

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

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Organisations endorsing the report

The following organisations have endorsed this report:

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

Executive Summary

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 Council Report 162 www.rcpsych.ac.uk/files/pdfversion/CR162.pdf) addressing care of adult patients. The rationale for a separate document is that the definition of MARSIPAN cases differs in young people, because serious underweight varies with age and gender; other aspects of risk differ in young people (for example, blood pressure norms); consent and capacity are addressed within different legal frameworks for young people; there are differences in service organisation for specialist child and adolescent mental health services (CAHMS) and there is a central role of paediatric 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 refeeding
- Management of eating disordered compensatory behaviours in a paediatric setting
- Management in primary care and paediatric outpatient settings
- Discharge from paediatric settings
- Management in specialist CAMHS inpatient settings

Key recommendations

- 1) All health professionals should be aware that anorexia nervosa is a serious disorder with life-threatening physical and psychological complications. Sick children and adolescent with eating disorders who need admission require the same level of care as a child with any other serious illness, and should be subject to the same emergency protocols (e.g. APLS).
- 2) For young people with anorexia nervosa some risk parameters need to be adjusted for age and gender. This includes Body Mass Index (BMI). We recommend using %BMI (BMI/Median BMI for age and gender x 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 increasing autonomy for the young person with age, developmental stage and capacity.
- 4) The role of the primary care team is to monitor patients and refer them 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 junior MARSIPAN patients in that setting. This includes admission to psychiatric units as well as acute hospitals
- 7) Every hospital into which a patient 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 MARSIPAN patients 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 yrs 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 rates of refeeding
 - b) manage, with the help of CAMHS staff, the behavioural manifestations of anorexia nervosa secondary to their fear of weight gain e.g. compulsive exercise
 - c) occasionally to treat patients under compulsion (using parental consent, the Children Act or the Mental Health Act, depending on the setting, their age and their capacity).
 - d) arrange transfer of the patient 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 whilst 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

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Final

I. Introduction

A. History of the project

This report supplements the MARSIPAN¹ (www.rcpsych.ac.uk/files/pdfversion/CR162.pdf) report providing guidance for the care of seriously ill adults with anorexia nervosa (AN). 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 in the area of medically at risk patients for the following reasons:

1. The definition used for the scope of the adult MARSIPAN document, namely patients with severe anorexia nervosa (BMI < 15) and admitted to medical wards or to Specialist Eating Disorder Units, 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 exists in the way of evidence to establish clear risk parameters.
 - b. Admission of children and adolescents with AN 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) outpatient and inpatient services, and that young people are usually brought for treatment 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 AN on paediatric wards from guidance on managing seriously ill patients with AN, regardless of setting.
 - c. Specialist Eating Disorders Units (SEDU's), as described in the adult MARSIPAN document, are not widely available in child and adolescent mental health services (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 outpatient, outreach and day patient CAMHS. For the majority of the UK, care for young people with severe AN within CAMHS is provided through generic adolescent CAMHS inpatient units. These vary in the extent to which they are specifically equipped to manage patients with AN, including their capacity for NG feeding, and their suitability for younger adolescents and children. This variation in inpatient provision for young people with AN makes recommendations about service setting more complex, but does mean that recommendations in the adult MARSIPAN document 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 SEDU's and to generic units specifically equipped for patients with anorexia nervosa.
2. Children and adolescents both psychologically and physiologically are not just small or scaled down versions of adults. Normal and cut-off physiological parameters like blood pressure vary with age, and danger thresholds therefore can differ significantly. The impact of severe

and moderate malnutrition upon growth and development, for example the acquisition of bone density, are also unique in this age group and require additional consideration.

3. The legal and ethical issues surrounding treatment are multifaceted in young patients. Balancing the wishes and feelings of the young person, the role of parents/carers in treatment and the duty of confidentiality in decision making is complex, and in some cases requires statutory intervention, with young people.

That said, 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.

Junior MARSIPAN was set up with multidisciplinary input from contributors offering a wide range of skills (Appendix 1). Like the adult MARSIPAN document, we hope that our guideline will form the basis of local policies and encourage the development of local protocols. We also hope 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 are notably lacking. But at heart this document is not aimed at any one profession, but rather attempts to address some of the consequences of the separation of paediatrics from mental health. Anorexia nervosa provides an excellent example of the way in which mind and body are intimately connected, and that the natural tendency to leave the very sick patients to paediatricians, and for paediatricians to leave mental health patients to the psychiatrists can have very dangerous consequences, as the examples in Appendix 4 show.

B. Procedure followed in producing the report

1. 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 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 Persons SIG of the RCPCH to put forward a briefing note to 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 dietitians and a general practitioner 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 sub-disciplines from renal medicine to academic nutrition, two specialist dietitians and a General Practitioner. An attempt was made to identify a nurse member for the group linked to the RCN, 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 hope will endorse the output. A website was developed to share key

documents and references, facilitate communication, and to 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 the following groups:

1. FOCUS listserve, a multidisciplinary list serve for CAMHS administered by the RCPsych
2. EDSIG listserve, for eating disorders psychiatrists via the RCPsych section for Eating Disorders
3. YPSIG listserve, an adolescent health special interest group of the RCPCH
4. RCPCH Nutrition Group
5. British Society of Paediatric Gastroenterology, Hepatology and Nutrition, a multidisciplinary organisation promoting standards of care for children with GI, liver and nutritional disorders
6. 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 revised accordingly.

2. 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
- Adult MARSIPAN document
- American Psychiatric Association Guideline for the treatment of patients with eating disorders
- American Academy of Paediatrics Guidelines
- Nottingham University NHS trust guideline for early recognition, assessment and initial management of eating disorders in children and young people.
- Finnish Guidelines for management of eating disorders in children and young people
- Australia and New Zealand clinical practice guidelines for the treatment of anorexia nervosa
- NHS Scotland management and treatment of eating disorders
- National Institute for Health and Clinical Excellence. Eating disorders: Core interventions in the treatment and management of anorexia nervosa, bulimia nervosa and related eating disorders. 2004. NICE, UK
- Guidelines for the nutritional management of anorexia nervosa Royal College of Psychiatrists London, October 2004

These guidelines had in common the following areas in which guidance was provided:

- Who should be involved
- Weight indicators to diagnose, monitor, treat
- Initial risk assessment
- Medical complications to look for on examination
- Criteria for admission

- Inpatient management : where, who?
- Feeding regime – how much, how
- Re-feeding syndrome : monitoring, preventing, treating.
- When to discharge
- Management during admission

Where the guidance differed were in the 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 2)

Dr's Moss and Ayton devised a survey to seek information on current services and to identify areas of difference in terms of practice around medically sick patients. The group used their professional groupings .i.e. YP-SIG , FOCUS, EDSIG listserve, to get feedback, comments, experiences, and anecdotes from clinicians.

A Medline and ISI WEB 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.²⁻⁸ The most commonly described physical complications included cardiac abnormalities,^{2;5;9;10} hypoglycaemia,^{11,12} electrolyte imbalances and re-feeding syndrome.¹³⁻¹⁷ Furthermore, there were several cases of brain tumours reported which initially presented as atypical anorexia.¹⁸⁻²⁵

A literature review was also carried out by Graeme O'Connor to identify published reports of the 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 3.

3. Establishing the scope of the guideline

Unlike the adult MARSIPAN document, this was one of the most difficult areas to agree on. The focus for this report is those most medically at risk, but this cannot always be disentangled from other aspects of risk. Furthermore, the risk maybe increased as result of interventions that precipitate more disordered behaviour. For example, a child of 11 with AN who also has severe separation anxiety may become more disturbed and less cooperative with re-feeding as a result of hospitalisation, meaning that restraint or medication were needed. So even when medical risks are 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. The rationale and risk assessment framework are discussed further in section II A.

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

4. Editorial independence

Although we are representing, to different degrees, different bodies including 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.

C. 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 nonetheless they do occur. What is apparent however, is that the initial experience of young people in relation to managing their eating disorder impacts their engagement with services, and consequently on the course of their illness. In addition, the complexity of eating disorders care for young people, contributed to by separate outpatient and inpatients CAMHS services and by the need for both paediatric and psychiatric care, does present particular problems when it comes to managing high risk patients.

In Appendix 4 we reproduce quotes from messages received by our 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 need for a prospective study of patients with AN admitted to medical wards with a wide range of physical and psychological measures to help identify those patients who are likely to be at particular risk, and to validate the risk assessment frameworks recommended in this and the adult MARSIPAN report.

II. Issues arising in ALL settings

A. Risk assessment: How ill is the patient?

Children and adolescents with eating disorders frequently present to Emergency departments and to Paediatric teams, and caring for them can be challenging. Patients with medical compromise secondary to eating disorders can be very unwell, and can die of complications. Sadly this can happen whilst under medical care, including as an inpatient.

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 families, which also impact 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, may resist or object to treatment and can be very sick, requiring systematic and considered acute care with mindfulness for the stresses for the child's family. Children and adolescents with eating disorders are no different. And while it is tempting to refer to CAMHS or psychiatry liaison services and wait, it is not '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 death (from suicide, sudden death and infection) or serious illness (acute pancreatitis or GI rupture). 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, whilst the most medically unstable patients can be a normal weight. It is intended as a guide to level of concern. Those with AN can be 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 below 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. Firstly, eating disorders are relatively common, whereas most of the syndromes that might otherwise account for these findings are not. Secondly, 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. Patients with mineralocorticoid deficiencies or hyperparathyroidism do not start secreting food, inducing vomiting or even become 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 level of concern is outlined below.

GUIDANCE BOX 1: RISK ASSESSMENT FRAMEWORK FOR YOUNG PEOPLE WITH EATING DISORDERS				
	RED (High risk)	AMBER (Alert to high concern)	GREEN (Moderate risk)	BLUE (Low risk)
Body mass	Percentage Median BMI (see section A1 for calculation of %BMI) <70%	Percentage Median BMI 70-80% [Approximates to between 2 nd and 0.4 th BMI centile]	Percentage Median BMI 80-85% [Approximates to between 9 th and 2 nd BMI centile]	Percentage Median BMI >85% [Approximates to

	[Approximates to below 0.4 th BMI centile]			above 9 th BMI centile]
	Recent loss of weight of 1kg or more/week for two consecutive weeks	Recent loss of weight of 500g-999g/week for two consecutive weeks	Recent weight loss of up to 500g/week for two consecutive weeks	No weight loss over past two weeks
Cardiovascular Health	Heart rate (awake) <40 bpm ¹	Heart rate (awake) 40-50bpm	Heart rate (awake) 50-60bpm	Heart rate (awake) >60bpm
		Sitting Blood Pressure Systolic <0.4 th centile (84-98mmHg depending on age and sex ²) Diastolic <0.4 th centile (35 -40 mmHg depending on age and sex ¹)	Sitting Blood Pressure Systolic <2 nd centile (88 - 105mmHg depending on age and sex ¹) Diastolic <2 nd centile (40 - 45mmHg depending on age and sex ¹)	Normal sitting blood pressure for age and sex with reference to centile charts ¹
	History of Recurrent Syncope Marked orthostatic changes (fall in systolic blood pressure of 20mmHg or more, or below 0.4th-2nd centiles for age, or increase in heart rate > 30bpm)	Moderate orthostatic cardiovascular changes (fall in systolic blood pressure of 15mmHg or more, or diastolic blood pressure fall of 10mmHg or more within 3 mins standing, or increase in heart rate up to 30bpm) Occasional syncope	Pre-syncope symptoms but normal orthostatic cardiovascular changes	Normal orthostatic cardiovascular changes
	Irregular heart rhythm (does not include sinus arrhythmia)			Normal heart rhythm
			Cool peripheries. Prolonged peripheral capillary refill time (normal central capillary refill time)	
ECG abnormalities	QTc > 460 ms (girls) or 40ms (boys) with evidence of bradyarrhythmia or tachyarrhythmia (excludes sinus bradycardia and sinus arrhythmia) ECG evidence of biochemical abnormality	QTc >460ms (girls) or 40 ms (boys)	QTc < 460ms (girls) or 40ms (boys) and taking medication known to prolong QTc interval, family history of prolonged QTc or sensorineural deafness	QTc < 460ms (girls) or 440 ms (boys)
Hydration Status	Fluid refusal Severe dehydration (10%): Reduced urine output Dry mouth Decreased skin turgor, sunken eyes Tachypnoea Tachycardia ³	Severe fluid restriction Moderate dehydration (5-10%): Reduced urine output Dry mouth Normal skin turgor Some tachypnoea Some tachycardia ³	Fluid restriction Mild <5%: May have dry mouth Or not clinically dehydrated but with concerns about risk of dehydration with negative fluid balance.	Not clinically dehydrated
		Peripheral oedema		
Temperature	<35.5°C (tympanic) or 35.0°C axillary	<36 °C		
Biochemical Abnormalities	Hypophosphataemia Hypokalaemia Hypoalbuminaemia Hypoglycaemia Hyponatraemia	Hypophosphataemia Hypokalaemia Hyponatraemia Hypocalcaemia		

¹ Patients with inappropriately high HR for degree of underweight are at even higher risk (see hypovolaemia). HR may also be increased purposefully through use of excess caffeine in coffee or other drinks.

² Jackson L et al. Blood pressures centiles for Great Britain. Arch Dis Child 2007;92:298-303

³Or inappropriate normal HR in underweight YP

	Hypocalcaemia			
Disordered eating behaviours	Acute food refusal or estimated calorie intake 400-600kcal 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 health care 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 (>2hrs per day)	Moderate levels of uncontrolled exercise in the context of malnutrition (>1 hr per day)	Mild levels of uncontrolled exercise in the context of malnutrition (<1 hr per day)	No uncontrolled exercise
Self harm and suicide	Self poisoning. Suicidal ideas with moderate-high risk of completed suicide	Cutting or similar behaviours. Suicidal ideas with low risk of completed suicide		
Other mental health diagnosis		Other major psychiatric co-diagnosis eg OCD, psychosis, depression		
Muscular weakness SUSS Test	Stand up from squat: Unable to get up at all from squatting (score 0)	Stand up from squat: 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)
	Sit up: Unable to sit up at all from lying flat (score 0)	Sit up: Unable to sit up from lying flat without using upper limbs (score 1)	Unable to sit up from lying flat without noticeable difficulty (score 2)	Sits up from lying flat 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	

1. Assessing and defining severe malnutrition

The use of simple weight or BMI has limited utility 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, sex and age as a minimum. In adolescents, WHO²⁶ recommended that the severity of wasting could be assessed by BMI for age in those 10 - 18 years old (< 5th centile). More recently, a UN ACC/SCN Report defined severe malnutrition in adolescents requiring therapeutic intervention as < 70% weight for height or BMI in adolescents plus either bilateral pitting oedema (nutritional), inability to stand, or apparent dehydration. 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) &/or weight for height (< 70%) or weight for height Z score (< -3) each predicts high risk of mortality²⁷⁻²⁹. The presence of bilateral (nutritional) oedema improves predictability. Independently, low serum albumin (< 16 g/l) is a major risk factor for mortality³⁰.

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. However for patients below the 0.4th BMI centile, as all MARSIPAN patients are, there is a need to quantify the degree of underweight. Furthermore, much of the literature on adolescent eating disorders uses some form of %weight for height (e.g. % Ideal Body Weight). It is also language that is easy for patients and parents to understand. The DSM IV diagnostic criteria for anorexia nervosa and the APA guidelines 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, which are not fully in agreement (see Appendix 2) although do approximate to one another within a few percent.

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

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

Median BMI for age can be read from BMI centile charts (www.healthforallchildren.com), or there are Excel programmes that will calculate %BMI using the UK BMI reference data (e.g. the weight for height programme developed at Great Ormond Street Hospital). Note that the reference data are not ethnically sensitive, so some ethnicities (e.g. Asian young people) will be over represented in underweight groups.

For a fuller discussion on methods of defining underweight, see Cole et al³¹.

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. Slow, chronic weight loss on the other hand can manifest as growth retardation, and previous growth charts should be examined when possible.

2. Cardiovascular risk

Bradycardia is a very common, well documented finding in young people with anorexia nervosa. **A heart rate (HR) of 50 bpm should raise concern, and a consistent HR of 40 bpm or below 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 pulse rate is normal or high despite low weight or with low blood pressure. There may or may not be variability with standing or stress. Some patients may drop their heart rate during sleep which will recover with waking, but consistently low HR even in sleep is a concern. 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 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 sex requires further assessment as an in-patient and should be discussed with local cardiology experts.

Hypotension. Blood pressure must be compared to age and sex based normal values from an appropriate comparative population. The criteria in our table are based on data from healthy UK children and young people³². **Syncope** and pre-syncopal symptoms are common in young people but are even more common in young people who are underweight with eating disorders. 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 15 mmHg, or a drop to below 0.4th-2nd 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: Sphygmomanometer and appropriate range of cuff sizes. 12 lead ECG machine. Calculator to calculate QTc. Cardiac monitoring equipment. Appropriate adjustable bed. Resuscitation equipment.

All patients who are medically compromised should have a 12 lead ECG performed and discussion with a paediatrician with expertise in cardiology if there is a significant abnormality and in particular if the QTc is prolonged.

3. Dehydration and oedema

Hydration status is assessed clinically by examining mucous membranes, sunken eyes, 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 a 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 in stages is safer.

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

4. Electrolytes

Patients 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 -5.5 mmol/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 suggests the possibility of laxative abuse. Oral supplementation is generally unpalatable and may induce vomiting but does provide some protection from accidental overdosage. A potassium value of less than 3.0 mmol/l merits admission to a paediatric unit and intravenous potassium correction. A Potassium value of less than 2.5 mmol/l and certainly less than 2 mmol/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 iatrogenic, and therefore can be the a sign of a very unwell patient. Serum levels should be above 135 mmol/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 knowledge of the 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, Hypomagnesaemia** are less common but increase the risk of arrhythmia. Hypocalcaemia < 1.1 mmol/l can lead to tetany, stridor, seizures, weakness, 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. Hypophosphatemia may occur secondary to starvation but in addition re-feeding syndrome (see below) results in a low total body phosphate 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 significant muscle breakdown in addition to an 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.

5. Haematological parameters

Abnormalities in haematological parameters may occur in any child or young person with malnutrition, including those with eating disorders, though they will usually resolve with weight gain and improved nutritional intake^{33;34;34}. Changes can involve a number of cell lines, including leukopenia, especially neutropenia, 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 hypocellular morphology which recovers with re-feeding. Whether malnourished patients 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 AN. 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 infection (e.g. tuberculosis).

6. Other biochemical abnormalities

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

7. 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 disorders, depression, and anxiety disorders.

Young people who are physically restrained for the purposes of feeding or who react to attempts to encourage them to feed with violence 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 CT/MRI scan is indicated in such situations, particularly if the eating disorder presentation is at all atypical.

8. Other

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 Test)** is useful to test for Muscle Strength: (see Guidance box 1 for scoring). 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 patient performs well. The SUSS test has two parts.

- **The Squat-Stand test:** The patient is asked to squat down on her haunches and is asked to stand up without using her arms as levers if at all possible.
- **The Sit up test:** The patient lies flat on a firm surface such as the floor and has to sit up without, if possible using her hands.

Symptoms of **dyspepsia** are not uncommon in eating disorders and are more common in those who control their weight by vomiting and may reflect gastro-oesophageal reflux and/or gastritis. Upper **gastrointestinal bleeding** in young people who control their weight by vomiting may be due to 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 BOX 2. KEY PHYSICAL ASSESSMENT PARAMETERS AND ACTION POINTS

Check for/ measure	What to look for	When to be concerned (amber or red in risk assessment framework)	Specific management
Heart rate	Bradycardia Postural tachycardia	HR < 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 ⁴) Check electrolytes	Prolonged QTc HR < 50 bpm Arrhythmia associated with malnutrition and or electrolyte disturbances	Nutrition and Correct electrolyte abnormalities Increased QTc bed rest, discuss with cardiologist. Medication likely to be unhelpful unless symptomatic or tachycardic. Should correct with nutrition and correct of electrolytes.
Blood pressure	Hypotension - Refer to standardized charts for	Systolic, diastolic or mean arterial pressure	Nutrition. Bed rest until postural hypotension

⁴ Bazett's formula : $QTc = \sqrt{QT/RR}$

	age and sex	below the 0.4 th centile for age and sex ⁵ and/or postural drop of more than 15 mmHg	improved. Echo likely to be abnormal whilst malnourished.
Hypothermia	Temperature <36 °C will usually be accompanied by other features. Beware <35°C		Nutrition Blankets
Assess for dehydration	Hypotension and bradycardia related to malnutrition usually not acute dehydration.	Significant dehydration and malnutrition	ORS orally or via NG preferred treatment unless hypovolaemic. Beware of giving fluid boluses unless hypovolaemic - may have cardiac compromise or be hyponatraemic. Check electrolytes and renal function.
Hypovolaemia	Tachycardia or inappropriate normal HR in undernourished young person, hypotension and prolonged capillary refill time		Senior paediatric review. Normal Saline 10ml/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 a contributor
Other features of severe malnutrition	Lanugo hair Dry skin Skin breakdown and / or pressure sores		Nutrition. If skin breakdown or pressure sores seek specialist wound care advise
Evidence of purging	Low K Metabolic alkalosis or acidosis Enamel erosion Swollen parotid glands Callouses 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 NB. Normal electrolytes does not exclude medical compromise	< 3 mmol/l admit Consider HDU, PICU or ICU if < 2-2.5 mmol/l	Correction. IV initially if <3 mmol/l Oral supplements may still be vomited ECG
Hyponatraemia or Hypernatraemia	Less common but important Consider water loading	<130 mmol/l admit Consider HDU, PICU or ICU if < 120-125 mmol/l	If IV Correction proceed with care

⁵ see Jackson L et al. Blood pressures centiles for Great Britain. Arch Dis Child 2007;92:298-303

Other electrolyte abnormalities	Check PO4, Magnesium, Calcium.		
Hypoglycaemia		Hypoglycaemia is a relatively rare finding at presentation and implies poor compensation or co-existing illness (e.g. infection) Admit [Once refeeding is established, brief hypoglycaemia can be found after meals but should normalise rapidly]	Oral or NG correction where possible (sugar drink, hypostop). IV bolus if severe (altered conscious or mental state; seizures): 2mls/kg of 10% glucose followed by ongoing infusion containing glucose e.g. 5ml/kg/hr 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 DSH and safeguarding procedures as needed

9. High dependency or Intensive care

For medically compromised inpatients 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, can allow a more frequent grasp of downward trends in observation as well as providing audible alarms whilst staff caring for the patient may be performing other important tasks. They also provide a stored record for review. It also raises a number of potential issues for the team caring for the patient including 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 HDU or PICU environment. This may be appropriate for very unwell patients, who should be assessed and discussed with local ICU teams or retrieval services before admission as for any seriously unwell child or adolescent. A decision should be negotiated sensitive to the patient and mindful of the availability of local services.

Sick children and adolescent with eating disorders who need 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 and needs senior paediatric review on admission and at least daily if there are paediatric (medical) issues.

B. Location of care: where will the patient be best managed?

When the decision has been made to admit the child or adolescent (referred to as child or children in this document) to hospital, the referrer's actions will be informed by many factors, not all clinical.

The options are usually as follows:

- 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 a specialist eating disorder bed (SEDB), often linked to an out-patient CAMHS service that has expertise in managing severely unwell patients with eating disorders (CAMHS OP ED).
- Specialist eating disorders unit (SEDU) bed, which for children and adolescents currently only two are in the NHS and are otherwise in the independent sector. 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 which 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 specialist eating disorders beds (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. Whilst 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 their child, and children with their friends and schools.

Alternatively, the child may be so physically ill that admission to a SEDB may not be possible and admission to a paediatric bed needed. In order to decide whether a particular patient can be admitted to a SEDB or not, the needs of that patient 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 needs are 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. SEDB.

Support that a unit offering SEDBs for children should include:

- a. Expertise in NG feeding (insertions may be performed off site)
- b. Daily biochemistry
- c. Frequent nursing observations, up to and including 1:1 when indicated

- d. Prevention of anorexic behaviours e.g. water loading, excessive exercising
- f. ECGs, daily if needed
- g. Management of the resisting child - including safe holding techniques, and the acute and medium term paediatric psychopharmacology of children with eating disorders
- h. Use and management of the Mental Health Act 1983/ 2007 in under 18s, with particular reference to the zone of parental control in eating disorder patients, the Mental Capacity Act (2005) in 16-18 year olds and the Children Act (2004)
- i. Assessment of tissue viability in emaciated patients and treatment of pressure sores
- j. Immediate cardiac resuscitation with staff trained to administer resuscitation
- k. Access to advice from paediatricians and paediatric dietitians 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 below for care in paediatric settings):

- a. IV infusions
- b. Treatment of serious medical complications
- c. Cardiac monitoring
- d. Provision of a paediatric "Crash" team
- e. CVP lines
- f. TPN
- g. Artificial ventilation

GUIDANCE BOX 3: ON LOCATION OF CARE

1. In most cases, unless the patient requires medical services that are not available, patients with severe anorexia nervosa should be cared for in a Tier-4 CAMHS Specialist Eating Disorders Bed (SEDB), with support from paediatric services when needed. For children age 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.
2. Should a SEDB be unavailable, for example due to waiting lists or lack of an appropriate facility, the choice is between a paediatric and a generic CAMHS unit bed. Several variables will influence the decision, such as the quality of liaison between paediatric and CAMHS Eating Disorder service (where these exist), the experience of generic CAMHS units in managing malnutrition, as well as the clinical state of the patients and requirements for monitoring. There should be a CAMHS Eating Disorder team responsible for the population and we suggest that a senior member of the CAMHS ED team consult with paediatric and CAMHS colleagues in order to develop a local Junior MARSIPAN strategy to address this problem.
3. Regarding NG feeding, this can sometimes be managed in a generic CAMHS in-patient unit as long as the experience, knowledge and skill is available to safely manage this procedure. It would be reasonable for a generic CAMHS unit to ask that a patient's NG 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 a SEDB a long distance from home.

C. 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 inpatient units, between medical units and specialist inpatient services, primary and secondary care). There are a variety of reasons for this. There is a higher risk 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 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 patient may deteriorate rapidly whilst waiting for an appointment. The CAMHS team may not realise the urgency of the referral if the information is limited.

Similarly, without agreed shared care arrangements, it is possible that inexperienced professionals will expect the patient to be admitted to a medical or paediatric ward whilst waiting for a CAMHS bed. The staff in the acute hospital may not feel confident to start re-feeding in a non-cooperative or distressed patient, and expect the CAMHS team to take responsibility, whilst the CAMHS team makes the assumption that the patient will be medically stabilised before the transition takes place. As a result, the patient can get worse in the paediatric setting, and may even be too unwell to transfer to the psychiatric unit once the bed becomes available. Young people 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 this age patient 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 paediatric or medical wards are usually very limited. Furthermore, most CAMHS inpatient 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 e.g. Scotland, where networks facilitate collaboration between local CAMHS, regional and national services.

The current emphasis on provider competition is likely to impair collaboration between services. Joint working between services can be lifesaving, and commissioning support is essential to achieve this (e.g. funding for CAMHS nursing staff whilst 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. Whilst 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 clarified, a sudden change of approach can cause confusion and dissatisfaction at best and tragedy at worst. Whilst it is recognised that transition is important³⁵, research in this area is limited. The TRACK study³⁶ 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.*' Whilst 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 BOX 4: TRANSFER BETWEEN SERVICES

1. Ideally, there should be joint protocols between services to ensure safe transfer and optimal transition between services of young people with severe anorexia nervosa. If this is not possible, when a patient is transferred from one service to another there should be a properly conducted and recorded meeting between representatives of the two services, usually including the patient and family, so that it is 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.
2. Safe care pathways and joint working between different organisations should be supported by commissioners.
3. Carers concerns need to form part of the risk assessment.

D. 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.³⁷⁻⁴⁷ Throughout this document, reference is made to English legislation in relation to compulsion and safe-guarding. In other jurisdictions, other legislative principles and practices will be used.

The NICE guidelines 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 non-consenting young people than in adults, particularly if the patient is under 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 new 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.⁴⁸⁻⁵⁰ 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 legal status.⁵¹ 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 impact decision making, but is not picked up in standard tests of competence. 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 patients for involuntary treatment. Nevertheless, the underlying principles of using Mental Health Legislation in the management of this client group are broadly applicable i.e. anorexia nervosa is a serious mental disorder, inpatient re-feeding is at times an essential and direct treatment for this, 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. In this document, the term 'Mental Health Act' is taken to refer to equivalent legislation in other countries of the UK as well.

In addition to Mental Health Law, children are subject to laws protecting children (under 18 years old), which can be used to provide health care in the case of non-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 an NG 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 him /her (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 shall be respected" (Article 5). Thus in young people, consideration of legal frameworks for treatment in the case of non-consent needs to balance young people'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.

GUIDANCE BOX 5: COMPULSORY ADMISSION AND TREATMENT

Patients with eating disorders have mental disorders, may be putting their lives at risk and may require inpatient treatment.

- Young people under 16 can be treated against their will if at least one parent consents to treatment on their behalf. However, if the child actively fights his/her parents' 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
- 16-18 year olds can be admitted under MHA and treated against their will, although this should rarely be required. It is essential, however, that it is done when it is 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 recognized 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, in a patient refusing treatment in A&E.

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 him/her and the consultant psychiatrist and the issue escalated until the patient's treatment is safe. There should be an identified CAMHS consultant with a special interest in eating disorders 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 consultant paediatricians can no longer be the responsible clinician for a patient 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 Health Providers to ensure that procedures and policies can be adhered to.

E. 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. An example of a protocol is given in appendix 4.

GUIDANCE BOX 6: PAEDIATRIC SERVICE POLICIES AND PROTOCOLS TO AGREE IN ADVANCE

1. Criteria for paediatric as opposed to psychiatric admission
2. Special nursing: Qualifications and supervision of 1:1 nurses; role of paediatric vs psychiatric nurses
3. Social work and Legal: Availability of advice in situations of non-consent to treatment by either young people or their parents/carers
4. Mental Health Act: Criteria for its use. Identification of Responsible Clinician. Identification of responsible manager.
5. Specialist Eating Disorder Beds (SEDB): consultation and referral, including consideration of provision for children 12 and under
6. Issues around funding (e.g. special nursing or SEDU referral)
7. Liaison Psychiatry services (where they exist) or Tier-4 CAMHS
8. Training role, involvement of consultants and trainees with patients admitted and consultation with ED specialists
9. A Junior MARSIPAN group with at least a paediatrician, a child and adolescent psychiatrist, a dietitian and a nurse as well as management be set up in their area to advise on services required in medical units

III. Management in different sectors

A. 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 disorder⁵². A 'wait and see' attitude is usually contraindicated.

Behavioural indicators of an eating disorder include being a reluctant attender at the surgery or clinic, seeking help for physical symptoms, resisting weighing and examination, covering body, secretive or evasive, increased energy (and in some cases agitation), and gets 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 ; disturbance in the way in which one's body is perceived; undue influence of body weight or shape on self-esteem; or denial of seriousness of current low body weight; in post menarcheal girls secondary amenorrhea). The SCOFF questionnaire, although validated only in adults, can provide a framework for screening⁵³.

After an eating disorder is identified, direct challenge or confrontation is unlikely to be helpful. Reasonable aims for a first presentation are to (a) feedback findings from physical examination, including degree of underweight if relevant; (b) establish weight monitoring, plus a plan to follow if weight falls; (c) discuss psychiatric risk as needed; (d) provide the family and young person with information about the nature, course, and treatment of eating disorders; (e) refer to the appropriate CAMHS or paediatric service depending on level of risk. In general, the threshold for intervention should be lower for adolescents than for adults. In patients younger than age 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 paediatric over CAMHS referral. However, the needs of the child should be the primary basis for decisions on 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 patients or patients where there is concern regarding continuing weight loss. Height, weight and BMI should be measured, and plotted on centile charts, and a %BMI calculated (see section A1.1). Some drugs (e.g. antipsychotics, often prescribed in 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 (i.e. rapid weight loss without signs suggestive of an ED is no reason to refer to CAMHS). If weight is below 80%, the referral should be considered urgent. If it is below 70% of median BMI referral should be made direct 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 longstanding 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

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, and renal function, including calcium, phosphate and magnesium, iron status, celiac 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 (Section B.6). Re-feeding syndrome is extremely rare but is more likely to occur in the young person with rapid weight loss, with BMI < 0.4th centile, who has eaten little or nothing in the past week or who has abnormal biochemical parameters. Support from dietitian 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 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 patient should be referred for paediatric/medical admission.

Until the patient 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, there may continue to be role for GP / general paediatrician to monitor physical health. In such instances of shared care regular communication, at least after each visit, is good practice.

GUIDANCE BOX 7: MANAGEMENT OF AN IN PRIMARY CARE AND OTHER OUTPATIENT SETTINGS

1. Rapid exclusion of other conditions
2. Risk assessment: age/sex specific BMI centile, BP, HR, temperature, baseline bloods and self harm.
3. Refer to CAMHS every young person with probable AN
4. Refer to paediatrics any child who has one or more criteria in High Risk (red – Guidance box1) with simultaneous referral to CAMHS
5. If re-feeding in the community, check electrolytes, phosphate, magnesium as for inpatient care (Guidance Box 8). Where regular bloods are not feasible, inpatient admission should be sought
6. Monitor at least weekly until seen by CAMHS or paediatrics

B. Management in Outpatient Paediatric settings

A paediatrician may see a young person with eating disorders in the outpatient setting for a variety of reasons:

- To exclude other diagnosis for weight loss
- To monitor physical health
- To provide health information

Referrals may come from GP, school nurse and CAMHS and other health care professionals.

A GP or school nurse may refer a young person with possible or probable eating disorder to a paediatrician to exclude an organic cause for weight loss or because young person and /or family are reluctant to be referred to CAMHS, afraid of possible stigma this may carry or when in denial of a possible eating disorder. In such occasions a paediatrician confirming concerns about an eating disorder and stressing the need for CAMHS input can be very helpful. Especially in the earlier stages of an eating disorder, a hospital referral can be beneficial to help young person understand the seriousness of situation, i.e. 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 the young person will eat even less. In such cases it can be extremely helpful if clinician takes over the responsibility for physical wellbeing through frequent monitoring of the young person. This can create the space for family to become more firm with diet. For example, if a certain meal is not prepared the young person with an eating disorder 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 assessment of physical health (see Guidance box 2), with further investigations and interventions as required. It may be to perform a baseline assessment (weight, pulse and BP) 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 short-term 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 main carer of 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 the young person seen by both specialties but especially for the ones only seen by the general paediatrician.

C. Management in Inpatient Paediatric settings

1. Reasons for Inpatient Paediatric Admission

As discussed in section I.A.1., there are various reasons for admission to a paediatric ward other than being seriously medically unwell. The principles outlined below should be considered whatever the reason for admission.

It is important to clarify and agree the necessity for and purpose(s) of the paediatric admission with the young person, family and team members. Medical reasons for admission in the severely unwell would include 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. In these situations the ideal would be to medically stabilize 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 eating disorders for reasons other than acute medical risk, as agreed locally, including respite for parents, assessment and investigation, deliberate self harm etc. These admissions are not the subject of this report, although some of the principles may apply.

2. Roles and responsibilities during an inpatient paediatric admission

Throughout any admission the consistent and co-ordinated care and support of the young person and their family is paramount. It is the responsibility of all to ensure that there is 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 re-feeding and underfeeding syndromes. Management of disordered eating and associated behaviours is clearly crucial. Treatment of co-morbidities such as anxiety or OCD may be required and medication used if indicated. A working knowledge of the Children and Mental Health Acts 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 dietitian. In order 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 give 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 use of steps necessary to ensure treatment if needed.

a) Recommendations for paediatric involvement

We recommend that every hospital into which a young person with severe anorexia nervosa is likely

to be admitted should identify a consultant paediatrician who should have the following qualities:

1. An interest in this patient group
2. Training in the clinical problems (medical and psychiatric) of patients with severe anorexia nervosa, and their management or can be supported to achieve this
3. Expertise in the nutritional support of those with anorexia nervosa and its complications or can be supported to achieve this
4. Is supported by a multidisciplinary team
5. Has access to inpatient beds
6. Have an association with a CAMHS team with an interest or expertise in eating disorders

This individual would be made aware whenever a patient with an eating disorder needs to be admitted or has been admitted as an emergency to the hospital, and should consult as soon as possible and coordinate care from a paediatric perspective, including ensuring protocols/procedures are in place to effect appropriate management and to call for opinions/expertise when needed. There should be clear arrangements for cover in the absence of the nominated paediatrician. It is strongly recommended that a system needs to be developed whereby a level of expertise is acquired, reliable senior leadership in the clinical management and multi-disciplinary 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 from a paediatrician with expertise with patients with eating disorders and who takes responsibility for managing many of the other specific issues associated with patients with anorexia nervosa outlined above, including the need for consistency over a prolonged period.

b) Liaison from psychiatric services in paediatric settings

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

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

1. An interest, training and expertise in this subject or can be supported in achieving this
2. Be in a position to be able to provide shared care for those admitted to a paediatric ward
3. Has an association with paediatric staff, specifically those with an interest or expertise in eating disorders

This individual would be made aware whenever an admission of a patient with an eating disorder is likely and if admitted to the hospital, 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 is to provide this role. The exact model of psychiatric input may vary e.g. it may come from an eating disorders, liaison psychiatry or Tier-4 service. Where both Liaison services and Eating Disorders services exist, a clear plan for deciding responsibilities in relation to MARSIPAN cases 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.

c) A partnership between paediatrician and psychiatrist

Patients 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.

In order to facilitate these arrangements it is recommended that the following practices are adopted:

1. Production of guidelines on medical management of severely unwell patients with an eating disorder aimed primarily at junior medical staff.
2. A guide for nursing and medical staff on supporting patients and families.
3. Regular staff meetings to ensure a consistent approach and minimize the risk of splitting (such as playing some staff off against others).

For each individual admission the following is recommended:

1. A regular multidisciplinary (MDT) meeting, usually weekly or more frequent if required, until discharge.
2. The MDT meeting requires the presence of senior paediatric, psychiatric and nursing staff – or those than can make decisions - together with dietetic involvement and other individuals as required. Input from trainees is welcomed as appropriate but they must be adequately supported by senior colleagues.
3. The role of this meeting should include reviewing progress with parents, the review of future plans and meeting with the young person to convey these as appropriate.
4. That there is a record of the MDT meeting which is circulated to all including the family and young person.
5. Discharge planning is included in the agenda of the MDT meeting when appropriate.

6. The formulation of a specific nursing care plan which addresses the specifics of patient care for those with an eating disorder.

3. Some practical considerations

a) *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. Whilst 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, and gives opportunities to exercise, dispose of nutrients and purge and may increase opportunities and therefore risk of engaging in acts of deliberate self harm. There is also always the risk that “out of sight is out of mind”. We therefore recommend 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 not nursing in a separate cubicle unless there are indications to do so.

b) *Nursing care*

Children with eating disorders admitted to paediatric wards can cause significant anxiety for staff. Paediatric wards, especially in non-children's hospital environments, are often skilled at managing short term admissions but may be less confident with children who may require intensive input over several weeks. Children exhibiting anorexic behaviours (e.g. refusing and hiding food, exercising excessively and vomiting) can prove particularly challenging for acute paediatric admission services. The ideal situation would be to have nursing staff that have training in both paediatric and mental health nursing. Whilst 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. In order to nurse individuals with severe anorexia nervosa it is important for staff to have a working knowledge of the illness. Part of the role of the psychiatry teams should be to support training of individuals in this area. However, this will need to be backed up by close liaison during the admission of any individual with anorexia nervosa. In some areas, 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 would recommend that a core group of nurses is 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 good reason to do so 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 come the questions of who should pay for specialist nursing. The key issue that should determine the answer to this question 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 upon commissioning arrangements that map onto physical health care. Is the extra nursing aimed at managing anorexic behaviours, to facilitate adherence to diet or support the care of a child with significant psychiatric co-morbidity, e.g. suicidal behaviours? If these are the issues demanding extra nursing time and skill then these become the financial responsibility of the commissioner responsible for CAMHS services. However, two factors need to be considered when extra nursing is provided.

Firstly, what is the role of the child's parents? On paediatric wards parents often stay for much or all of the time. If the presence of the child's 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 it is still required. However, there should not be an assumption by services 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 her 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.

Secondly in order for commissioners to be confident about what they are funding and therefore how much of the additional funding resource should be delivered by them, CAMHS ED 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, and are especially important in situations where the extra nursing provision is delivered by agency staff. Care by agency staff with little or no eating disorders experience should be avoided.

c) Education

Most paediatric wards will have access to teaching, especially for those who have prolonged or recurrent admissions although resources and arrangements will vary. For those who are severely ill it is likely that they will not be well enough to participate in academic work. When they are able to do so however, it is important to consider very carefully the amount and level of academic 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 to occur 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 delivery of education on the ward, subject to parental or the young person's consent (depending on age/capacity).

d) Social Interaction on Paediatric Wards

Whilst in general, those admitted to a paediatric ward for any reason may gain from the contact with other patients, there are areas 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 learned. Other vulnerable individuals on the ward may witness eating and other behaviours which may subsequently be adopted by them. The anorexic young person can

be exposed, especially in a prolonged admission, to other severely unwell individuals and sometimes even death.

Whilst it is important to include all on the ward in any opportunities and activities where possible, it is important that these do not interfere with the overall plan for the young person e.g. by interfering with snacks or mealtimes, and that there is an awareness that some activities such as baking may not always be suitable.

e) Time off Ward

Many paediatric in-patients will have periods out of the ward with parents even for short periods of time, e.g. visits to the hospital canteen or walks outside the hospital. 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 be able to be off the ward, they may take advantage of the time off the ward to over exercise, to dispense with food, to water load, or to use energy by simply not keeping warm in cold weather. In addition, their behaviour with parents out of the ward environment may be more difficult. It may therefore be necessary to consider restricting time off the ward.

4. Dietetic input

Paediatric dietitians 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 dietitians working in CAMHS, who should either be familiar with nutritional requirements for growth and paediatric formulations for nutritional supplements, or should consult accordingly. In the absence of an appropriately skilled dietitian, local expertise should be sought (e.g. paediatrician, eating disorders practitioner) and advice from a specialist centre sought. The paediatric dietitian ensures that essential nutrients are met for growth and development during this complex time. This is particularly important if the young person follows a special diet, such as 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 point of 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 meal plan with young person that gives a balanced diet. What works reasonably well is agreeing with the young person 3-5 dislikes, generally foods he/she also did not eat before developing an ED. A choice of snacks from a list of items with similar calorific value is helpful.

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

The meal plan should ideally comprise solid food; if meals are not completed then children / young people have 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 in the outset to avoid a nasogastric tube insertion. Dietitians 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 children are unable to meet the prescribed calorie intake within 24hrs of commencing the meal plan then a nasogastric tube insertion should be considered, balancing the level of risk and the young person's and parents' wishes. Such a discussion may help to improve the patient's compliance either with the normal diet or with accepting 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 (see below).

5. Managing disordered eating and drinking on the paediatric ward

a) Meal plans

Meal plans are often used (see above) and may need to be for both food and fluids. The meal plan should be overseen by a paediatric dietitian; ideally this should be someone with expertise in this area. The plan needs to be agreed wherever possible with the young person although their nutritional needs are paramount. It is important that a record of the meal plan is held by both staff and by the young person unless they prefer not to have a copy.

b) Snack time 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, the length of snack and meal times e.g. 15 minutes per snack and 30 minutes per meal all need to be agreed and documented. Any actions to be taken if a meal is not completed need to be agreed and documented in advance e.g. a volume of bolus feed to be given instead of the completed meal. Individual circumstances will help to dictate the exact needs of the young person and any help that may be needed with respect to helping them eat the required amount of food.

c) Nasogastric and other routes of feeding

The preferred option for re-feeding is oral food and fluid. Oral nutritional supplements can be helpful when food or fluids are being refused, and some young people need to be fed via nasogastric tube but neither of these should not preclude food continuing to be offered. Some young people prefer nasogastric feeding because it relieves them of the responsibility of eating⁵⁴, 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 undertaken in liaison with a dietitian.

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 e.g. hourly observations of the feed given.

Insertion of a nasogastric tube against the will of the patient usually requires the presence of mental health nurses trained in safe control and restraint techniques, and 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 severe or chronic cases, particularly when a rehabilitation approach is being taken, when the focus is on improving other areas of functioning.

d) Documentation

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

e) Weighing

Weighing in the same way and at the same time will help to minimise fluctuations in weight from non-nutritional reasons e.g. weigh on the same scales, in the morning before breakfast and after emptying bladder, in underclothes only (bearing in mind that items can be hidden in these).

An awareness of water-loading in order to mimic weight gain needs to be considered. This may need restriction of access to fluids and to have an awareness of drinking from other patients drinks, taps/toilets/showers and hence restriction to these may need to be arranged. If there is ongoing concern, measurement of urine specific gravity at the same time as being weighed may be necessary.

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

6. Recognizing 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 patients 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 last 3 months and those with abnormal electrolytes prior to re-feeding.

Recognising and avoiding re-feeding syndrome is the most controversial area as far as this and the adult MARSIPAN report are concerned. The tension lies between taking a cautious, 'safe' approach to re-feeding, based on the few cases of fatal re-feeding syndrome that exist, versus the extensive

clinical experience of re-feeding patients with eating disorders without incident, and a very realistic fear that an over cautious approach can be counterproductive in an illness that welcomes any opportunity to minimize even very low intakes. We are aware of patients with anorexia nervosa who have been admitted to paediatric wards because of medical instability, been re-fed according to a careful re-feeding protocol, and lost a further 3-4 kg as a result. This phenomenon, known as '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, 2009) to 60kcal/kg (Afzal 2002). Various formulae exist to calculate energy requirements based on Basal Metabolic Rate (BMR [Schofield Equation]) + Activity Factors (AF [1.1 – 1.3]), and some dietitians advocate aiming for 35-40% of calculated BMR (500-600kcal/day). Other clinicians take a much more pragmatic approach, starting at around 1000 kcal and increasing carefully with close monitoring of electrolytes. Even this is somewhat cautious, given recent data on the impact of more aggressive re-feeding. Whitelaw et al.⁵⁵, in a sample of 29 adolescents with a mean body weight of 72.9%, found that, starting at 1,900 kcal or higher in the majority of patients, 37% developed mild hypophosphataemia and no patients developed moderate or severe hypophosphataemia. However, 4 patients were considered sufficiently high risk to start with lower regimes, or on rehydration alone, and % ideal body weight was significantly associated with the subsequent development of hypophosphataemia.

Together with the small literature on re-feeding syndrome (Appendix 2) and our collected clinical experience, this suggests that for the majority of patients an overly cautious approach to re-feeding is not necessary, BUT that close monitoring is required and in very high risk patients 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, dependant on biochemistry. If phosphate drops, then intake should remain static, not reduce, until it stabilises. Typically, bloods are done daily during the at risk period, defined as days 2-5, in those who are being NG re-fed or have risk factors for re-feeding syndrome. In those with electrolyte disturbances they may need to be more frequent. Repeating after 7-10 days is recommended because of the risk late re-feeding syndrome. For those being orally re-fed without risk factors or 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 requirements 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 the first week, then meal plans should be altered to ensure continued weight gain of 0.5kg to 1kg 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 pre breakfast, post 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. Trends are more important than individual weight measurements.

Although risk of re-feeding syndrome is greatest in first few days of refeeding it may occur later and biochemical monitoring should continue for a fortnight or until electrolytes parameters are stable⁵⁶.

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

In adults, it is standard practice to prescribe thiamine replacement and prescribe 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 either level falls significantly. For older patients, following adult guidelines re prescription of thiamine is justifiable.

GUIDANCE BOX 8: MANAGEMENT OF RE-FEEDING

1. Starting intake should not be lower than intake prior to admission. For most patients starting at 20 kcal/kg/day or higher, such as 1000 kcal 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 <0.4 mmol/l.
2. In the highest risk patients, and usually in paediatric rather than psychiatric settings, it may be necessary to use lower starting intakes (e.g. 5–10 kcal/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, infections etc), or very low initial weight.
3. If low initial calorie levels (5–10 kcal/kg/day) are used, 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.
4. Re-feeding syndrome is most likely to occur in the first few days of re-feeding but may occur up to two weeks after. Biochemical monitoring should continue for a fortnight or until electrolytes parameters are stable

7. Behavioural management of patients 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 that can 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 AN will quickly pick up 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 of, 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 excessive numbers 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; preventing attempts to feed fully (disposing of food, recruiting friends and family to dispose of food,

turning off NG feeds and drips or aspirating the NG 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 go off 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, wearing weights or other items and gripping the weighing machine with long 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 they might be criticised as a result. As above, 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 challenging patients 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 and by observing patients during therapeutic activities such as group therapy. Patients whose behaviour is not controlled by these measures may need to be one to one (occasionally a higher ratio is required) for 24 hours a day. This is also used for suicidal patients. 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 eating disorders is unlikely to be successful in preventing a patient from engaging in all behaviours alluded to. 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 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, say absconding or attempts to sabotage feeds. Factors such as the patients' 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 – see section B12 below.

The more common behaviours that need consideration are:

a) *Exercise/activity*

Total bed rest may be indicated if the patient 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, e.g. not to be unsupervised in the bath or shower, unlocked bathroom or toilet doors but with provisions for privacy etc. needs to be explained, documented and maintained with consistency. Restriction of excessive activity and explanation of what is possible may be required.

If patients are being expected to bed rest it's absolutely essential that a program of pro-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.

b) Purging or other methods of avoiding weight gain

Self induced vomiting may be decreased by limiting access to toilets after food 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 wards e.g. from crash trolley, which may be in readily accessible place on ward, from treatment room if it has easy access or if staff inadvertently leave syringes by bed space. Laxative abuse requires a supply of laxatives which may be more difficult in hospital but nevertheless requires vigilance.

c) Bingeing

Although uncommon in the younger age group, it is possible and nursing staff need to be aware of the 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.

d) 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.

e) Co-morbid Conditions

It is not uncommon for individuals with anorexia nervosa to have other conditions such as obsessive compulsive disorder or anxiety. In these situations, advice about specific management is required from the psychiatry staff.

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

f) Management of violent and other disturbed behaviour

It is good practice for paediatric units and Trusts 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 will need to be supplemented by prompt discussion with psychiatric services about the situation and in particular 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 required. If physical restraint is likely to continue to be needed then it is important that this is undertaken by individuals that are specifically trained in this area. These individuals in practice are most likely to be psychiatric staff and appropriate arrangements will need to be made to ensure this.

GUIDANCE BOX 9: BEHAVIOURAL MANAGEMENT OF EATING DISORDERS IN A PAEDIATRIC SETTING

1. If weight gain is less than expected, that is less than 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 shifts of significant amounts of weight are observed e.g. 2kg within a few days, assume water loading and other fluid manipulations.
2. Early in the admission schedule a meeting of key staff responsible for treatment i.e. 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 patient in discussions about the treatment plan.
3. Establish the level of nursing supervision needed, and the level of parental care possible or appropriate. When possible, employ a nurse from the SED service to supervise and train nurses caring for these patients.
4. Write a management plan to be transferred between nurses with proper handover.
5. Schedule regular review meetings of key staff, preferably with parents and young person involved, to ensure treatment goals are met or revised if needed.
6. Be prepared to use the Children Act and/or Mental Health Act if necessary.

8. Families

Families do not cause eating disorders, and assumptions that family involvement is unhelpful should not be made prematurely. Parental anxiety is often valid, and all too often is 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 reach MARSIPAN criteria, they are likely 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 behaviour (such as driving to a particular shop at midnight in order to get one particular type of food). In younger patients with anorexia nervosa

(typically premenarcheal girls, or boys (in whom puberty is later)), separation anxiety is also a common feature.

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

a) Parents

Parents are best considered partners in the process of recovery, and appropriate involvement 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 nursing staff will be better able to feed the patient in some instances, by virtue of their emotional distance. 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 stay and level of ongoing treatment need. Providing opportunities to practice in different contexts (e.g. off the ward, at home) will help clarify the level of support the young person needs to eat and from whom.

Most paediatric wards will have open access 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 need to be balanced against the needs of the young person. Given that the admission is often much longer than the "usual" paediatric admission and there may be parental exhaustion, it is important that discussion is given to their needs and of other siblings. 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 may be advisable. Individual circumstances will need to be considered with respect to the presence or absence of parents at meal times.

b) Siblings

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

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

c) Other visitors

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

9. Criteria for discharge from paediatric inpatient admission

Ideally, patients should be discharged from the paediatric ward as soon as the reasons for admission have been addressed and physical health is robust enough for safe discharge. However, the decision

regarding the timing and placement after discharge requires careful consideration of the individual's needs and should not be influenced by factors such as the paediatric bed state. Discharge should be planned and agreed and a precipitous discharge avoided. Discharge planning involves the multidisciplinary discussion at senior level including both the paediatrician and psychiatrist in charge and other relevant personnel such as those in charge of a SEDB if required. Given that this takes a finite time it is important that discharge planning is started as soon after admission as possible to avoid unnecessary delays.

Discharge may be to a SEDB or the community. This decision should be made after the following factors have been considered:

- The original rationale for admission. Has this resolved?
- The current physical health and any continuing medical requirements
- Nutritional status, method of feeding and monitoring
- Mental health and specific requirements, is a SEDB required
- Whether the young person is subject to compulsory treatment and admission
- The family and individual's needs, circumstances and preferences

We suggest that the young person should not be discharged whilst they still meet the criteria for being severely unwell and at high risk, until a % median BMI of at least 70% is reached, an adequate rate of weight gain is established if they are discharged to the community, in particular that cardiovascular parameters as per Section II.A.2 are satisfactory 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 a SEDB. As per Guidance Box 3, 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 is adequate and safe provision for the safe monitoring and management of re-feeding syndrome if discharged from a paediatric setting to a SEDB or equivalent.

If a SEDB is deemed necessary after paediatric discharge, it may not be available immediately. In these circumstances it is likely that the individual remains a paediatric in-patient pending transfer and in these situations all the advice in sections regarding points to consider in an in-patient paediatric setting should be considered and continued until transfer is possible.

It is advised that transfer and discharge arrangements are agreed and documented. At the point of discharge appropriate documents and any follow up arrangements needed should be available to the receiving health professionals and family. See Guidance Box 4.

GUIDANCE BOX 10: DISCHARGE FROM THE PAEDIATRIC WARD

1. Criterion for transfer: Physically stable with clinical problems which safely can be managed in SEDB or community.
2. 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
3. Discharge planning should begin as soon as practicable after admission and the criteria for discharge agreed
4. The patient should no longer be severely physically ill as defined within section II.A. Any physical health reason(s) for paediatric admission should have resolved or can be safely managed elsewhere. It is not sufficient to have just addressed the physical factor that required admission e.g. hypoglycaemia
5. 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
6. Transfer to a 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.
7. Where the criterion for discharge is met but a SEDB if required is not immediately available, a continuing multidisciplinary plan for care must be agreed and implemented with consideration of the same factors as advised in section III.B until transfer is possible, with regular multidisciplinary meetings to assess risk, review progress and plan care accordingly
8. Full documentation and plans for post discharge care are required at the point of discharge with definite plans in place to address needs
9. All transitions are potential moments of increased risk

10. The role of commissioners in supporting Paediatric/Medical Inpatient services for MARSIPAN patients

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 mental health beds for children and adolescents are in generic adolescent units. Often these units also function as acute admission services for severely mentally ill children, or have diverse roles (providing a "psychosis" service) and can be functionally disconnected from Tier 3 services. Children who need paediatric care may need to be admitted to acute paediatric beds, often in very busy general hospitals cared 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 for the following services:

- a) A "top down" approach to ensuring that each region defines the location of the beds that will become SEDBs if these beds 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)
 - b) A clear view as to whether such beds 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 unit that does not take emergencies, that there are alternative arrangements for the timely admission of young people with severe anorexia nervosa (e.g. an identified paediatric ward).
 - c) When the location of SEDBs are identified, commissioners should be supported to ask about the establishment of links with (an) identified paediatric colleague(s) 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 and paediatric endocrinology and metabolic medicine. Funding appropriate mental health nursing supervision on paediatric wards when necessary is also an important consideration for commissioners. Furthermore, they should consider care pathways to ensure appropriate transition between services.
- This "Junior MARSIPAN" group (C&A psychiatrist, paediatrician, paediatric dietitian, paediatric and psychiatric/eating disorders nurses) would act as a focus for skill development and dissemination, advice when a child 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.
- d) The "Junior MARSIPAN" team should have explicit links with Tier 4 CAMHS ED services, who will work in conjunction with Tier 3 CAMHS services.

It is difficult to estimate how many such beds should be available and the need might vary depending on local Eating Disorder Services. We appreciate that not all Acute Hospital Trusts will be able to reach the level of provision we recommend, and suggest that 1 or 2 hospitals be identified within each SHA area (average population in England 5 million) so that patients can be transferred if required.

11. Decision making

It is important to have good communication amongst the multidisciplinary team and in turn with individuals and their families to ensure consistency with 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 will help to make sure that important information is not overlooked. How decisions are achieved may vary depending upon the severity of the illness and the setting of the care. It is vital that senior clinicians are directly involved but equally important to recognise the validity of all viewpoints of 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 important 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 are 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. As in section B9 above, parents should be central to decision making, provided they have the necessary information to do so. This sets the scene for the collaborative working style that underpins family work advocated for anorexia nervosa in young people.

12. Documentation

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

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

D. Management in Specialist Eating Disorders Beds (SEDBs)

1. Medical expertise in the SEDB admitting young people with severe anorexia nervosa

There are fewer specialist eating disorder units (SEDU) for young people (below 18 years of age) 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 (GAU), 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. 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 specialist eating disorder beds (SEDB), and commissioners should consult this document regarding the necessary resources needed on such units. In this section of the document, the abbreviation of SEDB is used to refer both to SEDUs and to GAU with dedicated eating disorders expertise and resources.

Medical, nursing and dietetic staff for SEDB 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 higher level than is usually encountered or required in general child and adolescent psychiatry.

Consultants for SEDB should, as part of their post-graduate training, attend a course in clinical nutrition, such as the Inter Collegiate Course on Human 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 a SEDB unless services required in their management are not available. This means that for some units, more medically ill patients will be treated in a SEDB than before 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 SEDB 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.

GUIDANCE BOX 11: SERVICES PROVIDED BY SPECIALIST EATING DISORDERS BEDS (SEDB)

1. Safe re-feeding, including access to dietetic advice
2. Expertise in NG feeding (insertions may be performed off site)
3. BP, Pulse, Temperature, and Serum glucose monitoring up to 4 hourly
4. Daily biochemistry
5. ECGs, daily if needed
6. Timely access to medical staff during and out of hours
7. Assessment of tissue viability in emaciated patients and treatment of pressure sores
8. Immediate cardiac resuscitation with staff trained to administer resuscitation
9. Access to advice from paediatricians and paediatric dietitians in a timely and flexibly responsive manner ideally in the form of a "Junior MARSIPAN" group
10. Frequent nursing observations, up to and including 1:1 when indicated
11. Prevention of anorexic behaviours e.g. water loading, excessive exercising
12. Management of the resisting child - including safe holding techniques and the acute and medium term paediatric psychopharmacology of children with eating disorders
13. Use and management of the Mental Health Act, expertise with the Mental Capacity Act with respect to 16 - 17 year olds and Children Act for children under 16 years
14. Psychological interventions for the young person and the family
15. Age-appropriate educational facilities

2. Dedicated Paediatrician to the SEDB

In order to maximize 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, is 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. The Paediatrician should be available to discuss abnormal results, and to supervise and teach on-call doctors who may be placed in the position of advising SEDB staff.

3. 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 not generally

available on SEDBs are listed in B2, while those that should be provided are listed in Guidance Box 10.

4. Practical considerations

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

5. 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 patients actively resists re-feeding and do not respond to verbal approaches. Under these circumstances, clinicians have to make the difficult choice between physical restraint or 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.⁵⁷⁻⁶⁰ in young people. Gowers et al⁶¹, in a retrospective case note study, found that twenty seven percent of 308 child and adolescent eating disorder cases (both inpatient and outpatients) in seven specialist CAMH services 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 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.

6. Additional nursing support

As above, the key determinant regarding funding 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 ED behaviours, consideration should be given as to whether that young person might be better placed in a SEDB.

In reality most children who need additional nursing support are going to require it 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 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 leave 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 SEDB in each area would assist with this. In this circumstance arrangements would be negotiated locally, within an agreed financial protocol, potentially shared and subject to quantitative and qualitative scrutiny.

7. Areas with limited local eating disorder provision

a) Responsibilities of health commissioners

The Royal College of Psychiatrists' (2000) report on eating disorders made recommendations on provision for eating disorders services for adults, but no specific recommendations for children and adolescents currently exist. The report is currently under revision, and includes a survey of eating disorders provision in all CAMHS services. In the absence of specific recommendations on provision, we urge all purchasers to ensure as soon as possible that young people living in their areas have access to a specialist eating disorders services, with appropriately trained staff, and including both inpatient and outpatient 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 patients with eating disorders in paediatric settings, providing appropriate expertise in relation to psychiatric and legal aspects of care.

b) 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 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 dietitian 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 Junior MARSIPAN cases, to include identification, resuscitation and preparation for transfer to a suitable treatment setting with SEDB.
3. In the case of urgent treatment needing to be provided locally, e.g. in a paediatric ward, eating disorders expertise should be sought to provide guidance and staff support, and arrangements made for SED support to be provided on site where possible. Many specialist eating disorders services see this type of outreach as part of their role.

E. Audit and review

1. 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 B-EAT 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@leedsaft.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 in 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 review in future.

2. Quality review of services

The Royal College of Psychiatrists is embarking on a nationwide Quality Network in which both inpatient and outpatient Eating Disorder 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 eating disorders patients are seen. For more information, see <http://www.rcpsych.ac.uk/rollofhonour/sections/eatingdisorders/qualityassuranceford.aspx>

3. Local Governance

Each Paediatric and Eating Disorders service must monitor quality of provision for management of severely ill patients with Anorexia Nervosa. A clear policy should be generated jointly and available in each setting. Any serious incident or “near miss” should be investigated jointly and a report issued which highlights changes in psychiatric or paediatric services or in liaison which should take place. Such recommendations should be followed up within a reasonable timeframe, say 3-6 months, to establish that the changes have occurred.

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Final

V. APPENDICES

Appendix 1: Contributors to the Junior MARSIPAN report

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Appendix 2: Comparison of two methods of calculating degree of underweight for females

Age (years)	Median height (cm)	Weight (kg)	BMI (kg/m ²)	% Median BMI for age & sex **	% Weight for height ***
10	133*	30	17.0	101.2	103.2
		25	14.1	83.9	86.0
		22.5	12.7	75.6	77.4
		20	11.3	67.3	68.8
		17.5	9.9	58.9	60.2
12	149*	40	18.0	99.4	100.6
		35	15.8	87.3	88.0
		30	13.5	74.6	75.4
		27.5	12.4	68.5	69.2
		25	11.3	62.4	62.9
14	159*	50	19.8	102.1	103.7
		45	17.8	91.8	93.3
		40	15.8	81.4	82.9
		35	13.8	71.1	72.6
		30	11.9	61.3	62.2
16	163*	55	20.7	101.5	97.6
		50	18.8	92.2	88.7
		45	16.9	82.8	79.9
		40	15.1	74.0	71.0
		35	13.2	64.7	62.1

*Median heights for 10,12,14,16 year old female respectively as per UK/WHO charts 2009

** Calculated from median BMI for 10,12,14,16 year old female respectively as per UK/WHO charts 2009, using the formula: %BMI = (actual BMI/median BMI for age and gender) x 100

*** From WHO/NCHS normalised reference data for females, using the formula: % weight for height = (child's weight/reference weight for child of the same height)*100

Appendix 3. Comments from GPs and parents/carers group

GP comments:

- Rare disorder, resulting in lack of experience.
- Not sure where 16-19 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 GP 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 pt does not want any help?
- When to be concerned?
- What investigations should be done?
- Patient may attend practice nurse who may not recognise underlying eating disorder and just refers to dietitian. 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 sufferer to eat an unrealistically large meal
- Specialist nutritional advice, meals, and guidance are not usually provided when a child is an inpatient, usually on a children's ward and offered that same meals as other patients.
- 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, lack of availability in staff.
- Lack of resources (leaflets/advice etc) to support sufferer/carers
- More feedback from health professionals, and more practical help would be useful.
- Education of nursing staff (Meals/Psychological intervention/Not discussing patient in front of patient 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
- Client 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/sufferers/siblings

Appendix 4: Summary of literature on re-feeding syndrome in children and adolescents

Articles that reported symptoms associated with the re-feeding syndrome (hypophosphatemia, hypotension, oedema and cardiac arrhythmias) following enteral nutrition in children or adolescents with anorexia nervosa are shown in the table below. All of the 25 reported cases of the re-feeding syndrome identified in the literature search commenced feeding 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 re-feeding of 27kcal/kg.

At present there is no scientific basis to recommend re-feeding at 10-60kcal/kg. These figures have been based on 25-75% of Total Energy Intake (TEI) and regardless of how cautious re-feeding is commenced, individuals at high risk could still go into the re-feeding syndrome. More research is needed in this area.

Table: Clinical findings from a literature review looking at Re-feeding Syndrome in children and adolescents with anorexia nervosa

Author	Age yrs	Ht/wt %	Initial feed rate (kcal/day)	Initial feed rate (kcal/kg)	Feed Type and route	Re-feeding Syndrome symptoms
Kohn 1998	12	61	500	16	Polymeric feed Naso –gastric tube	Bradycardia Hypotension Hypophosphatemia
	13	70	1200	36	Solid food oral intake	Hypotension Delirium Hypophosphatemia
	19	62	1000	27	Solid food oral intake	Oedema Bradycardia Delirium
Fisher 2000	16	50	1000	40	Solid food oral intake	Hypophosphatemia Hypotension Bradycardia
Ornstein 2002 – 19 cases of re-feeding syndrome	Mean 16.65	Mean 68	Mean 1645	Mean 22	Polymeric feed Naso –gastric tube	Hypophosphatemia
O'Connor & Goldin 2010	10	67%	600	40	NGT	Hypophosphatemia Cardiac arrhythmia

Appendix 5: Some cases reported to the Junior MARSIPAN group by colleagues

1. Transfer from independent sector SEDU to NHS adult services

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

The patient was offered outpatient 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. The treatment philosophy was based on the individual responsibility of the patient in contrast with the strong family approach of the CAMHS SEDU. The patient disengaged from the outpatient service, and was discharged due 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 A&E department. As she did not comply with re-feeding, was detained there, and N/G feeding was started against her will, whilst waiting for a SEDU admission. However, her behaviour could not be managed by the nursing staff of the medical ward, and she emptied her N/G feed into the sink in her bedroom. The commissioners tried to find the cheapest private inpatient 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 & cooperation between NHS and private sector
2. Differences of approach between CAMHS and adult services
3. Taking carer's concerns seriously
4. Discharge of a deteriorating patient due to DNA
5. Nursing supervision on the medical ward
6. The role of commissioners

2. Stigma against 'psychiatric' patients

A 12 year old boy was referred by a paediatrician to CAMHS with poor weight gain and growth. The parents were concerned about the possibility of a physical illness, but none was found, and the provisional diagnosis of EDNOS was made. The patient had a chronic fear of vomiting and poor dietary intake over the previous 18 months, in the context of long term faddy eating. The parents were very anxious about him, and they were unable to help him achieve sufficient dietary intake. After some weeks of unsuccessful outpatient treatment, the patient was admitted to the local Tier-4 unit. Here, he was able to gain some weight, but he and his family did not engage with psychological interventions, and they asked for discharge before weight restoration could be completed. The psychiatrist on the unit asked the referring paediatrician to review the case given the atypical presentation, but he did not think that there was an organic cause. The patient was diagnosed with

hypophysis germinoma a year after discharge. By that time, he was blind in one eye and had several metastases.

Issues:

1. Psychiatrists accepting the views of the referring paediatrician
2. Personal and family history clouding the issue
3. When to do brain scans on an atypical ED?
4. Stigma against 'psychiatric' patients?

3. 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 BP, low blood sugar levels, low temperature, acrocyanosis, and occasional tachycardia in the context of bradycardia. Her dietary intake was less than 500 kcal/day for about 8-10 weeks. A referral to the local Tier-4 CAMHS 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 N/G treatment, as the patient was refusing to eat on the ward and her dietary intake had reduced to about 2-300 kcal/day. The community CAMHS consultant felt that N/G feeding was not indicated as the patient still had a BMI of 14, and she was awaiting 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 NG feeding was started.

Issues:

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

4. No specialist on Friday

A 15 year old was transferred from a paediatric ward to a private SEDU with a history of severe AN. On admission, it turned out that his dietary intake had fallen to 200-300 kcal per day in hospital, and during the first night on the SEDU, his pulse dropped to 32/min 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 MAU, 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 dietitian input until Monday (3 days). The associate specialist running the unit at the time also commented that 2 weeks before another 17 year old patient with anorexia had died in the same bed. The SEDU staff were able to implement a gradual re-feeding programme, starting with 1000kcal per day, on the MAU behind the curtains in secret (as this was against the MAU staff's recommendation). The patient was returned to the SEDU 2 days later, as the safer option. The patient lived to tell the tale.

Issues:

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

5. Nobody's patient

A 16 year old girl with chronic AN, under the care of a CAMHS outpatient team, became medically unstable due to weight loss. She was eventually admitted to a paediatric ward, pending further discussion of her treatment needs. The specialist outpatient 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 her admission. Eventually the local adult ED service offered dietetic input on the ward in relation to refeeding, 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 outpatient, and was transferred to an SEDB.

Issues:

1. Nobody's patient, unclear responsibilities medicolegally
2. Poor and unfocussed paediatric care, influencing course of treatment

6. Inconsistent care and poor collaborative working

A 14 year old girl is admitted urgently to a paediatric ward with a potassium of 1.5 and a history of escalating intractable vomiting whenever she eats. She has a past history of AN, but both she and her parents identify this as different and the vomiting is not self induced. The paediatric team, who work on a 'consultant of the week' system, start investigating the vomiting once her potassium is stable. Investigations are normal and the paediatric team conclude that it must be an eating disorder, and refer to the CAMHS eating disorders team. Meanwhile she has lost a further 3kg on the ward while the investigations were taking place. By the time the ED team are involved she is 60% median BMI. The paediatric team want an eating disorder diagnosed and for her to be transferred to a psychiatric unit. The girl and her family are reluctant for the ED team to become involved and do not want another admission to an ED unit. The CAMHS ED team think the priority is to start nutritional rehabilitation and that she is at risk of refeeding syndrome, so should remain in the paediatric setting, which she does for the short term with an appropriate re-feeding schedule in place. The third consultant paediatrician to be responsible decides to discharge her after partial nutritional rehabilitation to 66% BMI without consultation with the CAMHS ED team.

Issues:

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

7. No appropriate treatment setting

A 12 year old girl with rigid eating behaviour, highly limited intake and escalating weight loss will only eat when fed by her mother. When challenged she becomes extremely distressed, running out from the house or attempting to jump out of windows. If she is restrained she bites and kicks or bangs her head against walls. She looks about 9 years old. She is admitted to the local paediatric ward, where some intake is re-established and a meal plan introduced, but on discharge her weight slowly drops again as the meal plan was not adequate for her needs. She is now 64% BMI and eating less than 400 kcal per day. She is medically stable, but her intake is declining daily. The only specialist ED inpatient provision in the area is in a General Adolescent Unit for patients age 13 and over, with a range of diagnoses. The unit is prepared to admit a 12 year old, but her parents refuse.

Issues:

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

8. A successful MARSIPAN case!

A 14 year old girl attended her GP after fainting episode. She was urgently referred to rapid access clinic with a diagnosis of probable AN where she was seen the following day together with her mother. During physical assessment the girl was had a BMI around 0.4th centile for age, her heart rate was 42/min and BP 90/55 mmHg. She described dizzy episodes. ECG and biochemical parameters were normal.

The girl was keen not to be admitted 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 dietitian. The local mental health service was able to see the family the next day and provide support 3x/ week for the 1st 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 diet and physical activity would result in admission, something she desperately wanted to avoid.

The girl showed good weight gain, initially of 1-2 kg per month, and after one year she was discharged from CAMHS and by the paediatrician.

Issues:

1. Close collaboration between mental health professionals and paediatricians is essential in young people with AN with physical symptoms

Appendix 6: Protocols for Junior MARSIPAN cases

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 for 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, together with some of the literature referred to in this document. They are not included here as each is a lengthy document

- <http://sites.google.com/site/marsipannini>

The Nottingham Eating Disorders Guideline, a paediatric care protocol, can be found at

- <http://sites.google.com/site/nottinghamchildhealth/guidelines/adolescent-health>

The Cheshire and Merseyside Adolescent Eating Disorder Service have produced a comprehensive protocol entitled 'Anorexia Nervosa within an Inpatient Paediatric setting - Protocol for the Nursing Management (including Dietetic Guidelines)'.

- http://www.cwp.nhs.uk/1/Documents/Anorexia_Nervosa_within_an_Inpatient_Paediatric_setting.pdf

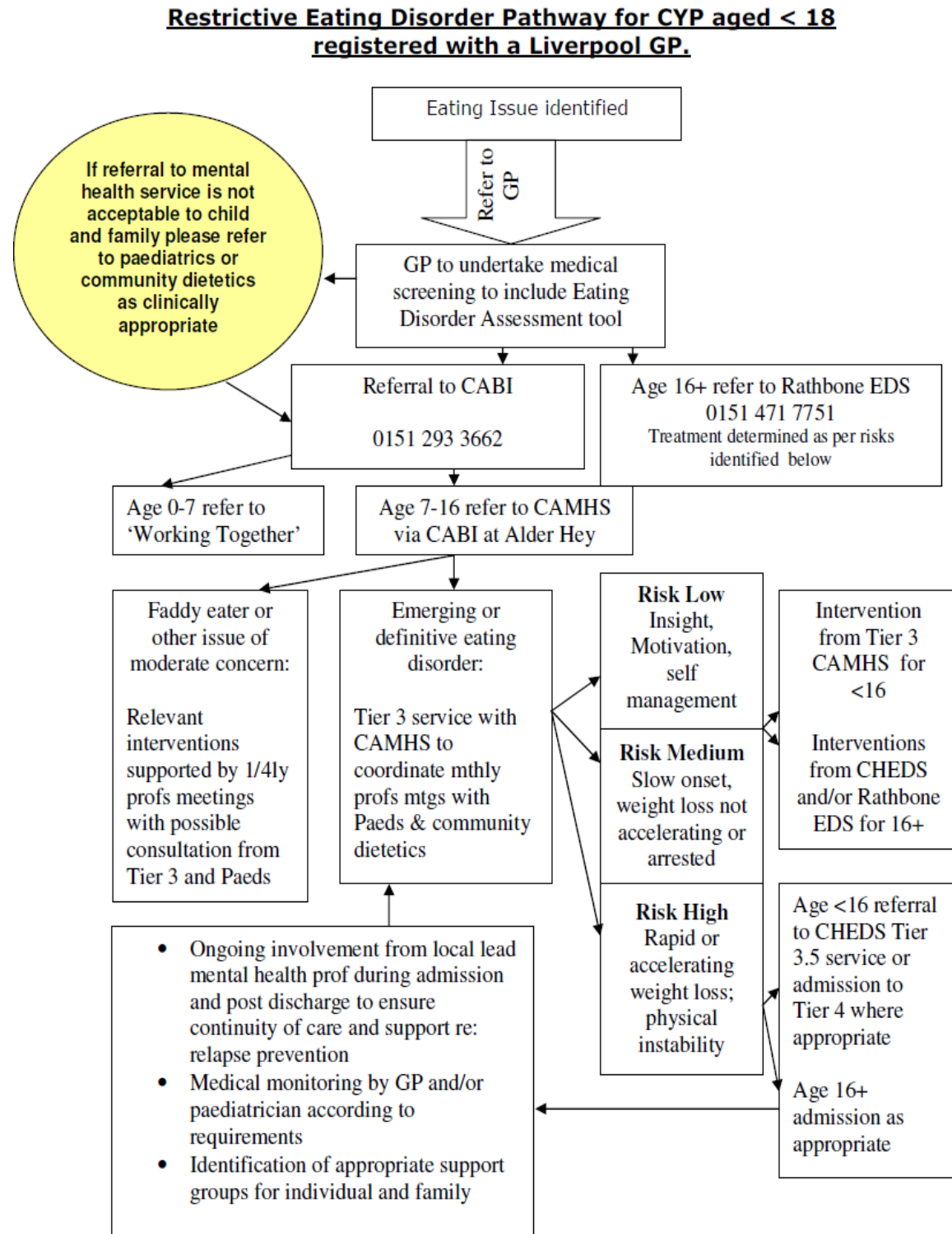
The Academy for Eating Disorders has produced a guide for early identification and management of eating disorders, which can be downloaded and printed off from the AED website.

- http://www.aedweb.org/Medical_Care_Standards.htm

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

Appendix 7: Example of a care pathway designed to improve speed of referral for young people with anorexia nervosa

[CABI = Centralised Assessment and Brief Intervention Service]



cypedpathway

versionvii 08/10.