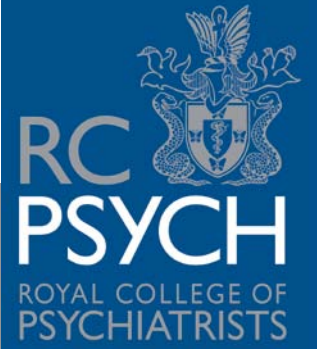


CR168



# Junior MARSIPAN: Management of Really Sick Patients under 18 with Anorexia Nervosa

January 2012

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Report from the Junior MARSIPAN group

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# Endorsing organisations

- Eating Disorders Section of the Royal College of Psychiatrists
- BEAT (Eating Disorders Association, eating disorders self-help charity)
- Young People's Health Special Interest Group of the Royal College of Paediatrics and Child Health
- Standing Committee on Nutrition for the Royal College of Paediatrics and Child Health
- British Society of Paediatric Gastroenterology, Hepatology and Nutrition
- British Paediatric Mental Health Group



**British Paediatric Mental Health Group**

# Junior MARSIPAN Working Group

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# Executive summary and recommendations

The Junior MARSIPAN working group was formed to develop guidelines for young people with anorexia nervosa to complement the report from the MARSIPAN group (Royal College of Psychiatrists & Royal College of Physicians, 2010) addressing the care of adult in-patients with anorexia nervosa. The rationale for a separate document is that the definition of very sick patients with anorexia nervosa differs in young people, because serious underweight varies with age and gender; other aspects of risk differ in young people (e.g. blood pressure norms); consent and capacity are addressed within different legal frameworks for young people than adults; there are differences in service organisation for specialist child and adolescent mental health services (CAMHS); and paediatric services have a central role in the care of young people.

The Junior MARSIPAN report provides guidance on:

- risk assessment, physical examination and associated action
- location of care and transition between services
- compulsory treatment
- paediatric admission and local protocols
- management of re-feeding
- management of compensatory behaviours associated with an eating disorder in a paediatric setting
- management in primary care and paediatric out-patient settings
- discharge from paediatric settings
- management in specialist CAMHS in-patient settings.

## RECOMMENDATIONS

- 1 All health professionals should be aware that anorexia nervosa is a serious disorder with life-threatening physical and psychological complications. A sick child or adolescent with an eating disorder who needs hospital admission requires the same level of care as a child with any other serious illness, and should be subject to the same emergency protocols (e.g. Advanced Paediatric Life Support (APLS), [www.alsg.org](http://www.alsg.org)).



- 2 For young people with anorexia nervosa some risk parameters need to be adjusted for age and gender. This includes the body mass index (BMI). We recommend using percentage BMI (BMI/median BMI for age and gender  $\times$  100) to quantify malnutrition below the second BMI centile.
- 3 Parents/carers should have a central role in care and decision-making up to the age of 18, with autonomy for the young person increasing with age, developmental stage and capacity.
- 4 The role of the primary care team is to monitor patients and refer them to appropriate services early.
- 5 The quality of liaison between paediatric and CAMHS eating disorder services and experience in managing malnutrition, as well as the clinical condition of the patient, should be the primary factors in deciding appropriate location of care.
- 6 Every hospital into which a young person with severe anorexia nervosa is likely to be admitted should identify a consultant paediatrician with the interest, training (or willingness to be trained) and expertise to coordinate paediatric care for patients with anorexia nervosa in that setting. This includes admission to psychiatric units as well as acute hospitals.
- 7 Every hospital into which a child or adolescent with severe anorexia nervosa is likely to be admitted should identify a consultant psychiatrist and team with the training and expertise to coordinate care and with whom a working relationship can be built to support an acute admission.
- 8 Clinicians and managers from paediatric and adult medical wards and CAMHS services likely to see young patients with anorexia nervosa should develop protocols in advance of situations of risk developing.
- 9 Transitions should include careful multidisciplinary planning supported by joint protocols where possible. Young people aged 16–18 need specific consideration.
- 10 The key tasks of the in-patient paediatric/medical team are to:
  - (a) safely re-feed the patient, avoiding re-feeding syndrome due to too rapid re-feeding, and underfeeding syndrome due to too cautious re-feeding;
  - (b) manage, with the help of the CAMHS staff, the behavioural manifestations of anorexia nervosa secondary to the fear of weight gain, for example compulsive exercise;
  - (c) occasionally treat young people under compulsion (using parental consent, the Children Act or the Mental Health Act, depending on the setting, age and capacity);
  - (d) arrange transfer of the young person to appropriate CAMHS care as soon as it is safe to do so.
- 11 Health commissioners should:
  - (a) ensure that robust plans are in place for the care of young people with anorexia nervosa, including adequately trained and resourced paediatric, nursing and dietetic staff in the acute services and appropriately skilled staff in specialist mental health services;

- (b) support joint working between services (e.g. funding for CAMHS nursing staff while the patient is in an acute hospital);
- (c) be aware of gaps in local resources and be willing to support referral to national centres for advice or treatment when necessary.

# Introduction

## HISTORY OF THE PROJECT

This report supplements the MARSIPAN report (Royal College of Psychiatrists & Royal College of Physicians, 2010), which provides guidance for the care of seriously ill adults with anorexia nervosa. The question arose whether the adult MARSIPAN report could or should include the needs of children and adolescents. After discussion, we considered that separate guidance for the care of children and adolescents was needed, to prevent adult advice being extrapolated to the younger patient medically at risk. The main reasons were the following.

- 1 The definition used for the scope of the adult MARSIPAN report, namely individuals who had severe anorexia nervosa (BMI < 15) and were admitted to medical wards or to specialist eating disorder units (SEDUs), cannot be used because neither the definition of underweight nor the treatment settings apply to children and young adolescents.
  - (a) The definition of serious underweight in children and adolescents is controversial and very little evidence exists to establish clear risk parameters.
  - (b) Admission of children and adolescents with anorexia nervosa to paediatric wards is a much more common event than admission of adults to medical wards. This is likely to be because of epidemiology, developmental differences in risk (including the fact that children and adolescents are less experienced at calculating risk), service factors, in that paediatric admission is often a stop-gap between (separate) out-patient and in-patient services, and because young people are usually brought for treatment regardless of whether they like it or not. The result is that patients on paediatric wards may not all be seriously ill. There is therefore a need to distinguish general guidance on managing patients with anorexia nervosa on paediatric wards from guidance on managing seriously ill patients with anorexia nervosa, regardless of setting.
  - (c) SEDUs, as described in the adult MARSIPAN report, are not widely available in CAMHS. Some CAMHS SEDUs do exist, but they are rare and provision across populations is inequitable. Many are in the independent sector, and are often quite separate from out-patient, outreach and day-patient CAMHS. For the majority of the UK, care for young people with severe anorexia nervosa within CAMHS is provided through generic adolescent CAMHS in-patient units. These vary in the extent to which they are specifically equipped to manage patients with anorexia

nervosa, including their capacity for nasogastric feeding, and their suitability for younger adolescents and children. This variation in in-patient provision for young people with anorexia nervosa makes recommendations about service setting more complex, but does mean that recommendations in the adult MARSIPAN report referring to a SEDU do not apply for young people. We have chosen to use the term specialist eating disorders beds (SEDB) to refer both to SEDUs and to generic units specifically equipped for managing young patients with anorexia nervosa.

- 2 Normal and cut-off physiological parameters such as blood pressure vary with age, and danger thresholds therefore can differ significantly for children and adults. The effects of severe and moderate malnutrition on growth and development, for example on bone density, are also unique in this age group and require additional consideration.
- 3 The legal and ethical issues surrounding treatment of young patients are multifaceted. Balancing the wishes and feelings of the young person, the role of parents/carers in treatment and the requirement of confidentiality in decision-making is complex, and in some cases requires statutory intervention.

Notwithstanding the above, many of the issues highlighted in the adult MARSIPAN report do apply to children and young people, including variations in confidence, skill, need for local protocols, problems with high-dependency nursing and general paediatric/psychiatric liaison. The Junior MARSIPAN group was set up and this report written with multidisciplinary input from contributors offering a wide range of skills. Like the adult MARSIPAN report, we hope that our guideline will form the basis of local policies and encourage the development of local protocols. We also hope that this will be the first of a series of documents aimed at providing guidance specifically for paediatricians in the UK on the management of anorexia nervosa, which at present is notably lacking. But at heart this guidance is not aimed at any one profession. Rather it attempts to address some of the consequences of the separation of paediatrics from mental health. Anorexia nervosa is an excellent example of the way in which mind and body are intimately connected. The tendency to leave the very sick patients to paediatricians, and for paediatricians to leave young people with mental health issues to psychiatrists, can have very dangerous consequences, as the case examples in Appendix D show.

## PROCEDURE FOLLOWED IN PRODUCING THE REPORT

### *MEMBERSHIP OF THE GROUP, STAKEHOLDER INVOLVEMENT AND CONSULTATIONS*

The lead for the Junior MARSIPAN group, Dr Dasha Nicholls, was approached by Dr Paul Robinson, lead author of the adult MARSIPAN report, through the Eating Disorders Section of the Royal College of Psychiatrists. Dr Nicholls approached the Chair of the Royal College of Paediatrics and Child Health (RCPCH) Nutrition Group to propose the idea of developing a guideline, and approached organisers of the RCPCH nutrition course. At around the same time, Dr Damian Wood was approached via the Young People's Health Special Interest Group (YPSIG) of the RCPCH to put forward a briefing note to the National Institute for Health and Clinical Excellence (NICE) for a technical

appraisal on the medical management of eating disorders in children. Through personal contacts and via the FOCUS and EDSIG listserves, they approached paediatricians, eating disorders psychiatrists, specialist dieticians and a general practitioner (GP) interested in the area.

Within a few months we had ten doctors, including two child and adolescent eating disorders psychiatrists, one general child and adolescent psychiatrist with an interest in growth and development in eating disorders, and seven paediatricians representing a variety of subdisciplines from renal medicine to academic nutrition, two specialist dieticians and a GP. An attempt was made to identify a nurse member for the group linked to the Royal College of Nursing, but without success. The group met in January 2010 to agree the scope of the document, membership of the group and the organisations or bodies we hoped would endorse the output. A website was developed to share key documents and references, facilitate communication, and enable others to keep track of progress (<http://sites.google.com/site/marsipannini>).

Once drafted, the guidelines were circulated for a 1-month consultation period to a number of groups:

- FOCUS listserve, a multidisciplinary list serve for CAMHS administered by the Royal College of Psychiatrists
- EDSIG listserve, for eating disorders psychiatrists via the Royal College of Psychiatrists' Eating Disorders Section
- YPSIG listserve, for the Young People's Health Special Interest Group of the RCPCH
- RCPCH Nutrition Group
- British Society of Paediatric Gastroenterology, Hepatology and Nutrition, a multidisciplinary organisation promoting standards of care for children with gastrointestinal, liver and nutritional disorders
- British Paediatric Mental Health Group, a group of professionals interested in developing and promoting the role of paediatricians in mental health.

Detailed feedback was received from over 20 individuals and groups, and the document was revised accordingly.

## *GATHERING INFORMATION*

Dr Hudson led a process reviewing existing guidelines, looking for areas of difference and consensus. Guidelines in English were sought. The following guidelines were reviewed:

- New South Wales Eating disorder handbook ([www.health.nsw.gov.au/resources/mhdao/ed\\_toolkit.asp](http://www.health.nsw.gov.au/resources/mhdao/ed_toolkit.asp))
- Adult MARSIPAN document (Royal College of Psychiatrists & Royal College of Physicians, 2010)
- American Psychiatric Association (2006) guideline for the treatment of patients with eating disorders
- American Academy of Paediatrics guidelines (Rosen & American Academy of Pediatrics Committee on Adolescence, 2010)

- Nottingham University NHS trust guideline for early recognition, assessment and initial management of eating disorders in children and young people (<http://sites.google.com/site/nottinghamchildhealth/guidelines/adolescent-health>)
- Finnish guidelines for management of eating disorders in children and young people (Ebeling *et al*, 2003)
- Australian and New Zealand clinical practice guidelines for the treatment of anorexia nervosa (Royal Australian and New Zealand College of Psychiatrists Clinical Practice Guidelines Team for Anorexia Nervosa, 2004)
- NHS Scotland management and treatment of eating disorders guidelines (Freeman & Millar, 2006)
- National Institute for Health and Clinical Excellence (2004) guidelines on eating disorders
- Royal College of Psychiatrists (2005) guidelines on the management of anorexia nervosa.

These guidelines had in common several areas in which guidance was provided:

- who should be involved
- weight indicators for diagnosing, monitoring, treatment
- initial risk assessment
- medical complications to look for on examination
- criteria for admission
- in-patient management – where, by whom, which patients
- feeding regime – how much, how
- re-feeding syndrome – monitoring, preventing, treating
- management during admission
- when to discharge.

Where the guidelines differed was in their specific recommendations. For example, on the subject of weight indicators of risk, four used weight for height/centile charts, two used ideal body weight, four used weight alone, seven used BMI (noting caution in children), and five used growth/rate of weight loss.

Dr Verhoeff undertook a survey of GPs and parents/carers in her local area to identify their perceptions of problems and service issues (Appendix B).

Drs Moss and Ayton devised a survey to seek information on current services and to identify areas of difference in terms of practice regarding medically sick patients. The group used their professional bodies (YPSIG, FOCUS, EDSIG listserv) to get feedback, comments, experiences and anecdotes from clinicians.

A MEDLINE and ISI Web of Knowledge search of the literature was carried out by Dr Ayton using the search term 'anorexia nervosa' in combination with 'child', 'adolescent death', 'paediatric', 'physical'. In contrast with the adult literature, there were very few fatalities reported (Beumont & Large, 1991; Møller-Madsen *et al*, 1996; Neumarker *et al*, 1997; Kohn

*et al*, 1998; Collins & Myatt, 2000; Lindblad *et al*, 2006; Lesinskiene *et al*, 2008). The most commonly described physical complications included cardiac abnormalities (Beumont & Large, 1991; Kohn *et al*, 1998; Lupoglazoff *et al*, 2001; Kim *et al*, 2009), hypoglycaemia (Ratcliffe & Bevan, 1985; Copeland & Herzog, 1987), electrolyte imbalances and re-feeding syndrome (Afzal *et al*, 2002; Ornstein *et al*, 2003; Castro *et al*, 2004; Katzman, 2005; Ulger *et al*, 2006). Furthermore, there were several cases of brain tumours reported which initially presented as atypical anorexia (Grossmann *et al*, 2002; Lin *et al*, 2003; Distelmaier *et al*, 2006; Rohrer *et al*, 2006; Sokol *et al*, 2006; Crawford *et al*, 2007; Song & Lonser, 2008; Kibayashi *et al*, 2009).

A literature review was also carried out by Graeme O'Connor to identify published reports on re-feeding syndrome in children and adolescents with anorexia nervosa. Original articles were identified by searching EMBASE, CINAHL and MEDLINE databases, using the following keywords in the title or abstract of articles: 'adolescent/children', 're-feeding/hypophosphatemia' and 'anorexia'. Findings from this review are reported in Appendix C.

## *ESTABLISHING THE SCOPE OF THE GUIDELINE*

Unlike the adult MARSIPAN report, the scope of this guideline was one of the most difficult areas to agree on. The focus is on young people most at risk medically, but this cannot always be disentangled from other aspects of risk. Furthermore, the risk may be increased as a result of interventions that precipitate more disordered behaviour. For example, a child of 11 who has anorexia nervosa and severe separation anxiety may become more disturbed and less cooperative with re-feeding as a result of hospital admission, meaning that restraint or medication will be needed. So even when medical risk is high it could be safer to try to manage that risk at home or at least in a setting that allows parents to be present.

Our solution was to develop a risk assessment framework and then to focus on those at the severe end. Based on this, the document refers to young patients at highest risk, i.e. those with less than 70% median BMI for age and gender, for whom hospital admission is likely. As for adult patients, children and young people losing weight very rapidly, and those with severe bulimic symptoms (vomiting and laxative misuse) and extreme over-exercise can have serious nutritional problems at higher percentage BMI. This guideline may be applied to such patients, but they were not our primary focus.

## *EDITORIAL INDEPENDENCE*

Although we are representing, to different degrees, different bodies, including several medical Royal Colleges, our views are independent. Further, all authors attest that they have no conflict of interest of financial involvement that might relate to this subject.

## THE PROBLEM

The adult MARSIPAN group came together after a number of serious untoward incidents involving adult patients with anorexia nervosa. The number of such incidents in young people is, thankfully, lower, but they do

nonetheless occur. What is apparent, however, is that the initial experience of young people in relation to having their eating disorder managed has an impact on their engagement with services, and consequently on the course of their illness. In addition, the complexity of eating disorders care for young people, compounded by separate out-patient and in-patient CAMHS services and the need for both paediatric and psychiatric care, does present particular problems when it comes to managing high-risk individuals.

In Appendix B we reproduce quotes from messages received by the Junior MARSIPAN Working Group, highlighting some of the problem areas covered in this document.

There is a large amount of information we do not have. We support the call from the adult MARSIPAN group for a prospective study of individuals with anorexia nervosa admitted to medical wards with a wide range of physical and psychological issues to help identify those who are likely to be at particular risk, and to validate the risk assessment frameworks recommended in this and the adult MARSIPAN reports.

Throughout this report, reference is made to English legislation in relation to compulsion and safeguarding. In other jurisdictions, other legislative principles and practices will be used. The term 'Mental Health Act' is taken to refer to equivalent legislation in other countries of the UK as well.



# Issues arising in all settings

## RISK ASSESSMENT: HOW ILL IS THE PATIENT?

Children and adolescents with eating disorders frequently present to emergency departments and paediatric teams, and caring for them can be challenging. Individuals who are medically compromised secondary to an eating disorder can be very unwell, and can die of complications. Sadly, this can happen while under medical care, including as an in-patient.

Young children and pre-pubescent adolescents may present without the typical features (e.g. absent periods or significantly low BMI) found in adults, and the behaviours associated with eating disorders are often covert. The complexities of managing these patients are compounded by the anxieties of the patient and their family, which also have an impact on the caring team. It can be easy to feel deskilled, but paediatric teams have many existing skills and experiences which can be applied. Paediatric patients frequently present with subtle findings on history and examination, may resist or object to treatment and can be very sick, requiring systematic and considered acute care with mindfulness of the stresses for the child's family. Children and adolescents with eating disorders are no different. And although it may be tempting to refer them to CAMHS or psychiatry liaison services and wait, it is not psychological therapy that will turn the course at this point, but the sort of skilled nutritional rehabilitation outlined in this document.

Risk assessment combines clinical assessment with investigations, assessment of motivation and engagement with treatment plans, and available parent/carer support likely to determine the risk of serious complications to a young person. These include serious illness (acute pancreatitis or gastrointestinal rupture) or death (from suicide, sudden death or infection). We have not provided an algorithm for application of this risk framework, since any such recommendations would not be evidence-based and would not allow for individual variation. For example, some (but not many) people are healthy and menstruating at 68% BMI, and the most medically unstable patients can have a normal weight. This report is intended as a guide to level of concern. Those with anorexia nervosa can seem deceptively well; no one parameter mentioned is a good indicator of overall level of risk or illness. The framework can be used to highlight areas useful to assess and grade concern, but are not a substitute for an overall experienced clinical assessment.

Finally, it is important to acknowledge that almost all the parameters outlined here (Guidance 1, see next page) have multiple aetiologies, and it is the fear of everyone, professionals and parents alike, that an underlying pathology has been missed. 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, if further investigation takes priority, the patient will often continue to lose weight, thus increasing the risk. If, after a careful clinical history, examination and initial investigations, there is no obvious underlying physical illness, then it is important not to delay re-feeding. Individuals with mineralocorticoid deficiencies or hyperparathyroidism do not usually hide food, instead inducing vomiting or even becoming extremely agitated at being fed. In situations of diagnostic uncertainty, introducing calories will predictably elicit calorie-avoiding behaviour in those with a drive for thinness and fear of weight gain.

The rationale for the parameters used to grade the level of concern is outlined in Guidance 1.

**Guidance 1 Risk assessment framework for young people with eating disorders**

	<i>Red (high risk)</i>	<i>Amber (alert to high concern)</i>	<i>Green (moderate risk)</i>	<i>Blue (low risk)</i>
BMI and weight	Percentage median BMI <70% (approx. below 0.4th BMI centile)  Recent loss of weight of 1 kg or more/week for 2 consecutive weeks	Percentage median BMI 70–80% (approx. between 2nd and 0.4th BMI centile)  Recent loss of weight of 500–999g/week for 2 consecutive weeks	Percentage median BMI 80–85% (approx. 9th–2nd BMI centile)  Recent weight loss of up to 500g/week for 2 consecutive weeks	Percentage median BMI >85% (approx. above 9th BMI centile)  No weight loss over past 2 weeks
Cardiovascular health	Heart rate (awake) <40 bpm <sup>a</sup>  History of recurrent syncope; marked orthostatic changes (fall in systolic blood pressure of 20 mmHg or more, or below 0.4th–2nd centiles for age, or increase in heart rate of >30 bpm)  Irregular heart rhythm (does not include sinus arrhythmia)	Heart rate (awake) 40–50 bpm  Sitting blood pressure: systolic <0.4th centile (84–98 mmHg depending on age and gender <sup>b</sup> ); diastolic <0.4th centile (35–40 mmHg depending on age and gender <sup>b</sup> )  Occasional syncope; moderate orthostatic cardiovascular changes (fall in systolic blood pressure of 15 mmHg or more, or diastolic blood pressure fall of 10 mmHg or more within 3 min standing, or increase in heart rate of up to 30 bpm)	Heart rate (awake) 50–60 bpm  Sitting blood pressure: systolic <2nd centile (98–105 mmHg depending on age and gender <sup>b</sup> ); diastolic <2nd centile (40–45 mmHg depending on age and gender <sup>b</sup> )  Pre-syncope symptoms but normal orthostatic cardiovascular changes	Heart rate (awake) >60 bpm  Normal sitting blood pressure for age and gender with reference to centile charts <sup>a</sup>  Normal orthostatic cardiovascular changes  Normal heart rhythm

*Continued*

**Guidance 1** *Continued*

	<i>Red (high risk)</i>	<i>Amber (alert to high concern)</i>	<i>Green (moderate risk)</i>	<i>Blue (low risk)</i>
			Cool peripheries; prolonged peripheral capillary refill time (normal central capillary refill time)	
ECG abnormalities	QTc>460 ms (girls) or 400 ms (boys) with evidence of bradyarrhythmia or tachyarrhythmia (excludes sinus bradycardia and sinus arrhythmia); ECG evidence of biochemical abnormality	QTc>460 ms (girls) or 400 ms (boys)	QTc<460 ms (girls) or 400 ms (boys) and taking medication known to prolong QTc interval, family history of prolonged QTc or sensorineural deafness	QTc<460 ms (girls) or 400 ms (boys)
Hydration status	Fluid refusal Severe dehydration (10%): reduced urine output, dry mouth, decreased skin turgor, sunken eyes, tachypnoea, tachycardia <sup>c</sup>	Severe fluid restriction Moderate dehydration (5–10%): reduced urine output, dry mouth, normal skin turgor, some tachypnoea, some tachycardia, <sup>c</sup> peripheral oedema	Fluid restriction Mild dehydration (<5%): may have dry mouth or not clinically dehydrated but with concerns about risk of dehydration with negative fluid balance	Not clinically dehydrated
Temperature	<35.5°C tympanic or 35.0°C axillary	<36°C		
Biochemical abnormalities	Hypophosphataemia, hypokalaemia, hypoalbuminaemia, hypoglycaemia, hyponatraemia, hypocalcaemia	Hypophosphataemia, hypokalaemia, hyponatraemia, hypocalcaemia		
Disordered eating behaviours	Acute food refusal or estimated calorie intake 400–600 kcal per day	Severe restriction (less than 50% of required intake), vomiting, purging with laxatives	Moderate restriction, bingeing	
Engagement with management plan	Violent when parents try to limit behaviour or encourage food/fluid intake, parental violence in relation to feeding (hitting, force feeding)	Poor insight into eating problems, lacks motivation to tackle eating problems, resistance to changes required to gain weight, parents unable to implement meal plan advice given by healthcare providers	Some insight into eating problems, some motivation to tackle eating problems, ambivalent towards changes required to gain weight but not actively resisting	Some insight into eating problems, motivated to tackle eating problems, ambivalence towards changes required to gain weight not apparent in behaviour
Activity and exercise	High levels of uncontrolled exercise in the context of malnutrition (>2 h/day)	Moderate levels of uncontrolled exercise in the context of malnutrition (>1 h/day)	Mild levels of uncontrolled exercise in the context of malnutrition (<1 h/day)	No uncontrolled exercise

*Continued*

<b>Guidance 1</b> <i>Continued</i>				
	<i>Red (high risk)</i>	<i>Amber (alert to high concern)</i>	<i>Green (moderate risk)</i>	<i>Blue (low risk)</i>
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		
Other mental health diagnoses		Other major psychiatric co-diagnosis, e.g. OCD, psychosis, depression		
Muscular weakness – SUSS Test				
Sit up from lying flat	Unable to sit up at all from lying flat (score 0)	Unable to sit up without using upper limbs (score 1)	Unable to sit up without noticeable difficulty (score 2)	Sits up from lying flat without any difficulty (score 3)
Stand up from squat	Unable to get up at all from squatting (score 0)	Unable to get up without using upper limbs (score 1)	Unable to get up without noticeable difficulty (score 2)	Stands up from squat without any difficulty (score 3)
Other	Confusion and delirium, acute pancreatitis, gastric or oesophageal rupture	Mallory–Weiss tear, gastro-oesophageal reflux or gastritis, pressure sores	Poor attention and concentration	

BMI, body mass index; bpm, beats per minute; ECG, electrocardiogram; OCD, obsessive-compulsive disorder; SUSS, Sit Up, Squat–Stand.

a. Patients with inappropriately high heart rate for degree of underweight are at even higher risk (hypovolaemia). Heart rate may also be increased purposefully through the consumption of excess caffeine in coffee or other drinks.

b. Jackson *et al*, 2007.

c. Or inappropriate normal heart rate in an underweight young person.

## ASSESSING AND DEFINING SEVERE MALNUTRITION

Weight or BMI tests alone have limited utility in assessing malnutrition in young people owing to the normal changes in weight, height and BMI in childhood and through puberty. Weight and BMI can be used to track changes in the individual but any comparison of weight against population norms needs to take account of height, gender and age as a minimum. In adolescents, the World Health Organization (WHO) recommended that the severity of wasting could be assessed by BMI for age in those 10–18 years old (<5th centile) (WHO, 1995). More recently, a United Nations Administrative Committee on Coordination/Sub-Committee on Nutrition report defined severe malnutrition in adolescents requiring therapeutic intervention as <70% weight for height or BMI plus either bilateral pitting oedema (nutritional), inability to stand, or apparent dehydration (Woodruff & Duffield, 2000). The risk of death in 'acute' malnutrition is closely related to its severity, assessed anthropometrically. Several studies have shown that low mid-upper arm circumference (MUAC <115mm) and/or weight for height <70%, or weight for height Z-score <-3 each predicts a high risk of mortality (Alam *et al*, 1989; Dramaix *et al*, 1996; Lapidus *et al*, 2009). The presence of bilateral (nutritional) oedema improves predictability. Independently, low serum albumin (<16g/l) is a major risk factor for mortality (Dramaix *et al*, 1993).

Together these studies suggest that assessment of a number of parameters is better than anthropometry alone, but that degree of underweight is an important factor in predicting risk from malnutrition.

It is perfectly correct to use BMI centile charts and to report BMI centile in young people (you can obtain the charts on [www.healthforallchildren.com](http://www.healthforallchildren.com); look for for 'Boys and Girls BMI "Identification" Charts 6 months – 20 years'). However, for young people with a BMI below the 0.4th centile, as is the case in all young people with severe anorexia nervosa, there is a need to quantify the degree of underweight. Furthermore, much of the literature on adolescent eating disorders uses some form of percentage weight for height (e.g. percentage ideal body weight). This is also language that is easy for patients and parents to understand. The DSM-IV diagnostic criteria for anorexia nervosa (American Psychiatric Association, 1994) and the American Psychiatric Association guidelines (2006) on eating disorders both refer to weight adjusted for height, but no method of calculation is recommended. There are a number of methods of estimating weight for height (Appendix A, p. 60); these are not fully in agreement, although they do approximate to one another within a few percent.

We recommend the use of a single method of calculating percentage weight for height (WFH), based on the percentage median BMI, in line with the WHO recommendation:

$$\text{Percentage BMI (or percentage WFH)} = \frac{\text{Actual BMI} \times 100}{\text{Median BMI (50th percentile) for age and gender}}$$

Median BMI for age can be read from BMI centile charts, or there are Excel programmes that will calculate percentage BMI using the UK BMI reference data (e.g. the Weight for Height programme developed at Great Ormond Street Hospital in London; please email author for details). Note that the reference data are not ethnically sensitive, so some ethnicities (e.g. Asian young people) will be overrepresented in underweight groups. For a fuller discussion on methods of defining underweight, see Cole *et al* (2007).

Change in weight is a marker of illness trajectory. Rate of weight loss increases cardiovascular risk and electrolyte instability, and rapid weight gain increases risk of re-feeding syndrome. The exact amount is hard to quantify, but generally weight loss of more than 1 kg per week in an already underweight child or young person is cause for concern. Similarly, rapid weight loss from overweight to the normal range can result in medical instability. On the other hand, slow, chronic weight loss can manifest as growth retardation, and previous growth charts should be examined when possible.

## CARDIOVASCULAR RISK

- Bradycardia is a very common, well-documented condition in young people with anorexia nervosa. A heart rate of 50bpm should raise concern, and a consistent heart rate of 40bpm or below is grounds for assessment by a paediatrician and consideration of admission for monitoring (including blood testing). However, this absolute value is only a guide. A more worrying indicator is when the pulse rate is normal or high despite low weight or with low blood pressure. There may or may not be variability with the tests undertaken with the young person standing or when under stress. In some individuals heart rate

may drop during sleep and recover with waking, but consistently low heart rate even in sleep is a concern. Electrocardiogram (ECG) should be checked for heart block as an alternative cause.

- Sinus arrhythmia is a common finding in young people and is not in itself a cause for concern. There are a number of possible causes of arrhythmia in young people with eating disorders, including underweight, prolonged QTc, electrolyte disturbances and medications. Any arrhythmia should be investigated further to exclude a correctable cause. Arrhythmias causing or likely to cause cardiovascular collapse 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.
- QT prolongation is caused by malnutrition and hypokalaemia and other electrolyte imbalance, but studies provide conflicting results on the association between underweight, prolonged QTc and sudden death in anorexia nervosa. In the absence of definitive data we propose a risk assessment based on known cardiovascular risk and prolonged QTc. A prolonged QTc for age and gender requires further assessment as an in-patient and should be discussed with local cardiology experts.
- Hypotension. Blood pressure must be compared with age- and gender-based normal values from an appropriate comparative population. The criteria in Guidance 1 and 2 (pp. 17–19 & 24–26) are based on data from healthy UK children and young people (Jackson *et al*, 2007).
- Syncope and pre-syncopal symptoms are common in young people but are even more common in young people who are underweight and have an eating disorder. The concern is that syncope may be a marker of cardiovascular instability and reflect a predisposition to sudden unexpected cardiovascular death in this group.
- Orthostatic hypotension is seen in underweight young people and is a marker of disruption of the normal homeostatic physiological cardiovascular mechanisms which control blood pressure with change in posture. A postural drop of more than 15mmHg, or a drop to below 0.4–2 centiles for age also necessitates admission.
- Poor peripheral perfusion, with cold hands, pale or blue peripheries and prolonged capillary refill time, is a common observation in underweight young people with anorexia nervosa. The importance of this finding in determining physical risk and its relation to body weight is unknown.

Resources required to monitor cardiac risk:

- sphygmomanometer and appropriate range of cuff sizes
- 12-lead ECG machine
- calculator to calculate QTc
- cardiac monitoring equipment
- appropriate adjustable bed
- resuscitation equipment.

All young people with anorexia nervosa who are medically compromised should have a 12-lead ECG performed. A discussion with a paediatrician with expertise in cardiology should be arranged if there is a significant abnormality and in particular if the QTc is prolonged.

## DEHYDRATION AND OEDEMA

Hydration status is assessed clinically by examining mucous membranes, eyes (whether sunken or not), skin turgor, pulse, blood pressure and capillary refill time, and considering urine output and recent weight changes. Young people with eating disorders who are underweight usually have baseline bradycardia, and a heart rate within the normal range or elevated may be a sign of hypovolaemia. No single sign of hypovolaemia is reliable in young people with eating disorders and requires the assessment of a range of clinical parameters. Caution must be taken in treating hypovolaemia in the context of malnutrition in case of precipitation of heart failure. Smaller aliquots administered in stages are safer.

The presence of oedema is usually multifactorial and reflects hypoalbuminaemia, nutritional deficiency, congestive cardiac failure or re-feeding syndrome.

## ELECTROLYTES

Young people with anorexia nervosa can be medically unwell with other features listed here and still have normal electrolytes.

Both low and high potassium levels can occur in young people with eating disorders. The serum potassium should be between 3.5 and 5.5mmol/l. Hypokalaemia is most likely to be secondary to self-induced vomiting, and may be associated with a metabolic alkalosis confirmed on venous blood gas. Hypokalaemia and acidosis in this context suggest the possibility of laxative misuse. Oral supplementation is generally unpalatable and may induce vomiting but does provide some protection from accidental overdosage. A potassium value of less than 3.0mmol/l merits admission to a paediatric unit and intravenous potassium correction. A potassium value of less than 2.5mmol/l and certainly less than 2mmol/l requires intensive monitoring and may need central venous access for correction. Such treatment would usually be undertaken in a critical care environment.

Hyponatraemia is less common but can be caused by water-loading to hide body mass loss. It may also be an indicator of underlying sepsis, the syndrome of inappropriate antidiuretic hormone hypersecretion (SIADH), excessive sodium loss due to diarrhoea/vomiting or iatrogenesis, and therefore can be a sign of a patient being very unwell. Serum levels should be above 135mmol/l. 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 will exacerbate hypokalaemia. Calculation of the fractional excretion of sodium can help in diagnosing the cause of the hyponatraemia. Causes of hyponatraemia in this context should be considered and if there is doubt about the aetiology, a full assessment is required, including clinical circumstances, fluid status and urine sodium concentration. It is important to realise that urine sodium concentration may reflect management, e.g. after interventions such as saline boluses.

Hypocalcaemia and hypomagnesaemia are less common but increase the risk of arrhythmia. Hypocalcaemia <1.1mmol/l can lead to tetany, stridor, seizures, weakness, atrioventricular (AV) block, a prolonged QTc, arrhythmias and a risk of sudden unexpected death. Refractory hypocalcaemia may be due to hypophosphataemia or hypomagnesaemia.

Phosphate is important in cellular energy and transport pathways throughout the body. Hypophosphataemia may occur secondary to starvation, but in addition re-feeding syndrome (see pp. 45–47) results in a low total body phosphate level which may be reflected as a low serum phosphate level.

Serum creatinine and urea need careful interpretation. Severe malnutrition may result in low serum creatinine due to low muscle mass and raised urea due to catabolism. However, a rise in creatinine may also occur if there is significant muscle breakdown in addition to any increase because of factors that decrease renal perfusion such as dehydration or primary renal impairment. Thus, as in all clinical situations, it is important that a rise in creatinine and urea is carefully assessed, including a clinical assessment of hydration status to avoid an assumption of dehydration which may lead inadvertently to unnecessary and potentially harmful fluid resuscitation.

## HAEMATOLOGICAL PARAMETERS

Abnormalities in haematological parameters may occur in any child or young person with malnutrition, including those with eating disorders, although they will usually resolve with weight gain and improved nutritional intake (Misra *et al*, 2004; Treasure *et al*, 2005; Ecklund *et al*, 2010). Changes can involve a number of cell lines, including leukopaenia, especially neutropaenia, and some thrombocytopaenia. Anaemia can occur, but as there is often a degree of dehydration, this is less commonly noted. Bone marrow aspirates can show hypo-cellular morphology which recovers with re-feeding. Whether malnourished individuals with anorexia nervosa specifically (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 adolescents with anorexia nervosa. It should be remembered that the haematological changes commonly found in anorexia nervosa have a number of differential diagnoses; primary haematological conditions such as leukaemia and lymphoma can present with pancytopenia and weight loss, as can both acute (e.g. sepsis) and chronic (e.g. tuberculosis) infection.

## OTHER BIOCHEMICAL ABNORMALITIES

Other biochemical abnormalities that occur in the context of anorexia nervosa include sick euthyroid syndrome and raised liver enzymes.

## MENTAL HEALTH

Young people with eating disorders have an increased risk of self-harm and suicide. Other common co-existing psychiatric diagnoses include obsessive-compulsive disorder (OCD), depression, and anxiety disorder.

Young people who are physically restrained for the purposes of feeding or who react to with violence attempts to encourage them to feed are at particularly high risk. Motivation is an important mediator of treatment outcome.

Poor attention and concentration are common when young people with eating disorders are underweight. Confusion and delirium are extremely worrying as they may reflect re-feeding syndrome, Wernicke's encephalopathy or be evidence of other infectious, metabolic or neoplastic



pathology. A neurological examination and a computed tomography/magnetic resonance imaging scan are indicated in such situations, particularly if the eating disorder presentation is at all atypical.

## OTHER ISSUES

- Exercise and activity levels increase risk if uncontrolled and result in overall negative energy balance. Hypothermia is also a requirement for admission.
- Muscular weakness is a sign of serious prolonged malnutrition resulting in muscle wasting. The SUSS Test (Sit Up, Squat–Stand) is useful to test for muscle strength (see Guidance 1 for scoring, pp. 17–19). 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:
  - the Sit Up test: the person lies flat on a firm surface such as the floor and has to sit up without, if possible, using their hands
  - the Squat–Stand test: the person is asked to squat down on their haunches and is asked to stand up without using their arms as levers if at all possible.
- Symptoms of dyspepsia are not uncommon in individuals with eating disorders and are more common in those who control their weight by vomiting; they may reflect gastro-oesophageal reflux and/or gastritis. Upper gastrointestinal bleeding in young people who control their weight by vomiting may be due to gastro-oesophageal reflux disease (GORD), gastritis or Mallory–Weiss tears. There is an increased risk of oesophageal and gastric rupture in those with bulimia nervosa.
- Acute pancreatitis is a rare but serious complication of malnutrition. The typical features are abdominal pain which radiates to the back in association with evidence of raised serum pancreatic enzymes.
- Central abdominal pain may also be a symptom of superior mesenteric artery syndrome, which results from compression of the third part of the duodenum between the aorta and the vertebral column behind, and the nerves and vessels of the superior mesenteric bundle in front. This is thought to occur when the cushion of fat protecting the bundle is lost.

**Guidance 2 Key physical assessment parameters and action points**

<i>Check for/measure</i>	<i>What to look for</i>	<i>When to be concerned (amber or red in risk assessment framework, Guidance 1)</i>	<i>Specific management</i>
Heart rate	Bradycardia, postural tachycardia	<50 bpm or symptomatic postural tachycardia	Nutrition, ECG
ECG (especially if bradycardic or any other CVS complication)	Other cause for bradycardia (e.g. heart block), arrhythmia, check QTc time (measure using Bazett's formula <sup>a</sup> ), check electrolytes	Prolonged QTc, heart rate <50 bpm, 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 unless symptomatic or tachycardic; should correct with nutrition and correct level of electrolytes
Blood pressure	Hypotension – refer to standardised charts for age and gender ( <a href="http://www.ucl.ac.uk/paediatric-epidemiology/pdfs/blood_pressure_centiles.pdf">www.ucl.ac.uk/paediatric-epidemiology/pdfs/blood_pressure_centiles.pdf</a> )	Systolic, diastolic or mean arterial pressure below the 0.4th centile for age and gender <sup>b</sup> and/or postural drop of more than 15 mmHg	Nutrition, bed rest until postural hypotension improved; echo likely to be abnormal while malnourished
Hypothermia	Temperature <36°C will usually be accompanied by other features; beware of <35°C		Nutrition, blankets
Assess for dehydration	Hypotension and bradycardia usually related to malnutrition, not acute dehydration	Significant dehydration and malnutrition	ORS orally or via a nasogastric tube preferred treatment unless there is hypovolaemia; beware of giving fluid boluses unless in hypovolaemia – cardiac compromise or hyponatraemia may occur; check electrolytes and renal function
Hypovolaemia	Tachycardia or inappropriate normal heart rate in undernourished young person, hypotension and prolonged capillary refill time		Senior paediatric review. Normal saline 10 ml/kg bolus, then review. If IV fluids are used then these should usually be normal saline with added KCl, with added electrolytes, e.g. phosphate, as required; consider other factors, e.g. intercurrent sepsis, as contributors
Other features of severe malnutrition	Lanugo hair, dry skin, skin breakdown and/or pressure sores		Nutrition; if skin breakdown or pressure sores present, seek specialist wound care advice

Continued

<b>Guidance 2</b> <i>Continued</i>			
<i>Check for/measure</i>	<i>What to look for</i>	<i>When to be concerned (amber or red in risk assessment framework, Guidance 1)</i>	<i>Specific management</i>
Evidence of purging	Low K, 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 supervision to prevent vomiting
Hypokalaemia	Likely to be due to purging. Note: normal electrolyte level does not exclude medical compromise	<3mmol/l – admit; consider an HDU, PICU or ICU if <2–2.5mmol/l	Correction; IV initially if <3mmol/l (oral supplements may still be vomited); ECG
Hyponatraemia or hypernatraemia	Less common but important; consider water-loading	<130mmol/l – admit; consider an HDU, PICU or ICU if <120–125mmol/l	If IV correction, proceed with care
Other electrolyte abnormalities	Check PO <sub>4</sub> , magnesium, calcium		
Hypoglycaemia		Hypoglycaemia is a relatively rare finding at presentation and implies poor compensation or co-existing illness (e.g. infection) – admit (once re-feeding is established, brief hypoglycaemia can be found after meals but should normalise rapidly)	Oral or nasogastric correction where possible (sugar drink, hypostop); IV bolus if severe (altered conscious or mental state; seizures): 2ml/kg of 10% glucose followed by ongoing infusion containing glucose, e.g. 5ml/kg/h of 10% glucose with 0.45% saline to minimise the risk of rebound hypoglycaemia after IV dextrose bolus; glucagon in malnourished patients may not be effective as glycogen storages are likely to be low
Mental health risk or safeguarding/family	Suicidality, evidence of self-harm, family not coping	Admit for comprehensive psychosocial assessment as per NICE self-harm guidance; admit for place of safety if necessary in the safeguarding context	CAMHS involvement, apply local self-harm and safeguarding procedures as needed

bmp, beats per minute; CAMHS, child and adolescent mental health services; CVS, cardiovascular system; ECG, electrocardiogram; HDU, high-dependency unit; ICU, intensive care unit; IV, intravenous; KCl, potassium chloride; NICE, National Institute for Health and Clinical Excellence; ORS, oral rehydration solution; PICU, psychiatric intensive care unit.

a. Bazett's formula:  $QTc = QT/\sqrt{RR}$

b. Jackson *et al*, 2007.

## HIGH-DEPENDENCY OR INTENSIVE CARE

For medically compromised in-patients with eating disorders, especially those with cardiovascular or electrolyte abnormalities, cardiac monitoring may be suggested or preferred by the admitting team. Cardiac monitoring allows continuous observation of a heart trace by an appropriately trained nurse or doctor and a more frequent grasp of downward trends in observation, as well as sounding audible alarms. It also provides a stored record for review. On the other hand, it raises a number of potential issues for the team caring for the patient such as education and training in use of cardiac monitoring, increased anxiety about how unwell the patient is, equipment availability and potential technical problems.

Staff may feel that the patient would be better monitored in the high-dependency or psychiatric intensive care environment. This may be appropriate for very unwell young people, who should be assessed and discussed with local intensive care teams or retrieval services before admission as for any seriously unwell child or adolescent. A decision should be negotiated that is sensitive to the patient and mindful of the availability of local services. Sick children and adolescents with eating disorders who need in-patient admission require the same level of care as with any other serious illness, and the same protocols and guidelines for stabilisation should be applied (local, APLS etc.). A sick child with an eating disorder should always be discussed with a senior doctor. Such a child needs senior paediatric review on admission and then at least daily if there are paediatric (medical) issues.

## LOCATION OF CARE: WHERE WILL THE PATIENT BE BEST MANAGED?

When the decision has been made to admit the child or adolescent to hospital, the referrer's actions will be informed by many factors, not all of them clinical.

The options usually are:

- a paediatric bed;
- generic CAMHS bed in a generic CAMHS in-patient unit; this may be a children's unit (usually up to age 14) or an adolescent unit (usually 13–18);
- generic CAMHS bed in a unit that has expertise managing children and adolescents with eating disorders in an SEDB, often linked to an out-patient CAMHS service that has expertise in managing severely unwell patients with eating disorders;
- a SEDU bed for children and adolescents, only two of which are currently in the National Health Service (NHS); the majority are in the independent sector and of these, only a small number are licensed for children under age 13.

The decision rests on the clinical state of the child, the services available locally as part of a network of care for children and adolescents with anorexia nervosa, and, where possible, on parental or patient choice. The child 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. The management of these behaviours, which may include food avoidance and concealment, exercising, falsifying weight, excessive water drinking, to name a few, is best achieved in a unit that is able to provide an SEDB, in either a generic or eating disorders-specific setting. However, for children, an additional consideration will be the proximity of the nearest SEDB to the child's home and family, with optimum care being offered as close to home as possible. Although this must not compromise clinical care, when children are admitted a long distance from home thought must be given to how families are supported to maintain links with the child, and how the child can stay in touch with their friends and school.

Alternatively, the child may be so physically ill that admission to an SEDB may not be possible and admission to a paediatric bed may be needed. To decide whether a particular child can be admitted to an SEDB or not, their needs must be matched with what can be provided; the key determinant of where care should be provided should be the primary need of the child. A child whose primary need is acute medical stabilisation should be admitted to a paediatric bed. A child whose primary need is to initiate in-patient care, including re-feeding in an appropriately managed therapeutic environment, should be admitted to a unit that is able to provide the appropriate level of expertise in managing young people with eating disorder, i.e. an SEDB.

A unit offering SEDBs for children should be able to provide:

- expertise in nasogastric feeding (insertions may be performed off-site)
- daily biochemistry
- frequent nursing observations, up to and including one-to-one observation when indicated
- prevention of anorexic behaviours, e.g. water-loading, excessive exercise
- ECGs, daily if needed
- management of the resisting child – including safe holding techniques, and the acute and medium-term paediatric psychopharmacology of children with eating disorders
- use and management of the Mental Health Act 1983 (and its 2007 amendments) in those under 18, with particular reference to the zone of parental control in children with eating disorders – the Mental Capacity Act 2005 in 16- to 18-year olds and the Children Act 2004 in those under 18
- assessment of tissue viability in emaciated patients and treatment of pressure sores
- immediate cardiac resuscitation by staff trained to administer resuscitation
- access to advice from paediatricians and paediatric dieticians in a timely and flexibly responsive manner, ideally in the form of a 'Junior MARSIPAN' group.

Children who need the following support should always be admitted to a paediatric ward, ideally one that has expertise in management of emaciated children (see care in paediatric settings, pp. 37–55):

- intravenous infusions

- treatment of serious medical complications
- cardiac monitoring
- provision of a paediatric resuscitation ('crash') team
- central venous pressure (CVP) lines
- total parenteral nutrition (TPN)
- artificial ventilation.

### **GUIDANCE 3** LOCATION OF CARE

- In most cases, unless the child requires medical services that are not available, children with severe anorexia nervosa should be cared for in a tier 4 CAMHS SEDB, with support from paediatric services when needed. For children aged 12 and under, this should be a unit that is suitable for younger patients. The exception would be children whose care needs are such that they can only be managed in a paediatric ward.
- Should an SEDB be unavailable, for example owing to waiting lists or lack of an appropriate facility, the choice is between a paediatric and a generic CAMH unit bed. Several variables will influence the decision, such as the quality of liaison between paediatric and CAMH eating disorder service (where these exist), the experience of generic CAMH units in managing malnutrition, as well as the clinical state of the child and requirements for monitoring. There should be a CAMH eating disorder team responsible for the population and we suggest that a senior member of the team consult with paediatric and CAMHS colleagues to develop a local Junior MARSIPAN strategy to address this problem.
- Regarding nasogastric feeding, this can sometimes be managed in a generic CAMH in-patient unit as long as the experience, knowledge and skill is available to safely carry out this procedure. It would be reasonable for a generic CAMH unit to ask that a patient's nasogastric tube be placed and position verified in a paediatric unit and that the initial few days of feeding be provided there, until the danger of re-feeding syndrome is past, as long as robust links are maintained between the two services. This may be especially important if the nearest SEDB is a long distance from the child's home and the decision that proximity to family and access to local social and educational links outweighs the need to access an SEDB a long distance from home.

CAMH, child and adolescent mental health; CAMHS, child and adolescent mental health service; SEDB, specialist eating disorders bed

## TRANSFER BETWEEN SERVICES

Transfer between services carries a potentially high risk for a young person with severe anorexia nervosa. We are aware of at least three deaths of young people and of many other near-miss incidents following transfer between services at all levels (transfer between CAMHS and adult services, between two in-patient units, between medical units and specialist in-patient services, primary and secondary care). There are a variety of reasons for this. The risk is higher if patients do not engage with services, for whatever reason (poor motivation for help, difficulties with social communication, lack of availability of appropriate therapist, poor therapeutic alliance).

In primary care, because severe anorexia nervosa is a relatively rare condition, there is a risk that recognition of the problem may be delayed, particularly if the family does not seek help early. Inexperienced healthcare professionals may be falsely reassured by normal blood tests or relatively preserved energy levels. Alternatively, they may expect that making a referral to other services would 'sort the problem out', and not be aware that a severely malnourished child may deteriorate rapidly while waiting for an appointment. The CAMHS team may not realise the urgency of the referral if the information they have is limited.

Similarly, without agreed shared care arrangements, it is possible that inexperienced professionals will expect the child to be admitted to a medical or paediatric ward while waiting for a CAMHS bed. The staff in the acute hospital may not feel confident to start re-feeding if the child does not cooperate or is in distress, and expect the CAMHS team to take responsibility, whereas the CAMHS team makes the assumption that the child will be medically stabilised before the transition takes place. As a result, the young person can get worse in the paediatric setting, and may even be too unwell to be transferred to the psychiatric unit once the bed becomes available. Young people aged between 16 and 18 are particularly at risk, as the links between CAMHS and adult medical wards are less well established, and most paediatric services do not cover this age group. We advocate specific discussion with local providers regarding patients in this age group, in which many 'paediatric' issues such as impaired growth and development are still prominent and in need of paediatric expertise.

Likewise, the links between specialist eating disorder services in the independent sector and local NHS paediatric or medical wards are usually limited. Furthermore, most CAMHS in-patient units provide services to a large geographical area served by many different acute and community trusts, making it very difficult to develop local protocols for transition and transfer between all services (primary and secondary care, emergency departments, paediatrics and general medical wards). The majority of specialist services accept patients nationally, and this limits opportunities for developing uniform protocols which would improve patient safety. Processes for developing local protocols also differ by jurisdiction, for example, in Scotland networks facilitate collaboration between local CAMHS, regional and national services (M. Morton & S. Hukin, 2011, personal communication).

The current emphasis on provider competition is likely to impair collaboration between services. Joint working between services can be life saving, and commissioning support is essential to achieve this (e.g. funding for CAMHS nursing staff while the patient is in an acute hospital).

Transfer between CAMHS and adult services can also be problematic. Often there is a significant cultural difference between these services. While most CAMHS emphasise the responsibilities of the parents, adult services focus on individual responsibility. Without a careful transition, making sure that the young person is indeed capable of taking responsibility or their capacity to make decisions about treatment is clarified, a sudden change of approach can cause confusion and dissatisfaction at best and tragedy at worst. Although it is recognised that transition is important (Treasure *et al*, 2005), research in this area is limited. The TRACK study (Singh *et al*, 2010) 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.' Although this study did not focus specifically on eating disorders, there is no reason to believe that transition

arrangements for young people with severe eating disorders are any more satisfactory.

#### **GUIDANCE 4** TRANSFER BETWEEN SERVICES

- Ideally, there should be joint protocols between services to ensure safe transfer and optimal transition of young people with severe anorexia nervosa between services. If this is not possible, when a young 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 young person and family, so that it is very clear what will happen during and after the transfer of care, and who is responsible for what. Such meetings should be continued until transfer is satisfactorily achieved.
- Safe care pathways and joint working between different organisations should be supported by commissioners.
- Carers' concerns need to form part of the risk assessment.

## COMPULSORY ADMISSION AND TREATMENT

Patients with severe eating disorders may refuse life-saving treatment, causing ethical dilemmas for the treating teams. As with many other Western countries, in England and Wales the compulsory treatment of severe eating disorders is controversial (Edwards, 1993; Tiller *et al*, 1993; Dyer, 1997; Draper, 2000, 2003; Russell, 2001; Giordano, 2003; Melamed *et al*, 2003; Webster *et al*, 2003; Mitrany & Melamed, 2005; Newton *et al*, 2005).

The NICE guidelines (National Institute for Health and Clinical Excellence, 2004) emphasise the importance of a collaborative approach in the treatment of young people with eating disorders, just as with adults. Motivation to change is seen as an important requirement for successful treatment, and for this reason, there are many clinicians who are reluctant to treat patients against their will. When feeding against the patient's will becomes necessary, it is recommended that this should only be done in the context of a clear legal framework. The adult MARSIPAN group reported misconceptions about using compulsory treatment in anorexia. Delay of treatment is probably less common in young people who do not consent to it than in adults, particularly if the patient is less than 16 years old. The NICE guidelines stress that although parental consent can be used to override the young person's refusal of treatment, relying 'indefinitely' on parental consent to treatment should be avoided. Following the introduction of the Mental Capacity Act 2005, parents cannot override their child's refusal of treatment after the age of 16 years if that child has capacity.

Studies by Tan *et al* (2003a,b,c) suggest that most families and patients accept that the use of the Mental Health Act may be necessary if the condition is life threatening. A UK study comparing the outcome of young people treated on a SEDU found that improvement was independent of the person's legal status (Ayton *et al*, 2009). However, the way that the Mental Health Act is used is fundamentally important, if compulsory intervention is to be seen as helpful by both the patient and the family, rather than as punitive and coercive. Tan *et al* have accumulated evidence showing that capacity to consent to treatment may differ in anorexia nervosa depending



on the stage of the illness. In addition, although patients with anorexia nervosa have a good understanding, reasoning and appreciation of their illness, the change in values and sense of identity that can result from anorexia nervosa have an impact on decision-making, but is not picked up in standard tests of competence. The issue of treatment acceptance and patient autonomy is therefore complex and not static.

Mental health legislation varies across the different countries of the UK, particularly in relation to the specific process of detaining individuals for involuntary treatment. Nevertheless, the underlying principles of using mental health legislation in the management of this patient group are broadly applicable, namely that anorexia nervosa is a serious mental disorder, in-patient re-feeding is at times an essential and direct treatment for anorexia, and 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.

#### **GUIDANCE 5** COMPULSORY ADMISSION AND TREATMENT

Eating disorders are mental disorders. Individuals with mental disorders may be putting their lives at risk and require in-patient treatment.

- Young people aged less than 16 can be treated against their will if at least one parent consents to treatment on their behalf. However, if the child actively fights the parent's decision regarding the necessity of the treatment, compulsory treatment needs to be considered. This applies to decisions within the zone of parental control (i.e. ones which parents would normally make on behalf of children that are in the best interests of the child).
- 16- to 18-year-olds can be admitted under the Mental Health Act and treated against their will, although this should rarely be required. It is essential, however, that it is done when necessary.
- 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.

Under the Mental Health Act feeding is recognised as treatment for anorexia nervosa and can be done against the will of the patient as a life-saving measure. Although a last resort, the decision to apply the Mental Health Act should be considered from the outset, for example, when a patient refuses treatment in an accident and emergency setting. If paediatric staff suspect that this course of action may be necessary, then psychiatric services should be contacted, as they will be familiar with arranging a Mental Health Act assessment. If the paediatric consultant is not satisfied with the opinion given, there should be direct contact between the consultant and the consultant psychiatrist and the issue escalated until the patient's treatment is safe. A CAMHS consultant 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 under the Mental Health Act for any reason, the matter must be similarly escalated between consultants and reasons documented for decisions made. Note that a consultant paediatrician can no longer be the responsible clinician for a young person detained under the Mental Health Act. Under the amended Act the responsible clinician must be an approved clinician, in this situation usually a psychiatrist. Trusts need to have managerial structures in place to receive and administer the Mental Health Act detention paperwork. Most paediatric services are in acute trusts, but these organisations should have links with local mental healthcare providers to ensure that procedures and policies are adhered to.

In addition to mental health law, children are subject to protecting laws (under 18 years old), which can be used to provide healthcare if there is no consent or lack of capacity to consent. For example, under the Children Act 1989, a Specific Issue Order (Section 8) can be used to pass a nasogastric tube; 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 (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 (UNCRC) 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). Thus in young people, consideration of legal frameworks for treatment in the case where 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.

## POLICIES AND PROTOCOLS

We recommend that clinicians and managers from paediatric and adult medical wards and CAMHS services likely to see young MARSIPAN patients develop a number of protocols in advance of situations of risk developing. Some exemplary sources of protocols are given in Appendix E.

### **GUIDANCE 6** PAEDIATRIC SERVICE POLICIES AND PROTOCOLS TO AGREE IN ADVANCE

- Criteria for paediatric as opposed to psychiatric admission.
- Special nursing: qualifications and supervision of one-to-one nurses; role of paediatric v. psychiatric nurses.
- Social work and legal aspects: availability of advice in situations of non-consent to treatment by either the young person or their parents/carers.
- Mental Health Act: criteria for use, identification of responsible clinician, identification of responsible manager.
- SEDB: consultation and referral, including consideration of provision for children aged 12 and under.
- Issues around funding (e.g. special nursing or SEDU referral).
- Liaison psychiatry services (where they exist) or tier 4 CAMHS.
- Training role, involvement of consultants and trainees with admitted individuals and consultation with eating disorders specialists.
- A Junior MARSIPAN group with at least a paediatrician, a child and adolescent psychiatrist, a dietician and a nurse as well as management to be set up in their locality to advise on services required in medical units.

CAMHS, child and adolescent mental health services; SEDB, specialist eating disorder bed; SEDU, specialist eating disorders unit.

# Management of children and adolescents with anorexia nervosa in different sectors

## MANAGEMENT IN GENERAL PRACTICE

It is often parents rather than young people who seek help initially, often after a long period of the problem unfolding and hope that it will not develop fully into an eating disorder. By the time help is sought, the young person is often very unwell, and a single consultation about weight and eating concern is a strong indicator of a possible eating disorder (Lask *et al*, 2005). A 'wait and see' attitude is contraindicated.

Behavioural indicators of an eating disorder include reluctant attendance at the surgery or clinic, seeking help for physical symptoms, resisting weighing and examination, covering the body, being secretive or evasive, having increased energy levels (and in some cases agitation), and getting angry or distressed when asked about eating problems. Eating disorders may of course co-exist with other disorders.

Diagnostic features of an eating disorder are:

- refusal to maintain body weight or failure to gain weight during a period of growth
- intense fear of gaining weight
- disturbed body perception
- undue influence of body weight or shape on self-esteem
- denial of seriousness of current low body weight
- secondary amenorrhoea in girls post-menarche.

The SCOFF questionnaire, although validated only in adults, can provide a framework for screening in children (Morgan *et al*, 1999).

When an eating disorder is identified, direct challenge or confrontation is unlikely to be helpful. Reasonable aims for a first presentation are to:

- feedback findings from physical examination, including degree of underweight if relevant
- establish weight monitoring, plus a plan to follow if weight falls
- discuss psychiatric risk as needed
- provide the young person and the family with information about the nature, course and treatment of the eating disorder

- refer to the appropriate CAMHS or paediatric service depending on the level of risk.

In general, the threshold for intervention should be lower for adolescents than for adults. In patients younger than 18, early intervention is associated with better outcome and a higher recovery rate than in later years. In practice, the referral may also depend on which service the parents or young person will accept, with preference often being for a paediatric over a CAMHS referral. However, the needs of the child should be the primary basis for decisions about referral. Any referral must be accompanied by a full referral letter explaining why a particular route has been chosen.

Initial assessment should include general examination, including pulse rate and blood pressure, and baseline blood tests, with an ECG for underweight individuals or where there is concern regarding continuing weight loss. Height, weight and BMI should be measured, plotted on centile charts, and a percentage BMI should be calculated (see p. 20). Some drugs (e.g. antipsychotics, often prescribed to patients with anorexia nervosa) can lengthen the QTc and hence enhance the cardiac ill effects of malnutrition.

If weight loss is rapid and the history suggestive of an eating disorder, referral to CAMHS should be made (but rapid weight loss without signs suggestive of an eating disorder is no reason to refer to CAMHS). If weight is below 80% of median BMI for age and gender, the referral should be considered urgent. If it is below 70%, referral should be made directly to paediatric services for initial assessment. Referral letters must include current weight and height as well as other information relevant to assessing risk. It is particularly helpful to include any previous measures of weight or height, since this gives an idea of how severe and long-standing the problem is. Extensive and time-consuming physical investigations should be avoided. Differential diagnosis includes:

- endocrine: diabetes mellitus, hyperthyroidism, glucocorticoid insufficiency
- gastrointestinal: coeliac disease, inflammatory bowel disease, peptic ulcer
- oncological: lymphoma, leukaemia, intracerebral tumour
- chronic infection: tuberculosis, HIV, viral, other
- psychiatric: depression, autism-spectrum disorder, obsessive-compulsive disorder (OCD).

Of these, an eating disorder is one of the most common. All children should have a routine blood screen including full blood count, electrolytes, liver function, renal function, including calcium, phosphate and magnesium, iron status, coeliac antibody screen, inflammatory markers, and thyroid function.

Rapid re-feeding in the community (which may be self-generated by means of bingeing) can risk re-feeding syndrome (pp. 45–47). Re-feeding syndrome is extremely rare but is more likely to occur in a young person with rapid weight loss and a BMI <0.4th centile, who has eaten little or nothing in the past week or who has abnormal biochemical parameters. Support from dietician should be sought to advise on feeding in any young person considered at risk of re-feeding syndrome. Patients and parents should be advised not to increase nutritional intake rapidly, even if motivated to do so. If risk for re-feeding syndrome is high, blood tests are needed

during the initial phase of re-feeding, particularly electrolytes, calcium, phosphate and magnesium. If the risk is high enough to require daily blood tests, the young person should be referred to hospital according to local protocol.

Until the young person is seen in the specialist clinic, he/she should be seen regularly (at least weekly) for weight monitoring, blood tests and ECG.

When a young person is under the care of CAMHS, a GP or general paediatrician may have to monitor their physical health. In such instances of shared care, regular communication between those responsible for the medical and mental health aspects of care, at least after each visit, is good practice.

**GUIDANCE 7** MANAGEMENT OF ANOREXIA NERVOSA IN PRIMARY CARE AND OTHER OUT-PATIENT SETTINGS

- Rapid exclusion of other conditions
- Risk assessment: age- and gender-specific BMI centile, blood pressure, heart rate, temperature, baseline blood tests and self-harm
- Refer to CAMHS every young person with probable anorexia nervosa
- Refer to paediatrics any child who has one or more criterion of a high risk (red, see Guidance 1) with simultaneous referral to CAMHS
- If re-feeding in the community, check electrolytes, phosphate, magnesium as for in-patient care (Guidance 8). Where regular blood tests are not feasible, in-patient admission should be sought
- Monitor at least weekly until seen by CAMHS or paediatric services.

BMI, body mass index; CAMHS, child and adolescent mental health services.

## MANAGEMENT IN OUT-PATIENT PAEDIATRIC SETTINGS

A paediatrician may see a young person with an eating disorder in the out-patient setting for a variety of reasons:

- to exclude other diagnosis accounting for weight loss
- to monitor physical health
- to provide health information.

Referrals may come from the GP, school nurse, CAMHS and other healthcare professionals.

A GP or school nurse may refer a young person with a possible or probable eating disorder to a paediatrician to exclude an organic cause for weight loss or because the young person and/or family are reluctant to be referred to CAMHS, afraid of possible stigma this may carry or in denial of a possible eating disorder. In such circumstances, it can be very helpful if a paediatrician confirms concerns about an eating disorder and stresses the need for CAMHS input. Especially in the earlier stages of an eating disorder, a hospital referral can be beneficial in helping a young person understand the seriousness of the situation, the need to address this and make a change.

Often, restrictive eating will slowly have become more limited and parents/guardians may be quite anxious to offer the young person a more balanced diet, worried that they will eat even less. In such cases it can be extremely helpful if a clinician takes over the responsibility for the young person's physical well-being through their frequent monitoring. This can create the space for the family to become more firm with diet. For example, if a certain meal is not prepared, the young person may threaten not to eat at all. The family not accepting the restricted diet is an important step on the road to recovery.

When a young person is known to CAMHS it is important that the role of the paediatrician is clear to all involved. This may be the assessment of physical health (see Guidance 2, pp. 25–26), with further investigations and interventions as required. It may be to perform a baseline assessment (weight, pulse and blood pressure) when this cannot form part of the CAMHS intervention, for example when the young person gets extremely anxious when being weighed. In this situation it should be clear that this is a short-term arrangement and that in time these assessments should take place at CAMHS appointments.

A paediatrician cannot replace the necessary input from CAMHS and should not be the main carer of a patient with anorexia nervosa for any significant amount of time. Structures should be put in place for regular communication between CAMHS and the general paediatrician for young people seen by both specialties but especially for the ones only seen by the general paediatrician.

## MANAGEMENT IN IN-PATIENT PAEDIATRIC SETTINGS

### *REASONS FOR IN-PATIENT PAEDIATRIC ADMISSION*

There are various reasons for admission to a paediatric ward other than being seriously medically unwell (for example, see p. 10). The principles outlined below should be considered whatever the reason for admission.

It is important to clarify and agree the necessity for and the purpose of the paediatric admission with the young person, family and team members. Medical reasons for admission if the child is severely unwell would include the need for intravenous fluids to correct electrolyte abnormality, re-feeding for severe malnutrition, management of physical complications of severe malnutrition and/or associated behaviours such as electrolyte disturbance secondary to purging, and the management of an acute medical illness unrelated to anorexia nervosa, if present. In these circumstances the ideal would be to medically stabilise the young person, with prompt discharge from the paediatric ward once it is safe to do so. As discussed above, paediatric settings may also have a role in the care of young people with eating disorders for reasons other than acute medical risk, as agreed locally, including respite for parents, assessment and investigation and self-harm. These admissions are not the subject of this report, although some of the principles outlined here may also apply.

### *ROLES AND RESPONSIBILITIES DURING AN IN-PATIENT PAEDIATRIC ADMISSION*

Throughout any admission the consistent and coordinated care and support of the young person and their family are paramount. It is the responsibility

of all to ensure multidisciplinary collaboration so that all aspects of management are addressed appropriately. These include physical and nutritional assessment; management of complications of malnutrition; re-feeding, which may include nasogastric tube feeding; and monitoring for, recognition of and management of the re-feeding and underfeeding syndromes. Management of disordered eating and associated behaviours is clearly crucial. Treatment of comorbidities such as anxiety or OCD may be required and medication used if indicated. A working knowledge of the Children Act and the Mental Health Act is necessary to ensure that treatment against the young person's consent can be provided if considered necessary.

The specific medical and nutritional aspects of this treatment fall within the remit of paediatricians, paediatric nursing staff and a dietician. To provide this care it is important for these staff to be conversant with eating disorders and their management. However, they need to be supported in this by the psychiatric service who should provide adequate support and advice so that medical care is given in an appropriate way, as well as offering advice about specific psychiatric treatments and the steps necessary to ensure treatment if needed.

#### RECOMMENDATIONS FOR PAEDIATRIC INVOLVEMENT

We recommend that every hospital to which a young person with severe anorexia nervosa is likely to be admitted identify a consultant paediatrician who should:

- have an interest in this patient group
- have had training in the clinical problems (medical and psychiatric) of young people with severe anorexia nervosa and their management, or can be supported to achieve this
- have expertise in the nutritional support of those with anorexia nervosa and its complications, or can be supported to achieve this
- be supported by a multidisciplinary team
- have access to in-patient beds
- have an association with a CAMHS team with an interest or expertise in eating disorders.

This individual would be made aware whenever a young person with an eating disorder needs to be admitted or has been admitted as an emergency to the hospital. They should consult as soon as possible and coordinate care from a paediatric perspective, including ensuring that protocols or procedures are in place to effect appropriate management and calling for opinions and expertise when needed. There should be clear arrangements for cover in the absence of the nominated paediatrician. It is strongly recommended that a system be developed whereby a level of expertise is acquired, reliable senior leadership in the clinical management and multidisciplinary work is ensured and consistent communication with all team members, the individual and their family occurs for what may be a longer admission than usual and may continue post-discharge. 'Consultant of the week' systems carry the risk of discontinuity of care, and effort should be made to ensure senior paediatric overview of care by a paediatrician with expertise with young people with eating disorders and who takes responsibility for managing many of the other specific issues associated with

anorexia nervosa outlined above, including the need for consistency of care over a prolonged period.

#### LIAISON WITH PSYCHIATRIC SERVICES IN PAEDIATRIC SETTINGS

All paediatric units into which a severely ill child with anorexia nervosa is likely to be admitted should have an identified psychiatrist available for consultation. Part of the psychiatrist's role should be to provide advice, training and support to paediatric units to develop a shared-care approach for the management of children with anorexia nervosa and their families.

We recommend that every hospital into which a child with severe anorexia nervosa is likely to be admitted identify a consultant psychiatrist and multidisciplinary team with whom a working relationship can be built to support the admission. They should:

- have an interest, training and expertise in this subject, or can be supported in achieving this
- be in a position to be able to provide shared care for children with severe anorexia nervosa admitted to a paediatric ward
- have an association with paediatric staff, specifically those with an interest or expertise in eating disorders.

This individual/team would be made aware whenever admission of a child with an eating disorder is likely, and in those already admitted would consult as soon as possible and take over care from a psychiatric perspective, unless the consultant psychiatrist and team for the individual at the time of admission are to provide this role. The exact model of psychiatric input may vary, for example it may come from an eating disorders, liaison psychiatry or tier 4 service. Where both liaison and eating disorders services exist, a clear plan for deciding responsibilities in relation to very sick young patients with anorexia nervosa in the acute setting, and during transition to other settings, will be needed. Finally, it is important that there is an agreed arrangement whereby this service may be provided promptly and reliably (with cover arrangements as needed) and to the full extent that may be required.

#### A PARTNERSHIP BETWEEN PAEDIATRICIAN AND PSYCHIATRIST

Children and young people admitted to a paediatric ward should have the full and ongoing support of a consultant psychiatrist, who should form a partnership with the paediatrician. Input from trainees is welcome, but must be backed by involvement of the consultant psychiatrist and regular contact between the two consultants. It is essential that psychiatrists providing support in this way be fully conversant with severe eating disorders and their management through specific training and experience, or can be supported to achieve this. This should lead to the development of a shared-care approach.

To facilitate these arrangements, the following practices are recommended:

- production of guidelines on medical management of severely unwell young patients with an eating disorder aimed primarily at junior medical staff
- a guide for nursing and medical staff on supporting patients and families



- regular staff meetings to ensure a consistent approach and minimise the risk of splitting (such as playing off some staff against others by the patient).

For each individual admission a set of measures are recommended:

- a regular multidisciplinary team meeting, usually weekly or more frequently if required, until discharge:
  - senior paediatric, psychiatric and nursing staff – or those that can make decisions – should be present, together with someone with dietetic expertise and other individuals as required; input from trainees is welcomed as appropriate, but they must be adequately supported by senior colleagues
  - the role of this meeting should include reviewing progress with parents, the review of future care plans and conveying these to the young person as appropriate
  - a record of the meeting should be prepared and circulated to all, including the young person and the family;
- discharge planning should be included in the agenda of the multidisciplinary team meeting when appropriate;
- a nursing care plan which addresses the specifics of patient care for children and young people with an eating disorder should be formulated.

## *SOME PRACTICAL CONSIDERATIONS*

### PLACE OF NURSING

The severity of illness and level of supervision required will influence the choice of where the young person is nursed on a paediatric ward. There are mixed views on the benefits of nursing young people with anorexia nervosa in a single room. Although it ensures privacy for someone in a disturbed mental state and staff may hope that it minimises disruption to the rest of the ward, it also isolates the young person with their persecutory thoughts, gives them opportunities to exercise, dispose of nutrients and purge, and may increase opportunities and therefore risk of engaging in acts of self-harm. There is also always the risk of staff unwittingly adopting an 'out of sight, out of mind' attitude. We therefore recommend that separate nursing is considered on a case-by-case basis, depending on problem behaviours, the young person's capacity for interaction with others on the ward, and the need for special psychiatric nursing, but with a preference for nursing on a general ward and not in a separate cubicle unless there are indications to do so.

### NURSING CARE

A child with an eating disorder admitted to a paediatric ward can cause significant anxiety for staff. Paediatric wards, especially in non-children's hospitals, are often skilled at managing short-term admissions but may be less confident with children who may require intensive input over several weeks. Managing children who exhibit anorexic behaviours (e.g. refusing and hiding food, exercising excessively, vomiting) can prove particularly

challenging for acute paediatric admission services. The ideal situation would be to have nursing staff who have been trained in both paediatric and mental health nursing. Although there may be a few individuals who are fortuitously trained in this way, this is not the norm for most nurses on a paediatric ward. To nurse children with severe anorexia nervosa it is important for staff to have a working knowledge of the illness and part of the role of the psychiatry teams should be to support paediatric staff training in this area. However, this will need to be backed up by close liaison during the admission of any child with anorexia nervosa. In some regions, secondments of mental health nurses on paediatric wards – and *vice versa* – are undertaken to help both groups develop their skills in each other's area of expertise.

We recommend that a core group of nurses be identified to take care of an individual during an admission so that continuity of care, which is very important, is maintained as far as possible. On occasion the young person will try to dictate which nurses will look after them. Such requests should be resisted unless there is a good reason to accommodate them from the ward perspective.

When 'special' additional nursing is needed, these staff need to be appropriately trained and induced, and arrangements made for handover and communication with the nursing and multidisciplinary team caring for the patient, in addition to written care plans, even if they change every day.

With specialist nursing comes the question of who should pay for it. The key issue that should determine this is the clear identification of the purpose of the nursing. Is it to manage a seriously physically unwell child requiring a high level of medical input? If so, perhaps the onus of the budgeting falls on commissioning arrangements that map onto physical healthcare. Is the extra nursing aimed at managing anorexic behaviours, facilitating adherence to diet or supporting the care of a child with significant psychiatric comorbidity, for instance suicidal behaviours? If so, these become the financial responsibility of the commissioner responsible for CAMHS services. Two factors need to be considered when extra nursing is provided.

First, what is the role of the child's parents? On paediatric wards parents often stay with the child for much or all of the time. If the presence of the parents is supportive and facilitates reduction of anorexic behaviour, then empowering parents to manage their child's illness can be encouraged. This may mitigate or alter the role of additional nursing, if that is still required. However, services should not assume that all parents are able to take on extra nursing duties. Often, by the time the child needs admission to hospital, parents are frightened and exhausted, which limits their ability to manage challenging behaviours. Nevertheless, with adequate support from both paediatric nurses and CAMHS, enabling parents to begin to help their child reverse the deterioration can be the beginning of an important relocation of control and responsibility, setting the scene for a family's involvement in the young person's recovery.

Second, for commissioners to be confident about what they are funding and therefore how much of the additional funding resource should be delivered, CAMHS eating disorders teams and paediatric services should develop behaviour-specific care plans to guide those providing extra nursing support. These plans should form a care pathway and be negotiated with the relevant commissioners as part of the service provision; they are especially important in situations where the extra nursing provision is delivered by agency staff. Care by agency staff with little or no experience in eating disorders should be avoided.

## EDUCATION

Most paediatric wards will have access to teaching, especially for children who have prolonged or recurrent admissions, although resources and arrangements will vary. Those who are severely ill may not be well enough to participate in school work. When they are able to do so, however, it is important to consider very carefully the amount and level of school work that they are able to undertake. It is also important for teaching staff to have an understanding of the young person's anorexia and for liaison regarding any areas of the teaching activities which may raise concerns.

In cases where the young person has fallen below recommended school annual attendance, it is of value for clinical staff to contact the school directly or through the ward teachers to ensure that the school is aware of the admission and teaching arrangements on the ward. This contact should be subject to parental or the young person's consent (depending on the young person's age and/or capacity).

## SOCIAL INTERACTION ON PAEDIATRIC WARDS

In general, those admitted to a paediatric ward for any reason may gain from the contact with other patients, but there are matters to be aware of. If more than one young person with anorexia nervosa is admitted to a paediatric ward at any one time, a degree of 'competition' may ensue and unhelpful behaviours may be learnt. Other vulnerable individuals on the ward may witness eating and other behaviours which may subsequently be adopted by them. The young person with anorexia can be exposed, especially during a prolonged admission, to other severely unwell children and sometimes even death.

Although it is important to include all children on the ward in any opportunities and activities where possible, it is important that these do not interfere with the overall care plan for the young person with anorexia, for instance by interfering with snack times or mealtimes, and that there is an awareness that some activities (e.g. baking) may not always be suitable.

## TIME OFF WARD

Many paediatric in-patients can leave the ward for short periods of time, e.g. visits to the hospital canteen or walks outside the hospital with parents. It is important to consider the potential impact of any time off the ward for the young person with anorexia nervosa. They may be too physically unwell to leave the ward, they may take advantage of the time off the ward to over-exercise, dispense with food, water-load, or to use energy by simply not keeping warm in cold weather. In addition, their behaviour with parents when not on the ward may be more difficult. It may therefore be necessary to consider restricting time off the ward for a child with anorexia.

## DIETETIC INPUT

Paediatric dieticians are an essential part of the eating disorders care team and should be contacted when a child with anorexia nervosa is admitted to hospital. In some areas, dietetic input is provided by specialist dieticians working in CAMHS, who should either be familiar with nutritional requirements to maintain normal growth and paediatric formulations for nutritional supplements, or should consult accordingly. In the absence of an appropriately skilled dietician, local expertise (e.g. paediatrician, eating

disorders practitioner) and advice from a specialist eating disorders centre should be sought. The paediatric dietician ensures that essential nutrients needed to support growth and development during this complex time are provided. This is particularly important if the young person follows a special diet, such as a vegetarian diet.

A safe meal plan will be devised and agreed with the team and the family to form the basis of a clear treatment plan, minimising communication errors and avoiding discussions around anorexic preoccupations and concerns at the time of a meal or snack. It is important to consult the parents when drawing up a meal plan, so that the family's usual diet can be accommodated as much as possible (including special diets in various ethnic groups). It may be very hard to agree with a young person a meal plan that gives a balanced diet. What works reasonably well is agreeing with the child three to five things they dislike, generally foods they also did not eat before developing an eating disorder. A choice of snacks from a list of items with similar calorific value is helpful.

The paediatric dietician, through discussion with the young person, family and/or assessing team, should estimate dietary intake before admission, with particular focus on carbohydrate and vitamin B intake in relation to re-feeding risk, and identify any self-restriction such as vegetarianism and veganism. In addition, history from family regarding normal eating patterns, including likes and dislikes before food restriction, makes meal planning easier.

The meal plan should ideally comprise solid food; if meals are not completed, the child/young person has the option to make up lost calories with nutritionally complete 2kcal/ml sip-feeds (Ensure® TwoCal, Fortisip® Compact). It is important that nutritionally complete supplements are used (i.e. not juice style or energy mixes) as these may form the predominant intake initially or be used to meet full nutritional requirements at the outset to avoid a nasogastric tube insertion. Dieticians should avoid adult supplements/feeds in younger patients and use age-appropriate paediatric supplements/feeds (e.g. 1.5kcal/ml feeds Fortini®, Paediasure® Plus and Frebini® Energy) during the early stages of re-feeding to help reduce the risk of the re-feeding syndrome. Using a fat-free supplement alone (e.g. Fortijuice®) is not advisable.

If the child is unable to meet the prescribed calorie intake within 24h of commencing the meal plan then a nasogastric tube insertion should be considered, balancing the level of risk and the wishes of the child and parents. Such a discussion may help to improve the child's cooperation in accepting either the normal diet or oral supplements. During the early stages of re-feeding, meal plans should ideally not exceed the recommended healthy eating guidelines of 50% carbohydrate total energy intake (TEI) to help reduce the risk of the re-feeding syndrome.

## *MANAGING DISORDERED EATING AND DRINKING ON THE PAEDIATRIC WARD*

### MEAL PLANS

Meal plans are often used and may need to be prepared for both food and fluids. The meal plan should be overseen by a paediatric dietician; ideally, someone with expertise in eating disorders. Wherever possible, the plan needs to be agreed with the young person, although their nutritional needs are paramount. It is important that a copy of the meal plan be held by both the staff and the young person (unless they prefer not to have one).

## SNACK TIMES AND MEAL TIMES

Observation at meal times (i.e. who is present at each snack and meal time and who has the responsibility for observation and documentation of the food and fluid that is consumed) and the length of snack and meal times (e.g. 15 minutes per snack and 30 minutes per meal) need to be agreed and documented. Any actions to be taken if a meal is not completed (e.g. a volume of bolus feed to be given instead of the completed meal) need to be agreed and documented in advance. Individual circumstances will help to dictate the exact needs of the young person and any assistance that may be needed with respect to helping them eat the required amount of food.

## NASOGASTRIC AND OTHER ROUTES OF FEEDING

The preferred option for re-feeding is oral food and fluids. Oral nutritional supplements can be helpful when food or fluids are being refused, and some young people need to be fed via a nasogastric tube, but neither of these should preclude food continuing to be offered. Some young people prefer nasogastric feeding because it relieves them of the responsibility of eating (Neiderman *et al*, 2001), but it also reduces opportunities to eat meals/snacks, and may occasionally be used for self-harm. Nasogastric feeding is usually a short-term measure, tailed off as oral intake improves. If supplemental drinks and/or nasogastric tube feeds are used, a prescription for them is required and should be arranged in liaison with a dietician.

Nasogastric feeds can be intermittent, bolus or continuous depending on the needs of the young person. Supplemental drinks or bolus nasogastric feeds need to be observed or closely monitored, even when given by pump feed. Many eating disorder specialists advocate day-time bolus feeds at mealtimes to mimic physiological demand and so that choice can be offered on each occasion ('Are you going to eat, drink or be fed this time?'). Night-time feeds are less helpful in anorexia nervosa than in many paediatric conditions, because patients often need to stay awake to monitor the feed and there is also a risk of aspiration of feed if the tube is dislodged. Continuous nasogastric feeds need to be closely monitored in the same way as for an intravenous infusion, for example hourly observations of the feed given.

Insertion of a nasogastric tube against the will of the young person usually requires the presence of mental health nurses trained in safe control and restraint techniques, and the use of an appropriate legal framework, but should not be avoided if feeding is necessary.

Other options such as percutaneous endoscopic gastrostomy (PEG) tube insertion may be considered in cases of severe or chronic anorexia, particularly when a rehabilitation approach is being taken, when the focus is on improving other areas of functioning.

## DOCUMENTATION

It is important that an accurate record of the food/drinks/supplements/tube feeds be kept by staff. If parents have some responsibility for this, the records need to be kept up to date by them as well.

## WEIGHING

Weighing in the same way and at the same time of day will help to minimise fluctuations in weight from non-nutritional reasons. This means weighing

on the same scales, in the morning before breakfast and after emptying the bladder, in underclothes only (bearing in mind that items can be hidden in these).

Water-loading that mimics weight gain needs to be considered. This may need restriction of access to fluids such as other patients' drinks, taps, toilets and showers. If there is ongoing concern, measurement of the specific gravity of the urine may be necessary when the individual is weighted.

Access to the ward scales may need to be restricted to decrease the likelihood of frequent weighing by the individual.

## RECOGNISING AND AVOIDING RE-FEEDING SYNDROME AND UNDERFEEDING SYNDROME

Sudden reversal of prolonged starvation by the reintroduction of food leads to a reciprocally sudden requirement for electrolytes involved in metabolising it, the so-called re-feeding syndrome. Phosphate levels can fall very rapidly within the first week of re-feeding, with neurological and cardiovascular consequences. Those most at risk of re-feeding syndrome are individuals with very low weight for height, minimal or no nutritional intake for more than a few (3–4) days, weight loss of over 15% in the past 3 months, and those with abnormal electrolytes before re-feeding.

Recognising and avoiding re-feeding syndrome is the most controversial area in both the Junior and the adult MARSIPAN reports. The tension lies between taking a cautious, 'safe' approach to re-feeding, based on the few cases of fatal re-feeding syndrome that have been recorded, *v.* the extensive clinical experience of re-feeding young people with eating disorders in hospital without incident, and a very realistic fear that an over-cautious approach can be counterproductive in an illness that welcomes any opportunity to minimise even very low intakes. We are aware of children with anorexia nervosa who have been admitted to paediatric wards because of medical instability, have been re-fed according to a careful re-feeding protocol, and lost a further 3–4kg as a result. This phenomenon, labelled 'under-feeding syndrome' in the adult MARSIPAN report, is as risky as overly aggressive re-feeding.

There are no evidence-based guidelines for the reintroduction of nutrition in children or adults with an eating disorder. There are suggested re-feeding guidelines that range from 10kcal/kg (NICE, 2006), 40kcal/kg (WHO, 1999), 45kcal/kg (Cape Town Metropole Paediatric Group, 2009) to 60kcal/kg (Afzal *et al*, 2002). Various formulae exist to calculate energy requirements based on the basal metabolic rate (BMR [Schofield Equation]) + activity factors (AF [1.1–1.3]), and some dieticians advocate aiming for 35–40% of calculated BMR (500–600kcal/day). Other clinicians take a much more pragmatic approach, starting at around 1000kcal and increasing carefully with close monitoring of electrolytes. Even this is cautious, given recent data on the impact of more aggressive re-feeding. Whitelaw *et al* (2010), in a sample of 29 adolescents with a mean body weight of 72.9%, found that, starting at 1900kcal or higher in the majority of the sample, 37% developed mild hypophosphataemia and no one developed moderate or severe hypophosphataemia. However, four adolescents were considered at a sufficiently high risk to start with lower regimes, or on rehydration alone, and percentage ideal body weight was significantly associated with the subsequent development of hypophosphataemia.

Together with the small literature on re-feeding syndrome (Appendix C) and our collective clinical experience, this suggests that for the majority of patients an overly cautious approach to re-feeding is not necessary, but close monitoring is required, and in patients at a very high risk a more careful approach may be needed.

Almost of greater importance than the starting energy intake is the rate of increase, because it is as a result of prolonged low intake that underfeeding occurs. Estimates on rate of increase also vary, but a common recommendation is to increase daily from baseline intake by 200kcal/day, dependent on biochemistry. If phosphate drops, then intake should remain static, not reduce, until it stabilises. Typically, blood tests are done daily during the at-risk period, usually days 2–5, in those who are being re-fed through a nasogastric tube or who have risk factors for re-feeding syndrome. In those with electrolyte disturbances the tests may need to be more frequent. Repeating after 7–10 days is recommended because of the risk of late re-feeding syndrome. For those who are orally re-fed without risk factors or who are being managed as out-patients 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 gain to begin in 5–7 days. If re-feeding is being undertaken at home or without access to dietetic guidance, a staged approach through portion size is advocated, starting at quarter portions, increasing to half portions, full portions, extra portions, etc. Once over the initial re-feeding period, usually after the first week, the meal plans should be altered to ensure continued weight gain of 0.5–1 kg a week. This requires relatively reliable weight measurement, which can be challenging given the propensity to falsify weights, and it is important that reliance on weights does not outweigh common sense. Weight is best monitored no more than twice a week, preferably before breakfast, after toilet and in underwear. Staff, parents and carers need to remain vigilant about food disposal, exercising, vomiting and water-loading, all of which can explain unexpected changes in weight. Weight trends are more important than individual weight measurements.

Although the risk of re-feeding syndrome is greatest in the first few days of re-feeding, the syndrome may develop later and biochemical monitoring should continue for a fortnight or until electrolyte parameters are stable (Ornstein *et al*, 2003).

Avoidance of re-feeding syndrome, which is insulin-mediated, can also be encouraged by restricting carbohydrate calories and increasing dietary phosphate. A diet that incorporates foods high in phosphate (e.g. milk) is helpful. If re-feeding by nasogastric feeds or nutritional supplements, those higher in concentration (e.g. 2 kcal/ml) have higher levels of carbohydrate and may therefore be more likely to produce re-feeding syndrome.

In adults, it is standard practice to prescribe thiamine replacement and a vitamin and mineral supplement. Practice with young people is more variable, and again the evidence base is limited. Prescribing a complete multivitamin and mineral supplement (e.g. Forceval®) is logical and carries minimal risk. Phosphate and magnesium supplements are necessary if the level of either falls significantly. For older adolescents, following adult guidelines on prescription of thiamine is justifiable. As there is no evidence to support any specific age when adult guidelines should be followed in adolescents, it is a judgement call of the clinician based on the developmental maturity of the patient.

**GUIDANCE 8** MANAGEMENT OF RE-FEEDING

- Starting intake should not be lower than intake before admission. For most young people starting at 20kcal/kg/day or higher, such as 1000kcal per day or quarter/half portions, appears to be safe. However, electrolytes and clinical state need careful monitoring and transfer to a paediatric unit may be required if, for example, phosphate falls to <0.4mmol/l.
- In the individuals who are at highest risk, and usually in paediatric rather than psychiatric settings, it may be necessary to use lower starting intakes (e.g. 5–10kcal/kg/day), especially in the presence of severity indicators such as ECG abnormalities or evidence of cardiac failure, electrolyte abnormalities before re-feeding starts, active comorbidities (such as diabetes or infections), or very low initial weight.
- If low initial calorie levels are used (5–10kcal/kg/day), clinical and biochemical review should be carried out twice daily at first, with calories increasing in steps unless there is a contraindication, and continuing to increase until weight gain is achieved. Low-calorie feeding should be discussed with an expert in clinical nutrition and a nutrition support team. Minor or even moderate abnormalities of liver function should not delay increased feeding.
- Re-feeding syndrome is most likely to occur in the first few days of re-feeding but may occur up to 2 weeks after. Biochemical monitoring should continue for a fortnight or until electrolyte parameters are stable.

ECG, electrocardiogram.

## ***BEHAVIOURAL MANAGEMENT OF CHILDREN AND YOUNG PEOPLE WITH EATING DISORDERS ON PAEDIATRIC WARDS***

It is the potential behavioural problems young people with eating disorders display that can cause greatest anxiety among those unfamiliar with managing them and increase risk if not predicted and managed appropriately. A core feature of anorexia nervosa is a drive for thinness; thus the presence of behaviours designed to lose weight confirm the diagnosis, rather than being a cause for alarm. Young people with anorexia nervosa will quickly realise if there are staff caring for them who do not understand this. 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 management of individuals with severe anorexia nervosa with good documentation of plans and any restrictions will help to maintain consistent care and help to avoid splitting between the young person, family and staff.

Common weight loss behaviours include compulsive exercising (such as running up and down stairs, standing, jiggling legs up and down when sitting, generally walking around, making an excessive number of trips back and forth between points on the ward, and secretive over-exercising (en-suite bathrooms are particularly well suited for this activity)); wearing few clothes in order to shiver to lose heat (energy); preventing attempts to feed properly (disposing of food, recruiting friends and family to dispose of food, turning off nasogastric feeds and drips or aspirating the nasogastric tube between bolus feeds); running away; vomiting in toilets or other



receptacles; becoming distressed or violent when specific requests (such as for a particular type of food or to be allowed to leave the ward) are not complied with. Falsifying weights is particularly to be expected if changes to meal plans are predicated on weight changes. Methods include drinking water before weighing (water-loading), hiding weights or other items in clothes (unless weighed in underwear only), and gripping the weighing machine with toes to increase weight.

Like parents, when staff discover a young person doing these or other things, it can be frustrating or even make them angry, particularly if they feel that they might be criticised as a result. However, the young person should be regarded as being under an irresistible compulsion and unless their mental state changes, unable to alter their behaviour without a lot of additional support. They may promise to stop, but are likely to break that promise. Staff in CAMHS units are used to managing these behaviours, especially if the patient is detained under the Mental Health Act. On paediatric units this can be more challenging, as the environment may not be suited to managing patients with challenging behaviours with, usually, inadequate staff numbers. As a result, young people who are already seriously ill are at even greater risk from behaviours that sabotage treatment.

These problems are not straightforward to deal with. Staff working on SEDBs use a number of strategies to address them, such as increasing staff numbers (special observations), agreeing a 'contract' with the patient, confining patients to areas that can be more easily observed, locking toilets and bedrooms during the day to prevent covert exercising and observing patients during therapeutic activities such as group therapy. Patients whose behaviour is not controlled by these measures may need to be under one-to-one supervision (occasionally a higher ratio is required) for 24 hours a day. This is also used for young people at risk of suicide. The most important factor contributing to the success of one-to-one observation is training and experience of the staff involved. A staff member, often from an agency, who knows neither the ward nor the issues encountered in individuals with eating disorders is unlikely to be successful in preventing a patient from engaging in the behaviours discussed here. This is an area where close collaboration between paediatric and psychiatric colleagues is essential.

An additional factor to be considered in young people with anorexia nervosa is the role of parents in managing these behaviours. Again, this is not straightforward: sometimes parents can be best at helping their child 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 young person craves this additional support and increases the behaviours to get more; and sometimes parents can be inflammatory to the situation, which can result in a greater risk of, for example, absconding or attempts to sabotage 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 parents in management of the behavioural aspects of a young person's anorexia nervosa should be made in the context of multidisciplinary meetings with senior staff responsible for the young person's care (p. 40).

The more common behaviours that need consideration are the following.

- 1 *Exercise/activity.* Total bed rest may be indicated if the young person is severely unwell, although this is only exceptionally needed. Some degree of gentle activity (watching TV with others, reading a book or

doing some crafts) can help reduce distress without any additional risk. However, it is important to keep the patient warm and supervised. Arrangements for toileting and washing will need to be considered and any observation required – supervised bath or shower, unlocked bathroom or toilet doors but with provisions for privacy – needs to be explained, documented and maintained with consistency. Restriction of excessive activity and explanation of what is possible may be required.

If a child is expected to bed rest it is absolutely essential that a programme of therapeutic, distracting, low mentally effortful activity is provided. Enforced bed rest is extremely distressing for young people with anorexia nervosa unless they are robustly supported.

- 2 *Purging or other methods of avoiding weight gain.* 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. Aspirating stomach contents via nasogastric tubes is aided by availability of syringes on the ward, for example from the crash trolley, which may be in a readily accessible place on the ward, from treatment room if it has easy access, or if staff inadvertently leave syringes by the bed. Laxative misuse requires a supply of laxatives which may be more difficult in hospital but nevertheless requires vigilance.
- 3 *Bingeing.* Although less common in young people than adults, bingeing is still possible and nursing staff need to be aware of this possibility. Clearly, a supply of food is required and this may be more 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.
- 4 *Self-harm.* An assessment by the psychiatry team is required if there is any concern about the risk of self-harm, actual self-harm or suicidal ideation. This would lead to a risk assessment and any further steps that may be required to manage this risk need to be considered and agreed.
- 5 *Comorbid psychiatric conditions.* It is not uncommon for individuals with anorexia nervosa to have other psychiatric conditions such as OCD or anxiety. In these situations, advice about specific management is required from the psychiatry staff.

On occasions, young people can become severely distressed, particularly about the prospect of eating or being fed. This may be at a level beyond that usually experienced by paediatric staff in many other situations. In this situation, psychiatric advice needs to be sought; specific psychiatric nursing may be needed and medication may be indicated.

- 6 *Management of violent and other disturbed behaviour.* It is good practice for paediatric units to have their own policies for the management of violent or otherwise disturbed behaviour. 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 paediatric ward, presuming that this is still necessary. If physical restraint is needed,

it is important that it is undertaken by individuals who are specifically trained in this area. In practice, these are most likely to be psychiatric staff, and appropriate arrangements will need to be made to ensure this.

**GUIDANCE 9** BEHAVIOURAL MANAGEMENT OF EATING DISORDERS IN A PAEDIATRIC SETTING

- If weight gain is less than expected (>0.5–1.0 kg/week), assume weight-losing behaviours. These are an inevitable part of the illness, and punitive responses should be avoided. If sudden significant changes in weight are observed (e.g. 2 kg within a few days), assume water-loading and other fluid manipulations.
- Early in the admission, schedule a meeting of key staff responsible for treatment, namely the paediatrician, paediatric nursing staff, child and adolescent eating disorders psychiatrist or liaison psychiatrist, other CAMHS staff involved in paediatric liaison or eating disorders care, to decide how to achieve treatment aims. Document the meeting clearly in the notes. Involve (usually) the parents and (usually) the young person in discussions about the treatment plan. If parents or the young person are not involved (e.g. too unwell to attend), document the reasons for this.
- Establish the level of nursing supervision needed and the level of parental care possible or appropriate. When possible, employ a nurse from the specialised eating disorder service to supervise and train nurses caring for these patients.
- Write a management plan to be transferred between nurses with proper handover from one shift to another.
- Schedule regular review meetings of key staff, preferably with parents and the young person involved, to ensure treatment goals are met or revised if needed.
- Be prepared to use the Children Act and/or the Mental Health Act if necessary.

CAMHS, child and adolescent mental health service.

## FAMILIES

Families do not cause eating disorders, and an assumption that family involvement is unhelpful should not be made prematurely. Parental anxiety is often valid, and is all too often the only reason that a young person has reached care. Furthermore, parents are often the only source of comfort to a severely ill child or young person, who may be very frightened despite their denial and seemingly self-destructive behaviour. By the time a 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. Anorexia nervosa organises the behaviour of others, such that family members do things that seem as unusual as the patient's own behaviour (e.g. driving to a particular shop at midnight to get one particular type of food). In younger patients with anorexia nervosa (typically boys (in whom puberty occurs later) or girls before menarche), separation anxiety is also a common feature.

On the other hand, it can be obvious to staff observing how the young patient and their family interact that the patient is unlikely to change their eating behaviour unless the responses of those around them also change. A non-judgemental attitude is essential if professionals are to work effectively with parents in helping young people recover.

## PARENTS

Parents are best considered partners in the process of recovery, and 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, by virtue of their emotional distance and training. This is not evidence of parental inadequacy. Trials of transfer of responsibility for feeding to parents or to the young person should be made as soon as possible, since this will determine the length of in-patient stay and level of ongoing treatment need. 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 who they need the support from.

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. However, the needs of the parent have to be balanced against the needs of the young person. Given that an admission for anorexia nervosa is often much longer than for other illnesses and that in time this may prove exhausting for parents, 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 their time on the ward may be a relief to parents. In other situations, a therapeutic limitation of visiting (as part of the management plan) may be advisable. Individual circumstances will need to be considered with respect to the presence or absence of parents at meal times.

## SIBLINGS

In most paediatric units there is no limitation on siblings visiting, although there may be restrictions in numbers visiting at any one time. Although the situation with anorexia nervosa is usually the same, the individual circumstances will dictate any restrictions on length and timing of visits, especially at meal times.

Vigilance is needed to ensure that siblings do not get drawn into parenting roles.

## OTHER VISITORS

Local practices and individual circumstances will vary and will dictate visiting with respect to other visitors, including extended family and friends.

## *CRITERIA FOR DISCHARGE FROM PAEDIATRIC IN-PATIENT ADMISSION*

Ideally, patients should be discharged from the paediatric ward as soon as the reasons for admission have been addressed and their physical health is robust enough for safe discharge. However, the timing and placement after discharge require careful consideration of the individual's needs and should not be influenced by factors such as the availability of acute paediatric beds. Discharge should be planned and agreed, and a precipitous discharge avoided. Discharge planning involves multidisciplinary discussion at senior level, including both the paediatrician and psychiatrist in charge, and other

relevant personnel such as those in charge of an SEDB if required. It is important that discharge planning is started as soon after admission as possible to avoid unnecessary delays.

A patient may be discharged to an SEDB or the community. This decision should be made after considering a number of factors:

- the original rationale for admission and whether this has been resolved
- the current physical health and any continuing medical requirements
- nutritional status, method of feeding and monitoring
- mental health and specific requirements, whether an SEDB is required
- whether the young person is subject to compulsory treatment and admission
- the family's and individual's needs, circumstances and preferences.

We suggest that the young person not be discharged while they still meet the criteria for being severely unwell and at high risk, until a percentage median BMI of at least 70% is reached, an adequate rate of weight gain is established if the person is discharged to the community (in particular that cardiovascular parameters are satisfactory; see pp. 20–21) and that there are no other medical issues that require paediatric admission. The need for nasogastric tube feeding itself should not be a reason to maintain a paediatric admission rather than an SEDB. As per Guidance 3 (p. 29), the use of nasogastric feeding should be a core skill of units with SEDBs, although it is recognised that some support from paediatric staff may be required if individuals are on a generic CAMHS unit. The dangers of re-feeding should have passed or there should be adequate and safe provision for the monitoring and management of re-feeding syndrome if discharged from a paediatric setting to an SEDB or equivalent.

If an SEDB is deemed necessary after discharge from paediatric care, it may not be available immediately. In these circumstances, it is likely that the individual will remain on a paediatric ward pending transfer; all the advice in this report regarding points to consider in an in-patient paediatric setting should then be taken into consideration and care continued until transfer is possible.

It is advised that transfer and discharge arrangements be agreed and documented. At the point of discharge appropriate documents and any follow-up arrangements should be available to the receiving health professionals and family (see Guidance 4, p. 31).

### *THE ROLE OF COMMISSIONERS IN SUPPORTING PAEDIATRIC/MEDICAL IN-PATIENT SERVICES FOR VERY SICK YOUNG PATIENTS WITH ANOREXIA NERVOSA*

Children and adolescents who have eating disorders and who have significant physical health needs should be cared for in environments that have designated facilities to provide both physical and psychiatric care. Most psychiatric beds for children and adolescents are in generic adolescent units. Often these units also function as acute admission services for children with a severe mental illness, or have diverse roles (providing a 'psychosis' service) and can be functionally disconnected from tier 3 services. Children with anorexia nervosa who need paediatric care may need to be admitted to acute paediatric beds, often in very busy general hospitals, and be cared

**GUIDANCE 10** DISCHARGE FROM THE PAEDIATRIC WARD

- Criterion for transfer: physically stable with clinical problems that can be safely managed in an SEDB or the community.
- The decision about discharge should only be made after multidisciplinary discussion at senior level, and should be based on the clinical needs of the patient.
- Discharge planning should begin as soon as practicable after admission and the criteria for discharge agreed.
- The young patient should no longer be severely physically ill (as defined and discussed at length on pp. 16–26). Any physical health reasons for paediatric admission should have been resolved or can be safely managed elsewhere. It is not sufficient to have just addressed the physical factor that required admission, for example hypoglycaemia.
- A full multidisciplinary assessment of physical, nutritional and mental health needs must have been undertaken and a plan agreed to meet all needs after discharge.
- Transfer to an SEDB should be possible if nasogastric tube feeding is still required but the individual is otherwise medically stable. Regular dietetic review will be needed, and it is accepted that paediatric nursing support may be required to re-site nasogastric tubes.
- Where the criterion for discharge to an SEDB is met but an SEDB is not immediately available, a continuing multidisciplinary plan for care must be agreed and implemented, with consideration of the same factors as advised earlier (pp. 36–37) until transfer is possible, with regular multidisciplinary meetings to assess risk, review progress and plan care accordingly.
- Full documentation and plans for post-discharge care are required at the point of discharge with definite plans in place to address needs.
- All transitions are potentially moments of increased risk.

SEDB, specialist eating disorder bed.

for by paediatric teams who have relatively little expertise in managing such patients. It is therefore recommended that commissioners require their local providers to develop strategies that can be agreed and appropriately commissioned and that certain services are established. The measures to be taken are as follows.

- 1 A 'top-down' approach to ensuring that each region specifies the location of SEDBs if these do not already exist. (It is important to balance the need for highly specialised services against the need for having appropriate treatment close to home.)
- 2 A clear view as to whether SEDBs will be co-located in units that accept emergency admissions of acutely disturbed adolescents with other mental disorders or whether a unit in a region that does not take emergencies will be identified as the location of SEDBs. However, it is important to ensure that if the only resource is a bed in a unit that does not take emergencies, alternative arrangements are in place for the timely admission of young people with severe anorexia nervosa (e.g. an identified paediatric ward).
- 3 When the locations of SEDBs are identified, commissioners should ensure the establishment of links with an identified paediatric colleague/colleagues with an interest in eating disorders and expertise in all or some of the following areas:

- paediatric gastroenterology and nutrition, including complexities and challenges of nasogastric feeding
- paediatric dietetics
- paediatric clinical chemistry
- paediatric endocrinology and metabolic medicine.

Funding appropriate mental health nursing supervision on paediatric wards when necessary is also an important consideration for commissioners. Furthermore, commissioners should consider care pathways to ensure appropriate transition between services.

A 'Junior MARSIPAN' group (child and adolescent psychiatrist, paediatrician, paediatric dietician, paediatric and psychiatric/eating disorders nurses) would act as a focus for skills development and dissemination, advise when a child with severe anorexia nervosa is admitted to a paediatric bed, and be located in a hospital that is able to admit such patients. In some areas it might be more practical to identify a local/subregional consultant with a special interest.

- 4 The 'Junior MARSIPAN' team should have explicit links with tier 4 child and adolescent eating disorders services, who will work in conjunction with tier 3 CAMHS.

It is difficult to estimate how many SEDBs should be available nationally, and the need might vary depending on local eating disorders services. We appreciate that not all acute hospital trusts will be able to reach the level of provision we recommend, and suggest that one or two hospitals be identified within each strategic health authority (average population in England 5 million), so that patients can be transferred if required.

## *DECISION-MAKING*

It is important to have good communication among the multidisciplinary team, and with young people and their families, to ensure consistency of decision-making and that roles and responsibilities are understood within the decision-making process. This avoids misunderstandings and the potential for splitting. Full consideration of the physical, nutritional, behavioural, mental health and social aspects of the presenting problem will help to make sure that important information is not overlooked. How decisions are agreed may vary depending on the severity of the illness and the setting of the care. It is vital that senior clinicians be directly involved but it is equally important to recognise the validity of viewpoints of all members of the multidisciplinary team. The resolution of any differences which may arise within the team can be helpful in modelling communication with the family. Once essential decisions are made it is important that they are documented, circulated and implemented as agreed.

Whenever possible, it is advisable that parents and young people be involved in decision-making. An 'It was decided in the ward round that...' approach can be counterproductive in securing cooperation. Even when young people do not have the capacity to make decisions for themselves, hearing how the decision was reached and having had an opportunity to voice objections, even if they are subsequently overruled, can be helpful in itself. Parents should be central to decision-making, provided they have the necessary information to do so. This sets the scene for the collaborative family work advocated for managing anorexia nervosa in young people.

## DOCUMENTATION

It is imperative that good, detailed and comprehensive documentation be maintained throughout an admission to a paediatric ward. We would recommend that specific nursing care plans be developed for such individuals. There should be good documentation of all decisions about care; these should be shared with the young person and family and relevant documentation given to them as necessary. If a meal plan is followed, it should be kept up to date and shared with the young person and family; a copy should be available for the nursing team and other staff to refer to. A record of any multidisciplinary meetings should be shared with all staff and copies distributed to the family and the young person.

Attention to all of the above will help to decrease the discussions that are needed regarding management, provide a framework for all to work within and help to contain difficult behaviour in many circumstances.

## MANAGEMENT IN SEDBs

### *MEDICAL EXPERTISE IN THE SEDB ADMITTING YOUNG PEOPLE WITH SEVERE ANOREXIA NERVOSA*

There are fewer SEDUs for young people (less than 18 years) than for adults. The majority (currently around 80%) of specialist beds are in the private sector. Approximately 60% of young people with severe eating disorders are managed on general adolescent units (GAUs), and the other 40% are treated on SEDUs. There are no data comparing specialist and non-specialist units in terms of the medical facilities available for young people with severe anorexia nervosa and patient safety and outcome, although SEDUs do achieve weight gain faster (Davies & Jaffa, 2005). As the majority of young people continue to receive treatment on GAUs, it is important that the same level of medical care can be provided in both settings. Many GAUs signal their special expertise by identifying SEDBs, and commissioners should consult this report regarding the necessary resources needed on such units. In this section of the report, an 'SEDB' is considered as being provided by either an SEDU or a GAU with certain provisos on the latter.

Medical, nursing and dietetic staff for SEDBs have a responsibility to gain and maintain the appropriate level of knowledge of nutritional problems in young people and of their treatment. For doctors this means medical knowledge at a level higher than is usually encountered or required in general child and adolescent psychiatry.

Consultants for SEDBs should, as part of their postgraduate training, attend a course in clinical nutrition, such as the Intercollegiate Course on Human Nutrition run by the Intercollegiate Group on Nutrition or the RCPCH nutrition course. Areas of expertise should include assessment of nutritional state, clinical risk, prevention and treatment of re-feeding syndrome and management of oral and nasogastric feeding.

Because of the difficulty of addressing behavioural and psychological problems on acute paediatric/medical wards, most patients should be treated in an SEDB unless services required for their management are not available. For some units, this means that more medically ill patients than before will be treated in an SEDB and medical expertise may therefore need to be at a higher level. Some units may decide that they do not wish to



specialise in this patient population if they cannot achieve this. It is essential that SEDBs develop an agreed protocol for patient transfer to an identified paediatric/medical ward if necessary, for example to evaluate potentially serious symptoms. However, they should be returned to the SEDB as soon as possible as long as the medical services they require are available there.

### *DEDICATED SEDB PAEDIATRICIAN*

To maximise medical expertise in SEDB caring for young people with severe anorexia nervosa, we recommend that a specific consultant paediatrician, preferably with an interest in nutrition, be identified as a link. Ideally, a regular commitment should be negotiated between provider organisations. The paediatrician would have the role of advisor to the SEDB staff, and be available for teaching and discussion as well as consultation about individual patients. They should be available to discuss abnormal results, and to supervise and teach on-call doctors who may be placed in the position of advising the SEDB staff.

### *CRITERIA FOR TRANSFER TO A PAEDIATRIC/MEDICAL UNIT*

Patients who do not require the specialist expertise and equipment available on paediatric/medical units should in general be transferred back to the SEDB. The decisions will need to be taken with reference to local provision as well as the clinical state of the patient. Facilities that should be provided in SEDBs are listed in Guidance 11 (p. 58).

### *PRACTICAL CONSIDERATIONS*

Medically compromised patients may require some modifications to standard ward furniture and equipment: special beds (e.g. with a ripple mattress, facilities for raising foot and head), drip stands, at least for nasogastric feeding, special flooring (e.g. to protect against spilt feed) and similar alterations.

### *SEDATION OF RESISTING OR AGITATED PATIENTS*

Most young people with severe anorexia nervosa recognise that they need re-feeding following hospital admission. Even if they are highly anxious, they usually accept support and reassurance from adults during weight restoration. However, a small proportion of young people actively resists re-feeding and does not respond to verbal approaches. Under these circumstances, clinicians have to make the difficult choice between physical restraint and sedation. There are no clinical trials evaluating emergency sedation in severe anorexia nervosa in young people. The adult MARSIPAN group carried out a small survey in adult specialist eating disorder units. The majority of them reported using oral and parenteral benzodiazepines and oral olanzapine. Olanzapine has been reported to be helpful in a number of small trials and case series in young people (Powers *et al*, 2002; Malina *et al*, 2003; Dunican & DelDotto, 2007; Bissada *et al*, 2008). Gowers *et al* (2010), in a retrospective case-note study, found that 27% of 308 children and adolescents with an eating disorder (both in-patients and out-patients) in seven specialist CAMHS in England received psychotropic medications,

most commonly antidepressants, olanzapine and benzodiazepines. Although side-effects were relatively common, they were usually mild. These medications were not being used solely for emergency sedation, and the study does suggest clinical experience with similar medications to those used in adults. In the absence of clinical trials in profoundly malnourished patients, clinicians should use the lowest doses possible because of the risk of physical complications, especially hypotension, respiratory arrest or extended QTc interval increasing risk of arrhythmia. Frequent monitoring of side-effects is essential.

### *ADDITIONAL NURSING SUPPORT*

The key determinant regarding funding of additional nursing support is the primary need of the child. However, if a young person is in a generic CAMHS unit and needs additional support to assist with the management of behaviours associated with an eating disorder, consideration should be given as to whether that young person might be better placed in an SEDB.

Children need additional nursing support for a mixture of reasons. All managers will agree to support additional funding if someone else picks up the tab. However, the costs can be very high, some patients requiring long-term one-to-one or sometimes two-to-one nursing. Given that this is a relatively uncommon and potentially life-threatening situation that involves two or three services, it would be reasonable to ask the primary care trust or other funding body to pay for the extra costs involved and for health providers to be explicit about what they are providing, rather than leaving it to one service to cope with a substantial cost. Ideally, a limited number of paediatric services with clear care planning arrangements and good links with SEDBs in each area would assist with this. In these circumstances arrangements would be negotiated locally, within an agreed financial protocol, shared and subject to quantitative and qualitative scrutiny.

### *AREAS WITH LIMITED LOCAL EATING DISORDER PROVISION*

#### RESPONSIBILITIES OF HEALTH COMMISSIONERS

The Royal College of Psychiatrists' (2001) report on eating disorders made recommendations on provision of eating disorders services for adults, but no specific College recommendations for children and adolescents currently exist. The report is currently under revision, and includes a survey of eating disorders provision in all CAMHS in the UK. In the absence of specific recommendations on provision, we urge all service purchasers to ensure as soon as possible that young people living in their area have access to age-appropriate specialist eating disorders services, with appropriately trained staff, including both in-patient and out-patient provision. Specific consideration should be given to the needs of those first presenting at age 17, shortly before transition to adult services, for whom links with adult services may be appropriate from early on. For children with anorexia nervosa as young as 8–11 years regional or national provision may be needed.

In addition, each area needs adequate liaison services that can support the care of young people with eating disorders in paediatric settings, providing appropriate expertise in relation to psychiatric and legal aspects of care.

## RESPONSIBILITIES OF LOCAL PROVIDERS

Lack of accessible specialist eating disorders provision is a substantial problem for sparsely populated areas, for those separated from the mainland, as well as those far from the nearest SEDB. In line with adult MARSIPAN report recommendations, we support the following principles of service provision.

- 1 Identify a local child and adolescent psychiatrist with training in, or willing to be trained in, eating disorders and a local paediatrician with training in, or willing to be trained in, nutrition. They should be joined by a dietician and a nurse to form a local 'Junior MARSIPAN' group, and be supported by the local specialist service.
- 2 This group should develop a local policy on severely ill children and young people with anorexia nervosa, to include identification, resuscitation and preparation for transfer to a suitable treatment setting with an SEBD.
- 3 In the case of urgent treatment needing to be provided locally, for instance in a paediatric ward, eating disorders expertise should be sought to provide guidance and staff support, and arrangements made for specialist eating disorders support to be provided on site where possible. Many specialist eating disorders services see this type of outreach as part of their role.

### **GUIDANCE 11** SERVICES PROVIDED BY SEDBS

- Safe re-feeding, including access to dietetic advice
- Expertise in nasogastric feeding (insertions may be performed off site)
- Blood pressure, pulse, temperature, and serum glucose monitoring up to 4-hourly
- Daily biochemistry
- ECGs, daily if needed
- Timely access to medical staff during and out of hours
- Assessment of tissue viability in emaciated patients and treatment of pressure sores
- Immediate cardiac resuscitation with staff trained to administer resuscitation
- Access to advice from paediatricians and paediatric dieticians in a timely and flexibly responsive manner, ideally in the form of a 'Junior MARSIPAN' group
- Frequent nursing observations, up to and including one-to-one observation when indicated
- Prevention of anorexic behaviours such as water-loading, excessive exercising
- Management of the resisting child, including safe holding techniques and the acute and medium-term paediatric psychopharmacology of children with eating disorders
- Use and management of the Mental Health Act, expertise with the Mental Capacity Act with respect to 16- to 17-year-olds, and the Children Act for children under 16 years
- Psychological interventions for the young person and the family
- Age-appropriate educational provision.

ECG, electrocardiogram; SEDB, specialist eating disorders bed.

## AUDIT AND REVIEW

### *CASE REPORTING*

We support the introduction of a case reporting system for seriously ill patients with anorexia nervosa, as advocated by the MARSIPAN report.

The Royal College of Psychiatrists and BEAT wish to collate information on all deaths from eating disorders so that the maximum possible can be learnt from these tragic events. The contact for this information is Dr John Morgan ([john.morgan@leedspft.nhs.uk](mailto:john.morgan@leedspft.nhs.uk)). All clinicians are urged to provide information as many cases are missed because the eating disorder may not be cited on a death certificate.

In addition, the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) and child death review systems record details of deaths of children and adolescents. In future, the RCPCH will have the ability to select specific groups of patients for investigation through the NCEPOD system, and we recommend that those with eating disorders are selected for such a review.

### *QUALITY REVIEW OF SERVICES*

The Royal College of Psychiatrists is working to establish a nationwide Quality Assurance Network for Eating Disorders in which both in-patient and out-patient eating disorders services will be assessed for quality of service provision. The medical care of patients seen in CAMHS will be included; it may be possible to include paediatric services where a considerable number of children and young people with eating disorders are seen. For more information, go to the College's website ([www.rcpsych.ac.uk/rollofhonour/sections/eatingdisorders/qualityassurancefored.aspx](http://www.rcpsych.ac.uk/rollofhonour/sections/eatingdisorders/qualityassurancefored.aspx)).

### *LOCAL GOVERNANCE*

Each paediatric and eating disorders service must monitor quality of provision for management of severely ill children and young people with anorexia nervosa. A clear policy should be generated jointly and made available in each setting. Any serious or near-miss incident should be investigated jointly and a report issued that would highlight changes in psychiatric or paediatric services or in liaison which should take place. Such recommendations should be followed up within a reasonable time frame, for example 3–6 months, to ensure that the changes have occurred.

# Appendix A. Calculating the degree of underweight for females: comparison of two methods

**Table A.1 Calculating the degree of underweight for young females: comparison of two methods**

<i>Age, years</i>	<i>Median height, cm<sup>a</sup></i>	<i>Weight, kg</i>	<i>BMI, kg/m<sup>2</sup></i>	<i>Median BMI for age and gender, %<sup>b</sup></i>	<i>Weight for height, %<sup>c</sup></i>
10	138	32.5	17.1	101.6	100.5
		30.0	15.8	93.8	92.7
		27.5	14.4	85.7	85.0
		25.0	13.1	78.1	77.3
		22.5	11.8	70.3	69.5
12	149	40.0	18.0	99.4	100.6
		35.0	15.8	87.3	88.0
		30.0	13.5	74.6	75.4
		27.5	12.4	68.5	69.2
		25.0	11.3	62.4	62.9
14	159	50.0	19.8	102.1	103.7
		45.0	17.8	91.8	93.3
		40.0	15.8	81.4	82.9
		35.0	13.8	71.1	72.6
		30.0	11.9	61.3	62.2
16	163	55.0	20.7	101.5	97.6
		50.0	18.8	92.2	88.7
		45.0	16.9	82.8	79.9
		40.0	15.1	74.0	71.0
		35.0	13.2	64.7	62.1

a. Median heights for girls as per the UK-WHO growth charts ([www.growthcharts.rcpch.ac.uk](http://www.growthcharts.rcpch.ac.uk)), incorporating cross-sectional stature and weight reference curves for the UK 1990 (Freeman, *et al*).

b. Calculated for girls as per the UK-WHO growth charts, using the formula: % BMI = (actual BMI / median BMI for age and gender) × 100.

c. From WHO/National Center for Health Statistics normalised reference weight-for-height for adolescents, using the formula: % weight for height = (child's weight/reference weight for child of the same height) × 100 ([www.motherchildnutrition.org/malnutrition-management](http://www.motherchildnutrition.org/malnutrition-management)).

# Appendix B. Comments from general practitioners and parents/carers group

These comments are from a survey conducted by Dr F. Verhoeff in Liverpool.

## COMMENTS FROM GENERAL PRACTITIONERS (GPs)

- 'Rare disorder, [which is why GPs] lack experience [in managing it]'
- 'Not sure where 16- to 19-year-olds should go'
- 'Difficult to make diagnosis: guidance for this required'
- 'Unclear who to refer, when to refer and who to refer to'
- 'No lack of services but generally much time delay: if family attends (general practice), and young person wants help, you can't afford to wait a month'
- 'Unclear who is responsible for what (GP, psychiatrist, paediatrician, etc.)'
- 'What to do when [the patient] does not want any help?'
- 'When to be concerned?'
- 'What investigations should be done?'
- 'Patient may [be seen by a] practice nurse who may not recognise an underlying eating disorder and just refers to a dietician. Simple tools required for other healthcare workers to recognise eating disorder.'

## COMMENTS FROM PARENTS

- 'No specialist support. Nursing staff do not seem to understand the condition at all, usually just trying to persuade the patient to eat an unrealistically large meal.'
- 'Specialist nutritional advice, meals and guidance are not usually provided when a child is an in-patient, usually on a children's ward and offered the same meals as other children.'

- 'What additional support is available if intervention offered doesn't work?'
- 'Availability of support, e.g. weekends, evenings after 5pm.'
- 'Generally, there seems to be a lack of consistency in support offered by CAHMS, staff inconsistency, sickness, staff unavailability.'
- 'Lack of resources (leaflets/advice, etc.) to support patient/carers.'
- 'More feedback from health professionals, and more practical help would be useful.'
- 'Education of nursing staff (meals/psychological intervention/not discussing the patient in front of them during handovers).'
- 'Lack of availability of beds with specialist care.'
- 'What happens when a child reaches age 16, there does not seem to be a seamless handover.'
- 'Patient confidentiality at age 16 is a huge problem, and means that parents/carers are not included in care plan.'
- 'Full involvement of parents in care plan, so that they know how best to support the child.'
- 'Feelings of isolation and lack of understanding.'
- 'Lack of education and information for parents/carers/patients/siblings.'

# Appendix C. Re-feeding syndrome in children and adolescents: literature summary

Articles that reported symptoms associated with the re-feeding syndrome (hypophosphataemia, hypotension, oedema and cardiac arrhythmias) following enteral nutrition in children or adolescents with anorexia nervosa are shown in Table C.1. In all of the 24 reported cases of the syndrome identified in the literature search, feeding was commenced well below the upper suggested rate of 40–60kcal/kg; the range of calorie intake during re-feeding was 16–40kcal/kg, with a mean starting rate of 27kcal/kg.

At present, there is no scientific basis to recommend re-feeding at 10–60kcal/kg. These figures are based on 25–75% of total energy intake (TEI) and regardless of how cautious a re-feeding is commenced, individuals at high risk could still develop the re-feeding syndrome. More research is needed in this area.

**Table C.1 Clinical findings from a literature review looking at re-feeding syndrome in children and adolescents with anorexia nervosa**

<i>Author</i>	<i>Age, years</i>	<i>Height/weight, %</i>	<i>Initial feed rate, kcal/day</i>	<i>Initial feed rate, kcal/kg</i>	<i>Feed type and route</i>	<i>Re-feeding syndrome symptoms</i>
Kohn <i>et al</i> , 1998	12	61	500	16	Polymeric feed, NGT	Bradycardia, hypotension, hypophosphataemia
	13	70	1200	36	Solid food oral intake	Hypotension, delirium, hypophosphataemia
	19	62	1000	27	Solid food oral intake	Oedema, bradycardia, delirium
Fisher <i>et al</i> , 2000	16	50	1000	40	Solid food oral intake	Hypophosphataemia, hypotension, bradycardia
Ornstein <i>et al</i> , 2003 (19 cases)	Mean 16.65	Mean 68	Mean 1645	Mean 22	Polymeric feed, NGT	Hypophosphataemia
O'Connor & Goldin, 2011	10	67	600	40	NGT	Hypophosphataemia, cardiac arrhythmia

NGT, nasogastric tube.



# Appendix D. Some cases reported to the Junior MARSIPAN group

## CASE 1. TRANSFER FROM INDEPENDENT SECTOR SEDU TO NHS ADULT SERVICES

A 17-year-old patient with a restrictive type of anorexia and comorbid depression was treated on a specialist adolescent unit for 7 months. She was discharged at 88% weight for height ratio (BMI 18.7) because she refused to complete her weight restoration treatment. There was a high risk of relapse and a need for psychiatric monitoring was identified on discharge.

The patient was offered out-patient services by the local adult eating disorder team, led by psychologists, but there was no psychiatric involvement, despite the clear recommendation from the private unit in which she was originally treated. The treatment approach was based on the individual responsibility of the patient, in contrast to the strong family approach of the CAMHS SEDU. The patient disengaged from the out-patient service, and was discharged owing to lack of engagement. The mother tried to contact her key-worker, but was turned away on the basis of patient confidentiality. Eventually, when the patient fainted as a result of malnutrition, she was admitted to the local medical ward through an accident and emergency department. As she did not cooperate with re-feeding, she was detained there, and nasogastric feeding was started against her will, while waiting for a SEDU admission. However, her behaviour could not be managed by the nursing staff of the medical ward, and she emptied her nasogastric feed into the sink in her bedroom. The commissioners tried to find the cheapest private in-patient unit. The cheapest one asked for medical stabilisation before transfer to them. After a few days of this negotiation, the patient collapsed and died on the medical ward.

### *ISSUES*

- 1 Trust and cooperation between the NHS and the private sector.
- 2 Differences of approach between CAMHS and adult services.
- 3 Taking carer's concerns seriously.
- 4 Discharge of a deteriorating patient because of non-attendance.
- 5 Nursing supervision on the medical ward.
- 6 The role of commissioners.

## CASE 2. TRANSFER BETWEEN MEDICAL AND PSYCHIATRIC UNITS – WHO IS IN CHARGE?

A 16-year-old patient was admitted to a medical ward with a 6 months' history of restrictive anorexia, low blood pressure, low blood sugar levels, low temperature, acrocyanosis, and occasional tachycardia in the context of bradycardia. Her dietary intake had been less than 500kcal/day for the past 8–10 weeks. A referral to the local tier 4 CAMH unit was made, but there was no immediate bed availability. The situation was explained to the tier 3 clinicians, who asked for further medical treatment in the general hospital. The medical ward felt that this was an inappropriate request, but reluctantly agreed to manage the patient until a bed became available. They recommended nasogastric feeding, as the patient was refusing to eat on the ward and her dietary intake had reduced to about 200–300kcal/day. The community CAMHS consultant felt that nasogastric feeding was not indicated as the patient still had a BMI of 14, and she was waiting for a tier 4 bed, where she would be 'sorted out'. The patient lost a further 2 kg on the medical ward in a week and eventually had to be transferred to a SEDU as an emergency, where nasogastric feeding was started.

### *ISSUE*

- 1 Nobody is in charge of the medical management of the case – 'somebody else's responsibility'.

## CASE 3. NO SPECIALIST ON FRIDAY

A 15-year-old boy was transferred from a paediatric ward to a private SEDU with a history of severe anorexia nervosa. On admission, it turned out that in hospital his dietary intake had fallen to 200–300kcal/day, and during the first night on the SEDU, his pulse dropped to 32 bpm and his blood sugar levels dropped to 2.1. He was transferred to the local NHS medical assessment unit as it was felt that he was too unwell to be managed on a site where resuscitation was not possible. On admission to the unit (Friday), the SEDU team were told that nothing could be done to help because the consultant responsible for re-feeding was away and there was no dietician input until Monday (3 days). The SEDU staff were able to implement a gradual re-feeding programme (starting with 1000kcal/day) on the medical unit in secret, behind the curtains, as this was against the unit staff's recommendation. The patient was returned to the SEDU 2 days later, as the safer option. He lived to tell the tale.

### *ISSUES*

- 1 False reassurance before the transfer from the paediatric unit.
- 2 Co-working between a private SEDU and an NHS medical assessment unit (lack of protocols).
- 3 'Not my problem' attitude.

## CASE 4. NOBODY'S PATIENT

A 16-year-old girl with chronic anorexia nervosa, under the care of a CAMHS out-patient team, became medically unstable owing to weight loss. She was eventually admitted to a paediatric ward, pending further discussion of her treatment needs. The specialist out-patient team, which covered a large geographic area, was unable to offer input to the ward. The local CAMHS team were not involved in her care, and did not have a liaison service. The paediatrician said that he did not want to be responsible for her, as this was not within his expertise. As a result, she lost a significant amount of weight during the first week of admission. Eventually, the local adult eating disorders service offered dietetic input on the ward in relation to re-feeding, but did not involve her parents, and did not want to become involved therapeutically while she was under the care of another team. By the end of this admission she was no longer well enough to be managed as an out-patient, and was transferred to an SEDB.

### *ISSUES*

- 1 Nobody's patient, unclear responsibilities medico-legally.
- 2 Poor and unfocused paediatric care influencing the course of treatment.

## CASE 5. INCONSISTENT CARE AND POOR COLLABORATIVE WORKING

A 14-year-old girl was admitted urgently to a paediatric ward with a potassium of 1.5 and a history of escalating intractable vomiting whenever she ate. The paediatric team, who worked on a 'consultant of the week' system, started investigating the vomiting once her potassium was stable. Investigations were normal and the paediatric team concluded that it had to be an eating disorder, referring the girl to the CAMHS eating disorders team. Meanwhile, she had lost a further 3kg on the ward while the investigations were taking place. By the time the eating disorders team were involved, her BMI was 60% median BMI. The paediatric team wanted an eating disorder diagnosed and for the girl to be transferred to a psychiatric unit, yet she and her family were reluctant for the eating disorders team to become involved and did not want another admission to an eating disorders unit. The CAMHS eating disorders team thought that the priority was to start nutritional rehabilitation and that the girl was at risk of re-feeding syndrome, so she should remain in the paediatric setting, which she did for a short term with an appropriate re-feeding schedule in place. The third consultant paediatrician to be responsible decided to discharge the girl after partial nutritional rehabilitation to 66% BMI, without consultation with the CAMHS eating disorders team.

### *ISSUES*

- 1 Failure to address malnutrition, irrespective of cause.
- 2 Discontinuity of paediatric care.
- 3 Poor collaboration between paediatric and mental health services.

## CASE 6. NO APPROPRIATE TREATMENT SETTING

A 12-year-old girl with rigid eating behaviour, highly limited intake and escalating weight loss would only eat when fed by her mother. When challenged, she became extremely distressed, running out from the house or attempting to jump out of windows. If she was restrained, she bit and kicked or banged her head against walls. She looked about 9 years old. She was admitted to the local paediatric ward, where some intake was re-established and a meal plan introduced, but on discharge her weight slowly dropped again, as the meal plan was not adequate for her needs. Her BMI dropped to 64% median BMI and she was eating less than 400kcal/day. She was medically stable, but her intake was declining daily. The only specialist eating disorders in-patient provision in the area was in a general adolescent unit for children aged 13 and over and with a range of diagnoses. The unit was prepared to admit a 12-year-old, but the girl's parents refused.

### ISSUES

- 1 Availability of age-appropriate treatment settings.
- 2 Admission resulting in increased separation anxiety.

## CASE 7. A SUCCESSFUL CASE

A 14-year-old girl attended her GP after a fainting episode. She was urgently referred to a rapid access clinic with a diagnosis of probable anorexia nervosa, where she was seen the following day along with her mother. Physical assessment showed that the girl had a BMI around the 0.4th centile for her age, her heart rate was 42bpm and blood pressure was 90/55mmHg. She described having dizzy episodes, but ECG and biochemical parameters were normal.

The girl was keen not to be admitted for in-patient treatment but the mother felt they would not be able to make any changes at home and was extremely worried about her daughter's health. Despite concerted efforts by her and her husband, her daughter's intake had become more restricted and physical exercise had increased.

Although the girl was at risk, she was stable and it was agreed that her physical health would be monitored in hospital on a daily basis. Meal plans were provided by a senior paediatric dietician. The local mental health service was able to see the family the next day and provide support three times a week for the first few weeks. It was agreed that if there was any deterioration in physical health, including a drop in weight, the girl would be admitted.

The family agreed with the plan, the mother feeling supported and reassured that her daughter's health was monitored closely. The girl realised that not making changes to her diet and physical activity would result in admission, something she desperately wanted to avoid. She showed good weight gain, initially 1–2kg/month, and after 1 year she was discharged from CAMHS and by the paediatrician.

### ISSUE

- 1 Close collaboration between mental health professionals and paediatricians is essential in managing young people with anorexia nervosa and physical symptoms.

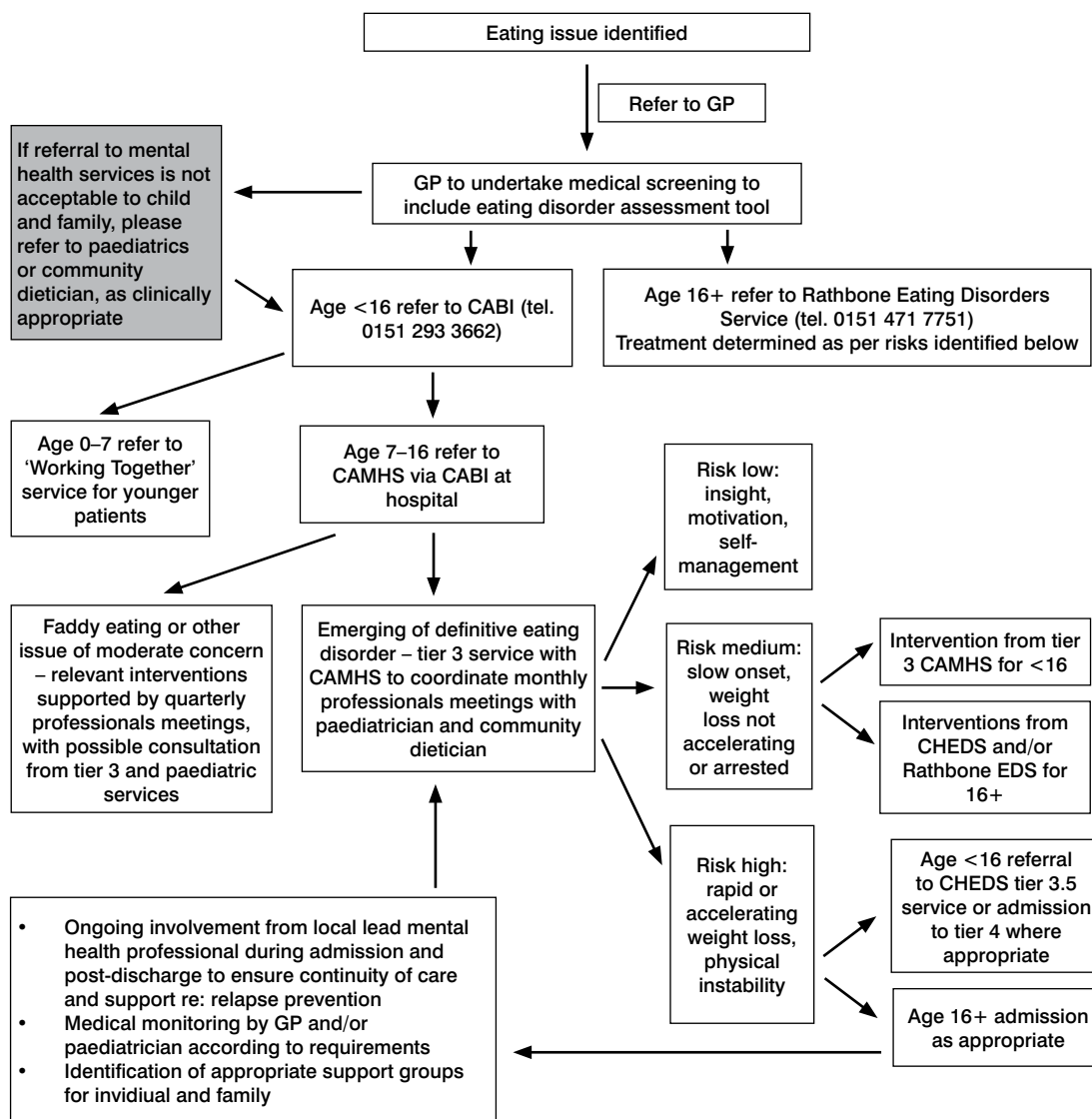
## Appendix E. Protocols for managing very ill young people with anorexia nervosa

A number of services have developed comprehensive protocols for the management of young people with eating disorders, for the guidance of both junior doctors and nursing staff. Examples of protocols and clinical guidelines for the care of children and adolescents with eating disorders can be found on the Junior MARSIPAN website (<http://sites.google.com/site/marsipannini>), together with some of the literature referred to in this document. They are not included here.

- The *Nottingham Eating Disorders Guideline*, a paediatric care protocol (<http://sites.google.com/site/nottinghamchildhealth/guidelines/adolescent-health>).
- The Cheshire and Merseyside Adolescent Eating Disorder Service has produced a comprehensive nursing management protocol, with dietetic guidelines, of anorexia nervosa within an in-patient paediatric setting ([www.cwp.nhs.uk/1/Documents/Anorexia\\_Nervosa\\_within\\_an\\_Inpatient\\_Paediatric\\_setting.pdf](http://www.cwp.nhs.uk/1/Documents/Anorexia_Nervosa_within_an_Inpatient_Paediatric_setting.pdf)).
- The Academy for Eating Disorders has produced a guide for early identification and management of eating disorders, which can be downloaded and printed off from their website ([www.aedweb.org/Medical\\_Care\\_Standards.htm](http://www.aedweb.org/Medical_Care_Standards.htm)).

Please contact the authors of these guidelines if you wish to cite them or use them in your care setting.

# Appendix F. Example of a care pathway designed to improve speed of referral



**Fig. F.1** Restrictive eating disorder pathway for children and young people aged <18 years registered with a Liverpool general practitioner.

CABI, Centralised Assessment and Brief Intervention service; CAMHS, child and adolescent mental health services; CHEDS, Cheshire Eating Disorders Service.

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