

iv. If the patient strongly resists refeeding

It is rare for a severely ill patient to engage in active resistance to attempts to feed them. However, the process can be terrifying for the patient because of the intense feelings engendered by the eating disorder. This situation can be very challenging to manage, particularly in acute settings. Restraint is a last resort, and all other alternatives should be tried first. These include helping the patient understand the need for nutrition, offering choice about the type of foods or supplements with the help of a dietitian experienced in helping people with eating disorders. Expert nursing support and distraction strategies can be helpful to reduce anxiety relating to eating or fear of weight restoration.

1. Psychological support and use of legal frameworks

Psychological support to manage the patients' distress can be important for the patient and the team. The possibility of comorbid ASD should be borne in mind when considering supportive interventions and how these are communicated about with the patient. Treatment against the patient's consent should only ever be done within an appropriate legal framework, such as the Mental Health Act or equivalent legislation, and only by staff trained in control and restraint techniques. We recommend clear instructions, with visual illustrations of techniques, to be given to staff regarding the details of how control and restraint is applied, particularly in the context of a physically frail person who may have osteoporosis.

2. Psychotropic medication

There is very little literature on the use of psychotropic medication during refeeding and there are medical problems that could arise when a dose of a sedative drug is given to a severely nutritionally compromised patient. Olanzapine has been used in anorexia nervosa,²⁰⁶ and is known to help with extreme anxiety, especially in early recovery, thus making it easier to adhere to the meal plan.

3. Summary of best practice

More research is needed to inform minimising restrictive practices in severely malnourished patients with anorexia nervosa. In the interim, best practice can be summarised as follows:

- medications used include oral olanzapine and oral and (rarely) parenteral benzodiazepines
- use the lowest dose possible because of the risk of physical complications, especially hypotension and respiratory arrest, in profoundly malnourished patients
- offer the patient access to psychological intervention in relation to their distress and offer clinical staff involved in delivering care, psychological supervision or consultation.

²⁰⁶ https://ejnpn.springeropen.com/track/pdf/10.1186/s41983-020-00195-y.pdf

- ensure sedation takes place in a setting where staff are trained to manage complications
- monitor in medical ICU for the most severely compromised patients
- staff using physical restraint methods (e.g. for patients pulling out a percutaneous endoscopic gastrostomy [PEG] tube) should be appropriately trained in safe restraint specifically for patients with eating disorders
- close working between psychiatrists, physicians/paediatricians/intensivists and anaesthetists is essential.

v. Refeeding patients with prominent autistic traits

For patients with diagnosed or suspected autistic traits it is important to consider that, at presentation, their malnutrition may be chronic and with multiple micronutrient vulnerabilities due to sensory aversions. This may increase refeeding risk. Sensory aversions need to be acknowledged and worked with when managing refeeding with an oral diet. Micronutrient supplementation may be difficult if the patient is unable to take medication orally and intravenous or intramuscular supplementation may need to be considered. Involving specialists in ASD will help support developing effective treatment plans.

5. Nasogastric and other routes of feeding

a. Introduction

The preferred option for refeeding will always be via oral food and fluids. However, some patients struggle to restore weight when fed orally and some may opt for nasogastric tube (NGT) feeding because they may feel less responsible for the weight gain, rendering it more acceptable.²⁰⁷ Most patients will accept an NGT if it is calmly explained why it is necessary (and that it is not a punishment), as will parents/carers. The nature of eating disorder cognitions means that the patient may experience an increase in distressing thoughts upon the reintroduction of an oral intake and relief from distress when nutrition is compelled. This is especially the case for individuals for whom the major threat is guilt due to the perception that they do not deserve to eat. In such cases, the fear is of their personal responsibility for eating/weight restoration more than its mere occurrence.

Others may resist weight gain by any means, and in such cases compulsory treatment (always under the relevant legislation) to enable NGT feeding may be necessary. This should certainly occur if the level of malnutrition is life threatening. Insertion of an NGT against the patient's will usually requires the presence of mental health nurses or other staff trained in safe control and restraint techniques.

Psychiatric opinion should be sought from an eating disorder specialist or a liaison psychiatrist regarding the appropriate legal framework in place before embarking on this procedure.

i. Duration of NGT feeding

NGT feeding is usually a short-term measure and can be tailed off as oral intake improves with psychological and nursing support. NGT feeding may reduce opportunities to eat meals/snacks and occasionally the tube could be used for selfharm (e.g. as a ligature) so a risk assessment is required. Some patients may require NGT feeding for several months while others, despite poor physical health, will be able to eat sufficiently within hospital settings having previously refused in the community. It should never be presumed that just because a patient requires hospital admission they would refuse to or be unable to eat when provided with the appropriate skilled support in a conducive environment.

ii. Dietetic assessment

Dietitians with appropriate expertise should facilitate a full dietetic assessment that includes consultation with the patient, family/carers and the EDS professionals involved. If supplemental drinks and/or NGT feeds are to be used, a prescription is required and the services of a dietitian utilised for appropriate monitoring and nutritional review. It is the role of the hospital dietitian to create, monitor and modify any meal plan that is needed during an acute hospital admission.

²⁰⁷ https://pubmed.ncbi.nlm.nih.gov/11285581/

iii. Continuous and intermittent feeding

Delivering a constant and controlled supply of nutritional replacement via continuous NGT feed is likely to be the safest way of minimising refeeding risk in the severely ill patient. However, intermittent or bolus feeding may be more appropriate for some patients, reflecting the pattern of normal food intake. Bolus feeding may reduce the opportunity for the patients to tamper with the feed and reduces the length of time of feeding when the patient is distressed. Hence, it is often the preferred method in specialist units.

b. When to consider NGT feeding

NGT feeding should be considered if:

- The patient is unable to achieve sufficient oral fluid and nutritional intake from food and/or sip feeds to stabilise and restore physical health, **or**
- The patient is unable to eat at all but is accepting of NGT feeding, or
- There is life-threatening weight loss (clinicians should use their judgement, but a rough guide is %mBMI <13 in adults; %mBMI <70 in children) or where there is immediate danger to the patient due to physical deterioration, **or**
- The patient presents with clinical or biochemical instability, including those associated with refeeding syndrome.

c. Monitoring

The patient should be offered food or prescribed dietary supplements in the first instance. If the patient is unable to achieve sufficient intake after 24 hours, NGT feeding should be considered in collaboration with the patient (as much as possible). Factors such as baseline medical risk, duration of restriction and an assessment of the likelihood that the behaviour will change (based on history) should be taken into account. If the patient refuses to consent, the application of the relevant legal framework should be considered, i.e. a Mental Health Act assessment or equivalent, in order to deliver life-saving treatment.

Weight needs to be closely monitored during NG feeding and the rate of feeding increased if weight gain is inadequate. Parents and carers should be kept informed of such changes so they can support the patient in coping with them.

i. Supplemental drinks and/or bolus NGT feeds

Supplemental drinks and/or bolus NGT feeds need to be observed or closely monitored. Some eating disorder specialists advocate day-time bolus feeds at mealtimes, to mimic physiological demand and so that choice can be offered on each occasion, e.g.: 'We can feed you by tube, but we'd rather you were able to have the food or the supplement drink. Have a sip', and, only after that: 'OK, would it be easier to have tube feeding this time?'

ii. Night-time feeds

Night-time feeds are less helpful in anorexia nervosa than in other conditions because patients often stay awake to monitor the feed or may tamper with it. There is also a risk of aspiration of feed if the NGT is dislodged while the patient is asleep. However, under some circumstances, e.g. when blood glucose is falling to hypoglycaemic levels repeatedly, slow continuous feeding may be medically advised, and may need to continue through the night. Continuous NGT feeds need to be closely monitored.

iii. NGT feeding protocol

NG feeding must be delivered in accordance with the clinical unit's protocol with, e.g., appropriate charting of the prescription, the volume administered and the safety checks carried out on the NGT. There is a risk that patients who are not adequately monitored may remove the NGT, to avoid having the appropriate nutrition. NGT can be interfered with by cutting, feed run into the bed or toilet, removed then re-inserted (with a risk of the NGT going into a lung), and tampering with pump and pump locks. NGT feeding in general, and when given via an enteral pump, is not advocated without close supervision.

NG feeding is dangerous if it does not follow a protocol so should only be carried out in situations where staff have appropriate training and experience. NGT feeding is often commenced on a medical/paediatric ward unless adequate monitoring and treatment is available in a SEDU/SEDB. Advice on the safe implementation of NGT feeding can be requested from the National Patient Safety Agency.

iv. Patient preference for NGT

Some patients may express a preference for NGT feeding. Such a request should be considered carefully by the multidisciplinary team and a plan agreed to support reintroduction of oral intake if NGT feeding is agreed. If the patient remains in hospital after stabilisation on dietary supplements or NGT feeding, introduction of solid food is a priority. The dietitian can advise on appropriate matches to the hospital menu.

v. Recording oral intake

It is important that an accurate record of food, drinks, supplements and NGT feeds are kept by staff at the initial phases of refeeding. In the case of younger patients, if parents/carers have some responsibility for this, the records need to be kept up to date by them as well. A fluid chart should be kept, away from the bedside and completed by nursing staff, or a parent/carer if appropriate. This information can also help actively engage the patient in treatment.

vi. Transitioning from NGT to oral intake

When considering commencing NGT feeding, there is a risk that the patient is unable to transition back to oral intake. The clinical formulation, based on the history and differential diagnosis, will assist with evaluating such risk. This should not prevent NGT feeding being used when required, but in all cases the manner of its presentation should include clear understanding for patient, carers and the multidisciplinary team of the steps for its removal and the route towards that aim.

d. NGT feeding under restraint

Occasionally patients may become so distressed that they resist weight gain by any means, and in such cases, NGT feeding under restraint may need to be considered as a life-saving intervention, although it should only be required very rarely. As a restrictive practice, it requires mental health staff trained in safe control and restraint techniques, and the use of relevant legislation. Hospital security staff may be trained in some forms of restraint, but they do not have training in the care of extremely frail patients with anorexia nervosa. Mental health staff should always be used for safe control, except in an extreme crisis where it is felt that there is a significant risk of injury or death occurring. The use of NGT feeding under restraint should always be a risk-based decision for each occurrence, carried out as infrequently as possible to follow principles of least restrictive practice and prevent traumatisation of patients and those around them.

Dietetic guidelines have been developed on the best practice for delivering enteral nutrition under restraint.^{208, 209} The key principles of this guidance include:

- delivery of feed via push syringe bolus (not gravity bolus or enteral pump)
- reducing the number of episodes of feeding to twice a day, and
- increasing the volume of the bolus delivered as tolerated up to 1000ml per bolus.

These principles ensure that feeds are given in line with the Mental Health Act (and equivalent UK legislation) code of practice.

Under the Mental Health Act,²¹⁰ feeding (including NGT feeding) is regarded as treatment for anorexia nervosa and is permissible against the patient's will in England and Wales. Compulsory treatment, including NGT feeding, can also be given under mental health legislation in other UK countries.²¹¹ Such treatment is lawful under Sections 2 and 3. Under other circumstances it may be necessary to administer urgent life-saving treatment under common law, or to consider the use of mental capacity legislation (see <u>Chapter 8</u>). In addition to mental health law, the Children Act 1989 (Specific Issue Order [Section 8], Care Order [Section 37] or Inherent Jurisdiction of the Court [Section 100]) can be used to pass an NGT if the patient is under 18 and thought to be at risk of significant harm because of care given or not given.

e. NGT feeding and veganism

Many vegans, in line with some religious practices, acknowledge that using products derived from animals may be necessary under certain circumstances. For many, life-saving or health-improving treatment would constitute such circumstances. In

²⁰⁸ <u>https://www.magonlinelibrary.com/doi/abs/10.12968/bjmh.2019.8.3.124</u>

²⁰⁹ <u>https://pubmed.ncbi.nlm.nih.gov/32020714/</u>

²¹⁰ <u>https://www.bl.uk/britishlibrary/~/media/bl/global/social-welfare/pdfs/non-secure/g/u/i/guidance-on-the-treatment-of-anorexia-nervosa-under-the-mental-health-act-1983.pdf</u>

²¹¹ https://www.mwcscot.org.uk/sites/default/files/2019-06/nutrition_by_artificial_means_final_0315.pdf

practice, the use of soya-based feeds with vegan patients is common because they contain fewer animal derivatives compared with standard feeds. Becoming vegan may be part of eating disorder pathology,²¹² in which case moving to a vegetarian diet may be justified. There are very few vegan enteral or sip feeds available in the UK (AYMES ActaSolve Smoothie²¹³ is one). Dairy or gluten intolerance must be confirmed by relevant tests performed to the satisfaction of the medical team.

f. Use of nasal bridles in NGT feeding

Nasal bridles should not be considered as standard practice, as they do not fit within Mental Health Acts principles of least restrictive practice. There are reported cases of bridles being pulled out by patients causing damage to the nasal septum. If a team is considering the use of this restrictive intervention, then it is vital that appropriate observations are in place, that it is utilised for the shortest possible time and that it forms part of a comprehensive treatment approach to facilitate recovery.

g. Nasojejunal and other feeding routes

Nasojejunal tube (NJT) feeding is not typically indicated, unless as management for gastric atony, or gastroparesis where it is desirable to feed beyond the ampulla of Vater.²¹⁴ Occasionally, patients with abdominal pain, bloating and vomiting may be found to suffer from superior mesenteric artery syndrome,²¹⁵ in which case the problem is typically resolved by weight restoration. NJT feeding can also be useful in situations where there is significant vomiting in the absence of a medical explanation, as a way of minimising vomiting and associated complications, such as weight loss and hypokalaemia. An opinion from an expert gastroenterologist should be sought before considering NJT feeding. It should be noted that specialist EDSs may not have the ability to manage a NJT and this can result in delaying a patient's transfer.

Note that bolus feeding is contraindicated in NJT feeding; therefore, continuous feeding must be used via enteral pump, and this will require constant supervision.

i. Percutaneous endoscopic gastrostomy

Percutaneous endoscopic gastrostomy (PEG) feeding is only very rarely indicated for the treatment of eating disorders unless there is also presence of a dysfunctional swallow and long-term nutritional adequacy cannot be achieved orally. PEG is an invasive intervention, and thus should discussed at a suitable multidisciplinary meeting, and performed and managed longer term by a suitably experienced nutrition team. The procedure has a significant morbidity and, rarely, mortality.²¹⁶ Cases of PEG placement in chronic anorexia nervosa have been described in patients

²¹² <u>https://www.rcpsych.ac.uk/docs/default-source/members/faculties/eating-disorders/vegan-patients-eating-disorders-mar19.pdf?sfvrsn=be96d428_2</u>

²¹³ <u>https://aymes.com/products/aymes-actasolve-smoothie</u>

²¹⁴ https://pubmed.ncbi.nlm.nih.gov/3124652/

²¹⁵ https://onlinelibrary.wiley.com/doi/epdf/10.1002/ccr3.2577

²¹⁶ https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4069302/

with long-term reliance on NGT feeding, but should be avoided in all, but the most severe cases as part of a 'recovery' approach to treatment.²¹⁷

ii. Parenteral nutrition

Parenteral nutrition is hardly ever indicated for the treatment of eating disorders. It should be reserved for rare cases when the gastrointestinal tract cannot be used safely, such as in cases of spontaneous perforation, or where surgery is required, or if the gut cannot be safely accessed. In rare cases, where an urgent surgical procedure is felt to be required in a patient with anorexia nervosa, any preoperative nutrition can be useful and appropriate nutritional support (if necessary, by the intravenous route) must be available postoperatively.

Any decision to administer parenteral nutrition must be taken as part of a multidisciplinary team approach, and with the supervision of a specialist nutrition team.

Non-emergency surgery

Non-emergency surgery in patients with an active eating disorder should always be discussed within a multidisciplinary setting and with the patient, including a properly balanced assessment of the risks for and against any procedure. The ability to make decisions about care can be selectively impaired in patients with eating disorders, so it should not be assumed that a patient with an eating disorder automatically does not have capacity to make decisions about other aspects of their care. Informed consent must always be determined on an individual case basis.

h. NGT feeding in psychiatric settings

The use of NGT feeding should be a core skill of units with SEDUs/SEDBs, and can sometimes be managed in a generic psychiatric inpatient units - as long as the experience, knowledge and skill is available to safely carry out this procedure. It would be reasonable for a generic unit to ask that a patient's NGT is placed and its position verified in a medical/paediatric unit and that the initial few days of feeding be provided there, until the danger of refeeding syndrome passes, and robust links are maintained between the two services. The need for NGT feeding itself should not be a reason to maintain a medical/paediatric admission rather than a SEDU/SEDB, as acute hospital setting is usually inappropriate for intensive psychological treatment.

If a patient is NG fed on a medical or paediatric ward, it is the responsibility of the team around the patient, including the SEDU/SEDS teams and commissioners, to ensure that the patient does not stay in an acute setting for longer than necessary. Where prolonged NGT feeding has occurred in an acute setting, a plan for ongoing care should be made which includes the possibilities of SEDU transfer or community care with or without NGT in situ. Consider seeking a second opinion where there is lack of consensus or considerable risk involved.

²¹⁷ https://pubmed.ncbi.nlm.nih.gov/26059633/

6. Management of behavioural manifestations of eating disorders on medical or paediatric wards

6. Management of behavioural manifestations of eating disorders on medical or paediatric wards

a. Introduction

Eating disorder behaviours arise from profound anxiety and distress, and may contribute to deterioration and, sometimes, death. On a busy medical ward full of patients requiring attention, it can be hard to supervise behaviours such as microexercising or disposing of food. Discovering that a patient is doing one of these or other apparently self-destructive behaviours sometimes leads to a sense of exasperation and anger (not to mention stress) among staff, particularly as they may worry about being criticised if the patient has a poor outcome. The patient should be regarded as being under an irresistible compulsion and, unless their mental state changes, they are very likely powerless to alter their behaviour without a lot of additional support. They may promise to stop, but not have the power or the ability to do so.

On medical units, treatment is generally provided to willing and cooperative patients with, usually, low staff–patient ratios. Staff on psychiatric units are used to patients, especially if detained under the Mental Health Acts, disagreeing with treatment, and feeling driven by their illness to resist care by, for example, spitting out tablets and absconding from the ward. The seriously ill patient with anorexia nervosa has a potentially fatal condition and is also subject to compulsions that appear to sabotage treatment. In addition, the patient may have impaired capacity to make decisions about treatment.²¹⁸

A key factor in responding to this difficult challenge is the provision of adequate mental health and general nursing staff to support the patient, as well as offering support and supervision and training for general or paediatric nursing staff to increase their understanding of eating disorders.



Case study 3: Not being able to control eating-disordered behaviours can be fatal

A 24-year-old female (BMI 11) on a general medical ward who, prior to a planned move to an eating disorders unit, exercised by standing and wiggling her toes and fingers for the whole weekend, day and night, in front of two 'special nurses'. She developed hypoglycaemia, which is unusual, with contribution from extreme undernutrition and over-activity and sadly died on the Monday morning. (Eating disorders psychiatrist)

²¹⁸ <u>https://www.cambridge.org/core/journals/bjpsych-open/article/mental-capacity-to-consent-to-treatment-in-anorexia-nervosa-explorative-study/54B77EC8D641E2CE260B5A3DFE195F14</u>

In this tragic case, the patient was driven by her illness to engage in excessive exercise combined with underfeeding that probably contributed to the fatal outcome. The nurses, understandably, underestimated how unwell she was. The lesson is that specialist teams (EDS or liaison psychiatrists) should support frontline staff in recognising when this may be happening and humanely addressing it with the patient. For example, staff might have tried to educate the patient about the dangers of what she was doing and helped her to engage her in alternative activities.



Case study 4: The need for constant observation

A 32-year-old male patient was admitted to a general psychiatric ward for refeeding. BMI was low (13.9) and a weight-gaining meal plan was provided. After 4 weeks, no weight had been gained. The patient was considered medically and psychologically stable and he was discharged. The next patient who occupied the room complained of a smell, and investigations revealed that the food provided had been hidden under the en-suite bath, from which the patient had removed and then replaced the side panel. (Eating disorders psychiatrist)

This case demonstrates the lengths to which someone with an eating disorder will be driven by their illness to avoid eating, and shows that staff need to be alert to the intensity of fear of weight gain and its behavioural consequences in order to better help the patient. The better the professional is trained and the more confident when talking with the patient about their eating disorder, the more likely they are to be trusted more than the patient's 'inner voice'.

b. Avoiding weight increase/restoration

Patients with eating disorders are subject to an extreme compulsion to pursue thinness and the presence of behaviours designed to lose weight confirm the diagnosis, and differentiate it from ARFID, and should not be a cause for alarm. This compulsion is driven by highly distressing cognitions that can leave the patient feeling unacceptable. The resulting drive to reduce these cognitions has been likened to an addiction²¹⁹ or obsessive-compulsive disorder²²⁰ – patients find it overwhelming. They may deny the strength of the compulsion to others and sometimes underestimate to themselves, and hardly be aware of their behaviours, only becoming aware when they are prevented to act on them.

These behaviours may include drinking water and consuming salt before weighing, wearing weights or other items, and gripping the weighing machine with toes to increase weight. Other behaviours include running up and down hospital towers (often following notices displayed on hospital stairs encouraging exercise), secret exercise or purging. These compensatory behaviours often increase when changes to meal plans are predicated on weight changes.

²¹⁹ <u>https://muse.jhu.edu/article/547029/summary</u>

²²⁰ https://pubmed.ncbi.nlm.nih.gov/30087453/

Some patients in extreme distress engage in microexercising, which can be defined as the increasing the expenditure of energy in restrictive feeding and eating disorders with minimal muscular activity. Examples include standing, removing clothing, or switching off heating in order to shiver, wiggling toes or fingers and adopting fixed postures with isometric muscle contraction. They may also dispose of food, e.g. running NGT feed into the sink or a pillow and turning off drips. They may vomit in sinks and toilets. They may ask friends and relatives to dispose of food, bring in laxatives etc. Occasionally, patients may become distressed or violent when specific requests (such as for a particular type of food or to be allowed to leave the ward) are not cooperated with. They may try to run away.

The more common behaviours that need consideration are as follows.

i. Exercise/activity

Some degree of gentle activity (watching TV with others, reading a book or doing crafts) or going for a brief walk with others (nursing staff or family) can help reduce distress without any additional risk. Total bed rest was used in the past in hospital treatment of severe eating disorders. A recent clinical review²²¹ concluded that in most cases enforced bed rest is unhelpful and should be avoided. Risks relating to enforced bed rest include psychological distress and physical complications such as pressure sores, infections, deep vein thrombosis, muscular atrophy and increased bone absorption.

Restriction of excessive activity with an explanation of the rationale and offering alternatives is helpful. It is important to keep the patient warm and supervised to prevent dysfunctional exercise. Assessment of functional abilities, transfers and mobility are required to ensure the individual is safe to engage in functional tasks and the level of support or assistance required. For example, an individual may be at risk of falls, having reduced balance and stability and may therefore require assistance to mobilise within the bed space or to the bathroom.

Arrangements for toileting and washing will need to be considered to prevent excessive exercise, such as supervised bath or shower/ unlocked bathroom or toilet doors, but with provisions for privacy. These interventions are intrusive and need to be explained, documented, and maintained with consistency if necessary.

ii. Purging and other methods of avoiding weight increase

Avoiding food intake due to fear of weight gain (e.g. disconnecting an NGT feed, tipping NGT feed or dietary supplements down the sink, hiding food), and misleading weight measurement are common behaviours to which nursing staff need to be aware of and help the patient not acting on these urges. There may need for restriction of access to fluids, such as other patients' drinks, taps, toilets and showers. If there is ongoing uncertainty, a low urine specific gravity may suggest water loading.

²²¹ <u>https://pubmed.ncbi.nlm.nih.gov/31003978/</u>

Self-induced vomiting may be decreased by limiting access to toilets after a meal or a snack for 1 hour and (where possible/if needed) maintaining close observation for this time. Preventing aspiration of stomach contents via an NGT is aided by ensuring that syringes, e.g. from a nursing or 'crash' trolley, in a treatment room or left by the bed, are not readily accessible. Laxatives for misuse may be more difficult to obtain in hospital, but nevertheless requires vigilance, as they may be brought in by friends or family after the patient complains to them, for example, that they are being denied treatment for distressing and painful constipation.

iii. Bingeing

A supply of food is required for a binge, and this may be difficult to achieve covertly in a hospital setting. However, excess amounts of food being requested from carers and visitors, and food going 'missing' from ward supplies, fridges, other patients, etc., may suggest bingeing. Patients able to leave the ward may stock up at the hospital shop. Although less common in young people than adults, bingeing is possible at all ages.

c. Self-harm and suicidal thoughts

Self-harm or suicide are risks to be considered if the patient is, for any reason, very distressed, or have a history of depression and previous suicide attempts. People with eating disorders have a high rate of comorbid depression, which increases the risk of suicidal behaviour.

The medical/paediatric team should consult NICE guidance on self-harm²²² and request an assessment by the liaison psychiatry team or EDS if there is any concern about the risk of self-harm, actual self-harm or suicidal ideation.²²³

d. Comorbid psychiatric conditions

Typically, the distressing cognitions that underpin an eating disorder will initially increase as the patient takes brave steps to re-introduce adequate nutrition and reduce compensatory behaviours. Patients value clinicians' maintaining a compassionate stance towards the distressing thoughts they are experiencing, combined with clarity that the changes are essential (and therefore challenge the eating disorder cognitions). It is common for people with eating disorders to have other psychiatric conditions. such as obsessive-compulsive disorder, depression or anxiety.²²⁴ They may also experience suicidal ideation and engage in self-harm behaviours including self-harm and attempted suicide, such as overdose and hanging attempts. In these situations, advice about specific management is required from the mental health team. On occasions, patients can become severely distressed at the prospect of eating or being fed, beyond the level usually experienced by paediatric/medical staff. In this situation, specialist psychiatric advice needs to be

²²² <u>https://www.nice.org.uk/guidance/cg16/chapter/Key-priorities-for-implementation</u>

²²³ https://pubmed.ncbi.nlm.nih.gov/24559792/

²²⁴ https://onlinelibrary.wiley.com/doi/full/10.1002/eat.23481

sought, specific mental health nursing may be needed, and medication may be indicated.

Eating disorders can be complicated by a range of other disorders including personality disorders, somatic symptom disorders, post-traumatic stress disorder, factitious disorders and functional syndromes. Admission to a SEDU may not be beneficial in the presence of these additional disorders (see <u>Chapter 2</u>). These issues are not easy to resolve, and we recommend a care planning meeting to decide on the best available options between relevant members of eating disorder, general psychiatry/CAMHS, liaison psychiatry and medical staff, as well as the GP, patient and a carer if possible, to make that decision.

Eating disorders themselves can cause symptoms that resemble other psychiatric disorders including depression, self-harm and OCD. These can resolve through weight restoration and treatment of the eating disorder. Careful differential diagnosis is essential for optimal management.

e. When the patient is driven to aggressive or other disturbed behaviour

It is good practice for medical/paediatric units to have their own policies for the management of aggressive or otherwise disturbed behaviour, including a rapid tranquilisation policy. These local policies should serve as a guideline for management of an acute situation, but psychiatric services also need to be contacted in such an event, particularly if any additional steps or resources are required to be able to continue to manage the situation on a medical or paediatric ward. If physical restraint is needed, it is important that it is undertaken by staff who are specifically trained in control and restraint. In practice, these are most likely to be mental health staff, and appropriate arrangements will need to be made to ensure this. In one case series, about a third of adolescents with anorexia nervosa required at least one episode of restraint²²⁵. If sedation is required, please consult <u>Chapter 4</u> on safe refeeding. Policies developed for general psychiatry will need to be modified for eating disorders as drugs used to manage disturbance can be hazardous at low BMI or with abnormal electrolytes, and control and restraint can lead to fractures in an underweight patient. Restraints and other incidents should be recorded on risk registers and through riskreporting mechanisms within hospitals and organisations. This helps not only to measure how often these interventions are needed, thus allowing planning for staffing, but also provides opportunities for learning.

f. Approaches to treatment of behavioural manifestations of eating disorders

Staff working on SEDUs/SEDBs use a number of strategies to address the challenging behaviours associated with eating disorders, such as increasing staff numbers, agreeing a 'contract' with the patient, treating patients in areas that can be more easily observed, locking toilets and bedrooms during the day to prevent covert

²²⁵ https://jeatdisord.biomedcentral.com/articles/10.1186/s40337-020-00297-1

exercising, and observing patients during therapeutic activities such as group therapy. Patients whose behaviour is not improved by these measures may need one-to-one supportive supervision (occasionally a higher ratio is required) for 24 hours a day. This is also used for people at risk of suicide.

i. One-to-one observation

This is an area where close collaboration between medical and mental health teams is essential. The most important factor contributing to the success of one-to-one observation is the training and experience of the staff involved, in both the ward and the issues encountered in people with eating disorders.

One-to-one nurses, and other staff who may be temporary, need to be inducted and integrated with the rest of the team, to avoid inconsistency of approach. If a nurse experienced in eating disorders cannot be found for a medical ward, the ward manager should seek advice from EDS team to explain to new staff how to support the patient, together with an agreed treatment plan which lists the known risks for a particular patient, how to manage them and who to turn to if more support is needed. Such a role could be taken up by a specialist liaison nurse from an EDS, if available. If the patient is detained under the Mental Health Act or related legislation in the devolved nations (see <u>Chapter 8</u>), the 'special nurse' will generally be mental health-registered, but may require as much induction as a general nurse.

- On the whole, our patients who are transferred to the medical ward do well... We have a system of working with one particular physician, with clear protocols and one-to-one nursing by a registered mental health nurse experienced in eating disorders." – Eating disorders psychiatrist
- Young people who require admission to a paediatric ward generally do well when there is a named paediatrician (rather than a consultant-of-the-week system, which is likely to result in inconsistencies) and when nursing staff have an understanding of eating disorders. One-to-one supervision can be provided by nursing staff and/or parents. Involving parents early in mealtimes facilitates timely discharge home."

– Paediatrician

While we agree with the above suggestion, having a dedicated consultant paediatrician/gastroenterologist permanently is not often practical. A satisfactory alternative would be to identify a lead consultant for eating disorders and for that consultant to be available to others for advice. Cover arrangements are essential to ensure continuity of expertise.

ii. Structured collaboration between staff and patients

People with eating disorders will quickly realise if staff caring for them do not recognise and understand their illness. Conveying to the patient that staff have knowledge about potential weight loss behaviours is an important element of providing a safe nursing environment. Patients are not always aware or in control of these behaviours.

A structured approach to the treatment of people with severe eating disorders, with good documentation of plans and any restrictions, will help to maintain consistent care, and help to avoid disagreements between the patient, family and staff. It is useful to have a regular meeting, at least weekly, between frontline nursing staff, medical and psychiatric (eating disorder/liaison) staff to discuss emerging issues in a patient's care and how to deal with them. A chronological summary of treatment in a medical/paediatric setting is given in <u>Box 4</u>.

iii. Involving parents and carers

The role of parents/carers in addressing these behaviours and making sure that their child/young person does not come to harm is not straightforward: sometimes parents/carers can be best at helping the child/young person manage not to act on their compulsion, by offering the sort of emotional support (e.g. after meals) that their child needs. However, sometimes the child/young person craves this additional support and increases the behaviours to get more. Sometimes, parents/carers may be understandably anxious and inadvertently inflame the situation, which can increase the risk of, for example, absconding or attempts to tamper with feeds. Factors such as the patient's age, and the severity and chronicity of their illness, may influence this. Decisions about how best to involve and support parents/carers in the management of the behavioural aspects of a child/young person's eating disorder should be made in the context of multidisciplinary meetings with senior staff responsible for the young person's care. Managing contact with relatives, who may be extremely (and usually justifiably) anxious and distressed, is addressed further in <u>Chapter 7</u>.

6. Management of behavioural manifestations of eating disorders on medical or paediatric wards

Box 4: Treatment of eating disorder behaviours in a medical or paediatric setting

 Early in the admission, schedule a meeting between key staff responsible for treatment (namely the physician/paediatrician, nursing staff, eating disorders psychiatrist or liaison psychiatrist, and other staff involved in paediatric liaison or eating disorders care), to decide how to achieve treatment aims.

Document the meeting clearly in the notes. Involve the patient and (usually) their parents/carers in discussions about the treatment plan. If they are not involved (e.g. too unwell to attend or an adult patient who requests exclusion), document the reasons for this.

2. Admission on paediatric/medical wards should not be prolonged, and every effort should be made by the EDS to support discharge to community care or transfer the patient to a SEDU/SEDB.

Establish the level of supportive nursing supervision needed and the level of parental/carer involvement in care that is possible or appropriate. Where possible, employ a nurse from the specialist EDS to supervise and train nurses caring for these patients.

- **3.** Write a clear care plan, to be transferred between nurses with proper handover from one shift to another.
- 4. Schedule regular review meetings of key staff, preferably with the patient and their parents/carers involved, to ensure treatment goals are met or revised if needed.
- 5. If, despite these measures, weight gain is less than expected, proceed as if the patient is engaging in covert behaviours to eliminate calories. These are an inevitable part of the illness, and punitive responses should be avoided. If sudden significant changes in weight are observed (e.g. 2kg within a few days), assume water-loading and other explanations.
- 6. Be prepared to use the Mental Health Act or other legal framework if necessary.

7. Helping parents, relatives and carers

Resources for families and loved ones

In the UK, Beat provide a range of information leaflets that are available online, and which many families, carers and patients have found helpful. We recommend that all services caring for people with eating disorders refer to their website: <u>https://www.beateatingdisorders.org.uk</u>.

FEAST is an international non-profit organisation of and for caregivers of loved ones suffering from eating disorders. FEAST's mission is to support and empower caregivers by providing information and mutual support, promoting evidence-based treatment, and advocating for research and education to reduce the suffering associated with eating disorders. We recommend that all services caring for people with eating disorders refer to their website: <u>https://www.feast-ed.org</u>

a. The family's role in treatment of the eating disorder

Families can (and usually want to) be a crucial resource in their loved one's recovery. However, blame has historically been placed on parents for their loved one's eating disorder, and families often blame themselves. This blame is unwarranted – families do not cause eating disorders.²²⁶ The overarching attitude to the family should be accepting and positive. Exploration of family dynamics might be a helpful part of therapy, because patterns of behaviour may be inadvertently maintaining some behaviours and families may need to learn how to better help the family member with the eating disorder.

The patient may be more able to change their eating behaviours if the responses of those around them also change. Eating disorders organise the behaviour of others, such that family members do things that seem as unusual as the patient's own behaviour.^{227,228} Caregivers may have found themselves giving inadequate portions or only serving certain foods, in an attempt to reduce distress, unaware that these actions may have been hijacked by the eating disorder mindset to promote the idea that the patient does not require (or deserve) adequate portions or variety of food. Parents have stocked up their food stores with binge foods such as biscuits, so that their sons or daughters are not frantically searching for these foods in the night. These and other family responses come from the family's best efforts to manage risk, and although understandable, they may not always be helpful. It is important that professionals adopt a non-judgemental approach to both the patient's symptoms and family's attempts to placate the eating disorder. Specialist programmes^{229, 230} can help develop the skills of parents/carers in supporting their loved ones.

²²⁶ https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5711426/

²²⁷ https://pubmed.ncbi.nlm.nih.gov/24888426/

²²⁸ <u>https://www.routledge.com/The-Clinicians-Guide-to-Collaborative-Caring-in-Eating-Disorders-The-New/Treasure-Schmidt-Macdonald/p/book/9780415484251</u>

²²⁹ https://pubmed.ncbi.nlm.nih.gov/24888426/

²³⁰ <u>https://xip.uclb.com/product/eating_disorders_parent_intervention#</u>!

b. How the family or carers may respond to the eating disorder

Having a loved one with an eating disorder can be extremely distressing for families and carers and supporting someone with an eating disorder can have a detrimental impact on both the physical and mental health of the whole family, including siblings. Family members may feel helpless in what to do and hopeless about the future, particularly when they are aware of how dangerous and lifethreatening the illness can be. They often experience feelings of guilt and anger over how things have reached this level of severity, and this can lead them to become extremely upset and, frustrated. For the medical/paediatric team, the complexities of supporting people with eating disorders can be compounded by the understandable anxieties of their family

Family distress can be for a variety of reasons. Parents and carers of people with eating disorders are often very knowledgeable about the condition, and they can be concerned that medical and nursing staff who are not used to working with people with eating disorders will not treat them seriously or may not be aware of how careful they need to be with the language they use around the patient. Medical and nursing staff need to listen to the family and carers and accept that they may have greater knowledge than themselves, while being clear that they are taking the situation seriously and following the guidelines. Staff should also recognise the important role that family and carers have in treatment and recovery and convey this to the person receiving treatment. Conversely, if the patient is newly diagnosed with an eating disorder, their family may have little knowledge of the condition and how to manage the situation. They may struggle to comprehend the risks involved, and inadvertently collude with patients in trying to minimise the seriousness of the situation, so they may turn to medical and nursing staff for guidance and support. The document 'Nine truths about eating disorders'²³¹ addresses the nature, causes and outcomes of eating disorders and is a useful introductory tool.



Case study 5: A young woman was admitted to an inpatient unit with severe malnutrition and self-harm. Her parents were seen regularly as a couple, so that they could remain informed about her progress and work with the inpatient team. The patient was aware of the meetings and agreed to them. She gradually improved, and when more physically healthy was able to participate in the meetings.

²³¹ <u>https://www.aedweb.org/publications/nine-truths</u>

c. Communication and confidentiality issues

Family members often report not receiving enough information about the treatment of their loved one and how best to support them. Families should be signposted to educational resources about eating disorders and their treatment, regardless of the patient's wish for their involvement in care. These are readily available on both the FEAST and Beat website. In addition, it is helpful to identify a member of staff to support the family, and also encourage the patient to share information with the family so that they can fully support and improve chance of recovery.

Often, although not always, a patient's objection to family being informed and involved in treatment modifies as trust in the treatment team improves. There are almost always ways to support the carers and family in managing the very distressing experience of having a child with a potentially fatal illness in hospital. It is important that family members are encouraged to communicate any concerns to the treating team, which may be crucial to decision-making.

From the legal point of view, confidentiality and lack of patient consent does not prevent clinicians from receiving third party information from families; patient consent is only necessary for providing confidential patient information. Where family members are important to the ongoing support of patients to be able to engage in and benefit from treatment, every effort should be made to persuade patients to allow appropriate communication so they can carry out this task. Where patients lack capacity, consideration should be given to which family members can or should have a legal right to involvement in decisions based on the relevant legislation.

Three scenarios are envisaged:

Scenario 1: An adult (>18 years) requests that no information be given to their parents or partner.

In this situation, staff are not legally able to give information about the patient's symptoms, e.g. weight gain or loss. It is important to explain this to the family and explore why the patient is concerned about information sharing with them. However, the relatives can meet with staff members to ask questions about managing an eating disorder at home, and to provide information they have about the patient. The staff can give advice as long as they do not divulge information about the patient. The patient may object to this, but legally the staff can continue to provide this service to the family. It is important to explore the patient's reasons for not involving their loved ones: this is often driven by shame and guilt, which may be resolved with appropriate support.

Scenario 2: A patient aged 16 to 18 requests that no information be given to their parents.

In this case, it is legal for staff to give information to the parents if they can show that the provision of that information is in the patient's interests and lies within the 'zone of parental responsibility' (i.e. information that is reasonable for parents of a child²³² to know). At this age, a patient can accept treatment without the parents' consent or knowledge, but parents still have a role if treatment is rejected.

Scenario 3: A patient aged under 16 requests that no information be given to the parents.

The patient has the same right to confidentiality as an older patient. However, while the patient can accept treatment without the knowledge or consent of parents if the doctor is convinced that the child understands the consequences of agreeing to the treatment ('The child must be capable of making a reasonable assessment of the advantages and disadvantages of the treatment proposed, so the consent, if given, can be properly and fairly described as true consent'²³³), they cannot decline treatment deemed essential. Parents therefore need the information necessary to make treatment decisions and exercise their parental responsibilities, including information about risk. Under the Children Act (applicable in England and Wales), the primary concern is the child's welfare.

For more information on decision-making and the law, a review is available.²³⁴ Also, see <u>Chapter 8</u> in this guidance.

²³² The law defines a person as a child up to the age of 18.

²³³ http://www.e-lawresources.co.uk/cases/Gillick-v-West-Norfolk.php

²³⁴ https://www.themdu.com/guidance-and-advice/guides/confidentiality-and-children

d. A collaborative approach

It is likely that the person with an eating disorder has relied on their family to support them in seeking help and in their treatment prior to this point; this is typically the case for children and adolescents, and often for adults too. It is therefore crucial that a collaborative approach is taken between the person, the primary care team, the treatment team, and the family. The family should be empowered to best support their loved one, and look after themselves, including siblings. This may involve helping them to achieve changes in their relationship with the person with the eating disorder to maximise the latter's chances of recovery and reduce their own stress.

Family members should be included in the treatment process and in supporting the patient, whatever their age, with consent in adults with capacity. As with any clinical presentation, the only exceptions are the rare examples in which safeguarding concerns arise because of reported abuse by a family member. Separation of patients from their families is still not uncommon in the UK due to out-of-area placements.²³⁵

e. Issues affecting mainly children and adolescents

Parental concern about their child needs to be taken seriously, especially as children and young people can become medically unwell very rapidly. By the time a child or young person is ill enough to need hospital admission, they are likely to be relying quite heavily on parental support to eat at all, and abrupt changes to this can be, at best, unhelpful. Furthermore, parents are an important source of comfort to a severely ill child or young person, who may be very frightened despite their denial and seemingly self-destructive behaviour.

Parents are essential to the first-line psychological treatment approaches²³⁶ and are best considered partners in the process of recovery, so appropriate involvement should be agreed as clearly as possible. For example, a trial-and-error process may be necessary to establish whether parental involvement in feeding on the ward is helpful or not. It is inevitable that, in some instances, nursing staff are better able to feed the child or young person, by virtue of their emotional distance and training. This is not evidence of parental inadequacy. The task of refeeding someone with anorexia nervosa or ARFID is not a normal part of parental skill sets, and parents need support to develop confidence in supporting treatment, such as reinforcing diet plans and managing mealtime distress which can be extreme. Trials of transfer of responsibility for feeding to parents or to the young person should be made as soon as possible because this will determine the length of inpatient stay, the treatment approach and the level of care needed. Providing opportunities to practise in different contexts (e.g. off the ward, at home) will help clarify the level of support the young person needs to eat, and

²³⁵ https://www.has-sante.fr/upload/docs/application/pdf/2012-

^{09/}anorexia_nervosa_information_families_and_patients.pdf

²³⁶ https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5459462/

who they need the support from. These skills can then be built on in the home context with support from the community EDS.

Where there are concerns about parental involvement or parent/**child** interactions, safeguarding discussions must include clinicians who have understanding and experience of working with people with eating disorders.

i. Parental visiting access

Most paediatric wards will have an open access policy for parents and, unless there is good indication to do so (e.g. concerns about child protection), it is usually against the ethos of paediatric wards to restrict parental visiting. Admissions for eating disorders are often longer than for other illnesses but should not be unduly prolonged after medical stabilisation has been achieved. Managing behavioural problems are within the realm of the psychiatric services, including CAMHS, SEDUs/SEDBs and general adolescent units, and those are the environments in which they should be treated.

The stress of the admission can be exhausting for parents, and it is important that their needs and those of other siblings are discussed with the ward staff. In some situations, an open discussion of limiting parents' time on the ward may be a relief to parents who feel guilty about leaving their child or neglecting other children. In other situations, a therapeutic limitation of visiting (as part of the management plan) may be advisable.

For most inpatient settings, there may be restrictions in numbers visiting at any one time. Individual circumstances will dictate any restrictions on length and timing of visits, especially at mealtimes. Vigilance is needed to ensure that family members, such as siblings, do not get drawn into parenting roles.

f. Issues affecting mainly adult patients

Adults may live alone or with others, and the role of family members in their treatment will vary from person to person, depending on, for example, prior relationships, proximity, and whether they have a partner and/or children. It is highly recommended to clarify with the patient who they regard as close family members. The closest person who is available to support treatment may be a partner, a sibling, a parent (in a couple or separated) or, occasionally, an adult child. It may also be a friend. For those living with family, while one parent may be custodial, the other may well be closely involved. Information should be provided to the indicated family members on eating disorders in general and, if the person agrees, they should be kept up to date by members of the team. If the patient does not agree, information should be managed as described in <u>Chapter 7.c</u> on communication and confidentiality issues. While family members or friends are not generally responsible for feeding the patient after leaving hospital, they should be involved in discussion about how they can support the patient after discharge. Mental health services may offer family sessions for them, and during

the admission it may be useful to include a family member in regular meetings with ward staff. Young adults often benefit from additional parental support.



Case study 6: A 24-year-old man with anorexia nervosa, complicated by a nutritionally induced psychosis, was in a general medical ward. His mother contacted the ward several times a day and made complaints against several nurses. A meeting with her, the ward manager and the eating disorders psychiatrist was held every week to understand her concerns. As issues were addressed in the meetings, it became easier for her to work collaboratively with the care team.

g. Dos and don'ts for carers, relatives and friends of people with eating disorders

Box 5 and Table 10 give some advice on how carers, relatives and friends can try and help the child, partner, parent or friend. Many carers of people with eating disorders feel the strain of that role, and it is not helpful to the carer if they also become unwell, so looking after themselves is vital. While they will want to help, they should try not to 'help' the eating disorder. Sometimes maintaining that distinction can be tough on everyone. If they have a son or daughter who has a binge and so leaves no cereal for the rest of the family, driving to an all-night store to replenish the cereal before it is missed at breakfast may be done for the best intentions. They, and other members of the family, may feel angry, but showing that anger and criticising the patient is likely to make things worse. So, in both of these instances, doing the right thing is really hard. They should make sure they have their own support, from a partner, a friend or a support group.

Box 5: Examples of how carers, relatives and friends can help their loved one

Here are some things carers, relatives and friends can do that can help:

- 1. Be sympathetic to the person with the eating disorder, who is, after all, experiencing terrifying intrusive thoughts and should not be blamed.
- 2. Find out what the person wants from their life and discuss how treatment can help them achieve those goals.
- 3. Avoid arguments: Try to find common goals with the patient.
- 4. Roll with resistance: If the person with the eating disorder won't do something you think is useful, accept it and try something else.
- 5. Look for the positive: Notice small steps of progress. Frame them as brave steps and acknowledge the intrusive thoughts they will have most likely endured to take them. If the person manages to follow a diet plan and then gives it up, label it a success after all, the plan did work for some time. If there is a failure, use the phrase 'set-back', 'how can we try again?', 'how can we best support you to remember that the bullying thoughts are not fair?'
- 6. Empathise and be warm: Say how sorry you are they are having these untrue, distressing thoughts

Table 10: Dos and don'ts for families and carers

| Do | Don't | Notes |
|--|--|---|
| Get your own support | | Try Beat, FEAST, local support groups, or therapy |
| | Talk about diets, weight and shape with the person with the eating disorder | These topics are so common that they're hard to avoid, but it's very important to do so. Don't allow 'fat talk' ²³⁷ |
| Ask to be involved in their treatment | | Collaborate with the team, don't work on increasing your loved one's weight without their knowledge |
| Make considered changes to support your loved one to overcome the eating disorder | Make unreasonable changes in your life to accommodate the eating disorder | If you need support to refuse a request made by your loved one, ask one of the members of staff |
| Make helpful changes suggested by the eating disorders team | Provide laxatives, or deny that there's a problem | |
| Empathise and be warm | Criticise or be hostile | Sometimes it's really hard to maintain this, but it does help |
| Communicate: If there is no progress, inform the team of your observations and request a review | Be secretive | With the person, others in the family, health care teams, sources of support |
| Work to achievable short- term goals | | Even just a small improvement in diet, bingeing or weight is well worth having, but it needs to be consistent |
| Talk about the family's strengths before the eating disorder started | Criticise other family members if they fall short of your expectations | |
| | Give up hope | Eating disorders can last for a long time, but most people do recover |

²³⁷ https://www.huffpost.com/entry/fat-talk-women_n_5331507

8. Compulsory admission and treatment

a. Introduction

For patients with eating disorders, motivation and collaboration are seen as important for recovery,^{238, 239, 240} and for this reason there are many clinicians who are reluctant to treat patients against their will. However, some patients with severe eating disorders may refuse life-saving treatment, causing ethical dilemmas for the treating teams. When treatment against the patient's will becomes necessary, it should only be done in the context of a clear legal framework. In England and Wales, as in many other countries, the concept of compulsory treatment of severe eating disorders has a wide range of differing views.

i. Capacity and consent

The evidence around the use of compulsory treatment was reviewed in the development of this guideline (<u>Appendix 2</u>). Studies by Tan *et al.*²⁴¹ suggest that most families and patients accept that compulsory treatment may be necessary if the condition is life threatening. A UK study comparing the outcomes of young people treated on an SEDU found that improvement was independent of the person's legal status.²⁴² How Mental Health legislation is used is fundamentally important, if compulsory intervention is to be seen as helpful to patient safety and a step in the care pathway by both the patient and their family/carer, rather than as punitive and coercive.

Accumulated evidence shows that capacity to consent to treatment may differ in people with eating disorders depending on the stage of the illness. In addition, although patients may have a good understanding, reasoning and appreciation of their illness, the change in values and sense of identity that can result from their illness can impact on decision-making, but this may not be picked up in standard tests of capacity. The issue of treatment acceptance and patient autonomy is therefore complex and not static. Establishing a helpful and caring relationship with the patient and family can help to improve the experience for all, even if some compulsion needs to be used. There is little evidence around issues of consent and capacity in patients with eating disorders other than anorexia nervosa.

²³⁸ https://bmcpsychiatry.biomedcentral.com/articles/10.1186/s12888-015-0516-8

²³⁹ https://pubmed.ncbi.nlm.nih.gov/19221912/

²⁴⁰ https://pubmed.ncbi.nlm.nih.gov/17080450/

²⁴¹ <u>https://pubmed.ncbi.nlm.nih.gov/33099675/</u>

²⁴² https://pubmed.ncbi.nlm.nih.gov/18666096/

ii. Compulsory treatment and the law

Box 6: Key questions and answers about compulsory treatment and the law

1. What are the criteria for compulsory admission and treatment under mental health legislation?

Mental health legislation, such as Section 3 of the Mental Health Act in England and Wales, the Mental Health (Care and Treatment) (Scotland) Act 2008 and the Mental Health (Northern Ireland) Order 1986, allows for compulsory admission and treatment of a patient of any age if:

- a. the person has a mental disorder of a nature or degree that makes it appropriate for them to receive medical treatment in hospital
- b. it is necessary for the health or safety of the person or for the protection of other persons that they should receive such treatment and it cannot be provided unless the patient is detained under this section, and appropriate medical treatment is available.

2. Is an eating disorder legally a mental disorder?

Eating disorders are classified as mental disorders and therefore are potentially subject to compulsory treatment under mental health legislation.

3. Is feeding regarded as treatment under mental health legislation?

This question has been through the courts in England and Wales²⁴³. They found that feeding (including NGT feeding) is regarded as a core component of treatment for anorexia nervosa, and can therefore be enforced, if necessary, under mental health legislation in England and Wales,²⁴⁴ and Scotland.²⁴⁵

4. Can an NGT be passed without legal proceedings?

An NGT can be passed if the patient (or their parents, if the patient is legally a child – see below) consents to it. Treating a patient against their will (e.g. passing an NGT using restraint) without using the proper authority could open the clinician to a charge of assault. Passage of an NGT or use of another invasive procedure (such as passing an NJT) against the patient's

²⁴³ <u>https://www.rlb-law.com/briefings/mental-health-law/court-orders-force-feeding-of-anorexic-patient/</u>
²⁴⁴ <u>https://www.cqc.org.uk/sites/default/files/20140911_mental_health_act_code_of_practice_detailed_cons_ultation_return_1.pdf</u>

²⁴⁵ https://www.mwcscot.org.uk/sites/default/files/2019-06/part_16_final__2_.pdf

will can be supported by requesting a report from a second opinion under mental health legislation.²⁴⁶

5. Do patients with anorexia nervosa have capacity to consent?

When making decisions about treatment, the patient's capacity to accept or refuse treatment needs to be considered (<u>Appendix 2</u> has details of both the Mental Health Act 1983 and the Mental Capacity Act 2005, which apply in England and Wales). A person who has capacity must be able to show:

- a. A general understanding of the decision
- **b.** An understanding of the likely consequences of making or not making the decision
- c. An ability to understand, use and weigh up the relevant information
- d. An ability to communicate the decision.

Anyone over the age of 16 is assumed to have capacity unless it can be demonstrated otherwise. Generally, patients with eating disorders fulfil all of these abilities except the ability to weigh up the relevant information. The severely undernourished patient who states 'I cannot accept tube feeding (or another refeeding plan) because I cannot tolerate weight gain' is making the decision based on the anxiety about weight restoration inherent to the diagnosis, and hence lacks capacity to accept the need for adequate nutrition.

Capacity is a subjective judgement, and it is not unusual for very unwell patients to be assessed as capacitous, even by experienced psychiatrists, who aren't familiar with this patient population. Patients with eating disorders are often extremely persuasive and articulate and may, for example, persuade emergency department staff to allow them to go home when this would be against their best interests or put them at risk. However, several legal cases in England and Wales have found that patients with severe anorexia nervosa did lack capacity; in these cases, the patients were found to not fulfil the criterion of being able to 'use and weigh the relevant information'.²⁴⁷ Therefore, it is important that assessments of capacity should carefully look at the ability of patients to 'use and weigh' for the decision in question and the impact of anorexia nervosa on this.

²⁴⁶ <u>https://www.cqc.org.uk/guidance-providers/mental-health-services/second-opinion-appointed-doctors-soads</u>

²⁴⁷ <u>https://dro.dur.ac.uk/21834/1/21834.pdf?DDD19+mzft75+d700tmt</u>

6. Is mental health law different across countries of the UK?

Mental health legislation varies across the different jurisdictions of the UK, particularly in relation to the specific processes of detaining patients for involuntary treatment. Nevertheless, the underlying principles of using mental health legislation in the management of this patient group are broadly applicable, namely that:

- eating disorders are serious mental disorders
- inpatient refeeding is at times an essential and direct treatment
- decision-making capacity can be impaired
- in rare situations, where there is life-threatening physical risk and an unwillingness or inability to agree to treatment, compulsory treatment can and should be instituted.

<u>Figure 5</u> guides decision-making when assessing the need for compulsory treatment.

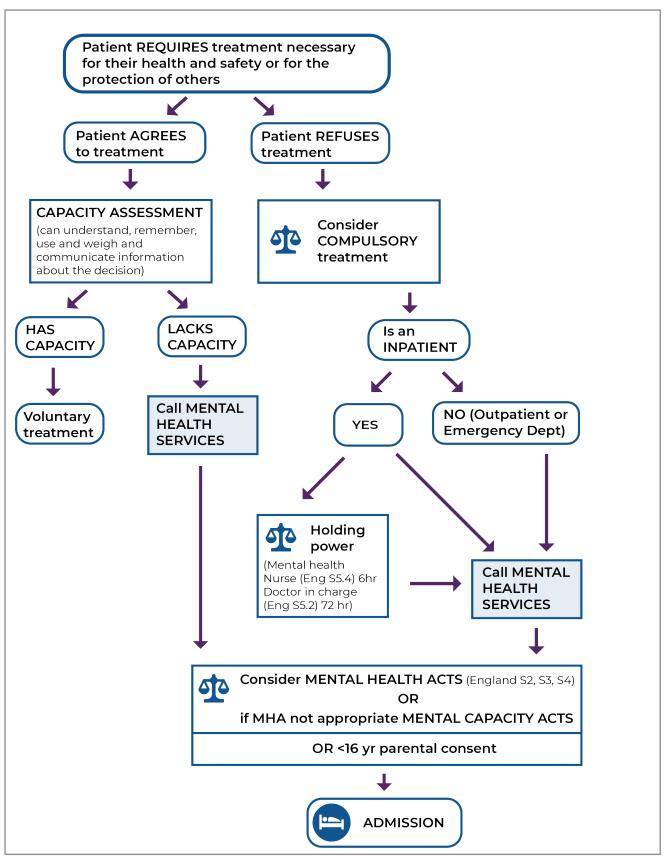


Figure 5: Compulsory treatment decision tree

b. Use of mental health legislation in emergency departments and medical/paediatric settings

In an emergency, where there is imminent risk to life due to acute deterioration, or threat of acute deterioration, staff need to act decisively and, in the person's, best interest. When a patient is very unwell or highly distressed, they may lack capacity/competence. In these situations, teams should document the nature and level of risk, and the nature of the best interest decision and act to reduce risk and preserve life. Where there is doubt or controversy, Mental Health Act assessment sections or emergency incapacity judgements can be obtained. Debates within and between teams about legal status in a rapidly deteriorating patient are at best unhelpful and delay treatment, and at worst can be life threatening.

i. When to apply the Mental Health Act

Although a last resort, the decision to apply the Mental Health Act should be considered from the outset, e.g. when a patient refuses treatment in an emergency department setting. If medical/paediatric staff suspect that this course of action may be necessary, then emergency holding powers to detain the patient for assessment can be used as long as the patient is an inpatient. Psychiatric services should be contacted, as they will be familiar with arranging a Mental Health Act assessment.

If the medical/paediatric team are not satisfied with the opinion given, there should be direct contact between the consultant physician/paediatrician and the consultant psychiatrist specialising in eating disorders and the issue escalated until the patient's treatment is safe. An eating disorder consultant, or a liaison psychiatrist with a special interest in eating disorders should be identified to provide second opinions in cases where there is a disagreement or uncertainty. Moreover, if staff believe that the patient is being denied treatment, e.g. if the physician refuses to request or implement the Mental Health Act, the matter must be similarly escalated between consultants and reasons documented for decisions made.

c. Mental health law

The Mental Health Act (England and Wales), published in 1983, was substantially amended in 2007 and is due for further amendment.²⁴⁸ Because of the changes to the England and Wales legislation, and those applicable in Scotland²⁴⁹ and Northern Ireland,²⁵⁰ we will outline only the principles. Non-psychiatrists should consult a psychiatrist with up-to-date training in local mental health legislation in specific cases. The nearest relative should be informed when a patient is detained under one of the Mental Health Acts and when a significant change occurs,

²⁴⁸ https://www.legislation.gov.uk/ukpga/1983/20/contents

²⁴⁹ https://www.mwcscot.org.uk/law-and-rights/mental-health-act

²⁵⁰ https://www.mentalhealthlaw.co.uk/Mental_health_law_in_Northern_Ireland

including discharge. The patient can object to part, or all of the information being given and the approved mental health professional can take that objection into account

The functions most likely to be relevant to an inpatient setting are:

- **1.** Nurses' holding power
- 2. Doctors' holding power
- 3. Admission for assessment
- 4. Admission for treatment
- 5. Use of mental health legislation (e.g. under Section 63 in the English Mental Health Act, only if the patient is already detained) to:
 - o prevent a patient from leaving the ward
 - o require a patient to stay in bed
 - prevent a patient from engaging in unhealthy activities such as exercise
 - o require a patient to accept a prescribed diet
 - require a patient to accept a procedure to improve nutrition, e.g. NGT.

d. Holding powers

A patient who has been admitted to a medical ward for treatment of a severe eating disorder may decide to leave the hospital.



Case study 7: A patient aged 45 with a long history of low weight, probably due to undiagnosed anorexia nervosa, was admitted to a medical ward for investigation. She considered that her difficulty gaining weight was related to gastrointestinal problems, which she expected would be addressed on the medical unit. The physicians suspected an eating disorder and a psychiatrist was called. During the assessment, the possibility of a Mental Health Act section was mentioned. After the interview, the patient left the ward and went home.

In this case, the patient could legally have been prevented from leaving by ward staff under nurses' or doctors' holding powers. These powers can be used by the doctor or responsible clinician in charge of the patient's care (e.g. a medical consultant) or their nominated deputy (e.g. an on-call registrar) or a nurse working at the hospital who is either a registered mental health nurse or a registered learning disabilities nurse. Holding power lasts 72 hours for doctors and 6 hours for nurses, and can only be used for patients admitted to the hospital, i.e. not in the emergency or outpatient departments. While it may be a vital intervention to prevent someone leaving the unit and coming to harm, we must also be aware how brutal and unfair this may seem to the patient at the time, although he/she may be thankful for it later. The relationship between staff and patient is crucial here, so that patients are encouraged to try and understand why the holding power is being invoked and conveying that the staff understand how distressing this will be.

e. Common law

Common law allows life-saving treatment to be given if the patient is incapacitated. This covers resuscitating someone who collapses in the street or is run over by a car. It rarely applies to eating disorders but could be used if, e.g., an informal patient (a patient who has consented to hospitalisation) collapses with hypoglycaemia. In practice, the Mental Capacity Act is more relevant in situations arising in the context of eating disorders.

f. The Mental Capacity Act

The concept and testing of capacity have been discussed above. An unconscious patient with hypoglycaemia or hypokalaemia clearly lacks capacity and could be treated legally under common law or the Mental Capacity Act²⁵¹ until they gain consciousness at which point consent can be obtained, or the Mental Health Acts considered.

Some patients with eating disorders lack capacity but agree to treatment:



Case study 8: A 21-year-old woman with anorexia nervosa is categorically against having any nutrition because it would lead to weight gain. However, she agrees to admission and treatment, 'To please my parents'. It could be argued that the patient's consent is not valid because she lacks capacity. She understands the potentially fatal effect of weight loss, but when she tries to 'use and weigh' that information she concludes that she should not accept treatment because, even at a very low BMI, she finds weight gain intolerable.

In this case, the clinician could consider formally treating the patient under the Mental Capacity Act.

g. Organisational issues

Trusts will have managerial structures in place to receive and administer the Mental Health Act detention paperwork. If the patient is in an acute trust, these organisations should have links with local mental healthcare providers to ensure

²⁵¹<u>https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/497</u> 253/Mental-capacity-act-code-of-practice.pdf

that procedures documenting her capacity and why the treatment is necessary to save her life. The Mental Capacity Act (see the Code of Practice) acknowledges the doctor, in this situation as the 'decision maker'. We do not recommend use of either parental consent or the Mental Capacity Act to enforce treatment on a patient refusing lifesaving interventions and regard the Mental Health Acts as appropriate in that circumstance.

If an **adult** patient lacks capacity, everything needs to be done in the best interests of the patient. First, an extremely thorough and well-documented capacity assessment must be done; if necessary, in contentious or borderline instances, it should be carried out by an external expert. Then, having ascertained that the patient lacks capacity, a best interests meeting should be held. It may be in the best interest of the patient for families to receive information, but that would not be an automatic right and it depends on whether it is essential for the welfare of the patient to override any refusal to share information. For instance, if the patient does not live with family members and they have no role in keeping the patient safe, it could be argued that the family do not have the right for the patient's wish for confidentiality to be overruled. In practice, most relatives and carers would be living with or very close to the patient, and they could be given information if the patient is shown to lack capacity.

If, having convened a best interests meeting, the patient vigorously asserts that they do not want confidentiality breached but the clinicians think it is in the patient's best interests to do so, the clinicians should seek legal advice and consider asking a court to decide. Moreover, if the patient is under a section of one of the UK Mental Health Acts, the nearest relative has to be informed about the admission. If the patient is sent on leave and lacks capacity, the relative may receive information against the will of the patient, if it is in the patient's best interests. As indicated, in a contentious case, legal advice and the courts may need to be consulted and policies adhered to.

h. Compulsory admission and treatment for under-18s

See <u>Figure 5</u> for the compulsory treatment decision tree.

i. Introduction

In addition to mental health law, children (defined as under 18 years old) are subject to protecting laws, which can be used to provide healthcare if there is no consent or lack of capacity to consent. This is based on the principle that parents have the right and the duty to make sensible decisions about their child's health. For example, under the Children Act, a Specific Issue Order (Section 8) can be used to pass an NGT; a Care Order (Section 37) can be applied if a child is thought to be at risk of significant harm because of care given or not given; or the Inherent Jurisdiction of the Court (Wardship, Section 100) can be used to treat against a child's will when there are wider-ranging and longer-term issues. In addition, although the United Nations Convention on the Rights of the Child 1991 emphasises the importance of children having the right to form and express views on matters affecting them (Article 12), it also has the best interests of the child as its priority (Article 3), and outlines 'the responsibilities, rights and duties of parents [...] to provide, in a manner consistent with the evolving capacities of the child, appropriate direction and guidance in the exercise by the child of [their] rights' (Article 5). Furthermore, the Mental Capacity Act applies to young people from the age of 16. Please note that the age of legal majority and full consent varies across countries; it is 16 years in Scotland.

Thus, in young people, consideration of legal frameworks for treatment when there is no consent needs to balance the young person's right to be involved in decision-making, their right to privacy and confidentiality, and their right to refuse treatment against the right of their parents to provide care for them, the duty of others to protect them, and their best long-term interests.

ii. Making decisions about compulsory treatment for children and young people

Attempts must always be made to find points of collaboration to try and engage the child or young person in being a participant in their recovery. Even if they lack capacity or are under compulsory treatment, they should always be informed, have situations and decisions explained to them, and be able to contribute a view even if it is not determinative.

The key decision rests on the welfare of the person. This determines the balance of restriction and deprivation of liberty, and, for children and young people, it is likely to include considerations of the ability of the parent(s) to prioritise and support the needs of the child or young person (which may include high levels of enforcement of diet plans, so may be difficult for parents), and the likely benefits and risks of having or refusing treatment.

1. If the patient is 15 or under: Ask them for their views and discuss with them. Check their long- and short-term retention and encourage them to communicate information back to you in a way that shows that they have understood.

If you consider them **Gillick-Fraser competent**²⁵² (note that this has a higher threshold than adult capacity):

- a. and they say 'yes' to what you advise and can give you good reasons why, record those reasons and proceed.
- b. and they say 'no', consider whether this is likely due to their mental disorder. If so, you should advise a Mental Health Act assessment. It is unwise to overrule, even with parental consent unless it is urgent or relatively non-invasive, and within the zone of parental responsibility, i.e. a decision which parents would normally make on behalf of a

²⁵² <u>https://learning.nspcc.org.uk/child-protection-system/gillick-competence-fraser-guidelines</u>

child and that is in the best interests of the child. Alternatives include applying to the court.

If they are **not competent** (there is no assumption of competence at this age):

- c. The views of the young person do not determine treatment decisions. Parents can make decisions within the zone of parental responsibility (only one parent needs to consent, although it is advisable to have consent from both, if possible).
- **d.** If invasive, it is best to ask for a Mental Health Act assessment or apply to the courts.



Case study 9: A 14-year-old girl with anorexia nervosa appears to fully understand the reasons for her hospitalisation and the medical risks associated with her eating disorder. However, she cannot contemplate eating the hospital food and as a vegan she is opposed to use of nutritional supplements or nasogastric feeds. Her parents make the decision that her health needs are more important than her vegan beliefs in the short term, and agree to her being fed with non-vegan supplements. She resists the intervention, and a Mental Health Act assessment is requested.

2. <u>If the patient is 16–18 years old</u>: Ask their views and discuss. Start from an assumption of capacity. Record what they say verbatim. Note that in Scotland people aged 16 and above are considered adults.

If you assess them to **have capacity** for the decision (e.g. admission, NGT feeding): i.e. they can understand, retain, weigh the information given and communicate their decision back to you e.g. ('I have had enough of this eating disorder, I just want to return back to my old life, I think if I get treatment/admission/NGT fed, although I would find it difficult, it will help me').

- a. If they say 'yes' to treatment, proceed.
- **b.** If say 'no', you will need to request a Mental Health Act assessment.

If they do not have capacity:

- c. Even if they say 'yes' to treatment, you cannot proceed. Incapacitated consent is not consent. This might look like, 'I know you will section me if I don't say yes'. We advise requesting a Mental Health Act assessment. (We do not recommend gaining parents' consent on the young person's behalf unless the decision clearly falls into the zone of parental responsibility).
- d. If they say 'no' to treatment, move to Mental Health Act assessment.

- e. Alternatively, use the Mental Capacity Act, although this gives the patient fewer safeguards and is not considered ideal for the exercise of compulsory treatment, which is within the remit of the Mental Health Act. However, the Mental Capacity Act may be more appropriate if patients are incapacitous yet compliant, and decisions need to involve issues beyond treatment of eating disorders, e.g. if the patient has a learning disability and decisions about personal care and place of residence need to be made as well.²⁵³ Additionally, if any restraint is required, it would have to be clearly documented that it was proportionate to the risks faced.
- 3. <u>Both parent and **child** refuse treatment</u>: If both the child and the parent refuse treatment, local safeguarding procedures should be followed and use of the Children Act might be necessary. The Children Act applies up to the age of 18.

²⁵³ https://www.mentalhealthlaw.co.uk/HL_v_UK_45508/99_(2004)_ECHR_471

9. Eating disorders and type 1 diabetes mellitus

Key aspects of <u>Annexe 3</u>: Type 1 diabetes and eating disorders (T1DE)

a. Definitions and clinical features

- 1. Criteria for TIDE:
 - a. Type I diabetes
 - **b.** Intense fear of weight gain, body image concerns or fear of insulin promoting weight gain
 - c. Recurrent inappropriate direct or indirect restriction of insulin and/or other compensatory behaviour to prevent weight gain
 - **d.** Insulin restriction, disordered eating or compensatory behaviours causing at least one of the following: harm to health, clinically significant diabetes distress, impairment of daily functioning.
- 2. Characteristic 'red flag' symptoms
 - a. Biochemical: erratic blood glucose, multiple hospital admissions for uncontrolled diabetes, recurrent ketosis, recurrent severe hypoglycaemia
 - b. Beliefs, behaviours and functioning: over-exercising, impaired hypoglycaemia awareness, extreme dietary restriction, binge eating, history of weight loss, fear of weight gain, body image concerns, eating disorder, diabetes distress, fear of hypoglycaemia, mental health comorbidity
 - c. Relationships: secrecy about diabetes management, failure to request regular prescriptions, disengagement from diabetes services. Poor school or work performance or attendance. Conflict at home around meals and eating or diabetes management.

b. Recommended healthcare team

Management of TIDE requires close multidisciplinary collaboration between key professionals. These include:

- 1. The diabetes team, including adult or paediatric diabetes:
 - a. consultants
 - b. specialist nurses
 - c. specialist dietitians
- 2. Registered mental nurse (RMN) to support nursing care plan
- 3. RMN or mental health support worker

- 4. Eating disorders dietitian liaising with diabetes dietitian
- 5. Consultant psychiatrist in eating disorders treating medical or paediatric team
- 6. Psychologist or other therapist delivering psychological intervention

c. Assessment and treatment

Principles of assessment and initial appointment, and annually, include attention to BMI, undernutrition, need for refeeding and need for re-insulinisation.

Details are given in the TIDE supplement (<u>Annexe 3</u>) on treatment of specific areas, from general medication and nutritional to diabetes related, such as management of hypoglycaemia and raised ketones, as well as the key ways psychiatric management can differ in the recognition and management of eating-disordered behaviours through to support for family members.

10. Policies and protocols

a. General principles

Too often, assessing and managing patients presenting in mental and physical crisis with an eating disorder is done without reference to policies, leaving room for errors and luck. Equally, policies must allow some flexibility for pragmatism for the individual needs of patients with complex problems. We recommend that specialist EDSs and acute trusts which are likely to assess and treat people of all ages with eating disorders develop a formal group, either jointly (between paediatric and adult services) or separately, to bring together psychiatrists with a special interest in eating disorders, liaison psychiatry services, paediatricians, physicians, nursing staff (from both mental health and acute care), dietitians, GPs and representatives from clinical commissioning groups, with the aim of:

- developing joint protocols and clear policies across the different tiers of healthcare services
- ensuring seamless transitions of care
- clarifying the roles and responsibilities of the members, including the lead professional(s)
- collating contact details of relevant services
- agreeing frequency of reviews, and process for seeking advice and consultation

Communication between teams and with the patient and their family/carer is key for effective care. A high-level agreement at Trust or Board level that describes the treatment pathway for patients with eating disorders and how they will be managed in the local context is ideal. It should encapsulate the principles set out in this guidance and document any deviations and why they are required. The policy should be subject to consultation and should have the agreement of the services involved, including commissioners (or in Scotland, Wales and Northern Ireland, the relevant Health Boards). A policy will usually agree the principles of treatment and should have at its heart the wellbeing and safety of patients.

Detailed description of how the service will be delivered will usually be described in a series of standard operating procedures or protocols, which for convenience will be referred to as 'protocols' hereafter. The precise terminology may differ between boards and trusts, but the basic principles should be clearly discernible; that there are agreements of principle between the relevant services enshrined in a written policy and a set of protocols that define, in clear operational terms, how the policy will be delivered and patients cared for and developed proactively in advance of situations arising where patients might be put at risk. The purpose of this guidance is to help commissioners and boards design their services in a way that ensures patients are looked after safely, and to provide a set of criteria against which existing services can be measured and compared.

Protocols should include clearly documented arrangements that ensure the safe transfer and optimal transition of people with severe eating disorders between services. If, for any reason this is not possible, there should be a properly conducted and recorded meeting between representatives of the services, usually including the patient and family/carer, so that it is very clear what will happen during and after the transfer of care, and who is responsible for what. Meetings should continue until the transfer is satisfactorily achieved.

Safe care pathways and joint working between different organisations should be supported by commissioners and boards through their agreed policies. All services treating people with eating disorders should audit their outcomes against NICE quality standards,²⁵⁴ be members of the peer review quality networks for eating disorders²⁵⁵ and audit their performance against those standards.

b. Suggested areas to be covered by an oversight group within a protocol for managing severe eating disorders

i. Structure of the oversight group

The terms of reference for the local group tasked with oversight of the pathway for management of severe eating disorders should include its membership, including service user and family/carer input, and the frequency of meetings. The group should consider systems pathways, including referral processes, contact details for the local acute ward setting and members of the oversight group. The management of out-of-hours admissions for patients with eating disorders should also be determined in advance. A clear communication pathway should be established, to ensure that a thorough handover of patient care is carried out at each point of transition between services. This should include consultant-to-consultant, care coordinator-to-nurse and dietitian-to-dietitian handovers, so that continuity of care is maintained and patients are not lost to services during transitions.

ii. Clinical guidance

Acute hospitals should follow the recommendations in this guidance and have written guidance for staff (see <u>Annexe 1</u> for examples of such guidance). A ward should be identified, with links to an EDS or, if no local EDS exists, a liaison psychiatry service, that develops appropriate expertise, to minimise the risk of patients slipping through the net and to focus training programmes for staff who may be unfamiliar with the management of patients with eating disorders within an acute medical setting.

3. Admission and discharge across services

The oversight group, together with primary care representatives, should agree the criteria for paediatric or adult acute medical admissions and should consider other alternatives, such as community eating disorder care in conjunction with physical monitoring by a medical team or admission directly to a psychiatric unit. Ideally, the frequency of visits by the community EDS while the patient is on a paediatric/medical ward should also be established in advance of an admission.

Likewise, the criteria for discharge back to community EDS or a SEDU/SEDB, should be agreed in advance between secondary providers and primary care. Acute hospitals

²⁵⁴ <u>https://www.nice.org.uk/guidance/gs175/chapter/Quality-statements</u>

²⁵⁵ <u>https://www.rcpsych.ac.uk/improving-care/ccqi/quality-networks-accreditation/eating-disorders-qed</u>

should have guidance for staff relating to safe discharge of patients with medical complications of eating disorders, such as hypokalaemia or dehydration. The guidance should emphasise the importance of taking a holistic view of the patient's physical and mental health and should include advice on the assessment of medical risk and the frequency of blood tests after discharge. In the community context, the long-term effects of eating disorders such as osteoporosis, growth retardation and chronic intestinal and renal dysfunction should be taken into account.^{256, 257, 258} In some cases they may be irreversible.²⁵⁹

Psychiatric teams must be aware of the intense pressure on beds experienced routinely by most acute medical units. This pressure is even more intense during a Covid-19 pandemic. A clear discharge plan, including where the patient will be managed after refeeding is complete, can be very reassuring to staff on a medical ward and may reduce the chance of a poorly planned discharge occurring in response to bed pressures.

4. Psychiatry input

It is important that once a patient with a severe eating disorder has been admitted to a medical ward, there is support from a specialist eating disorder psychiatrist. The consultant psychiatrist providing support should have specific experience and training in the management of severe eating disorders and may be an eating disorders specialist, a liaison psychiatrist or a community psychiatrist with additional training. See the Royal College of Psychiatrists' 2018 report 'Safe patients and highquality services²⁶⁰' (CR207, p. 62) for an outline of the responsibilities and skills expected of an eating disorders psychiatrist. There should be regular communication between the consultant psychiatrists and the consultant paediatricians or physicians, and joint planning should occur between the services. While input from psychiatric and medical trainees is always welcome, it must be backed by involvement and regular contact between their consultants.

The psychiatric liaison service in an acute hospital can be very helpful, especially in the context of the shortage of specialists in eating disorders psychiatry. The Royal College of Psychiatrists' 2013 report, 'Liaison Psychiatry for Every Acute Hospital' (EC7),²⁶¹ which notes that 'People with severe anorexia nervosa are dying in acute hospitals because of avoidable physical or mental health complications related to lack of understanding of the combined physical and mental health needs', is particularly welcome, as are its recommendations. The PHSO report 'Ignoring the alarms'²⁶² gave a similarly damning view about the care received by Averil Hart (see page 12). Several deaths, some avoidable, have come to the attention of coroners,²⁶³ such that, "Coroners were so

²⁵⁶ https://pubmed.ncbi.nlm.nih.gov/22349551/

²⁵⁷ https://pubmed.ncbi.nlm.nih.gov/29417593/

²⁵⁸ https://pubmed.ncbi.nlm.nih.gov/26407541/

²⁵⁹ <u>https://pubmed.ncbi.nlm.nih.gov/30819332/</u>

²⁶⁰ <u>https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-reports/college-report-cr207.pdf?sfvrsn=b2229b95_2</u>

²⁶¹ https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr183.pdf?sfvrsn=1c625881_4

²⁶² <u>https://www.ombudsman.org.uk/publications/ignoring-alarms-how-nhs-eating-disorder-services-are-failing-patients</u>

²⁶³ <u>https://www.theguardian.com/society/2020/jan/19/eating-disorders-12-deaths-in-seven-years-led-to-coroner-warnings</u>

alarmed by the failings that they sent official warnings to 11 trusts that provided care for people with anorexia nervosa and bulimia between 2013 and 2019". Every hospital in which a patient with a severe eating disorder may be treated, should have ready access to a psychiatrist with specialist training in eating disorders. If an eating disorders psychiatrist is not available at all, or only at certain times, the liaison psychiatrist should fulfil that role. Strengthening future consultant workforce and training is essential to improve patient safety.

3. Nutritional rehabilitation

See <u>Chapter 4</u>.

The oversight group should discuss and agree meal plans, refeeding rates, and the use of NGT/NJT/PEG feeding, in line with this guidance, so that a common stance is presented to patients. We recommend that the dietetic service in an acute hospital likely to receive patients with severe eating disorders liaises with a dietitian in an EDS to develop protocols for refeeding and be in contact when a patient is admitted.

All paediatric units offering short stabilisation admissions for paediatric eating disorders should have an identified lead dietitian for eating disorders who has additional training in the management of paediatric eating disorders, will assist in the development of guidelines, manage risks, contribute to training, and address catering issues. Dietitians should all receive training in the nutritional management of eating disorders. These would bring it to par with other disorders such as type 1 diabetes, liver and renal disease and cancer, where there is a need for specific and additional expertise and leadership with an understanding that all dietitians need some basic level of postgraduate training in eating disorders care.

For dietitians on acute adult wards, the same principles apply, although in practice the minimum training would be a post qualification course in eating disorders dietetics.

In 2018, around 80% of hospitals had nutrition support teams,²⁶⁴ but they are not universal even in some larger hospitals. We recommend that all acute trusts caring for patients with severe eating disorders aspire to the provision of a nutrition support team within a defined time frame.

4. Physical complications

See <u>Chapter 2</u>.

Local protocols should include information on the management of specific physical complications (e.g. hypophosphataemia, hypokalaemia, hypoglycaemia, refeeding syndrome and bradycardia). In addition, they should provide information on monitoring patients, such as what standard blood tests should be carried out, when patients should be weighed, and when ECG monitoring should be considered, the frequency with which they should be performed and for how long they should be continued.

²⁶⁴ https://gut.bmj.com/content/gutjnl/67/Suppl_1/A174.2.full.pdf

5. Responsibilities of primary care teams

Involvement of primary care in monitoring of severely ill patients with eating disorders in the community varies in different locations. A number of important concerns have been raised, including: (1) patients may disengage from follow-up in primary care; (2) it would be difficult in the community to keep track of patients who do not have their blood tests taken; (3) that the results may be too complex to interpret; and (4) it would increase workload.

We strongly recommend that the Royal College of Psychiatrists and Royal College of GPs form a working group to decide on how community care of these high-risk patients can be shared. Possible outcomes could be:

- 1. development of a model of care and recall, perhaps along the lines of sharedcare protocols for monitoring of ADHD medication in children²⁶⁵
- 2. for the small number of severe eating disorders in a practice, GPs to have access to an eating disorder specialist 'hotline'; or
- 3. for additional funding to primary care to be allocated to deal with the monitoring of this group of patients.

6. Behavioural manifestation of eating disorders advice

See <u>Chapter 6</u>.

There should be local protocols and training in place for the management of behavioural manifestations of eating disorders, including psychological support, and use of psychotropic medication, physical restraint and mental health legislation. To avoid confusion, it is important that these are in line with local policies.

Local protocols should consider issues such as the management of compensatory behaviours, such as over-exercising, purging or other methods of avoiding weight gain, bingeing, self-harm, and of violent or other disturbed behaviours. A physical restraint protocol should make it clear exactly what restraints are acceptable and should not use euphemisms such as 'behavioural support'. Hospital security teams may not be aware of how physically frail patients with severe anorexia nervosa can be. Physical restraint of patients should only be considered when absolutely essential and for the shortest period of time and should be carried out by nurses or other staff trained in control and restraint.

7. Nursing

Policies and protocols will need to consider arrangements for special nursing cover, particularly for patients detained under mental health legislation. They should include recommendations on necessary qualifications, the supervision of one-to-one nurses, the role of paediatric or general medical nurses (as opposed to mental health nurses) and the opportunities for training and debriefing sessions. The funding of special (one-to-one) nursing for patients with severe eating disorders is often a source of

²⁶⁵ https://www.nice.org.uk/guidance/ng87/chapter/Recommendations#maintenance-and-monitoring

disagreement between medical and mental health management. Local policies should pre-empt such disputes and clarify the budget funding these services.

8. Legal framework

Consideration of the legal framework is important when caring for patients with severe eating disorders. This must include:

- Social work and legal advice in situations where consent to treatment is withheld by either the patient, their parents or carers
- The use of appropriate mental health legislation, including the criteria for its use, identification of the responsible clinician, and who will need to be involved in treatment decisions on an ongoing basis (see <u>Chapter 8</u>)

A policy for handling advance directives should be in place. Some patients may be frightened of NGT feeding and may have specific requests such as the use of a narrower tube if possible. The validity of an advance directive, such as a request not to apply NGT feeding, needs to be evaluated with psychiatric, medical and legal help in each case, as the issue arises. and must be viewed in the context of the whole case.

c. Responsibilities of different local health care providers

The oversight group should consider funding arrangements as part of its policies. This should include the roles and responsibilities of all stakeholders, as well as discussion and agreements around funding of special nursing, referral to a SEDU or specialist eating disorder bed (SEDB), and cover for the cost of the various investigations. Agreement may also be needed from primary care services if monitoring is to continue in the community. We are concerned that some primary care services are no longer providing medical monitoring for eating disorders. Where inquests on the deaths of five women criticised medical monitoring^{266, 267} it has been proposed that all monitoring is done by the EDS, excluding primary care. We believe that this issue requires further consideration at national level.

d. Training and continuing professional development

We expect that this guidance will be used in educating medical students, and in training of all postgraduate and post-qualification doctors, and allied healthcare professionals, including dietitians, nurses and psychologists. The Academy of Medical Royal Colleges is working on developing a shared curriculum for postgraduate medical training, which will include medical emergencies in eating disorders. In addition, it is the responsibility of the oversight group to ensure that regular and *adhoc* training, supervision and debriefs are provided for paediatric and medical wards. We recommend that job plans for consultants in eating disorders and liaison psychiatry allow a session for training other professionals in paediatric and medical

²⁶⁶<u>https://www.cambridgeshireandpeterboroughccg.nhs.uk/easysiteweb/getresource.axd?assetid=19407&type=0&servicetype=1</u>

²⁶⁷ https://www.bbc.co.uk/news/uk-england-cambridgeshire-53920996

wards. We welcome the inclusion of eating disorders in the new curriculum for the Royal College of Emergency Medicine.²⁶⁸

The group should reflect on the current service, including areas of good practice, so that learning forms part of the regular continuing professional development of staff. Specific cases, serious incidents or 'near misses' should be investigated jointly, and a report issued that highlights any necessary changes in the services or in the agreed policy arrangements. Any recommendations should be followed up within an agreed time frame, e.g. 3–6 months, to establish that the changes have been acted on.

While it is important to improve services locally, it is important that any learning, particularly where a death has occurred, is shared nationally. Information collected by the National Patient Safety Agency on all deaths and serious incidents involved in a patient's care provides opportunities for the Royal College of Psychiatrists and Beat to consider what learning might be secured to improve future outcomes.

e. Appropriate care settings and other considerations

The treatment of adolescents can be complicated by the age limit of paediatric wards. While some acute hospitals admit young people up to the age of 18 years into paediatric wards, others only cater for young people up to the age of 16 years, with those over 16 being admitted to general medical wards. It is helpful to ascertain what the arrangements in the area are, and to ensure that this is reflected in the local policies and protocols. If transfer to a specialist inpatient unit is required, provision is typically up to the age of 18 and there may be different provision for children under the age of 12 years as opposed to teenagers.

Local protocols should reflect that eating disorders can affect people of all gender preferences and can occur at any age. Treatment on a medical ward should be tailored to meet any specific age needs (e.g. flexible visiting time for people with children, mobility issues). In particular, eating disorders may occur during pregnancy and in the immediate postpartum period, therefore patients may need help with decisions about feeding as well as facilities to allow breastfeeding if this is their wish and they are able to do so. Patients requiring admission in the immediate postpartum period must have the wellbeing of the baby addressed as well as that of the mother, which may mean finding appropriate accommodation for both.

The welfare of children and other dependents can be particularly challenging. Sometimes issues of safeguarding arise, as well as practical concerns about childcare and safety, if a parent has to be admitted under a compulsory treatment order or if the patient is living in an unsafe or unsupportive environment.

²⁶⁸ <u>https://www.rcoa.ac.uk/sites/default/files/documents/2021-12/2021%20Curriculum%20for%20ACCS%20Training%20v1.1.pdf</u>

11. Challenges for commissioners and managers

a. Overview

i. Urgent inpatient care

People with eating disorders who require urgent medical or paediatric treatment should be cared for in environments that have designated facilities to provide both physical and psychiatric care. Such patients may need to be admitted to an acute medical or paediatric bed, often in busy general hospitals, where they may be cared for by medical/paediatric teams who have relatively little expertise in managing eating disorders. However, this is changing as NHS strategy focuses on better integration of physical and mental health.

Given that there are often several teams and organisations involved in the care of such patients, there can be a functional disconnect between services that leads to delayed treatment, lack of clarity over responsibilities, and avoidable deaths. It is therefore essential that safe care pathways and joint working between organisations are developed, governed through local working groups whose membership includes representatives from the relevant teams and organisations involved in care (see <u>Box 7</u>).

It is crucial that these care pathways and working groups are supported by managers and commissioners to develop strategies that can be agreed and appropriately commissioned, to ensure care is established and maintained in line with national standards and to facilitate this through joint training between medical/paediatric and psychiatric teams.

Box 7: Specific measures to promote safe care pathways and joint working

- Knowledge and training about the content of this guidance should be required for all frontline staff. Trusts and other relevant NHS organisations should ensure junior and senior medical and nursing staff, dietitians and other relevant staff receive mandatory training, both at induction and ongoing.
- Local health commissioners should require that an oversight group with at least a physician/paediatrician, a psychiatrist specialising in eating disorders, a primary care representative, a dietitian, a nurse and a manager be set up in their area to support joint working between organisations in the care of patients with severe eating disorders.
- Local health commissioners should ensure that robust plans are in place for the care of adults and young people with eating disorders in acute medical/paediatric settings to safely and effectively deliver care.
- There should be clear guidance on the funding of special nursing. Special nursing can be a life-saving intervention, but is also costly. A recent survey of care of people with severe eating disorders across the UK highlighted significant variation in

budgeting approaches, with a lack of advance funding arrangements being commonplace. We recommend that when special nursing is required, funding should be shared equally by all teams/organisations involved in the care of the patient.

- Local health commissioners should ensure that there is a clear commissioning arrangement to support transfer between services and organisations, the interface between acute medical/paediatric and local SEDU/SEDS services being a crucial aspect of the care pathway. Different SEDUs have different criteria for admission. For example, some may accept patients requiring nasogastric feeding and others not. The commissioners should become acquainted with these aspects of potential provider units and ensure that pathways are in place to support discharge back to community care.
- Local health commissioners should ensure that acute medical/paediatric services are registered to admit patients detained under the Mental Health Act and that trusts have managerial structures in place to receive and administer the Mental Health Act detention paperwork.
- Local health commissioners should be aware of gaps in local resources and be willing to support referral to national centres for advice or treatment when necessary. For example, the lack of specialist day care provision for eating disorders as an evidence-based alternative to inpatient care is a significant limitation of current provision in most areas.²⁶⁹
- Commissioners and managers should support and incentivise quality improvement activity aligned with the NICE quality standards for eating disorders (in particular standard 5, 'Coordinated care across services', and standard 6, 'Risk assessment when moving between services').
- Regional commissioning bodies should consider utilising targeted commissioning (e.g. Commissioning for Quality and Innovation) to incentivise local organisations to develop dedicated pathways and groups for patients with severe eating disorders, particularly in areas where care pathways are lacking or not in keeping with national standards.

Patients with severe malnutrition or electrolyte imbalance may be treated in the emergency department (e.g. until serum potassium is in the normal range) or admitted to a medical bed. Admission of young people to paediatric wards is not a rare event because young people destabilise physically more rapidly than adults.

Staff in general psychiatric or medical wards may be unfamiliar with working with patients with eating disorders, and may not have been trained, and the environment could be so busy that paying adequate attention to a patient with an eating disorder

²⁶⁹ <u>https://www.beateatingdisorders.org.uk/uploads/documents/2019/10/day-and-home-based-treatment-report.pdf</u>

may be difficult. In such a context, staff may preferentially attend to severely ill patients with cardiac or other life-threatening conditions. The pressure on beds may result in patients with eating disorders being discharged prematurely. We recommend that any patient seen in the emergency department or any other medical setting for treatment of a serious symptom of an eating disorder such as hypokalaemia should, after treatment, be referred for urgent eating disorder assessment and treatment, and in the meantime followed up, possibly in primary care, until the specialist assessment is done.

The checklist in <u>Appendix 3</u> can aid decision-making in non-specialist settings.

ii. Brief inpatient followed by outpatient care

Brief medical stabilisation admissions have become more common recently. Effective management of these brief admissions is crucial. Evidence in children and young people suggests that when a brief admission is followed immediately by evidence-based outpatient care, this is as cost effective – or more, in some cases – than longer admission for achieving weight restoration.²⁷⁰ In general, long paediatric admissions are almost always a poor use of scarce resources. Admissions should ideally be under 3 weeks, with care provided simultaneously in the physical and mental health domains. There is no similar evidence for brief admission for adults.

- It is essential that local barriers to shared acute care (e.g. funding, activity monitoring) are identified and addressed by the local oversight group.
- Audit of admission times is recommended.

iii. Psychiatric inpatient care

A few patients admitted for medical/paediatric care will require transfer to psychiatric inpatient care. Most psychiatric beds for children and adolescents with eating disorders are in generic adolescent units. For adults, a SEDU is the most common location of inpatient care, although there are no specialist units in Wales and in Northern Ireland, where patients are admitted to general psychiatric units.

iv. Increase of specialist eating disorder beds

Eating disorders hospitals admissions have increased by 84% in the last five years. A new Royal College of Psychiatrists analysis of hospital data for eating disorders shows 11,049 more admissions in 2020/21 compared to 2015/16. Children and young people with eating disorders are the worst affected with a rise of 89% in the five-year period, from 3,541 to 6,713 episodes, and a 35.4% increase in 2020/21 alone. An alarming increase of 79% is also seen in adults over the age the age of 19 across the five years. We propose that in areas without a SEDU, psychiatric units develop resources and training to treat patients in SEDBs. Not all generic adolescent units are able to offer NGT feeding, and this can put increased pressure on SEDUs and paediatric wards to provide treatment for these patients.

²⁷⁰ https://pubmed.ncbi.nlm.nih.gov/24439238/

v. Integrating inpatient and community care

Inpatient treatment should be as close to home as possible, and be well integrated with community care, to facilitate discharge. Access to day care and other intensive community treatment options is a commissioning priority.

vi. The role of commissioners and managers

Commissioners and managers have a crucial role to play in improving the clinical care of patients with eating disorders. They can demand that awareness of the issues raised in this guidance is integrated into policy and practice in all relevant NHS contexts, especially emergency departments, medical and paediatric wards and psychiatric inpatient units (see <u>Table 11</u>). Awareness should also be expected in private inpatient units, especially those accepting patients with eating disorders.

The Care Quality Commission and the RCPsych Quality Networks for Eating Disorders (QED) should examine all relevant units' readiness to care for patients with eating disorders by inspecting policies and the availability of relevant documentation.

We strongly recommend that this guidance be adopted by managers, commissioners, royal colleges, regional eating disorder provider collaboratives and other influential professional bodies, as required reading and implementation for all services in which a patient with a severe eating disorder could potentially be assessed and/or treated.

Table 11: Examples of priorities for commissioners to consider in mental health care for people with eating disorders

| Priorities for commissioners | Notes |
|---|---|
| Establishment of safe care pathways | For admission and treatment of patients <18 and >18 with severe eating disorders |
| Setting up oversight groups for severe eating disorders care pathways | Accessible to all medical and psychiatric units and primary care staff in the area |
| Ensure training and resources | For frontline staff in primary care, medical and psychiatric units |
| Guidance and funding for special nursing | Avoiding tension between mental health and medical budgets |
| Provision of specialist eating disorder dietetic intervention to paediatric and adult wards providing care for children, young people and adults with severe eating disorders | Requires a training programme for adult and paediatric dietitians, as well as increased resources |
| Quality standards for transfer between units | From medical or paediatric to psychiatric units, from primary to secondary care, and between secondary care services in both directions |

| Managerial structures to administer compulsory assessment and treatment | i.e. Mental Health Act in England and Wales, and other legal frameworks in other countries in the UK |
|--|--|
| If local services inadequately resourced, support funding for transfer to a national or other better-resourced centre | |
| Support development of day care for severe eating disorders | To reduce pressure on beds in SEDSs |
| To support general adult psychiatric wards to provide a SEDB, with input from liaison services, to allow appropriate transfer from medical beds | To meet the need for such beds |
| Consider targeted commissioning, e.g. Commissioning for Quality and Innovation framework | To facilitate the above standards |
| To require that standards are audited, monitored and maintained | Locally and using national standards including NICE, MEED, RCPsych and QED |

vii. Impact on resources

We acknowledge that provision of specialist services (SEDBs) within a general psychiatric inpatient service will have resource implications and will almost certainly require additional funding. At present, we regard this development as aspirational, but extremely important. The main outcome to monitor in an audit is the time spent inappropriately in medical or paediatric beds by patients for whom a specialist bed cannot be found.

b. Responsibilities of those commissioning care

The responsibility for commissioning care varies across the UK:

- England: Health care commissioners
- Scotland: Health boards
- Wales: Local health boards
- Northern Ireland: Health and social care trusts

i. Workforce

The foundation for modern effective care is a team which includes a psychiatrist specialising in eating disorders. Part of their role is to act as a source of support for both general adult/CAMHS and liaison psychiatry services and physicians/paediatricians with a subspecialty interest in nutrition, to enable the provision of care for patients with severe eating disorders. The shortage of consultant psychiatrists in the field has been highlighted in multiple national documents,

including the RCPsych 2021 Census,²⁷¹ and a recent Prevention of Future Death Report, which stated:

"continuing and serious shortage of eating disorder specialists across the country with many Trusts finding it difficult to fill vacancies; such shortages inevitably impact upon the level and quality of support available to primary care providers and other specialists and therefore, in my view, risks avoidable future deaths²⁷²"

Those responsible for commissioning care should refer to 'Adult Eating Disorders Guidance for commissioners and providers'²⁷³ and the 'Children and Young People Eating Disorders Access and Waiting Times'²⁷⁴ documents, which outline the optimal composition of teams that can deliver safe and timely evidence-based treatment. The latter document also includes a workforce calculator. It is important to note that there is a lack of parity across the age range in terms of access and waiting times. The inequality was highlighted by the PHSO report in 2017, and it will need to be addressed as soon as possible.

The Royal College of Psychiatrists and Health Education England has started a pilot credentialing programme which is aimed to help with training the future consultant workforce. We recommend increasing the number of training posts in eating disorders to help develop the future workforce.

Commissioners should map the journey of care from primary care to specialist services and back again for both adults and younger people. This map should be used to identify where there are gaps in provision, and to plan how to overcome them.

ii. Best practice and shared protocols

Many areas will have some or all the necessary components, but they may not be organised or working together in a coordinated, patient-focused and collective way. Commissioners, therefore, have an equally important duty to bring services together in a way that ensures they function coherently. This does not mean that all services must be on the same geographical site but that they must cooperate effectively in a streamlined way and develop shared protocols to allow for the safe care of these patients. Commissioners need to specify that services follow best practice, using the principles outlined in this guidance, that they share protocols, and that they meet on a regular basis to review practice.

If it is not possible to bring the necessary components together locally, then specific arrangements need to be put in place, either through Managed Clinical Networks, provider collaboratives, or by formalising arrangements for a hub-and-spoke service. It is essential that the capacity of the resulting arrangements is adequate to meet the needs of the combined populations. Any deficits in funding and resource allocation relative to commissioning guidance and other standards (e.g. QED) should be

- ²⁷³ https://www.england.nhs.uk/wp-content/uploads/2019/08/aed-guidance.pdf
- ²⁷⁴ https://www.england.nhs.uk/wp-content/uploads/2015/07/cyp-eating-disorders-access-waiting-timestandard-comm-guid.pdf

²⁷¹ https://www.rcpsych.ac.uk/docs/default-source/improving-care/workforce/census-2021-completed-draft.pdf
²⁷² https://www.judiciary.uk/publications/averil-hart/

discussed with managers and commissioners in the first instance, with supporting evidence.

iii. Monitoring standards

Requiring that standards be monitored should be an essential part of commissioning of EDSs. This can be achieved using existing inspection processes (CQC and QED) and standards set and continuing to be developed (e.g. NICE and this guidance). Effective engagement with experts by experience, service users and their families/carers should form part of monitoring.

c. Areas with limited local eating disorders provision.

i. General principles.

The key to good care is an integrated approach with trust and cooperation between specialist EDS, medical/paediatric specialties, liaison psychiatry, primary care, managers and commissioning bodies. Different models may suit different areas, but *ad-hoc* arrangements convened at the last minute on a case-by-case basis, constitute a significant risk to a group of patients who have an ability to slip through gaps in the system.²⁷⁵

ii. Models of care for remote settings

In larger centres, a formal oversight group (<u>Chapter 10.b</u>) can enable joint protocols and policies for transitioning and transferring patients so that systems can respond appropriately when a patient presents in need of care. Likewise having an identified ward for every acute trust with links to a specialist EDS can minimise the risk of patients slipping through the net and focus training programmes for staff unfamiliar with the management of patients with eating disorders in a medical setting. In areas where not all the key components or links are present, a hub-and-spoke approach developing strong links with a major centre may be an alternative. Having an identified expert clinician (or two) in such a centre with whom to communicate during the treatment of a severely ill patient gives a clear point of contact for advice.

In Scotland the concept of the Managed Clinical Network has been very successful in some areas.²⁷⁶ The North of Scotland Network cares for some of the most remote communities in the UK, including the Highlands and the Island Health Boards, and has pioneered video-conferencing for the assessment of cases prior to admission, progress reporting and discharge planning and even facilitating designated sessions for physicians on the SEDU itself. In other areas, EDS (e.g. CONNECT: The West Yorkshire and Harrogate Adult Eating Disorders Service²⁷⁷) have collaborated with acute trusts across a wide geographical area to develop a regional network of care pathways supported by oversight groups on each site linking into one SEDU, thereby ensuring a safe and consistent approach to risk management on a large scale.

²⁷⁵ https://pubmed.ncbi.nlm.nih.gov/16260812/

²⁷⁶ https://www.hi-netgrampian.org/people-networks/managed-clinical-networks/

²⁷⁷ https://www.leedsandyorkpft.nhs.uk/our-services/connect-west-yorkshire-adult-eating-disorders-service/

Together with our proposal for SEDBs in acute psychiatric units, the association with a regional EDS suggests a training role for the latter in establishing the former.

The common factors in successful services seem to be cooperation, trust, shared protocols, regular networking and intensive, proactive (rather than reactive) care.

iii. Recommendations for clinical care pathways in areas with limited provision

Lack of accessible specialist eating disorders provision is a substantial problem for sparsely populated areas, for those separated from the mainland as well as for those far from the nearest EDS.

Under these circumstances, the principles of service provision laid out in <u>Box 8</u> may help.

Box 8: Principles of service provision for sparsely populated areas

- 1. Identify a local psychiatrist with training in eating disorders and a local physician/paediatrician with training in nutrition. All child and adolescent psychiatrists should have reasonable training in eating disorders. If expertise in eating disorders is not available locally, try to establish an arrangement with an established centre and form a working relationship, preferably with one or two named experts. If either of the above is unavailable, the primary care trust or equivalent should identify suitable consultants and arrange for them to be trained by a recognised expert. It is essential that the psychiatrist has knowledge and experience in the use of mental health legislation. Eating disorder credentialing is aimed at improving training for consultants wishing to specialise in this area.
- 2. Nutritional expertise may be found in a range of medical specialties as well as in dietitians but is recognised as a particular subspecialty interest in gastroenterology. Paediatricians specialising in adolescent medicine may have particular expertise in eating disorders.
- 3. The named psychiatrist and physician/paediatrician should be joined by a dietitian and a nurse to form a local oversight group. Ideally, a group should have an agreed point of contact with a specialist service or unit for detailed advice and to facilitate training as part of continuing professional development, as well as having expertise to treat adolescents and adults, and understand the main areas of difference with respect to risk assessment and management. In England, training is one of the designated responsibilities of specialist services. In Scotland, training is part of the role of Managed Clinical Networks and educational events can often be arranged.
- 4. Develop a local policy on managing severely ill patients with eating disorders, to include identification, resuscitation and preparation for transfer to a suitable unit with experience in the field. Identifying a single ward or unit to admit patients can be helpful so staff can be trained and develop experience in treating patients with eating disorders. Wards/units with very short stays and high turnover are not ideal for the management of patients with eating disorders who require close observation. A gastrointestinal unit, general medical ward, paediatric ward and, if needed, a medical high dependency unit may offer more stability.
- 5. Utilise video-conferencing or secure internet links in remote and rural areas. Technology is routinely used in, for example, the North of Scotland Managed Clinical Network for Eating Disorders, covering Shetland, Orkney, the Western

Isles, NHS Highland, Tayside and Grampian, an area of land equivalent to about 20% of England and Wales.

6. While frequent visits from an eating disorders specialist should be provided in all settings, these visits are particularly important where there is limited access to an inpatient eating disorders service. In addition, we recommend active supervision of nurses providing one-to-one observation of patients to make them fully aware of behaviours to look for and what to do if they observe them.

12. Recommendations for audit and research

a. National Confidential Enquiry into deaths from eating disorders

Every death or near-miss incident provides a learning opportunity. The reporting of deaths from eating disorders is lower than expected, likely due to recording factors. An up-to-date review of mortality in eating disorders and associated factors is needed. The government should fund and commission a system that allows for learning from deaths associated with eating disorders.

b. The impact of guidelines on treatment of eating disorders

Engagement in quality improvement activity should be an expectation in health care services. The introduction of new policies or treatment guidelines provides an opportunity for PDSA (Plan-Do-See-Act) cycles to drive improvement in medical, paediatric, psychiatric and primary care environments.

c. Studies of capacity in eating disorders other than anorexia nervosa

Further research is needed on the impact of compulsory treatment on outcome across the eating disorder diagnoses.

d. Risk factors and feeding rates in refeeding

The majority of research on refeeding risk has been undertaken in adolescents. Case series and controlled studies examining factor predicting refeeding risk and determining safe rates of refeeding are needed, particularly in adult populations.

e. Validation of the risk assessment framework

In this document, most parameters for assessing risk in severe malnutrition are based on expert consensus. Validation of the risk assessment framework is needed. .

f. Audit of admissions to acute medical and paediatric units of patients with eating disorders

Such an audit should record any adverse events including death, refeeding syndrome, self-harm, level of cooperation between medical and psychiatric staff, outcomes and use of and adherence to MEED guidelines.

Glossary of abbreviations and terms

Abbreviations

| %mBMI | Median percentage body mass index |
|-----------|--|
| ADHD | attention deficit hyperactivity disorder |
| ALT | alanine aminotransferas |
| ARFID | avoidant restrictive food intake disorder |
| ASD | autism spectrum disorder |
| AST | aspartate aminotransferas |
| BDA | British Dietetic Association |
| BMI | body mass index |
| BP | blood pressure |
| bpm | beats per minute |
| CAMHS | child and adolescent mental health service |
| CCQI | College Centre for Quality Improvement |
| СК | creatine kinase |
| CRT | cognition remediation therapy |
| СҮР | children and young people |
| ECG | electrocardiogram |
| EDS | eating disorder service |
| ECG | electrocardiogram |
| EDS | eating disorder service |
| ERG | expert reference group |
| EUPD | emotionally unstable (borderline) personality disorder |
| HDU | high dependency unit |
| HGS | hand grip strength |
| HR | heart rate |
| ICU | Intensive care unit |
| MARSIPAN | Management of Really Sick Patients with Anorexia Nervosa |
| MEED | Medical Emergencies in Eating Disorders (formerly MARSIPAN) |
| NCCMH | National Collaborating Centre for Mental Health |
| NGT | nasogastric tube |
| ΝЈΤ | nasojejunal tube |
| NICE | National Institute for Clinical Excellence |
| OCD | Obsessive compulsive disorder |
| OSFED | other specific feeding and eating disorders |
| PEG | percutaneous endoscopic gastrostomy |
| PHSO | Parliamentary Health Services Ombudsman |
| QED | Quality Networks for Eating Disorders |
| QTc | corrected QT (start of the Q wave to end of the T wave) interval |
| SEDB | specialist eating disorder bed |
| SEDS | specialist eating disorder service |
| SEDU | specialist eating disorder unit |
| SG | specific gravity |
| SMI | severe mental illness |
| SUSS Test | Sit-Up– Squat Stand Test |
| UFED | Unspecified feeding or eating disorder |
| WHO | World Health Organization |
| WTE | whole-time equivalent |
| | |

Glossary of terms

| Term | Definition according to ICD-11 criteria |
|---|---|
| Anorexia nervosa | Significantly low body weight for the person's height, age and developmental stage that is not due to another health condition or to the unavailability of food. A commonly used threshold is BMI less than 18.5kg/m² in adults and BMI-for- age under 5th percentile in children and adolescents. |
| | Rapid weight loss (e.g. more than 20% of total body weight within 6 months) may replace the low body weight guideline as long as other diagnostic requirements are met. |
| | Children and adolescents may not gain weight as expected based on the individual developmental trajectory rather than weight loss. |
| | Low body weight is accompanied by a persistent pattern of behaviours to prevent restoration of normal weight, which may include behaviours aimed at reducing energy intake (restricted eating), purging behaviours (e.g. self-induced vomiting, misuse of laxatives), and behaviours aimed at increasing energy expenditure (e.g. dysfunctional exercise), typically associated with a fear of weight gain. Low body weight or body shape is central to the person's self-evaluation or is inaccurately perceived to be normal or even excessive. |
| Avoidant/ restrictive food intake disorder (ARFID) | Avoidance or restriction of food intake that results in: the intake of an insufficient quantity or variety of food to meet adequate energy or nutritional requirements that has resulted in significant weight loss, clinically significant nutritional deficiencies, dependence on oral nutritional supplements or tube feeding, or has otherwise negatively affected the physical health of the person; or significant impairment in personal, family, social, educational, occupational or other important areas of functioning (e.g. due to avoidance or distress related to participating in social experiences involving eating). |
| | The pattern of eating behaviour is not motivated by preoccupation with body weight or shape. Restricted food intake and its effects on weight, other aspects of health, or functioning is not due to unavailability of food, not a manifestation of another medical condition (e.g. food allergies, hyperthyroidism) or mental disorder, and are not due to the effect of a substance or medication on the central nervous system including withdrawal effects. |

| Binge eating disorder | or me A bin the p eatin to sto Binge accor Howe not re beha vomi exerc There signi | uent, recurrent episodes of binge eating (e.g. once a week ore over a period of several months). ge eating episode is a distinct period of time during which berson experiences a subjective loss of control over eating, g notably more or differently than usual, and feels unable op eating or limit the type or amount of food eaten. e eating is experienced as very distressing and is often mpanied by negative emotions e.g. guilt or disgust. ever, unlike in bulimia nervosa, binge eating episodes are egularly followed by inappropriate compensatory viours aimed at preventing weight gain (e.g. self-induced ting, misuse of laxatives or enemas, dysfunctional cise). e is marked distress about the pattern of binge eating or ficant impairment in personal, family, social, educational, pational or other important areas of functioning. |
|--|---|---|
| Bulimia nervosa | or ma A bin the p eatin to sto Binga comp (e.g. s dysfu The p stron There inapp impa occu | Lent, recurrent episodes of binge eating (e.g. once a week bre over a period of at least 1 month). Ige eating episode is a distinct period of time during which berson experiences a subjective loss of control over eating, g notably more or differently than usual, and feels unable op eating or limit the type or amount of food eaten. e eating is accompanied by repeated inappropriate bensatory behaviours aimed at preventing weight gain self-induced vomiting, misuse of laxatives or enemas, unctional exercise). berson is preoccupied with body shape or weight, which gly influences self-evaluation. e is marked distress about the pattern of binge eating and propriate compensatory behaviour or significant irment in personal, family, social, educational, pational or other important areas of functioning. berson does not meet the diagnostic requirements of exia nervosa). |
| Pica | - | Ilar inappropriate consumption of non-nutritive tances, such as non-food objects and materials (see DSM- |
| Rumination- regurgitation disorder | | itional and repeated bringing up of previously owed food (See DSM-5) |

Appendix 1: Stakeholder organisations

- Academy of Medical Royal Colleges
- Aneurin Bevan University Health Board
- Beat Beat Eating Disorders charity
- Black County Healthcare NHS Foundation Trust
- Bodywhys Eating Disorders Association of Ireland
- British Dietetic Association
- British Psychological Society
- Cambridgeshire and Peterborough Foundation Trust & NHS England/Improvement Experts of Experience Eating Disorders Clinical Network
- Dorset Healthcare University NHS Foundation Trust
- Evelina London Children's Hospital at Guy's and St Thomas'/British Academy of Childhood Disability
- F.E.A.S.T.
- First Steps ED, Mental Health and Specialist Eating Disorders charity
- Forward Thinking Birmingham / Birmingham Women's and Children NHS Foundation Trust
- GP Partner Affinity Care
- NHS Wales
- NHS England (London) Clinical Reference Group for Adult Eating Disorders
- North London Adult Eating Disorder Provider Collaborative (Central and North West London NHS Foundation Trust – Vincent Square, Barnet, Enfield and Haringey Mental Health Trust - St Ann's, North East London NHS Foundation Trust)
- Physiotherapy Eating Disorder Professional Network
- Priory Group
- Priory Group Stockton Hall NHS Trust
- Royal College of Physicians Advisory Group on Nutrition, Weight and Health
- Richardson Eating Disorder Service, Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust
- Royal College of Emergency Medicine
- Royal College of General Practitioners
- Royal College of Paediatrics and Child Health
- Royal College of Psychiatrists, Faculty of Child and Adolescent Psychiatry
- Royal College of Psychiatrists, Faculty of Eating Disorders
- Royal College of Psychiatrists, Liaison Faculty
- Tees, Esk and Wear NHS Foundation Trust
- West Midlands Clinical Network for Adult Eating Disorders, NHS England and NHS Improvement
- West Suffolk Hospital

Appendix 2: Literature reviews and guideline comparisons

a. A comparison of the assessment and determination of risk of serious complications in current evidence-based guidelines for eating disorders: a systematic review

i. Aim

This research aimed to determine how evidence-based guidelines for eating disorders (anorexia nervosa, bulimia nervosa and binge eating disorders) compare in their recommendations for assessment and determination of risk of serious complications.

ii. Method

The electronic databases MEDLINE, EMBASE, CINAHL and PsycINFO were searched as well as the International Guideline Library and ECRI Guidelines Trust. A combination of the search terms 'anorexia nervosa' or 'bulimia nervosa' or 'eating disorder' or 'binge eating disorder' and 'guideline' were used. Searches were performed on 14 December 2020 and re-run on 31 March 2022. Searches were restricted to publications from the year 2009 as well as those published in English. The bibliography of recent reviews of clinical guidelines will be checked for relevant evidence-based guidelines as well as the bibliography of included guidelines. Two reviewers independently screened the titles and abstracts of all identified references. The full texts of potentially relevant guidelines were screened independently in duplicate by two reviewers. Data from each relevant guideline was extracted in duplicate.

Previous versions of guidelines, guidelines published before 2009, those not published in English and those that do not have a national or international scope were excluded.

iii. Results

Study characteristics

Twenty-six full text articles were screened for inclusion and 12 evidence-based guidelines for eating disorders were included. Three guidelines were identified from

the UK,^{278, 279} Denmark^{280, 281} and Canada^{282, 283} and one each from Australia and New Zealand,²⁸⁴ France,²⁸⁵ Spain,²⁸⁶ USA,²⁸⁷ and Germany.²⁸⁸ One guideline had an international scope.²⁸⁹ Hilbert *et al.* (2017)²⁹⁰ completed a systematic review and comparison of international guidelines for eating disorders in 2017. Since this time two new guidelines have been published, one in the UK²⁷⁹ and Canada²⁸³ in 2020, followed by the German guideline published in 2019.²⁸⁸ The UK NICE guideline²⁷⁸ and the Danish guidelines^{280, 281} were published within the previous 5 years (2017 and 2016, respectively). All other guidelines were published over 5 years ago. An evidence watch was produced in 2012 for the US guideline.²⁸⁷ Three of the included guidelines were specific to anorexia nervosa^{279, 280, 285} and one was specific to bulimia nervosa,²⁸¹ all other guidelines had a wider scope. Most guidelines were developed by a multidisciplinary group.^{278, 282, 283, 284, 285, 286, 288}

Risk assessment

One of the UK guidelines focused on refeeding under restraint and was specifically aimed at dieticians.²⁷⁹ This guideline did not include recommendations for assessment of general medical risk. The full Danish guidelines are not available in English.^{280, 281} The quick guides that are published in English do not have recommendations for the assessment of medical risk. There are also no recommendations for the assessment of risk given in the guidelines developed by the World Federation of Societies of Biological Psychiatry, that have an international scope²⁸⁹ or the Guideline for Eating Disorders produced by the Scottish Intercollegiate

²⁷⁸ NICE. Eating Disorders: Recognition and Treatment. London: NICE; 2020. Available at: <u>https://www.nice.org.uk/guidance/ng69</u>.

²⁷⁹ Fuller SJ, Philpot U, Working Group. The development of consensus-based guidelines for dietetic practice in nasogastric tube feeding under restraint for patients with anorexia nervosa using a modified Delphi process. Journal of Human Nutrition and Dietetics. 2020;33(3):287–94.

 ²⁸⁰ Danish Health Authority. 2016. National clinical guideline for the treatment of anorexia nervosa. Quick guide. Available at: https://www.sst.dk/da/udgivelser/2016/~/media/36D31B378C164922BCD96573749AA206.ashx.
 ²⁸¹ Danish Health Authority. 2015. National clinical guideline for the treatment of moderate and severe bulimia. Quick guide. Available at: https://www.sst.dk/-/media/Udgivelser/2015/NKR-Bulimi/EN_194413_Quick-Guide-NKR-Bulimi_print.ashx?la=da&hash=54B13E57E7515B317B889CCFD1B9F7725F72C69F.

²⁸² British Columbia Ministry of Health. 2010. Clinical Practice Guidelines for the BC Eating Disorders Continuum of Services. Available at:

https://mh.providencehealthcare.org/sites/default/files/BC%20Eating%20Disorders%20Clinical%20Practice%20Guidelines.pdf.

²⁸³ Couturier J, Isserlin L, Norris M, Spettigue W, Brouwers M, Kimber M, et al. Canadian practice guidelines for the treatment of children and adolescents with eating disorders. <u>Journal of Eating Disorders</u>. 2020;8(1):4.
²⁸⁴ Hay P, Chinn D, Forbes D, Madden S, Newton R, Sugenor L, et al. Royal Australian and New Zealand College of Psychiatrists clinical practice guidelines for the treatment of eating disorders. Australian & New Zealand Journal of Psychiatry. 2014;48(11):977–1008.

 ²⁸⁵ Haute Autorite de Sante. 2013. Clinical Practice Guidelines. Anorexia nervosa: management. Available at: https://www.has-sante.fr/upload/docs/application/pdf/2013-05/anorexia_nervosa_guidelines_2013-05-15_16-34-42_589.pdf
 ²⁸⁶ Catalan Agency for Health Technology and Research. 2009. Clinical Practice Guideline for Eating Disorders.

²⁸⁶ Catalan Agency for Health Technology and Research. 2009. Clinical Practice Guideline for Eating Disorders. Available at: <u>https://portal.guiasalud.es/wp-content/uploads/2019/01/GPC_440_Eat_Disorders_compl_en.pdf</u> ²⁸⁷ Yager J, Devlin MJ, Halmi KA, Herzog DB, Mitchell JE, Powers P, Zerbe KJ. 2006. Practice Guideline for the Treatment of Patients with Eating Disorders, 3rd Edition. Available at:

https://psychiatryonline.org/pb/assets/raw/sitewide/practice_guidelines/guidelines/eatingdisorders.pdf ²⁸⁸ Herpertz et al., 2019. Joint German Guideline. Diagnosis and treatment of eating disorders. S3 guideline. Available at: <u>https://higherlogicdownload.s3.amazonaws.com/AEDWEB/27a3b69a-8aae-45b2-a04c-</u> 2a078d02145d/UploadedImages/Resources/German_ED_diagnosis_and_treatment.pdf

²⁸⁹ Aigner M, Treasure J, Kaye W, Kasper S, WFSBP Task Force on Eating Disorders. World Federation of Societies of Biological Psychiatry (WFSBP) Guidelines for the Pharmacological Treatment of Eating Disorders, The World Journal of Biological Psychiatry. 2011;12:400–43, DOI: 10.3109/15622975.2011.602720.

²⁹⁰ Hilbert A, Hoek HW, Schmidt R. Evidence-based clinical guidelines for eating disorders: International comparison. Current Opinion in Psychiatry. 2017;30: 423–37.

Guidelines Network. <u>Table A</u> contains a summary of the criteria recommended to assess medical risk for adults in the guidelines included in this review and <u>Table B</u> contains the recommended risk assessment for children and young people.

The UK NICE guidelines reference the <u>MARSIPAN</u> (2014) and <u>Junior MARSIPAN</u> (2012) reports, and this is therefore the criteria entered in <u>Table A</u> and <u>Table B</u>.

Quality assessment

The Appraisal of Guidelines for Research and Evaluation (AGREE) II was used to assess the quality of the guidelines included in this review.^{291,292,17,18}

AGREE II consists of 23 items covering six domains:

- 1. Scope and purpose 4. Clarity of presentation
- 2. Stakeholder involvement 5. Applicability
- 3. Rigour of development 6. Editorial independence.

Guidelines were appraised independently in duplicate by two researchers. Domain scores were calculated and an overall assessment of quality was determined by consensus, taking into consideration the domain scores. If information required to score items was referenced in other documentation not available in the English language, these items were not scored or included when calculating the domain scores. Table B presents the overall assessment scores, which are on a scale from 1 (lowest possible quality) to 7 (highest possible quality).

iv. Conclusion

There is significant variation between international clinical guidelines in the criteria recommended to assess medical risk for patients with an eating disorder. There are differences in both the recommended categories for medical examination as well as the specific criteria within those categories.

²⁹¹ Brouwers MC, Kho ME, Browman GP, Burgers JS, Cluzeauet F, Feder G, al., for the AGREE Next Steps Consortium. AGREE II: Advancing guideline development, reporting and evaluation in healthcare. Canadian Medical Association Journal. 2010; 182: E839–E842.

²⁹² AGREE Next Steps Consortium. 2017. The AGREE II Instrument. Available at: <u>http://www.agreetrust.org</u>

| | UK Adult (NICE/ MARSIPAN) | Australia and New Zealand Adult | France | Spain | USA | Canada | Germany |
|-------------------|------------------------------|---|---|--------------------|---|--|--|
| Medical history | y and examination | | | | | | |
| Weight loss | | Psych. admission: Rapid weight loss of 1kg per week over several weeks or grossly inadequate nutritional intake (<100kcal daily) or continued weight loss despite community treatment. | Loss of 30% of body weight in 3 months | • • • | Generally <85%; acute weight decline with food refusal even if not <85% of healthy body weight | Part 4: Rapid and progressive weight loss | Rapid or sustained weight loss (>20% over six months) |
| BMI and weight | BMI <13 | Psych. admission: BMI <14 Med. admission: BMI <12 | BMI <14kg/m² | Inpt care: BMI <16 | | Part 8: BMI <13 | Severe underweight (BMI <15kg/m²), suggests inpatient admission. Severe underweight: class 1 = 13 to 15.99; class 2 = <13kg/m2 |
| HR (awake) | <40bpm | Med admission: =40bpm or 120bpm | | | <40bpm | Part 4: HR < 40bpm or severe bradycardia. Part 8: Bradycardia, <40 BPM | Bradycardia with HR <40bpm. |

| | UK Adult (NICE/ MARSIPAN) | Australia and New Zealand Adult | France | Spain | USA | Canada | Germany |
|--------------------------|---|---|---------------------------|--|------------------------------|--|---|
| | | | | | | | Tachycardia with a HR>110bpm |
| Cardiovascular health | Bradycardia Low BP | Med admission: Postural tachycardia >20/min systolic blood pressure <80mmHg Psych. admission: Systolic blood pressure <90mmHg | Hypotension <90/60mmHg | Emergency hosp.: • Bradycardia of <40bpm. • Syncopes or hypotension with SBP <70mmHg | blood pressure <90/60mmHg | Part 4; BP <90/60mmHg orthostatic hypotension (with an increase in HR of >20bpm) orthostatic hypotension a drop in BP of >10-20mmHg/ minute from lying to standing). Part 8: Arrhythmia associated with malnutrition and electrolyte disturbances symptomatic postural tachycardia, increase in pulse of >20bpm Marked orthostatic | a decline in BP o >20mmHg in the orthostatic test increase in HR >20mmHg in the orthostatic test BP <90/60mmHg |

| | UK Adult (NICE/ MARSIPAN) | Australia and New Zealand Adult | France | Spain | USA | Canada | Germany |
|----------------------|---|---|--|---------------------------------|-------------|--|---------------|
| | | | | | | hypotension with decrease in BP | |
| | | | | | | of 20mmHg upon standing | |
| Hydration status | | | Clinical signs of dehydration. Natraemia: <125mmol/L (excessive fluid intake, risk of convulsions), >150mmol/l (dehydration) | Emergency hosp.: Dehydration | Dehydration | Part 4: Dehydration that does not reverse within 48 hours Part 8: Significant dehydration and malnutrition BUN/creatinine ratio greater than 20:1. Hypernatremia < 130mmol/l admit, consider ICU if < 120–125mmol/l | |
| Temperature | <35°C | Med admission: <35°C or cold/blue extremities Psych. admission: <35.5°C or cold/blue extremities | Hypothermia <35.5°C | | <97.0°F | Part 4: <35.5℃ or 95.5°F Part 8: <35℃ | <36°C or less |
| Muscular weakness | SUSS score <2, especially if scores falling | | Marked amyotrophy with axis hypotonia | | | Part 4: Muscular weakness or diaphragmatic wasting not | |

| | UK Adult (NICE/ MARSIPAN) | Australia and New Zealand Adult | France | Spain | USA | Canada | Germany |
|-------------------------|------------------------------|---|--------|---|---|--|---|
| | | | | | | accounted for by a correctable deficiency | |
| | | | | | | Part 8: • Sit-up–Squat- stand test: O: Unable 1: Able only using hands to help 2: Able with noticeable difficulty 3: Able with no difficulty | |
| Other clinical state | | Confusion and delirium Acute pancreatitis, gastric or oesophageal rupture Estimated glomerular filtration rate (eGFR) <60ml/min/1.73m² or rapidly dropping (25% drop within 1 week) | | Emergency hosp.: Consciousness disturbances Convulsions Severe liver or kidney disturbances Pancreatitis High digestive haemorrhage: hematemesis, rectal bleeding Acute gastric dilation Inpt care: Hemametesis | Hepatic, renal or cardiovascular organ compromise requiring acute treatment Poorly controlled diabetes | Part 4: Poorly controlled diabetes Severe acrocyanosis Pregnancy with an at-risk fetus (infant birth rate is lower in mothers with AN; the miscarriage rate for women with BN is higher than for healthy women) | An acute abdomen, for instance in the case of acute dilatation of the stomach, is rare. This constitutes an acute life- threatening danger |

| | UK Adult (NICE/ MARSIPAN) | Australia and New Zealand Adult | France | Spain | USA | Canada | Germany |
|------------------------------|---|--|--|--|--|---|--|
| | | | | • Rectal bleeding | | Signs of inadequate cerebral perfusion (confusion, syncope, loss or decreased level of consciousness, organic brain syndrome, ophthalmo- plegia, seizure, tetany, ataxia) | |
| Physical invest | igations | | | | | | |
| ECG abnormalities | Raised QTc (>450ms) non-specific T- wave changes | Med admission: Any arrhythmia including QTc prolongation, nonspecific ST or T- wave changes including inversion or biphasic waves | ECG abnormalities | Emergency hosp.: Serious arrhythmia or conduction disorder Other ECG disorders | | Part 4: Arrhythmia as seen on ECG Part 8: prolonged QTc, >0.04ms between QT intervals | Arrhythmogenic effects of a mitral valve prolapse represent an additional risk factor in patients with pronounced underweight |
| Biochemical abnormalities | Hypokalaemia potassium <3.0mmol/L or hypokalaemic changes Raised transaminases Low sodium <130mmol/L | Med admission: Potassium 3.0mmol/L Phosphate below normal range Blood sugar 2.5mmol/L | Hypokalaemia <3mEq/L Hypophosphore mia <0.5mmol/L Symptomatic hypoglycaemia <0.6g/L or asymptomatic if <0.3g/L | Emergency hosp.: Decreased potassium <3mEq/l Sodium (<130 or >145) Inpt care: lonic disturbances | Hypokalaemia <3mEq/L Glucose <60mg/dl Electrolyte imbalance, | Part 4: Potassium <2.3mmol/l Hypophosphatae mia; phosphorous below normal on fasting | Hypokalaemia concentration of 3.0mmol/l, especially in conjunction with ECG changes Phosphate changes |

| UK Adult (NICE/ MARSIPAN) | Australia and New Zealand Adult | France | Spain | USA | Canada | Germany |
|------------------------------|---|--|-------|-----|--|---|
| | Zealand Adult Sodium <125mmol/L Magnesium below normal range Albumin <30g/L Liver enzyme markedly elevated (AST or ALD >500) Psych. admission: Potassium below normal range Blood sugar below normal range Sodium <130mmol/L Albumin below | France Hepatic cytolysis >10xN Renal failure, creatinine clearance <40mL/min | Spain | USA | Sodium Sodium 127mmol/l Hypoglycaemia; blood glucose 2.5mmol/l Magnesium 0.6mmol/l (normal above 0.7mmol/l) Part 8: Potassium level 2.7mEq/l Metabolic alkalosis/ acidosis: Elevated serum bicarbonate due to: – vomiting or diuretic abuse or low bicarbonate | A glucose concentration lower than 60mg/dl is a risk indicator Exceeding liver enzyme reference range further diagnostics required |
| | normal range • Liver enzymes mildly elevated | | | | level due to laxative abuse; high risk – Severe >33–35mEq/l | |
| | | | | | Other electrolyte abnormalities to look for: Check PO4, Magnesium, Calcium, ECG | |

Marked changes in blood count

| | UK Adult (NICE/ MARSIPAN) | Australia and New Zealand Adult | France | Spain | USA | Canada | Germany |
|---|------------------------------|---|--|---|--|--------|--|
| | | 109/L Psych. admission: neutrophils <1.5 x 109/L | neutrophils <500/mm³) | | | | |
| Behavioural an | d psychiatric symp | otoms | | | | | |
| Disordered eating behaviours | | Several days of no oral intake, supervision required for every meal | Uncontrollable vomiting. | Emergency psych. assessment: Absolute refusal to eat or drink Inpt care: No food intake, especially liquids | Needs supervision during and after all meals and in bathrooms | | |
| Engagement with or success of management plan | | Outpatient treatment is not working | Previous failure of satisfactorily managed ambulatory care Uncooperative patient, or cooperating solely in highly structured care setting Insufficient motivation, hindering compliance with ambulatory care Failure of outpatient- based refeeding | Inpt care: Due to the psychopathology presented, the patient is unable to follow guidelines in the outpatient programme: frequency of visits, limitation of physical activity, recommended diet, etc. | | | Sustained weight loss or insufficient weight gain over 3 months despite outpatient or day hospital treatment excessive demands in the outpatient setting (too little structure in the guidelines about mealtime structure, amount of food, feedback on eating |

| | UK Adult (NICE/ MARSIPAN) | Australia and New Zealand Adult | France | Spain | USA | Canada | Germany |
|--------------------------|------------------------------|------------------------------------|--|-------|--|-------------------------|---|
| | | | Refeeding: need for refeeding via nasogastric tube, or another feeding method that cannot be used on an outpatient basis Insufficient motivation, hindering compliance with ambulatory care. No ambulatory care available for lack of facilities (distance may be an obstacle) Failure of ambulatory care (aggravation or development of chronic illness) | | | | behaviour; for children and adolescents: breakdown of family resources • necessity for treatment by a multi- professional team (multimodal treatment program integrating psychological and medical treatment methods as wel as social work and creative arts therapies) within a hospital settin (psychosomatic, psychiatric hospital treatment) |
| Activity and exercise | | Uncontrolled exercise | Excessive and compulsive physica exercise (in association with another indication for hospital admission) | | Some degree of external struct beyond self-co required to pro patient from compulsive exercising; rare | cure ontrol event | Excessive urge to exercise, which cannot be mastered in an outpatient setting |

| | UK Adult (NICE/ MARSIPAN) | Australia and New Zealand Adult | France | Spain | USA | Canada | Germany |
|-----------------------|------------------------------|--|---|---|--|-------------------------|---|
| | | | | | sole indication for increasing the level of care | | |
| Purging behaviours | | Uncontrolled purging | Purge behaviours (vomiting, use of laxatives or diuretics): inability to control intensive purge behaviour without help | Inpt care: Repeated self- induced vomiting, laxative abuse and use of diuretics | Unable to control multiple daily episodes of purging that are severe, persistent, and disabling, despite appropriate trials of outpatient care, even if routine laboratory test results reveal no obvious metabolic abnormalities. | | Severe bulimic symptoms (e.g. abuse of laxatives/diuretics, severe binge eating with vomiting) |
| Self-harm and suicide | | Psych. admission:Suicidal ideationActive self-harm | Suicide attempt or failed attempt Precise suicide plan Repeated self- injury | Emergency psych. assessment: significant self- injurious behaviour Inpt care: Serious self- injurious behaviour | If suicidality is present, inpatient monitoring and treatment may be needed depending on the estimated level of risk Specific plan with high lethality or intent; admission may also be indicated in patient with suicidal ideas or | Part 4: Suicide risk | Suicidality |

| | UK Adult (NICE/ MARSIPAN) | Australia and New Zealand Adult | France | Spain | USA | Canada | Germany |
|-------------------------------------|------------------------------|------------------------------------|---|---------------------------------|---|--------|---|
| | | | | | after a suicide attempt or aborted attempt, depending on the presence or absence of other factors modulating suicide risk | | |
| Other mental health diagnosis | | | Any co-occurring psychiatric disturbance where severity warrants hospitalisation: Depression Substance abuse Anxiety Psychotic symptoms Obsessive-compulsive disorder Anorexia nervosa: Intrusive, constant, obsessive ideations, inability to control obsessive thoughts | symptoms with autolytic risk | Any existing psychiatric disorder that would require hospitalisation | | Pronounced mental comorbidity. A hospital treatment can also be necessary in patients with less severe underweight if the have a serious psychological comorbidity (e.g. trauma-relate disorders, borderline personality disorders) |

| | UK Adult (NICE/ MARSIPAN) | Australia and New Zealand Adult | France | Spain | USA | Canada | Germany |
|---|------------------------------|---|---|-------|--|--------|---|
| Other | | Psych. admission: moderate to high agitation and distress | | | | | |
| Community su | ipport | | | | | | |
| Parent/carer capacity to provide support | | | Family problems or absence of family to accompany ambulatory care Family exhaustion Serious family conflict High levels of parental criticism Severe social isolation | | Severe family conflict or problems or absence of family so patient is unable to receive structured treatment in home; patient lives alone without adequate support system Treatment program is too distant for patient to participate from home | | Social or family factors which strongly hamper the healing process (e.g. social isolation, problematic family situation, insufficient social support) |

Note: Psych. admission = Psychiatric admission indicated; Med. admission = Admission to a medical ward indicated; Emergency psych. assessment = Referral to emergency psychiatric assessment; Inpt care = Inpatient care (complete hospitalisation) criteria; Emergency hosp. = Emergency hospitalisation; Part 4 = Primary care, physical indicators for inpatient hospitalisation; Part 8 = High-intensity inpatient treatment, key physical assessment parameters.

Table B: Recommended criteria in clinical guidelines for the assessment of medical risk in children and young people with an eating disorder

| | UK (NICE/ MARSIPAN) | Australia and New Zealand Adult | France | Spain | USA | Canada | Germany | Society for Adolescent Health and Medicine ²⁹³ |
|-------------------|--|--|---|---------|----------------|---|---------------------------------|--|
| Medical histo | ry and examination | | | | | | | |
| BMI and weight | %mBMI <70% (approx. below 0.4th BMI centile) | Weight < 75% of expected body weight | BMI <14kg/m ² at 17 years or over, or BMI <13.2kg/m ² at ages 15 and 16, o BMI <12.7kg/m ² at ages 13 and 14 | BMI <16 | Generally <85% | Part 4: <75% of ideal body weight or ongoing weight loss, body fat <10% Part 8: Percentile charts for weight and height for age should be part of the physical assessment | a fall below the 3rd centile | |

²⁹³ The Society for Adolescent Health Medicine. 2015. Position paper of the Society for Adolescent Health and Medicine: Medical management of restrictive eating disorders in adolescents and young adults. Journal of Adolescent Health. 56, 121-25.

Although the position paper did not meet the criteria for this review, the risk assessment criteria are widely used, particularly in the USA. Therefore, it has been included in the table for comparison purposes.

| | UK (NICE/ MARSIPAN) | Australia and New Zealand Adult | France | Spain | USA | Canada | Germany | Society for Adolescent Health and Medicine ²⁹³ |
|--------------------------|--|--|--|---|--|---|---|---|
| Weight loss | Recent loss of weight of 1kg or more/week for two consecutive weeks. | Rapid weight loss | Rapid loss of weight: more than 2kg/week | Emergency hosp.: Weight loss >50% in the last 6 months (30% in the last 3 months) Inpt care: - Weight evolution does not follow the rate indicated in the weight restoration programme | Acute weight decline with food refusal even if not <85% of healthy body weight | | rapid or sustained weight loss (>20% over 6 months) sustained weight loss or insufficient weight gain over three months (earlier for children and adolescents) despite outpatient or day hospital treatment | |
| HR (awake) | <40bpm | <50bpm | Extreme bradycardia: pulse HR<40bpm, irrespective of time of day Tachycardia | | Near 40bpm | Part 4: HR <50bpm daytime; <45bpm nighttime Part 8: HR<50bpm | Bradycardia 40bpm Tachycardia with a heart rate >110/minute | Severe bradycardia (HR <50bpm daytime) |
| Cardiovascular health | Irregular heart rhythm (does not include sinus arrhythmia) | Cardiac arrhythmia Postural tachycardia | Postural tachycardia HR increase of >20bpm | Emergency hosp.: • Bradycardia of <40bpm. | Postural tachycardia HR increase of >20bpm | Part 4: • Postural tachycardia HR increase >20bpm | • Decline in BP of >20mmHg in the orthostatic test | Hypotensior (<90/45mml g) Orthostatic increase in |

| UK (NICE/ MARSIPAN) | Australia and New Zealand Adult | France | Spain | USA | Canada | Germany | Society for Adolescent Health and Medicine ²⁹³ |
|--|---|--|---|---|--|------------|---|
| sitting BP: systolic <0.4th centile (84– 98mmHg depending on age and gender); diastolic <0.4th centile (35–40mmHg depending on age and gender) History of recurrent syncope; marked orthostatic changes (fall in systolic BP of ≥20mmHg or more, or below 0.4th– 2nd centiles for age, or increase in HR of >30bpm) | HR increase of >20bpm • Orthostatic hypotension; decrease in BP >10–20mmHg • blood pressure <80/50min • postural hypotension >20mm | Low systolic blood pressure (<80mmHg), BP <80/50mmhg | Syncopes or hypotension with SBP <70mmHg | BP <80/50mmHg orthostatic BP changes >10- 20mmHg drop) | increase in HR Orthostatic changes of >20bpm increase in HR Systolic BP <90mmHg Part 8: Postural tachycardia Systolic, diastolic or mean arterial pressure below the 0.4th centile for age and sex, and/or postural drop of more than 15mmHg Hypovolemia Tachycardia or inappropriate normal HR hypotension and prolonged capillary refill time | <90/60mmHg | pulse (>20bpm) o decrease in blood pressure (>20mmHg systolic or >10mmHg diastolic) |

| | UK (NICE/ MARSIPAN) | Australia and New Zealand Adult | France | Spain | USA | Canada | Germany | Society for Adolescent Health and Medicine ²⁹³ |
|---------------------|---|---------------------------------------|---|------------------------------------|---------|---|---------------|--|
| Hydration status | Fluid refusal Severe dehydration (10%): reduced urine output, dry mouth, decreased skin turgor, sunken eyes, tachypnoea, tachycardia | | Refusal to drink | Emergency hosp.: Dehydration | | Part 4: Dehydration. Part 8: • Significant dehydration and malnutrition, • Hyper- natremia sodium >145mmol/l, commonly called dehydration • Consider HDU, PICU or ICU if <120- 125mmol/l | | Dehydration |
| Temperature | <35.5°C tympanic or 35.0°C axillary | <35.5 °C | Hypothermia <35.5°C. Hyperthermia | | <97.0°F | Part 4: Temperature <35.6°C/96.0°F Part 8: Temperature <36°C will usually be accompanied by other features Beware <35°C | <36°C or less | Hyperthermia (body temperature <96°F, 35.6°C) |

| | UK (NICE/ MARSIPAN) | Australia and New Zealand Adult | France | Spain | USA | Canada | Germany | Society for Adolescent Health and Medicine ²⁹³ |
|-------------------------|---|---------------------------------------|---|---|-----|---|---|--|
| Muscular weakness | SUSS Test Sit up from lying flat: Unable to sit up at all from lying flat (score 0) Stand up from squat: Unable to get up at all from squatting (score 0) | | | | | Part 8: SUSS Test. O: Unable I: Able only using hands to help 2: Able with noticeable difficulty 3: Able with no difficulty | | |
| Other clinical state | | | Occlusive syndrome. Acetonuria (urine test strip), | Emergency hosp.: Consciousness disturbances convulsions Severe liver or kidney disturbances Pancreatitis High digestive haemorrhage: hematemesis, rectal bleeding acute gastric dilation | | Part 4: Intractable vomiting Oesophageal tears Hematemesis: poorly controlled diabetes syncope | An acute abdomen, for instance in the case of acute dilatation of the stomach, is rare. This constitutes an acute life- threatening danger | Arrested growth and developmen Acute medical complicatio of malnutrition (e.g. syncopy seizures, cardiac failure, pancreatitis etc.) Comorbid medical condition th |

| | UK (NICE/ MARSIPAN) | Australia and New Zealand Adult | France | Spain | USA | Canada | Germany | Society for Adolescent Health and Medicine ²⁹³ |
|------------------------------|---|---------------------------------------|---|---|--|---|--|---|
| | | | | Inpt care:Hematemesisrectal bleeding | | | | prohibits or limits appropriate outpatient treatment (e.g. type 1 diabetes mellitus) |
| Physical invest | igation | | | | | | | |
| ECG abnormalities | QTc >460ms (girls) or >450 (boys) with evidence of bradyarrhythmia or tachyarrhythmia (excludes sinus bradycardia and sinus arrhythmia); ECG evidence of biochemical abnormality | QTc >450msec | | Emergency hosp.: Serious arrhythmia or conduction disorder. Other ECG disorders | | Part 4: Cardiac arrhythmias including prolonged QTc Part 8: Arrhythmia associated with malnutrition and or electrolyte disturbances Prolonged QTc | Arrhythmogenic effects of a mitral valve prolapse represent an additional risk factor in patients with pronounced underweight | EKG abnormalities (e.g. prolonged QTc or severe bradycardia) |
| Biochemical abnormalities | hypokalaemia Hypophos- phataemia hypokalaemia | Hypokalaemia | Severe hydro- eletrolytic or metabolic disturbances, in particular: hypo- | Emergency hosp.: • Decreased potassium <3mEq/l | Hypokalaemia Hypophos- phataemia Hypo- magnesaemia | Part 4: • Potassium <3mEq/l or 3.2mmol/l Part 8: | • Hypokalaemia concentration of 3.0mmol/l, especially in conjunction | Electrolyte disturbance (hypokalaemia, hyponatraemia hypo- phosphataemia |

| | UK (NICE/ MARSIPAN) | Australia and New Zealand Adult | France | Spain | USA | Canada | Germany | Society for Adolescent Health and Medicine ²⁹³ |
|------------------------------------|---|---------------------------------------|--|---|--|---|--|--|
| | hypoalbumin- aemia, hypo- glycaemia hypo- natraemia hypo- calcaemia | | alkalaemia, hypophos- phoraemia, hypo- natraemia, hypo- magnesaemia • Hypo- glycaemia <0.6g/L • Creatinine elevation (>100 μmol/L) • Thrombo- paenia (<60,000 /mm ³) | sodium (<130 or <p>>145mmol/l) </p> Inpt care: Ionic disturbances | | Potassium <3mmol/l admit consider HDU, PICU or ICU if <2–2.5mmol/l Serum chloride concentration <88mmol/L Part 8: Hypoglycaemia | with ECG changes Phosphate changes A glucose concentration lower than 60mg/dl is a risk indicator exceeding liver enzyme reference range, further diagnostics required | r |
| Haematology | | Neutropenia | Leuconeu- tropaenia (<1000/mm³) | | | | Marked changes in blood count | |
| Behavioural ar | nd psychiatric symp | toms | | | | | | |
| Disordered eating behaviours | Acute food refusal or estimated calorie intake 400– 600kcal per day | Uncontrolled eating disorder | Refusal to eat: total aphagia | Emergency psych. assessment: Absolute refusal to eat or drink Inpt care: No food intake, especially liquids | Needs supervision during and after all meals and in bathrooms | Part 8: uncontrolled vomiting with risk of oesophageal and other visceral tears | | Acute food refusal |

| | UK (NICE/ MARSIPAN) | Australia and New Zealand Adult | France | Spain | USA | Canada | Germany | Society for Adolescent Health and Medicine ²⁹³ |
|---|------------------------|---|---|--|---|--|---|--|
| Engagement vith or success of nanagement olan | | Failure to respond to outpatient behaviour | Previous failure of satisfactorily managed ambulatory care Uncooperative patient, or cooperating solely in highly structured care setting Insufficient motivation, hindering compliance with ambulatory care Failure of outpatient- based refeeding Refeeding: need for refeeding via nasogastric tube, or another feeding method that | to follow guidelines in the outpatient programme: frequency of | preoccupied with intrusive repetitive thoughts; patient | Part 4: • failure to respond to outpatient treatment | Sustained weight loss or insufficient weight gain over three months despite outpatient or day hospital treatment. – excessive demands in the outpatient setting (too little structure in the guidelines about mealtime structure, amount of food, feedback on eating behaviour; for children and adolescents: breakdown of family resources) necessity for treatment by a multiprofessional team (multimodal treatment program integrating | outpatient treatment |

| | UK (NICE/ MARSIPAN) | Australia and New Zealand Adult | France | Spain | USA | Canada | Germany | Society for Adolescent Health and Medicine ²⁹³ |
|-------------------------|---|---------------------------------------|--|-------|--|--------|--|--|
| | | | cannot be used on an outpatient basis Insufficient motivation, hindering compliance with ambulatory care No ambulatory care available for lack of facilities (distance may be an obstacle) Failure of ambulatory care (aggravation or development of chronic illness) | | | | psychological and medical treatment methods as well as social work and creative arts therapies) within a hospital setting (psychosomatic/ psychiatric hospital treatment) | |
| Activity and xercise | High levels of uncontrolled exercise in the | | Excessive and compulsive physical exercise | | Some degree of external structu beyond self- | | Excessive urge to exercise, which cannot be | |

| | UK (NICE/ MARSIPAN) | Australia and New Zealand Adult | France | Spain | USA | Canada | Germany | Society for Adolescent Health and Medicine ²⁹³ |
|--------------------------|---|---------------------------------------|---|--|---|---|---|--|
| | context of malnutrition (>2h/day) | | (in association with another indication for hospital admission) | | control required to prevent patient from compulsive exercising; rarely a sole indication for increasing the level of care | | mastered in an outpatient setting | |
| Purging behaviours | | | Purge behaviours (vomiting, use of laxatives or diuretics): inability to control intensive purge behaviour without help | Inpt care: repeated self- induced vomiting, laxative abuse and use of diuretics | Unable to control multiple daily episodes of purging that are severe, persistent and disabling, despite appropriate trials of outpatient care, even if routine laboratory test results reveal no obvious metabolic abnormalities | | Severe bulimic symptoms (e.g. abuse of laxatives/diuretic s, severe binge eating with vomiting) | Uncontrollable bingeing and purging |
| Self-harm and suicide | Self-poisoning, suicidal ideas with moderate to high risk of completed suicide | D | Suicide attempt or failed attempt Precise suicide plan Repeated self- injury | Emergency psych. assessment: Significant self- injurious behaviour Inpt care: Serious self- injurious behaviour | Specific plan with high lethality or intent; admission may also be indicated in patient with suicidal ideas or after a suicide attempt or aborted attempt, | Part 4: suicide risk. Part 8: check for/measure 'suicidality' | Suicidality | Suicidal ideation |

| | UK (NICE/ MARSIPAN) | Australia and New Zealand Adult | France | Spain | USA | Canada | Germany | Society for Adolescent Health and Medicine ²⁹³ |
|-------------------------------------|--|---------------------------------------|---|--|--|--------|--|--|
| | | | | | depending on the presence or absence of other factors modulating suicide risk | | | |
| Other mental health diagnosis | Other major psychiatric co- diagnosis, e.g. OCD, psychosis, depression | Severe psychiatric comorbidity | Any co-occurring psychiatric disturbance where severity warrants hospitalisation: - Depression - Substance abuse - Anxiety - Psychotic symptoms - Obsessive- compulsive disorder - Anorexia nervosa: Intrusive, constant, obsessive ideations, inability to control obsessive thoughts | Emergency psych. assessment: Depressive symptomatology, with autolytic risk Inpt care: There are significant depressive symptoms with autolytic risk. | Any existing psychiatric disorder that would require hospitalisation | | Pronounced mental comorbidity. A hospital treatment can also be necessary in patients with less severe underweight if they have a serious psychological comorbidity (e.g. trauma-related disorders, borderline personality disorders) | Comorbid psychiatric condition that prohibits or limits appropriate outpatient treatment (e.g severe depression, obsessive- compulsive disorder) |

| | UK (NICE/ MARSIPAN) | Australia and New Zealand Adult | France | Spain | USA | Canada | Germany | Society for Adolescent Health and Medicine ²⁹³ |
|---|------------------------|--|---|-------|--|--------|---|--|
| Community sup | port | admission: - moderate to high agitation and distress | | | | | | |
| Parent/carer capacity to provide support | | | Family problems or absence of family to accompany ambulatory care Family exhaustion Serious family conflict High levels of parental criticism Severe social isolation | | Severe family conflict or problems or absence of family so patient is unable to receive structured treatment in home; patient lives alone without adequate support system Treatment program is too distant for patient to participate from home | | Social or family factors which strongly hamper the healing process (e.g. social isolation, problematic family situation, insufficient social support). | |

Note. Psych. admission = psychiatric admission indicated; Med. admission = Admission to a medical ward indicated; Emergency psych. assessment = Referral to emergency psychiatric assessment; Inpt care = Inpatient care (complete hospitalisation) criteria; Emergency hosp = Emergency hospitalisation; Part 4 = Primary care, physical indicators for inpatient hospitalisation; Part 8 = High-intensity inpatient treatment, key physical assessment parameters.

b. A review of patient experiences and perceptions of compulsory treatment for eating disorders: results of a scoping search

A scoping search was conducted in December 2020 using Google Scholar and Prospero to identify any recent systematic reviews and gauge the breadth of available literature.

A systematic review by Akther *et al.* (2019)²⁹⁴ was identified. This systematic review and qualitative meta-synthesis aimed to synthesise the available qualitative evidence on patients' experiences if being formally assessed for compulsory hospital admission and being legally detained under mental health legislation. This research was not specific to eating disorders, only included studies of adults and patients with experience of involuntary treatment, studies that had a mixed sample of both voluntary and involuntary admitted patients with no separate analysis were not included. Only one study with a focus on anorexia nervosa by Seed *et al.* (2016)²⁹⁵ was included.

A further, recent systematic review of the research addressing patients' experiences and perspectives on involuntary psychiatric admission, conducted by Sugiura *et al.* (2020)²⁹⁶ was identified. Similar to Akther *et al.*,²⁹⁴ this review was not specific to eating disorders. The review identified the study by Seed *et al.* (2016) and an additional study by Tan *et al.* (2010)²⁹⁷. This latter study explored the attitudes of patients with anorexia nervosa towards compulsory treatment and coercion. Both studies included both participants who had experienced involuntary treatment and those who had not.

The study by Seed *et al.* analysed data from 12 participants (women aged between 18 and 55). The authors found that four overarching categories conceptualised people's experiences: "the battle with clinicians", "withdrawing into a bubble where the individual starts to feel some relief that they are no longer in control of their eating", "stepping out of the bubble" and the "anorexic self". The authors made recommendations to embed person-centred recovery-focused practice into inpatient services.

Tan *et al.* (2010)²⁹⁷ explored the experiences and opinions of 29 young women (aged between 15 and 26). The authors found that the women considered compulsion and formal compulsory treatment to be appropriate when the condition was lifethreatening, with how they perceived coercion affected by their relationships with parents and clinicians.

²⁹⁴ Akther SF, Molyneaux E, Stuart R, Johnson S, Simpson A, Oram S. Patients' experiences of assessment and detention under mental health legislation: systematic review and qualitative meta-synthesis. BJPsych Open. 2019;5(3).

²⁹⁵ Seed T, Fox J, Berry K. Experiences of detention under the Mental Health Act for adults with anorexia nervosa. Clinical Psychology & Psychotherapy. 2016;23(4):352–62.

²⁹⁶ Sugiura K, Pertega E, Holmberg C. Experiences of involuntary psychiatric admission decision-making: a systematic review and meta-synthesis of the perspectives of service users, informal carers, and professionals. International Journal of Law and Psychiatry. 2020;73:101645.

²⁹⁷ Tan JO, Stewart A, Fitzpatrick R, Hope T. Attitudes of patients with anorexia nervosa to compulsory treatment and coercion. International Journal of Law and Psychiatry. 2010;33(1):13–9.

The scoping search identified a review on perspectives of involuntary treatment of anorexia nervosa by Clausen (2020).²⁹⁸ Although this is not a systematic review it appears to be comprehensive, giving a clear overview of the literature on patients' perspectives of involuntary treatment of anorexia nervosa. The author found that compulsory treatment is usually appraised negatively by patients, clinicians and families and suggested that clinicians should seek out alternative strategies and interventions, reducing compulsory treatment where possible 'without neglecting its lifesaving purpose and outcome'.

One further study was identified: Tan *et al.* (2003).²⁹⁹ This study of 10 young women (aged between 13 and 21) was part of a broader piece of research that explored patient's competence and capacity to refuse treatment for anorexia nervosa. Most participants thought that compulsory treatment under the Mental Health Act was justified for anorexia nervosa if the patient was at serious risk of death. Although alternative views were also expressed (e.g. 'should never be used', 'should be used more often' or 'earlier in illness'), the use of compulsory treatment was acknowledged by all participants to be a problematic and emotive issue. Some participants spoke of it in terms of inflicting 'suffering', as a 'prison', and as a 'punishment', and it was described negatively even by those who felt that it was ultimately the right decision in the circumstances.

The results of the scoping search suggest there is little research that has explored patients' experiences and perspectives of compulsory treatment for eating disorders. There have been recent systematic and non-systematic reviews on the topic.

It can therefore be concluded that a further systematic review would not yield any new evidence.

²⁹⁸ Clausen L. Perspectives on involuntary treatment of anorexia nervosa. Frontiers in Psychiatry. 2020;11:1068.
²⁹⁹ Tan JO, Hope T, Stewart A, Fitzpatrick R. Control and compulsory treatment in anorexia nervosa: the views of patients and parents. International Journal of Law and Psychiatry. 2003; 627–645.

c. A review of a systematic review looking at differences in clinical outcomes for those who experience compulsory treatment for eating disorder and those who do not

A preliminary search identified a systematic review and meta-analysis by Atti *et al.* (2020).³⁰⁰ This was assessed by the review team to be of moderate quality, using AMSTAR. The review team therefore concluded that that there would be no benefit in conducting a separate systematic review, or updating the existing one given how recent it was.

Atti *et al.* (2020) retrieved 905 articles, and included nine for analysis, allowing comparisons between 242 patients undergoing compulsory treatment and 738 patients having treatment voluntarily. The authors found that there were no significant differences between the comparison groups in terms of mean illness duration, BMI at discharge and BMI variation. However, mean BMI was slightly lower in patients having compulsory treatment. Average length of stay in hospital was 3 weeks longer for compulsory-treated patients, but this did not result in a higher increase in BMI. No significant risk difference on mortality was estimated (based on three studies).

The authors concluded that: "Compulsory treatments are usually intended for patients having worse baseline conditions than voluntary ones. Those patients are unlikely to engage in treatments without being compelled but, after the treatments, albeit with longer hospitalisations, they do achieve similar outcomes. Therefore, we can conclude that forcing patients to treatment is a conceivable option."

³⁰⁰ Atti AR, Mastellari T, Valente S, Speciani M, Panariello F, Ronchi D de. Compulsory treatments in eating disorders: a systematic review and meta analysis. Eating and Weight Disorders – Studies on Anorexia, Bulimia and Obesity. DOI.10.1007/s40519-020-01031-1.

Appendix 3: Medical emergencies in eating disorders risk checklist for clinicians

Assessing

Does the patient have an eating disorder?

- Yes: Anorexia nervosa- Bulimia nervosa-Other
- Not sure: Request psychiatric review

Is the patient medically compromised?

- BMI <13 (adults); m%BMI <70% (under 18)?
- Recent loss of >1kg for 2 consecutive weeks?
- □ Acute food or fluid refusal/intake <400kcal per day?
- □ Pulse <40?
- □ BP low, BP postural drop >20mm, dizziness?
- \Box Core temperature <35.5°C?
- □ Na <130mmol/L?
- □ K <3.0mmol/L?
- □ Raised transaminase?
- \Box Glucose <3mmol/L?
- \Box Raised urea or creatinine?
- □ Abnormal ECG?
- □ Suicidal thoughts, behaviours?

Is the patient consenting to treatment?

Yes:

No: Mental health assessment requested

Refeeding

High risk for refeeding syndrome?

- \Box Low initial electrolytes
- BMI <13 (adults) or %mBMI <70% (under 18s)
- \Box Little or no intake for >4 days
- □ Low WBC
- Serious medical comorbidities, e.g. sepsis

High risk? Management:

- <20 kcal per kg per day
- Monitor electrolytes twice daily
- build up calories swiftly
- avoid underfeeding

Lower risk? Management:

- Start at 1,400–2,000kcal per day (50 kcal/kg/day) and build by 200 kcal/day, to 2,400kcal/day or more
- Aim for weight increase of 0.5–1kg/week
- Avoid underfeeding

Monitoring

- □ Electrolytes (especially P, K, glucose)
- □ ECG
- □ Vital signs
- □ BMI

Managing

Are medical and psychiatric staff collaborating in care?

Yes: No: Psych. consultation awaited

Are nurses trained in managing medical and psychiatric problems?

Yes

No and appropriately skilled staff requested/training in place

Are there behaviours increasing risk?

- □ Falsifying weight
- □ Disposing of feed
- □ Exercising
- □ Self-harm, suicidality
- □ Family to stress/anxiety
- □ Safeguarding concerns

Mobilise psychiatric team to advise on management

Note:

%mBMI = mean percentage BMI

Please do not use BMI as a single indicator of risk

Appendix 4: Handover template from one clinical area to another for eating disorders

| 1. Units invo | I. Units involved a. Sending unit | | | | | |
|---------------|--------------------------------------|--|--|--|--|--|
| a. Sending u | | | | | | |
| Name | of unit | | | | | |
| Addre | ss of unit | | | | | |
| Туре с | of unit | | | | | |
| Representat | ive health worker | | | | | |
| Name | | | | | | |
| Role | | | | | | |
| Addre | SS | | | | | |
| email | address | | | | | |
| Phone | enumber | | | | | |
| b. Sending u | ınit | | | | | |
| Name | of unit | | | | | |
| Addre | ss of unit | | | | | |
| Туре с | of unit | | | | | |

Representative health worker

Name

Role

Address

email address

Phone number

2. Patient data:

Name

Hospital number

NHS number

Address

email address

Phone number

3. Carer data:

Name

Address

email address

Phone number

4. Primary care data:

Name of GP

Address of practice

email address

Phone number

5. Clinical data

a. Problems being addressed

b. Diagnoses if made

c. Risk factors

d. Description of history of problems and current management

e. Reason for transfer

f. Treatment currently receiving

g. Previous treatment received

h. Relevant clinical information including investigations

6. Patient's expectations and views about transfer

7. Carer's expectations and views about transfer

8. Legal aspects

9. Meeting to discuss transfer of care

a. Date

b. Place

c. Time

d. URL if online

e. Invitees