

Maudsley Service Manual for Child and Adolescent Eating Disorders

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Revised July 2016

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Introduction

The Maudsley service manual for the treatment of child and adolescent eating disorders has been developed over many years out of a series of treatment evaluation studies and their application in clinical practice in a multidisciplinary team context resulting in models of intervention described here for the treatment of anorexia nervosa, bulimia nervosa and other related eating disorders.

The manual draws together all of the treatment elements that have been developed by the Maudsley team and used in clinical practice by the Maudsley Child and Adolescent Eating Disorders Service (CAEDS). Conceptually this service model, while drawing strongly on family systems theory, aims towards integration of different systemic approaches and also remains open to other psychotherapy models in general. These approaches range from systemic therapy for anorexia nervosa, through multi-family therapy for anorexia and bulimia nervosa, and individual and group models using systemic, cognitive behavioural, dialectical behavioural theories and neuropsychological conceptualizations. We will also describe the specialist Intensive Treatment Programme (ITP), which incorporates all of the aforementioned modalities within an intensive out-patient day programme.

It is suggested that therapists should familiarise themselves with all sections in order to develop an understanding of the crucial differences and similarities between the presentation of and resulting approaches to the treatment of patients with different types of eating disorder. They should first become familiar with the main theoretical principles and the model of change described here as this will influence many aspects of the therapy that they carry out using the specialist eating disorders manual. They should consider the main conceptual principles that influence their own current practice and the connections they may make between these principles and those set out in this manual. Therapists should reflect specifically on how this applies to their own experience of working with children and adolescents with an eating disorder and their families, which may reveal important differences or similarities. While using this material, therapists would be expected to retain important elements of their individual therapeutic style whilst at the same time ensure treatment adherence to the crucial central concepts and interventions which have contributed to the robust evidence base for the family treatment for anorexia nervosa and the emerging understanding of the treatment needs of young people struggling with bulimia nervosa

The manualized out-patient family therapy approach for child and adolescent anorexia nervosa (FT-AN) described here is the most comprehensively developed treatment and is supported by the strongest empirical evidence and for this reason provides the central component of the Maudsley service manual. The other treatments (multi-family therapies for anorexia or bulimia nervosa and individual treatments for bulimia nervosa) are at an earlier stage of development and have less evidence supporting them. A significant amount of the systemic theory and techniques remain relevant to these other treatments but they also strongly draw on other theories and these will be found in the relevant sections as part of the manualized approaches to these other treatments. The early sections are of course equally relevant to all the treatments (multidisciplinary team working, team structure etc.)

Ethical practice

All therapists and clinicians using the manual should be guided by codes of conduct and ethical guidelines relevant to their profession e.g. Association for Family Therapy (AFT) Code of Ethics and Practice, UKCP Code of Ethics, BPS Code of Ethics and Conduct Codes, HCPC Standards of Conduct, Performance and Ethics Codes, NMC Standards of conduct, performance and Ethics, GMC Code of Practice code, NHS Clinical Governance and Practice guidelines etc.

The Maudsley service model for treatment of child and adolescent eating disorders

Brief history

The Maudsley Child and Adolescent Eating Disorders Service (CAEDS) and the treatments described in these manuals emerged out of clinical experimentation (Dare 1983) and a number of research trials conducted at the Maudsley Hospital dating back to the 1980s and 1990s (Russell et al., 1987; Dare et al 1990; Le Grange et al 1992; Eisler et al., 1997; 2000; 2007) and later developments of Multifamily therapy for anorexia nervosa (MFT-AN)(Dare & Eisler, 2000) and treatments for bulimia (Dodge et al 1995; Schmidt et al 2007; Stewart et al 2015). It has also been informed and influenced by developments of systemic theory (Minuchin et al 1978; Dare et al 1990; Eisler 2005; Eisler et al 2015), the influence of feminist ideas on these developments (Hoffman, 1985; 1990) and the impact of narrative concepts on systemic therapy (White & Epston, 1990; Wallis et al 2007). A broadening of the research base (Robin et al 1999; Lock et al 2005; 2006; 2010; Madden et al 2014; Le Grange et al 2007; 2014) has provided strong empirical support for the efficacy of a systemic approach for the treatment of eating disorders in young people alongside clear evidence of a lack of family aetiology (Jacobi et al., 2004; Keele & Forney, 2013; Konstantellou, et al 2012).

The Maudsley CAEDS was set up as a small specialist service in 1995 and over the next decade grew to become a well-resourced comprehensive specialist outpatient service. It has continued to develop and evaluate new treatments both for outpatient work and for application in its Intensive day Treatment Programme (ITP), which was opened as part of CAEDS in 2010. Before describing the working of the complex multidisciplinary team and the treatments provided by the team a brief account of two studies is given that provide the main rationale for offering specialist services for anorexia nervosa and other eating disorders on both clinical and cost grounds.

The London Care Pathways Study

A study carried out by House and colleagues in 2012 highlighted the major differences in case identification, consistency of care and rates of in-patient admissions for young people presenting with an eating disorder to child and adolescent mental health services (CAMHS) dependant on the type of service available to them; specialist child and adolescent eating disorders service (CAEDS), specialist CAMHS with a specialist “mini” eating disorders service or generic CAMHS.

Within the 3 different classifications of service, presentation rates varied widely (rate = per 100,000 13-17 year olds a year); for the CAEDS and specialist CAMHS the rate of presentation was 62.6%, 74.4% respectively and 26.9% for generic CAMHS.

Where the patient received a specialist assessment followed by specialist treatment, admission rates to hospital ran at 15.1% while in the group of patients who received non-specialist assessment followed immediately by specialist outpatient treatment 18.8% of patients were admitted. However, for the patients who received a non-specialist assessment followed by non-specialist treatment, in-patient admissions ran at 40%.

Major differences were also highlighted in relation to continuity of care dependant on which type of care pathway was available; for those accessing specialist assessment and treatment, 83% remained in the original treating service over the following 12 months. This number dropped to 75% in the non-specialist assessment to specialist treatment group while only 41.7% of patients starting treatment in non-specialist CAMHS remained in their original service over the next 12 months. These differences in treatment patterns were also found to have major cost implications with treatments costs for patients assessed and treated in generic services being 2-3 times higher than the cost in specialist services (Schmidt et al 2016)

This study provides important evidence to show that the specific, manualized treatments cannot be divorced from the context in which they are delivered and that service context may have a far greater impact over and above the specific treatment approach being used as it determines who receives treatment and at what stages of the illness as well as the expertise and confidence with which the treatments are delivered.

The Maudsley CAEDS prospective service evaluation study

A prospective service evaluation study of 357 consecutive referrals treated in the service between September 2009 and January 2012 provides a picture of how the research findings from randomised trials translate into clinical practice in a day-to-day specialist service setting. Overall the study showed that approximately 75% of patients were treated on a purely outpatient basis with the remaining receiving additional day and/or inpatient treatment. At the end of treatment (AN/EDNOS-R: median number of FT sessions 17.4 + 10.3 individual sessions with a median length of treatment 11 months; BN/EDNOS-BN median number of FT sessions 7.7 + 10.4 individual session over a median of 7 month treatment) nearly 85% of those with a restricting presentation and nearly 75% with a BN presentation were discharged either back to primary care or in a small proportion of cases to their local CAMHS for treatment of comorbid problems such as anxiety or depression¹. Approximately 12% continued to require treatment for their eating disorder and at 18 were transferred to the adult ED service. Just over 4% of the AN/EDNOS-R and just under 14% of the BN/EDNOS-BN group either did not engage with treatment or dropped out early (for further details see *weblink*; see also Simic et al in preparation). It is important to note that these findings do not represent the outcome of a particular treatment. Thus for instance while FT-AN was the main treatment for those with a restricting presentation this was often combined with MFT-AN and nearly half the young people also received some individual therapy. The length of treatment was also more variable than would be the case in a carefully controlled efficacy trial.

Multidisciplinary team working and service structure

While randomised treatment trials have focused primarily on the efficacy of specific treatments such as family therapy or cognitive behaviour therapy, the treatment of eating disorders generally requires a more complex approach combining expertise in a number of different areas which is best provided by a multi-disciplinary team consisting of staff with shared, overlapping clinical skills and knowledge.

These skills include clinical work with individuals, families and groups, understanding of individual and family developmental and life-cycle needs, understanding of the conceptual ideas and theories underpinning psychological treatments including systemic family therapy, cognitive behavioural therapy, a knowledge of eating disorders, nutrition and the effects of starvation, and knowledge of the medical risks associated with eating disorders and their management. A Multi-Disciplinary Team will therefore consist of a range of professionals who can provide this diversity of expertise and commitment to multi-disciplinary working.

In thinking about the overall structure of the team it is important to think beyond the role of clinical staff. For instance, it is important that team administrators should have some understanding of the treatment focus in order to develop an understanding of, for example, the centrality of parental involvement in treatment; administrators are usually the first people that referrers and families speak to when approaching a service for treatment. Administrators are often in an important position to

¹ Since the completion of this study the CAEDS team has expanded and in most cases CAEDS staff will provide treatment of any comorbid problems. Ongoing referrals to CAMHS are therefore now rarely needed and patients are discharged back to primary care at a point where no further treatment is considered necessary.

support and convey the right sense of urgency and concern when arranging assessment dates for example. Administrators are also required to make important judgements about the need to seek guidance and support from other team members both for themselves but also on behalf of parents and referrers. This necessitates a good level of understanding of risks and associated protocols for managing safe patient care.

The size and composition of teams will vary widely depending on the specific health service context in which they were set up; each specialist team delivering treatment for eating disorders will be shaped by the available local resources, by unique local needs, by local guidelines, governance and commissioning or health insurance requirements. We recognise that the empirical evidence that could be used to guide specific aspects of multi-disciplinary team working is limited. The described treatments in this manual assume a general level of therapeutic skills and knowledge but additional training is required to ensure that the treatments are delivered in a consistent and effective way. Team composition, structure and training is therefore crucial if timely, consistent, effective and safe treatment is to be established.

Whilst therapeutic engagement with the family is primarily between the patient, her/his family and their allocated treating clinician, in a broader sense the family is also engaged with the specialist MDT as a whole, with different clinicians being involved during assessment, through regular team discussion and supervision and in many instances by directly contributing to the treatment at different points in the process.

The specialist MDT involvement contributes to the sense of a secure therapeutic base, which is essential to the positive process and outcome of treatment. This sense of a shared team endeavour can be introduced on first meeting the family when the assessing clinician describes the team composition. As all phases of the treatment model require parents to find new and challenging ways to respond to their sick child, it is essential that parents are confident in their treating clinician and team; confident that the therapist and team will stand alongside them in the attempts they make to help their child and confident that they can communicate their needs when faced with difficult emotions and behaviours.

Integrating different professions within the team (clinical skills, expertise, knowledge)

Multidisciplinary teams will vary in size, composition and service configuration. Nevertheless, consideration should always be given to the range of skills and knowledge that will be required for safe and expert practice with input from a range of specialist professionals with a shared purpose and understanding of the treatment needs of this patient population.

The expertise and skills that a specialist eating disorders team requires should always include, knowledge of eating disorders and a broad range of common co-morbid disorders including anxiety, OCD, depression and self-harm; an understanding of physical and psychological development of young people and how these are affected by starvation; a knowledge of nutrition and of the neurobiological predisposing factors found in young people with an eating disorder. Clinical skill are needed for managing physical and medical risks associated with malnutrition, risks of self-harm and safe re-feeding of a malnourished young person as well as psychological treatment skills of working with families, individuals and groups including multi-family groups. All of these need to be held within the MDT at the very highest levels although the degree to which individual team members hold the required knowledge and skill will vary and will cut across usual professional demarcations.

As much as families need a secure base located in the therapist and MDT so too do the clinicians; the intensity of the therapeutic relationship demands a high level of self-reflection on the part of the therapist. The strength of the engagement and resulting therapeutic relationship is both a driver of therapeutic change and recovery, however this intensity also has the capacity to become a hindrance

to progress if the therapist cannot continually reflect on the therapeutic relationship and on the processes of therapy. In order to support this reflective position the MDT needs to provide space for reflection and support both through individual clinical supervision but also team case discussion and team supervision.

Given the evidence of the effectiveness of family therapy in the treatment of eating disorders, specialist ED teams should include at least one well trained, experienced family therapist who can provide supervision in addition to seeing families. All clinicians on the team, regardless of their basic clinical training e.g. clinical psychology, nursing, psychiatry will need to be able to work with families and will be expected to deliver FT-AN as described here in addition to the other manualized treatments. Similarly other expertise in the team is shared and held by more than one member of the team. Medical expertise in the management of eating disorders should be an integral component of the teamwork and is an important part of providing safe and expert treatment.

All therapists need to have a good level of knowledge and understanding of the usefulness of a range of clinical treatment modalities in order to know when an additional intervention might be indicated. Likewise a good understanding of co-morbid presentations that might develop or become more apparent during the course of treatment is essential as this might require individual psychological treatment, psychiatric review, prescribing of medication, physical examination/review or other interventions.

Treating therapists should also have knowledge and skills related to both medical and psychiatric risk in treating eating disorders, firstly in order to assess levels of risk and to respond appropriately, and secondly in order to know when the involvement of an MDT colleague is indicated e.g. the involvement of a team doctor if the patient has lost an excessive amount of weight in a short period of time, or if concerning psychiatric symptoms such as self-harm or depressive symptoms become more pronounced and the risk around these is assessed to have increased. ***Therapists should have access to medical, nutritional and psychiatric advice and clear protocols for managing the medical and psychiatric risks.***

Assessing medical risk

(see also Appendix A - Medical assessment and management in outpatients)

At presentation the young person is assessed for their risk of medical instability including risk of developing the refeeding syndrome. At the Maudsley Hospital, patients who are deemed very high risk of refeeding syndrome are admitted to King's College Hospital and refed cautiously with low calorific rates, regular review and incremental calorie increase with close monitoring according to national Junior Marsipan guidelines (<http://www.rcpsych.ac.uk/files/pdfversion/CR168nov14.pdf>). Parameters of physical instability are related to findings on assessment, both on history and examination. Risk assessment tools identify cut offs in heart rate and blood pressure, level of hydration, or investigation findings (ECG or electrolytes) below which risk is deemed unacceptable to tolerate as an outpatient. This is because they represent decompensation in what is a chronically compensated state. The UK national group Marsipan has formalised this risk assessment process providing a framework to assess malnourished young people and decide on medical admission (<https://www.rcpsych.ac.uk/pdf/CR189checklistXX.pdf>).

The majority of young people, however, can be managed on an outpatient basis. Depending on their level of attributed physical risk, young people are encouraged to remain at home for the first week with minimal exercise, and if necessary undertake additional visits to the clinic over that period for blood tests and clinical monitoring. Any concerns raised at those reviews, or by families at other times lead to reassessment. The careful monitoring of the medical risks is important not only to ensure safe practice but also plays an important role in the process of engaging the family with the team by giving

them confidence that treatment (much of which will take place with the parents' help at home) will be managed in a safe way. This is particularly important when parents feel out of their depth and believe that the only way forward is to hand over to “experts” in a hospital setting.

In addition to a child and adolescent psychiatrist being a part of the team it is also important to have access to a paediatrician, preferably with dedicated time on the team allowing for joint assessments and attendance at team meetings on a regular basis and to provide a bridge between the team and the paediatric ward.

The role of the paediatrician in the multi disciplinary team

(see Appendix B for a more detailed description)

The paediatrician provides a high level of medical expertise in managing young people presenting with eating disorders who can be physically very unwell. This includes being able to assess both the short term and longer term consequences of starvation and compensatory behaviours associated with eating disorders as well as in some cases potential life-threatening risks. The priority of the paediatrician in this context is to exclude all other physical causes of weight loss, quantify the degree of risk associated with malnutrition, and to support the “prescription” by the treating therapist of a robust and safe plan for restoring healthy nutrition for the family to follow to allow the young person physically to rehabilitate. An additional but no less important role of the paediatrician is to communicate their findings and their concern in a supportive but objective way illustrating how the specific medical findings are consistent with what is known generally about the effects of starvation.

Psychoeducation forms an integral part of treatment of ED and the paediatrician's contribution has a key role in its delivery. This is partly due to their experience in the diagnosis and management of malnutrition in other organic disorders, and their knowledge about growth, puberty and emotional/psychological development. Importantly though their experience of assessing and talking to families when children are unwell conveys the strong message that the young person is ill and needs special care from the parents. The presence of a paediatrician at the initial assessment of the young person therefore both serves to ensure that assessment and early management of risk is safe, but also consolidates the process of engagement with the team and shapes the direction of future therapy.

During the early phase of the illness, where engagement is key, the paediatrician can become the voice of concern, and the meal plan and clinical health surveillance measures become the metaphor for the path to recovery. Later, issues relating to growth and puberty, fertility, menstrual health, bone and skeletal health, can all be brought back to nutrition.

Paediatric admissions

(see also Appendix C – Medical Management on a Paediatric Ward)

Practice varies internationally with regard to the medical stabilisation of malnourished children. Most agree with a comorbidity-oriented hospital-admission strategy, rather than one purely based on arbitrary weight cut-offs. The threshold for medical admission is based on the findings of the medical assessment which has four objectives. It must:

1. attribute a risk of physical instability (a measure of frailty)
2. attribute a risk of developing the refeeding syndrome (which dictates how cautious and closely monitored reintroduction of nutrition should be),
3. exclude other medical cause of weight loss
4. serve to reinforce the psychoeducational messages to the young person and the family

The role of the medical admission is first and foremost about safety: identification of the malnourished and ill young person, and management of the refeeding and stabilisation process with maximum support and monitoring. If handled well, it has a secondary benefit of containing anxiety for the young person and their family through the early steps towards recovery.

A further important role of a medical admission, however, is in engaging the young person. At assessment many young people come across as reluctant participants, passive and even hostile recipients of care, and frequently, at least overtly, in denial of their frail physical state. The explicit concern of medical professionals towards their physical well-being can be a powerful motivator in helping them see how ill they are. This is unavoidable during a medical admission, as busy medical wards are staffed by large numbers of teams who change shifts twice a day - the medical concern is reinforced by every new shift arriving, and the physical state can be clearly charted for all to see with the observations: heart rate, temperature and blood pressure.

By its nature therefore a medical admission should be practical and short - it is there to stabilise and support until acute risk has passed and the real work of recovery can begin in earnest. It is important therefore that the medical admission is not a disconnected event from the rest of the treatment process. During the time of admission there are often unique opportunities for the therapist to engage with the young person and her family in a way that is very different from what happens in sessions in the clinic. There will also be opportunities for the therapist to note changes in the young person's attitude and the family's perceptions that can be referred to and built on in subsequent treatment sessions

Risk of refeeding syndrome

(see also Appendix C for a more detailed discussion of refeeding syndrome)

This remains a controversial area, with advice in some quarters suggesting cautious and very low levels of calorie reintroduction at the outset with slow incremental increase, while other centres have published more aggressive refeeding guidance (Madden et al, 2015). It is known that those at risk tend to be those with lower weights, a longer period of abstinence, and those for whom plasma phosphate, and white blood cell titres are low before starting the refeeding process. Low body temperature is an important physical sign.

Calories should be reintroduced carefully and with close clinical and biochemical monitoring. The literature disagrees on the optimum - some advocate nasogastric feeding at the outset, the suggestion being that it smooths out surges in various regulatory and counter regulatory hormones (such as insulin and glucagon) implicated in the steps leading to refeeding syndrome. Others advocate starting with food, as this releases its energy slowly and has the benefit of being a more active process: the young person taking an active step towards recovery by eating. Meal plans should be consistent and unchanging, limited choice and no discussion or negotiation with regard to amount or content (with some minor flexibility only). Food should be provided regularly across the day, in the form of up to 6 separate meals or snacks. Bathroom visits should be curtailed around meal times, which should have explicit times and durations, with clear plans for meals left uncompleted. Meals should be supported at all times by staff, with encouragement from families and or the therapist where possible.

Exercise and activity should be discontinued, and strict rest advised (though bedrest is rarely essential). If marked bradycardia is present a cardiac monitor is indicated and correction of electrolytes, with regular observations. Hypothermia should be corrected as it adds further metabolic stress, and fluids may be given intravenously in the short term if necessary (though the intention should be to rehydrate and refeed gradually).

Calorie-targets should be set each day, with blood monitoring to inform decisions. Supplementation of phosphate and B vitamins (with thiamine) may be necessary, as well as vitamins D and K and zinc.

Resources required for a paediatric admission.

Managing profoundly underweight young people with eating disorders in medical inpatient settings is challenging. Their medical care requires access to specialist dietetics, gastroenterology, endocrinology, cardiology and high dependency. They need supportive and understanding nursing, and the medical ward staff need confidence in handling young people who are often distressed by eating. All medical and nursing staff need clear guidelines and protocols in place. The psychological care of the young people equally requires close collaboration with the child and adolescent eating disorders team (see Managing eating if the patient has been admitted to a paediatric ward in Phase 1). In setting up a service therefore it is essential to have locally agreed pathways and robust joint working across mental and physical health to ensure the different needs of the young people are met.

The role of the dietitian in the multidisciplinary team and the use of meal plans

The dietitian provides expertise on the team on nutrition and the safe management of restoring healthy eating. Most patients can achieve this through being supported to eat according to a standardised meal plan developed by the dietician. In some instances meal plans may need to be tailored to meet specific dietary needs (for example in demonstrated food allergy where certain foods must be avoided or to address religious or cultural food practices). In such situations the dietitian will generally be asked to join the family session with the treating therapist to provide their specialist guidance. It is unusual in FT-AN for a dietitian to meet with a patient or their family without the therapist also being present at any stage in treatment. During the course of treatment there may be other times when expert dietetic advice may be needed for instance if a patient appears to be compliant with the meal plan but is failing to increase their weight for example or if a young person has been encouraged to take up sport again and their nutritional needs increase.

Families are generally offered a meal plan to guide them in how to restore healthy nutrition in the young person. Most families readily accept this although some parents may feel they can manage without and unless there are clear concerns about medical risks they can be supported in this. The initial standardised meal plan aims to provide 1500 kCal/d (described as 'Establishing regular eating' plan). This is dairy-rich (and therefore phosphate-rich) to reduce the risk of refeeding syndrome. It is prescriptive, with clear amounts and only two to three choices per meal or snack, to avoid confusion and conflict. If by the end of the first week all blood tests and clinical monitoring have proven normal, the treating therapist will recommend changing the 1500kcal/d meal plan, to a weight restoration plan of 2500kcal/d (described as 'Working towards a healthy weight'). Blood and clinical monitoring is performed one further time following introduction of this new plan and generally thereafter medical investigations are relaxed if there is evidence of weight gain and clinical improvement is observed (examples of the above meal plans can be found in Appendix D)

Later on in treatment (in Phases 3 and 4) the dietitian may be consulted by the therapist, when either patient or parents request specific dietetic education or advice about normalization of eating. This is usually straightforward and a meeting with the dietitian provides a helpful solution to a dilemma or question. In some instances, however, such a request may be unduly influenced by the young person's anorexic cognitions which are driving her to pursue an opportunity for potentially undermining negotiation around food choices. Such requests can sometimes happen at a time when parents feel exhausted or emotionally depleted by the demands of the illness. It is not unusual for parents to become caught up in "anorexic" dilemmas involving the minutiae of what their child will or more likely, will not eat, for example. Therapists should therefore not hesitate in consulting with a dietitian to ensure their patient's dietary needs are being considered and addressed but they should also be wary of being side-tracked into missing an important message and information that may be being conveyed.

THE MAUDSLEY FAMILY THERAPY MANUAL FOR CHILD AND ADOLESCENT ANOREXIA NERVOSA

The following chapter provides a manualized guide to family therapy for child and adolescent anorexia nervosa (FT-AN)². It is aimed primarily at those who work with young people with an eating disorder in the context of a specialised outpatient eating disorders service where the MDT hold the combination of knowledge and skills needed to deliver expert treatment. Those working in other contexts e.g. generic CAMHS services or working on their own in private practice will need to consider how the expertise and support that is needed can be accessed in their specific treatment contexts.

The chapter starts with a brief overview of family systems theory and its application to the treatment of eating disorders. We recognize that for some readers the account of theory will be too cursory while others may feel that they are sufficiently familiar with the theory and family therapy techniques and may wish to go straight to the account of the aspects of treatment that are specific to family therapy for anorexia nervosa. We would remind readers that treatment manuals are not mere lists of instructions in how to conduct therapy and that an understanding of the concepts informing the treatment is needed in order to be able to tailor interventions to different circumstances, the specific needs of individual patients and their families as well as patient wishes and preferences. The order in which readers choose to approach the more general and the more eating disorder specific sections will be individual and we recommend that readers do this in a way that best suits their own learning styles and existing knowledge. Where appropriate, we include theoretical ideas as part of the description of interventions and similarly we provide clinical examples when trying to explain theory. Those who are less familiar with specific treatment intervention techniques that can be used with families should also read Appendix F.

Use and limitations of therapy treatment manuals

The value of treatment manuals is that they operationalise and make explicit the general tenets of a therapy, specifying goals at different stages and outlining the types of interventions that can be used to achieve these. It does not replace the skill, experience and clinical judgement of individual clinicians but can enhance these by providing them with a tool that guides them and focuses their work. The manual also provides a language for clinical discourse whether in relation to individual cases or treatment in general.

The main limitation of treatment manuals is our current lack of knowledge of mechanisms of change. While there is a steady growth in the evidence of what treatments work, how they work is still largely a matter of conjecture and theory. Caution is therefore needed in making assumptions as to which aspects of the treatment described in the manual are essential to achieving good outcome. When the treatment is progressing well, following the manual is straightforward. When treatment is not working, the way in which the manual should guide treatment is less clear and will vary from case to

² A note on terminology: Various labels have been used for eating disorders focussed family therapy including Maudsley Family Therapy, Maudsley Model Therapy and in recent years most commonly Family Based Treatment or FBT. These terms can be misleading because they imply theoretically distinct model of treatment rather than a treatment which has a shared theoretical frame with other systemic therapies but with a specific focus on treating an eating disorder. The term FBT is also ambiguous because it is sometimes used just to refer to treatments using a specific treatment manual (Lock & Le Grange, 2013) and sometimes to all studies using an eating disorders focussed family therapy. Our use of the term FT-AN emphasizes that this is a treatment that draws on family systems theory and uses a broad range of family therapy intervention techniques while its specificity derives from its focus on treating an eating disorder (Eisler, 2013).

case. In a proportion of cases it will be due to the fact that the manualized guide has not been adhered to appropriately and therapists may need to use supervision to get back on course to rectify this. While this possibility should always be considered (particularly when therapists are less experienced), it is by no means always the case that sticking rigidly to the manual is the most productive solution. There is evidence that the relationship between manual adherence and treatment outcome is not linear (Webb et al 2010) and is moderated by a number of factors such as the strength of the therapeutic alliance, level of therapist experience or individual and family motivation to change (Castonguay et al 2010; Escudero et al 2012; Lambert et al 2012; Barber et al 2006). Thus for instance when there is a disruption to the therapeutic alliance, continuing with interventions that are usually effective can be counterproductive and can lead to further deterioration. In such instances broadening of the theoretical frame (Scott & Dadds, 2009) to include e.g. attachment theory, CBT or DBT concepts may provide clinicians with useful alternative strategies, which should be considered as part of team or individual supervision and case discussions. To put the manualized treatment described here in context we refer the reader to Appendix G which provides a brief comparison with two other manuals for family therapy for adolescent anorexia nervosa, the Robin and Siegel manual for Behavioural Family Systems Therapy for anorexia nervosa (Robin et al 1994; 1999) and the Lock/Le Grange manual of Family Based Treatment for anorexia nervosa (Lock et al 2001; Lock & Le Grange 2013)

Basic principles of systemic theory and their application to the treatment of eating disorders

The description of the theory incorporated in this manual draws on the systemic family therapy manual originally developed by Pote and colleagues (2001; 2003) at the Leeds Family Therapy & Research Centre as part of a research project funded by the Medical Research Council, later modified as part of the Self-Harm Intervention Family Therapy (SHIFT) study (Boston, et al 2011). While we provide a basic overview of the conceptual and theoretical underpinnings of family systems practice we strongly recommend that readers unfamiliar with basic systemic concepts should read one Vetere & Dallos (2003) or Rivett & Street (2009) in conjunction with this treatment manual.

Reorganization of the family around illness

Early family therapy conceptualizations assumed that individual “disorders” could be understood as an expression of an underlying family dysfunction and interventions were therefore aimed at correcting such dysfunctional family interactions (for a historical account of the development of the family therapy for anorexia nervosa see Eisler et al 2015). Anorexia nervosa, for example, was understood as being part of a “psychosomatic family” transactional pattern (Minuchin et al 1978) which interacted with a specific vulnerability in the child and gave the child a specific role in managing intergenerational patterns of conflict resulting in the behavioural eating disorder symptoms. The lack of clear empirical evidence of a family aetiology of eating disorders (Eisler 1995; Jacobi et al 2004; Konstantellou et al 2012) together with a general shift in the family therapy field away from the notion of treating family dysfunction means that a different way of thinking about the family dynamics that we observe when working with families is required. Illness family models (Rolland, 1993; 1994; Steinglass et al., 1987) offer a perspective for understanding the processes through which families accommodate to serious and enduring problems. As clinicians we may observe unusual or strange interactions in families but often these become readily understandable when viewed in the context of the impact of the illness on the family (Nielsen & Bara-Carril, 2003). Steinglass (1998) described in some detail the process of such family reorganization as an increasing disruption of family routines and family regulatory mechanisms, where day-to-day decision-making becomes more difficult, to the point where the problem becomes the central organizing principle of family life. Family responses will vary depending on the nature of the illness, the type of family organization and interactional style and the particular life-cycle stage they are at when the illness occurs. What may be

less variable is the way in which the centrality of the eating disorder magnifies certain aspects of the family's dynamics and narrows their range of adaptive behaviours. We have suggested (Eisler, 2005) that the following are some of the ways in which families become reorganized around AN:

The central role of the illness in family life The high levels of preoccupation with thoughts of food and weight in the young person is paralleled by the way that issues around food and eating take centre stage in the family. Much of the interaction between family members focuses on food, eating, or weight until all relationships in the family seem to become defined by them. Just as the young woman may judge her self-worth by whether she is able to resist eating, so interpersonal relationships feelings and emotions in the family become moderated by food and weight related behaviours.

Narrowing of time focus to the here-and-now An alteration of the perception of time and a change in the salience of past, present and future time frames is a well-documented phenomenon associated with a range psychological disturbances (Wyllie, 2005; Cutting, 1997; Keough et al., 1999). We have observed a similar phenomenon affecting the whole family (Whitney & Eisler, 2005). The anxiety engendered by the intensity of mealtimes result in the family gradually being unable to focus on anything other than the present. This narrowing of the families' time frame makes it difficult to tolerate uncertainty and take any risks. Trying anything new may feel impossible because nothing beyond any initial negative response seems to matter. This tends to lead to an avoidance of difficult circumstances or a failure to challenge illness behaviours, which become increasingly entrenched. Families will often comment that they feel that time has come to a standstill. The low tolerance of uncertainty in the family goes hand-in-hand with the elevated levels of intolerance of uncertainty found in individuals who develop an eating disorder (Frank et al 2012; Konstantellou et al 2011) and are likely to be mutually reinforcing of each other.

Inflexibility in daily life patterns When asked to describe what they have tried to do to help their daughter, families will typically describe having tried a range of different approaches but an increasing experience of their efforts being ineffective results in an ever narrowing repertoire of behaviours. Their patterns of interaction can become ever more predictable and the roles that each person takes on more fixed. To the clinician the limited patterns of interaction may appear as rigidity but this may simply reflect the narrowing of the family routines in response to the illness.

The amplification of aspects of family functioning Family adjustment to living with AN may lead to pre-illness patterns of family functioning becoming more pronounced and may become perceived as part of the problem. For instance, if one member of the family tends to take on the role of "peacemaker" when differences of opinion appear, this role may become more prominent with increasing attempts "not to make things worse". Similarly, pre-existing differences in closeness and distance of relationships may become more pronounced. It is probably this process that above all gives rise to the assumption that what we are observing is a manifestation of family dysfunction rather than the family's adjustment to the illness

Diminishing ability to meet family life-cycle needs As the illness takes hold on family life the expected developmental changes in the family such as moving towards increasing autonomy of their adolescent child and the gradual move to a more adult-adult relationship seems impossible and if anything the family may feel that they are regressing to an earlier stage in the family life-cycle. Meeting the varied needs of different family members be it siblings, parents or the family as a whole becomes ever more difficult which is often accompanied by strong feelings of guilt on the part of the parents (Perkins et al., 2004). Paradoxically, the sufferers themselves may feel bad about the extra attention they are receiving, feeling guilty about the additional burden they are imposing on the family and at the same time often experiencing the extra attention as intrusive rather than caring.

The loss of a sense of agency (helplessness) When first meeting a family seeking help for their child, often the most striking aspect is their sense of helplessness and despair. This is generally as true of the

parents as it is of the young person. While winning the battle with hunger may give the young person a brief sense of mastery and control, the battles around food at mealtimes have the opposite effect, regardless of how successful she may be in resisting her parents' exhortations to eat. Parents will similarly recount that they feel helpless and have no control over what their daughter does and indeed that they have lost control over their lives (Cottee-Lane et al., 2004).

The Family Life-Cycle

An important aspect of family therapy theory is the notion of Family Life-Cycle (Carter & McGoldrick, 1999), which provides a developmental lens for understanding the way the family as a system evolves over time. Families need to provide stability and predictability but they also have to be able to change in order to adapt to new circumstances and the developmental demands of individual family members (Byng-Hall, 1991; Eisler, 1993). For instance, the child's need for dependence and attachment require a degree of stability and constancy in the family but as the child develops, the family must find ways of meeting his or her needs for independence and separation as well. As the family evolves through the predictable stages of the family life-cycle, it needs to be able to adapt and change its habitual style of functioning. The specific ways in which families respond to these demands will be shaped by the expectations that the parents bring from their own family of origin, by their social and cultural beliefs but also by the temperamental and personality predispositions that each family member brings to the family mix. Recent research on the neurobiological predispositions towards the development of anorexia nervosa has highlighted the role of temperamental factors such as increased predisposition towards anxiety, low tolerance of uncertainty, reward insensitivity, and cognitive inflexibility and rigidity (Kaye et al 2013; 2015; Lilenfeld 2011). Understanding how these factors interact with, are shaped by and shape the family system is an important part of evolving current the conceptualisation of FT-AN.

The expected stages of the family life cycle can be complicated by unexpected events such as illness, death, family separation or migration and the combined stress can contribute to the development of problems. There is evidence that at these transitional times there is an increased vulnerability and increased psychological morbidity (Hetherington, 1989; Gorell Barnes et al, 1998; Ritsner & Ponizovsky, 1999; Kendler et al 1999; Varnik et al 2005). The way the family responds to an emerging problem may be a crucial factor in determining the extent of individual vulnerability to such pressures (Walsh, 1997). When an eating disorder begins to emerge in a family member, the family's response will be determined both by its own unique way of managing family life-cycle transitions and the general demands of the particular developmental stage they are at. Thus while in general the younger the child, the easier it is likely to be for parents to accept having a strong parental role in managing their child's eating, the way the family manages this will also be determined by the family specific nature of relationships and attachments. Where pre-existing relationships are characterised by insecurity or hostility, attempts on the part of the parents to help the child eat may be experienced as intrusive and controlling rather than helpful by the young person and this in turn may evoke a critical response from the parent. In such situations a slower and more cautious stance may be required by the therapist to avoid both alienating the young person and to guard against reinforcing feelings of guilt and blame in the family.

Circularity, patterns of interactions and the narratives and meaning attached to them

Family Systems Theory provides the key conceptual framework for much of the thinking about working with families. While it has evolved considerably over the years many of the original concepts remain central. The original notion of the family as a system was strongly influenced by cybernetic concepts (von Bertalanffy, 1968), describing a number of features such as the recursive nature of relationships, the multi-level nature of communication (Ruesch & Bateson, 1951; Bateson, 1972), the

development of recognizable patterns of interaction, the role of relationships and beliefs, and the evolution of roles that family members take on (Bateson et al 1956, Palazzoli et al 1978).

More recent theoretical developments in family therapy theory have come from social constructionism (Berger & Luckman, 1966) and in particular narrative therapy (White & Epston, 1989). This emphasizes that what we consider as objective, everyday reality is, at least in part derived from and maintained by social experiences and that through social interactions, we develop narratives to make sense of our own lived experience. When meeting with families in therapy it is crucial that the therapist acknowledges and works openly with the subjective and unique nature of individual perspectives, the specific language used to describe these and the variability of perceptions between family members. Without exploring these unique perspectives we may misinterpret or fail to understand the explanations and descriptions that families and patients bring to therapy and we may also miss vital opportunities to develop new mutual meanings and understandings. An example, described in more detail later, is the use of externalising conversations to separate the illness from the young person. This is often a powerful intervention but cannot be applied uniformly across all families without exploring their own understanding. Some young people dislike the notion of anorexia being separate from them but may accept it if the therapist asks them to use their own words to the degree to which they feel they can control the illness driven cognitions of behaviours.

Patterns of behaviour develop within social systems and are often recognizably repetitive and circular with the behaviour of one member influencing other members in predictable ways and in turn invoking predictable responses. Such patterns are influenced by the expectations of how others are likely to respond and by the meanings attached to behaviours. Some of the developing patterns may become connected to the difficulties by reinforcing problem behaviours or beliefs while others may have a helpful role. The patterns of interactions that develop in (all) families and the meanings attached to them may be experienced differently by each family member although often there is a narrative that dominates accounts of what happens which shapes both perceptions of self and perceptions of others. Accessing the alternative meanings and reinforcing the more helpful, positive narratives can be a key mechanism of change when working with families. Thus, for instance, we will describe later the importance of reframing the meaning of parents helping the young person to change her eating behaviour from “taking over control of eating” to “caring for an ill child”. This change has to happen for both the parents who need to be able to see themselves as caring parents and for the young person, who has to feel looked after in order to be able to accept her parents’ help.

It is important that therapists maintain an open and flexible stance and do not too readily draw conclusions about the meaning of their observations. A useful starting point is to assume that what they observe in the family has been transformed by the experience of managing the demands of the illness (Steinglass, 1998, see above) rather than assuming that family relationships, beliefs or patterns of behaviour have somehow been the cause of the illness. A position of enquiring curiosity encourages the therapist and the team to maintain a non-blaming and flexible stance.

The process of any systemic therapy should enable family members to consider their shared family and individual beliefs from new and/or different perspectives. However, within treatment of eating disorders these explorations will need to be considered and paced dependant on risks and on the phase of treatment. Early on, when the emphasis is on reducing medical risk and helping the family to initiate changes in the eating behaviours of the young person, explorations of broader issues is of necessity limited and should not detract from the critical need for the parents to support their child to eat. If the therapist conveys a sense of having time to reflect on beliefs without also conveying the importance of the need to act urgently, there is a danger that too much reflection results in avoidance of the early tasks with resulting risks to the patient and to recovery. However, some exploration is vital in order to begin developing an understanding of the family’s unique characteristics and strengths and to develop a shared sense of purpose of the treatment. Cultural differences, for example

may need early exploration in relation to parenting roles, beliefs and practices. Assumptions should not be made during treatment with any family regarding unique differences in beliefs and behaviours; collaborative exploration of these areas should identify strengths within these differences and opportunities to find shared understandings and flexible solutions. Similarly, family and individual beliefs about adolescent development, independence and freedoms may need closer attention during the later phases of treatment when physical risks have reduced and the space for reflection is opened up by the diminishing influence of the illness.

A key aspect of working with families and eating disorders is to gain an understanding of the specific beliefs that have evolved within the family around the eating disorder. These beliefs along with the emerging relationships and behaviours will form part of an important focus of attention from the start of treatment as certain beliefs may have led to behaviours and relationship patterns, which often begin to perpetuate and maintain the illness. However, as treatment progresses towards discharge, the central role of the eating disorder will become diminished and the focus will turn to other aspects of family and individuals' lives. In these later stages the therapeutic focus may helpfully explore the family and individuals' new beliefs, identities, relationships and behaviours.

The process of therapeutic change

The treatment approach described here reflects current positions in the field of family therapy, where less emphasis is placed on the specific therapy model or specific theories of change and more on the integration of a range of conceptualisations both from within the field of family therapy and from other therapeutic approaches. The principal assumption is that there are three interlocking elements contributing to change:

- (a) Changes in individual perceptions, feelings and behaviours of any member of the significant system
- (b) Changes in significant relationships reflected in and shaped by changes in (a)
- (c) Changes in shared meanings reflected in and shaped by changes in (a) and (b)

All three elements need to be held in mind by the therapist even when they may be focussing on one element as a particular focus in therapy. Although therapists will be influenced by their own experiences and theoretical preferences, they will need to reflect how these relate to concepts explicated in the manual and integrate them in a way that fits the family and the context. It is essential that whilst therapists have a good understanding of the process of therapeutic change as described here, they should not lose sight of the fact that early weight gain is the single most important driver of cognitive improvements and physical recovery. Therefore in the early stages of treatment of anorexia there is a strong focus on behavioural change, consistent with empirical findings that early positive change in behaviour leading to early weight gain for example is more likely to result in a positive treatment outcome (Le Grange, et al 2014). It is important, however, that the therapist continues to hold in mind the broader notions of change described; partly because they have an important role in the development and maintenance of a positive therapeutic alliance and partly to lay the ground for the therapeutic work in the later phases of treatment.

Common factors in therapy

Therapists should be familiar with the evidence that specific treatment factors account for a relatively small amount of the variance in outcome (Asay & Lambert, 1999; Sprenkle, et al 2009) and that variables which apply across therapies, such as client motivation, family resilience, therapeutic alliance, client hope or the expectancy or service context may account for a high proportion of outcome. This does not mean that one needs to be skeptical about the impact of specific treatments

but rather that the way in which interventions described in the manual operate need to be understood in the context the in which they are used and that they interact with a wide range of factors. The manual for instance provides an account of how to conceptualize the impact of the expertise of a specialist service on the development of the therapeutic alliance and how this can be utilized over the course of treatment.

Frameworks for change

Historically, different models of family therapy tended to place emphasis on a particular area of change which guided the focus for interventions, for example: Structural Family Therapy's attention to family organisation, boundaries and life cycle needs (Carter & McGoldrick, 1999; Minuchin & Fishman, 1981), Milan Systemic Therapy's notion of circularity, the importance of difference and pattern, feedback and interactional patterns (Cecchin, 1987; Jones, 1993), Strategic Therapies' aims of blocking fixed patterns that have arisen out of failed attempts at solutions (Haley, 1976; Madanes, 1991), Narrative Therapists emphasis on the social construction of the 'problem saturated identity' and development of unique outcomes and the absent but implicit alternatives (Freedman & Combs, 1996; Lerner, 1996; White, 1986). Similarly, CBT emphasises the importance of cognitive restructuring, addressing beliefs and problematic thinking as well as addressing the role of changing behaviour to bring about changes in thoughts, emotions and feelings (Beck, 1967; 1976). Below we outline a set of frameworks that offer a way of thinking about the focus for therapeutic intervention and the process of change which draws on many of the above ideas but assumes that change happens on a number of different levels. The delineation of frameworks for change aims to provide therapists with a way of conceptualising specific aspects of therapy. They are not a set of mutually exclusive categories, as we would argue that all therapies encompass each of these frameworks. An integrative approach requires therapists to continue to reflect on all these aspects at the same time and be aware of the interplay between them.

Problem framework and the development of a systemic formulation

Concerns about eating and weight will be the identified problem that brings families to therapy, and the therapeutic focus, at least initially is likely to remain primarily on that issue. An important context for thinking about the process of change, however, will be the broadening of the focus to other areas that are seen to contribute or perpetuate the eating disorder or are in other ways important for the family. The family accounts of the role that an eating disorder plays in the life of the individual and the family will vary, as will their understanding of its origins. Families may explain the eating disorder as resulting from any number of possible areas; individual characteristics, catastrophic events, negative influences of others, biological givens or parental failings. As the therapist listens and elicits these explanations from the family and observes their interactions, both begin to place the experience in a new framework, developing an agreed formulation which offers the possibility of change. Individual family members will come to therapy with different beliefs about the possibility of change and/or different levels of willingness to acknowledge the possibility of change. The therapist should be mindful of this, particularly in the early stages of treatment when an initial formulation may need to acknowledge the sense of scepticism, hopelessness or overt expressions on the part of the young person of a lack of desire to change. The acknowledgment that these are present should not mean that the therapist adopts a neutral stance to the question of change but an acceptance that it may take time before change may seem possible (see also the section on Working with Time). In the process of developing the formulation, the therapist will aim to introduce a systemic perspective on the illness (described in the section on formulation), framing (or reframing) the offered explanations in a non-blaming way and placing emphasis on positive motivation to help, on strengths, resources

and hopes for change. The formulation will evolve during the course of treatment but will remain an important framework for thinking about change with the family.

Relationship framework

Thinking about relationships is clearly a key aspect of all psychotherapies including family therapy. This includes the relationship of the therapist with the family as well relationships within the family or with significant others. Early on in treatment the development of the therapeutic alliance and a shared sense of purpose of treatment (Flaskas & Perlesz, 1996; Friedlander et al 2011) will be a central focus. In FT-AN the development of a balanced alliance may appear difficult to achieve as the adolescent may overtly espouse a lack of interest or need for therapy. Engaging the adolescent as well as parents is, however, important and therapists need to be aware of and respond to, often subtle, cues from the young person to achieve this.

The nature of the therapeutic alliance will evolve over the course of treatment and will vary from family to family and therapist to therapist. In general, however, in the early stage of treatment of adolescent anorexia nervosa it will be shaped on the one hand by the high levels of anxiety generated by the illness, the wish on the part of the patient and the family for greater certainty and on the other hand by the therapist's and team's expertise and confidence in providing guidance to the family. Therapists will need to be aware of the sense of dependence that this tends to foster and be clear that this has to be a temporary (albeit at this stage of treatment perhaps necessary) state of affairs and that over time this will have to be reversed. The temporary dependency of the family on the therapist thus parallels the temporary dependency that that therapist is recommending the young person to allow herself to accept in her relationship with her parents. We will describe later in the manual some of the specific work around altering the therapeutic alliance in subsequent stages of treatment.

FT-AN is generally very task focussed early on in treatment and relationship issues are typically not a major focus of conversation at that stage. Therapists attend to them often indirectly e.g. stressing the importance of fathers' involvement in the therapy or when reframing the parental task of managing the young person's food intake as caring rather than controlling behaviour. In the minority of families where the instrumental task of helping the young person eat is not progressing, relationship issues may need to be more prominent focus from the start. These are often families where there are unresolved attachment issues (either between young person and parents or parents' own attachment patterns), which may give rise to negativity, self or other blame (Besharat et al 2001) and ruptures in therapeutic alliance. In such families addressing the unresolved attachment issues may help move the treatment on (Dallos 2004).

The relationship framework also provides a context to consider the exploration and management of emotions and feelings in the family. How overtly and at what stage in treatment these need to be addressed will vary from family to family. In many families this may only become a focus in later stages of treatment and may be confined to explorations of how different family members manage and show their feelings and ways in which AN has become part of this. In some families, particularly where relationships are characterised by hostility, criticism and anger, working with emotions and feelings may be necessary early on in treatment as a way of addressing road blocks in treatment (Robinson et al 2013) which may include addressing ruptures in attachments between the young person and parent(s) (Dallos, 2004; Diamond et al 2014)

Finally this framework is one that includes the therapist self-awareness and use of self as part of the treatment process (Rober, 1999; 2005; Roberts 2005). The nature of the illness that FT-AN has to address has a strong impact on the therapeutic relationship and demands a high level of self-reflection on the part of the therapist. The intensity of the engagement and resulting therapeutic relationship is both a driver of therapeutic change and recovery but also has the capacity to become a hindrance if

the therapist cannot continually reflect on this relationship and on the process of the therapy. Ongoing supervision and team case discussions are crucial in ensuring appropriate management of this aspect of the treatment.

Maintenance framework

The notion of maintenance does not make any assumptions about the origin of difficulties but postulates that families become organised around problems in a way that may contribute to their maintenance either by directly reinforcing problems or by disrupting adaptive or change processes. When working with families, a significant component of any therapist's activity will be to observe how family members interact, the connections between individuals and explore the way in which the difficulties that the family brings appear connected with the family system. In a clinical context, three important points need to be emphasised.

First, observed patterns of interaction that appear to have acquired a maintaining role should not be confused with causal or aetiological accounts. Indeed, it is important when exploring such patterns with families, that therapists are clear that they are not looking for an explanation of what role these patterns may have played in the development of difficulties and focus more on the way that the family has become organised around problems and how patterns of interaction that may have been helpful in the past have become unhelpful and what makes it difficult to change them.

Second, we need to be clear what we mean by patterns. Traditionally, the main focus when describing patterns has been on behaviours (who does what, how others respond etc.), but observed patterns of behaviour cannot be understood without also exploring the meanings that people attach to them and the context from which they developed. Here reference to pattern includes particular stories told and how these stories shape interactions and responses and alternative meanings that can be attached to the same behaviour (*"in that brief exchange we have just talked about where you more aware of your Mum's irritation or her worry about you?"*). The process of change in this framework can happen at all these levels.

Third, as clinicians we are often primed to notice what is not working, how things are stuck and what maintains problems. While this is important we need to be sure that we also notice patterns of resourcefulness, strengths and resilience. These may not be so obviously apparent and we need to be on the lookout for these, commenting on them when appropriate or note them for future reference.

Observing or exploring patterns of interaction and meaning is not a discrete activity done by a therapist as a detached observer of the family. On the contrary it is done as a joint activity with the family, and is concerned both with interactions in the here-and-now in the therapy room and patterns described by family members in other contexts and in their evolution over time. When therapists share their observations they need to do it in a way that does not impose their view on the family but is offered as a possible construction as viewed by the therapist. They communicate this by asking family members how they see things and making sure that their own account is offered in a tentative, hypothetical way and is followed up by questions of whether this fits the family's own experience.

When discussing patterns that may be connected to a specific problem such as anorexia or comorbid difficulties such as self-harm, the therapist has an important role in framing or asking questions that evoke non-blaming descriptions. The aim here is partly to avoid reinforcing disabling feelings of guilt and blame and partly to set a context which encourages family members to be self-reflective and to consider their own part in the pattern and what they can do to bring about change.

From the perspective of a maintenance framework, change can take place through interventions that directly aim to change patterns or sequences of behaviours e.g. reinforcing certain behaviours (*"I liked the way you were able to tell people directly how upset you are, rather than by making yourself sick"*)

or blocking repetitive patterns (“*Mum, why don’t you sit this one out and see if you daughter and her Dad can find a way of resolving their differences without your help*”), using a range of verbal or non-verbal interventions (a small gesture encouraging the continuation of a conversation, perhaps accompanied by, “*keep going you’re doing great*”). Change can also take place through conversations that invite self-reflection by the family on their patterns (“*I have a sense that people seem to be trying to avoid saying things that might upset you? Do you agree with that? Do you want them to tiptoe around you or would you prefer them to be more upfront? What do you think you could do for them to start doing things differently?*”).

A maintenance frame may focus on immediate here-and-now processes, such as the therapist's decision to draw attention to a significant moment between family members. This might include interrupting an escalating argument during a session; the therapist might intervene by saying, for example; “*Hold on! Let’s slow this down and think about what’s happening. Is this how conversations can unfold at home? Is this how it always ends up? Would it be helpful to find a different way to have these conversations so that they can become more helpful/more productive/less fraught? How would you like to be able to respond to one another?*”. Between sessions, tasks may require family members to interact in a particular way suggested by the therapist or preferred by family members, with the aim of interrupting unhelpful, repetitive patterns.

In the early stages of treatment of anorexia nervosa a significant proportion of the work will focus on patterns of interaction around food either directly observed during a family meal or reported by the family as they try to take on a different way of managing mealtimes. When discussing such patterns it is important to discuss not only the common pattern that the family feel stuck with but also the exceptions when things go differently.

When exploring patterns in the family it is often helpful to normalize the experience e.g. by providing information about some of the temperamental predisposing factors (e.g. raised levels of anxiety or intolerance of uncertainty) and how families tend to respond to this and then asking them to reflect on how this may apply to their family. This may take the form of: “*We know from research...*” or “*When talking to other families in your position they say...*”; “*Does this fit with your experience or is it different?*”

Frameworks focusing on changes in beliefs and meanings

In one sense, all therapies are concerned with meanings and creating an alternative understanding of problems that clients are seeking help for, although therapies vary in the extent to which this is an explicit part of the process of therapy. In systemic family therapy the importance of meanings and narratives arises out of the idea that all difficulties are embedded and shaped by their social context and to a lesser extent also help to shape this context.

From the perspective of this framework, change may occur through several processes. Focused attention to small aspects of neglected or unnoticed narratives may give the family members a perspective about the individual or the family (“*Did you notice that when you your daughter described you (Mum) secretly checking what was left in her lunch box she actually didn’t sound even irritated; is she learning to tolerate that sometimes you are worrying more than you still need to?*”). A negative, constraining narrative may be replaced by a more positively supported alternative that has come to the notice of the family or the therapist. The basis of this new narrative may be explored in terms of what hopes it offers for the future, alternative strengths, abilities and personal values. Grounding the newly constructed identity in additional accounts or as inhabiting other relationships tends to strengthen that new identity. The availability of alternative accounts may allow individuals in the family to take a more self-reflexive stance and/or to distance themselves from the emotional impact of others’ behaviours. The therapist’s respectful interest in the alternative stories that different

family members bring will often be an important validating experience that may also encourage a greater willingness on the part of family members to step back from the immediacy of their own emotionally driven interchanges.

In the treatment of anorexia nervosa there are some key changes in meaning that have a central role in the therapy process. This includes a change in the perception of the parental task of helping their child to eat from one of control to care and support which we describe in more detail later and addressing a sense of hopelessness arising from a perception that anorexia is a life-long chronic illness. When narratives that families bring about themselves or each other are dominated by hopelessness there also tends to be high levels of negativity, blame or self-blame. The language used by the family to describe their beliefs, cognitions and favoured narratives can provide important insights as to what reinforces the hopelessness. The way in which a therapist explores the narratives and meanings that families bring to therapy invites change by setting the scene for different meanings to emerge.

In exploring beliefs about hopelessness the therapist might offer their own beliefs about the possibility of change and recovery based on their own experience as therapists working with other families and patients who have had similar negative beliefs but have overcome the obstacles inherent in managing the illness and have achieved recovery. This can often be usefully reinforced by providing information about recovery rates for adolescent anorexia nervosa either from the literature or from service audit.

Other changes in meaning may be more family specific. For instance, when enquiring about the reasons for Dad's absence at the assessment meeting the therapist is told that it is because he is too busy (implying that work is a greater priority or that he does not care enough). The therapist might hypothesize that Dad's absence may have an alternative meaning and ask *"Is your Dad not here because he doesn't care enough or because he feels useless and doesn't think he would be able to help"* or *"If your Dad believed that him coming here would make a real difference to your recovery, would he come? What would need to happen for him to start believing that"*? The shift in perception of Dad's behaviour that follows such an exploration is often all that is needed to ensure his attendance in subsequent sessions.

The exploration of alternative meanings that can be attached to particular behaviours may allow individuals in the family to take a more self-reflexive stance and/or to distance themselves from the emotional impact of others' behaviours. The therapist's respectful interest in the alternative stories that family members bring will often be an important validating experience, which may encourage family members to step back from the immediacy of their own emotionally driven response and to try to understand what it is like for others in the family.

Influencing framework

The interventions considered under this heading are primarily characterized by their goal directed nature and the therapists' understanding of why and when they chose specific interventions and how this might lead to change. While a great deal of therapeutic interventions can be operationalized in a way that provides clinicians with guidance how to use them, a significant proportion of what therapists do is determined by their clinical judgment of how best to intervene at any point in time to bring about change. Much of the minutiae of the therapy process, such as the choice and sequencing of interventions, the specific type of questions used, how and when to use expert knowledge or when on the other hand to emphasise the limits of our expertise and invite families to look for their own solutions can be understood as part of the influencing framework. This applies both to interventions whose purpose is immediate change in the room as well as to interventions that have longer-term aims for bringing about change. The following two examples illustrate the different kind of decisions that therapist may have to make:

During a session an adolescent responds angrily to what she perceives as a critical comment from her mother and a heated argument ensues. The therapist, aware that this is a repetitive pattern, which usually escalates decides to intervene to try to contain the situation. There will be a range of intervention that could be used to achieve this end e.g.:

The therapist turns to the mother and daughter commenting *“this sounds like the familiar runaway - can we try to deal with it differently this time”* and suggests that instead of continuing talking to each other they take turns to speak through the therapist (the aim here being to slow down and interrupt the usual pattern, making it less likely that each responses will be driven by immediate emotion being triggered by what has just been said)

The therapist addresses the daughter, commenting: *“I have noticed that often when your Mum makes a suggestion you respond as if you feel got at by her and I was wondering if you are more aware of your Mum’s worry or of the tone of her voice which I think you feel sounds critical”*; if daughter says that she is aware of both this could be followed up by asking which of the two is she responding to (the aim here is to offer alternative descriptions of the same behaviour that can validate both daughter’s and mother’s experience and to invite a conversation about negativity and criticism without simply being critical of mother’s behaviour)

The therapist could achieve a similar end by addressing mother directly and asking if she is aware that she is coming across as critical rather than concerned. This is potentially a risky intervention that can easily invite a very defensive response but can be very effective if the therapist judges that the therapeutic alliance with mother is strong enough for her to be able to hear it and reflect on it.

The following is an example of an intervention which had a longer-term aim: The therapist noticed that the young person who had been making slow but steady progress in terms of weight, was beginning to join conversations during sessions a bit more actively and seemed less negative about the possibility of change. The parents, however, were more preoccupied with the slow pace of change and the therapists attempts to focus on the positives were met by a “yes, but” response. Turning to the adolescent the therapist asked: “Have you yet reached the point when you are sometimes pleased that you resisted the urge not to eat”; after a brief hesitation she responded “I’m not really sure - sometimes but it doesn’t last very long”; the therapist nodded and said “that makes sense, people nearly always find that this happens very gradually; keep an eye out for when this happens next and make sure that you remember it - this is the sort of thing that will help you at times when you are finding things difficult to cope with” – “I suppose it is still too early for you to be able to let your parents know when this has happened”; the young person grinned and said “only if Mum promises not to make a song and dance about it” to which both parents responded by laughing. (The therapists aim was to invite self reflection in the young person and to make visible a process that he suspected was beginning to emerge. It also allowed him to deal in a more useful way with his own sense of frustration with the parents’ “unwillingness to see the progress” their daughter was making.

Which intervention the therapist chooses in a specific situation with a particular family will be determined by a number of things: the stage of treatment and the particular goals for that stage of therapy; the therapist’s relationship with the each family member and the family as a whole; judgment of how different people might respond; the therapist’s personality and their therapeutic style, their level of experience etc. The interventions considered here often draw on the clinicians therapeutic authority and require therapists to be self aware and self-reflective because such interventions can have both positive and negative effects.

Therapeutic Principles

Collaborative working, professional expertise, power imbalances and the therapeutic relationship

Systemic family therapy generally aims for treatment to take place in the context of an open and collaborative relationship between the therapist and the family. The therapist and the family form part of the same system, and share responsibility for change and the process of therapy. Therapists, however, need to recognise the intrinsic power differentials that exist within the therapeutic relationship, as well as within family relationships. As described earlier, in FT-AN the therapeutic relationship early on in treatment is determined by the need to provide a safe context for treatment, through the expertise of the therapist and team, which may reinforce the inequality of the relationship. Although this does not preclude an open and respectful relationship with the family, the therapist needs to pay particular attention to this aspect of the relationship.

Therapists must be aware of the inherent responsibilities that go with the role of therapist; e.g. to ensure that clients have adequate information to make informed choices, they must be aware of the professional obligations in relation to abuse and risk and the potential impact of the questions, comments or other interventions they make (Anderson & Gehart, 2007; McNamee & Gergen, 1999). The therapist will generally aim to support the less powerful members of the family to have their voice heard in sessions, challenging oppressive relationships, whilst acknowledging appropriate power and responsibility of family members (Wilson, 1998). The young person suffering from anorexia nervosa will often attend sessions at the beginning reluctantly and may not want to contribute much. While the therapist may side with the parents' decision to insist on her attending treatment, it is important that the young person's point of view is heard and that every effort is made to engage with her in an empathic and respectful way.

When using their expertise e.g. their knowledge of research on eating disorders, the effects of starvation or general professional knowledge about families, therapists should always be mindful of the impact on the family and the therapeutic relationship of adopting an expert position. Even during the early stages of treatment a useful distinction for therapists to make in this context is being expert in the illness (i.e. having knowledge about eating disorders) and being non-expert in the family (i.e. how their general knowledge might or might not apply to the unique context of the individual family). In the treatment of potentially life threatening conditions such as anorexia nervosa, expertise of the therapist and the MDT as a whole plays an important role not only in ensuring safe practice but also in the way that it shapes the therapeutic relationship. The family's perception that they are being seen by people with expertise can helpfully contribute to a sense of having a safe base for therapy particularly during the early stages of treatment. Providing information about eating disorders, the effects of starvation, giving advice about diets or discussions of medical risks can have a powerful impact on how the family experiences and engages in the treatment process. The therapist of course needs to be mindful that the young person may experience this differently from the parents.

It is particularly important for the therapist and the team to be aware of the potential impact this expertise may have on the family e.g. reinforcing temporary dependency and being less likely to recognise the families' own resourcefulness and strengths. Such issues need to be addressed openly with the family e.g. through team reflections about the value and risks of giving advice or offering opinions. In later phases of treatment the therapists need to work towards a different relationship, in which the therapists expertise and knowledge is progressively less prominent. This will be discussed in more detail later on in the manual.

Attention to wider context

The therapist should consider the importance of context both in the way that families are impacted by their immediate as well as broader societal contexts as well as the context of the treatment setting and their interaction. In considering the specific context of each family, therapists need to attend to the real and perceived differences of culture, race, religion, gender, sexuality, ability and class (Bateson,

1972; Bertrando, 2000; Krause, 2010; McGoldrick, 1994). Therapists should consider how best to address working inter-culturally where the physical and psychiatric aspects of anorexia nervosa are understood very differently and pay particular attention to both their own power as clinicians as well as that derived from their organisation

Key principles of family therapy for anorexia nervosa (FT-AN)

Systems focus on understanding the family in the context of a potentially life threatening illness where the family is needed as a resource help their child recover

The systemic model for treatment of anorexia nervosa should not be thought of as a distinct model of family therapy (in the sense that e.g. structural, strategic or narrative models have been described in the past) but rather as an application of a general integrative systemic family therapy approach to the treatment of a specific condition. It is the latter that gives it its distinctiveness, rather than a particular theoretical model or concept of change. The nature of the illness and the impact it has on the young person and her/his family gives the treatment its specificity and shapes the direction of the treatment while the broader theoretical frame offers a way of conceptualising the process of change which informs moment-to-moment clinical decisions with individual families.

Families will often have asked themselves the question “what have I/we done wrong for my/our child to have developed an eating disorder?”. Therapists need to be clear that the family is not the cause of the illness but that they are needed to help the child recover. In other words, treatment of anorexia nervosa should be understood as a treatment *with* the family as opposed to treatment *of* the family. This critical shift in conceptualisation can be found in the early development of family therapy for eating disorder (Eisler et al 2015) but also mirrors the development of systemic theory in general and as such the FT-AN model described in this manual is consistent with current systemic thinking.

An influential concept in this development has been the illness model of family functioning (Steinglass, et al 1987; Steinglass 1998; Rolland 1993; 1994) which offers an understanding of the way in which families can become highly organised around persistent problems until they reach a point where that illness becomes “a central organising principle” in the family’s relationships, behaviours, interactions and beliefs about themselves. When first meeting the family at assessment the clinician is seeing the family at a specific point in the development of the effects of the illness and particularly at this early stage of the treatment process should not make assumptions that the patterns of family interaction they are observing are a reflection of family dysfunction but that at least a major part is the outcome of a process of adjusting to living with a serious life threatening illness (Eisler 2005). Thinking about this from the perspective that Steinglass offers is extremely important and helpful for clinicians in order to avoid reaching unhelpful pejorative assumptions about families managing this illness.

In working systemically, a central focus should be on the relational system as well as considering the needs of each individual family member. The system may usefully be thought of as the household or wider family and may include friends, people in institutions (e.g. school, work, church) as well as the professional network. For young people being treated for eating disorders, the most important part of the system to involve and engage are any adults who are in either in a parenting or significant and involved parenting-type role. For some families this will mean involvement of both parents in therapy, in others it will mean involving step-parents, grandparents, foster carers, older (adult) siblings etc.

Expecting parents to take a lead in managing their child’s eating in the early stages of treatment whilst emphasizing the temporary nature of this role

Working with the significant relational system enables therapists to develop a fuller appreciation of the presenting concerns as well as helping to discover the resources available to support change. The treatment approach described here places parents and carers in a central position in relation to the process of recovery. This is true for both the treatment of bulimia and anorexia; both demanding rapid learning on the part of the parent to understand their child's needs and demands on parents or carers to respond in different and flexible ways. From the outset of treatment parents and carers are required to confront and begin to overcome the most difficult aspects of the illnesses. While some parents come to treatment with the expectation that they will have an active role in helping their child, others believe that they are ill equipped to do this and assume that it is for the professionals to provide the required "cure". Most will readily accept the explanation that restoring nutrition is a key aspect of recovery but find the expectation that they as parents will have a major role in this, unimaginable. Nearly all will have tried to get their child to eat and while most will have found a way of persuading and cajoling their child to eat at least small amounts they will be sceptical that it is possible for them to achieve any more. They will need reassurance that the therapist and team will provide the support that they will need and that outpatient treatment will only proceed as long as it is safe to do so.

The manner in which the family is engaged to take on this task is of key importance. The parents are often fearful that they will make things worse and this is reinforced when they witness the immense distress their daughter experiences when faced with food. The young person notwithstanding her protestations that nothing is wrong and that she just wants to be left alone will in most instances feel unhappy with the way things are but will gain at least temporary respite from being able to resist the temptation to eat. Starvation will have reinforced her need for certainty and not eating provides her with some sense of being at least temporarily in control. In order for the parents to be able to start taking on the role of helping their child to eat both the young person and parent/s have to begin to perceive that this is not a matter of controlling the wilful behaviour of a child but an act of care in looking after an ill young person who is in the grip of an illness she cannot resist on her own. By the same token the young person can only begin to accept the parents helping her to eat if she feels she is being looked after. While she may go on protesting and only accept the need for help grudgingly, unless at some level she accepts the necessity of this step the parents are unlikely to succeed. Externalising the illness as described in more detail below and the strong early focus on the medical aspects of the illness will often have a key role in enabling the shift in perception that is required at this stage.

Who should be included in the treatment

Individuals and family subsystems may be worked with together or separately in the context of this work (Rivett and Street, 2009; Gehart 2010; Carr 2012). In the early treatment phases for anorexia, individual work with the patient is rarely advised for severely unwell patients (see section below on working individually). However other parts of the family may require individual attention; it is sometimes the case that parents will need separate individual support and consideration if there are particular concerns impinging on their ability to cope or respond appropriately to their child's treatment needs.

Consideration of the immediate and wider systems will require early exploration at assessment and in early sessions with a focus on important connections and contexts, which may impinge on or support the process of recovery. Young people presenting with an eating disorder will often have family and non-family connections which may be extremely important in the recovery process; grandparents, aunts, older siblings and child-minders, nannies, school staff and faith leaders may all have a different role in the process of recovery and may need including in the treatment process to one extent or another dependant on their role in the child's life. Extended family members may be involved in the care of the child and will need to know how to support treatment. Some families will be able to

convey what they have learned to these family members whilst others prefer to bring these other family members to sessions. If this is helpful then any such treatment options should be considered.

Decisions and conversations around the needs of siblings are extremely important. Parents often need space to think about the needs of other children in the family and the therapist has a responsibility not to forget the needs of these children. Involvement of siblings should be negotiated and their age and emotional maturity should be considered in relation to the appropriateness or otherwise of their involvement in certain areas of treatment. Siblings are routinely included in the MFT-AN process and many siblings will become a part of the FT-AN process following negotiations and conversations with their parents about the pros and cons of their involvement.

Any decisions about who else the family may call upon to support them through the treatment process should be made collaboratively but parents may often need some encouragement to break a silence that may have surrounded their struggle with the illness resulting in isolation from those people around them who may be willing and able to help them.

Psychoeducation in the treatment of anorexia nervosa

Psychoeducation forms an essential component of the treatment for anorexia nervosa especially in the early stages; many parents and patients develop their own expertise as the process of treatment develops but early on the clinician acts as both therapist and educator. Further examples of psychoeducation are described within the treatment “Phases” sections and also within the addendum describing the role of the Paediatrician.

While a growing number of parents or patients will have researched current evidence based treatment approaches and will increasingly expect to be involved, many are likely to be quite surprised by the high level of involvement of parents in the front line of treatment especially in relation to the management of their child’s eating. Parents will often feel bewildered and sometimes even frightened by the notion that their child will not immediately be offered in-patient treatment or individual psychological therapy to overcome the illness. Families may need a great deal of persuading by the therapist that it is possible to treat the illness in the family home with parents in charge of supervising the re-feeding process. Other families might feel a huge sense of relief that they can finally feel both supported by professionals and also learn how to do something themselves to help their sick child. In either instance it is important that the family and patient are offered information that makes sense of the rationale for this family based approach. This is especially important at assessment when the assessing clinician moves from diagnosis to explaining the treatment plan that will initially focus on restoration of appropriate nutrition.

Psychoeducation is therefore not just about information giving; it also forms a key part of the process of engagement in treatment, providing a sense of safety and by describing the medical aspects of the illness and the physiological effects of starvation contributes to the separation of the illness from the person of the child. The clinician makes a judgement about the extent of psychoeducation they might offer at assessment. Below are examples of the information that might be shared with a family at assessment and in early sessions. The level of information given to the family might be informed by the clinician's sense of how much the family needs this information in order to be motivated to act in a robust way to support their child to eat. If the clinician senses that the parents are already aware of the dangers in not acting and seem ready to meet the challenge of re-feeding their child at home, it might be unnecessary to labour these points. However, even when parents are quite knowledgeable they will often find it reassuring to be receive confirmation that they are right to be concerned and for this to be made explicit in front of their child.

Psychoeducation in relation to the urgency of re-feeding

The assessing clinician needs to explain the effects of starvation not only on physical health but also on psychological functioning. When the patient is seen by a medic, either psychiatrist or paediatrician, these physical health risks can be amplified by the examining doctor. For example the patient and their parents are told about the relationship between low body-weight and loss of periods (amenorrhoea) or stunted growth and the need to reverse this phenomenon as effectively and quickly as possible.

The clinician describes the impact of *amenorrhoea* in relation to bone development, describing the way in which healthy bone development is laid down during a short window of opportunity during adolescence when important hormones are released during menstruation. This release of hormones supports the development of healthy bones. Parents and patients are informed that in the absence of regular periods the patient is at risk of developing *osteopenia*, a potential precursor to osteoporosis (or low-density bone formation). Emphasis is placed on the possibility of reversing the effects of amenorrhoea on bone development but only if weight restoration is achieved in good time whilst this window of opportunity is open.

The clinician will often weave psychoeducation into the conversation that develops through the assessment process, drawing on the physical phenomena (described under the biology of starvation/role of a paediatrician). However, unlike the paediatrician who is more likely to offer a straightforward physical explanation, the clinician should provide a reframing or psychological intervention in relation to some of these physical phenomena. For example with “Delayed Gastric Emptying” which can become a perpetuating factor in anorexia (as it causes discomfort when the patient attempts to eat even small amounts of food after a period of chronic restriction, (Robinson et al 1988), the clinician describes how this very real physical phenomenon is reversed when normal regular eating is restored through exercising the digestive muscles. Families will often be convinced that reports of feeling full or bloated after eating small amounts of food are “anorexic excuses” on the part of the young person to avoid eating. Highlighting that this is an effect of starvation (rather than an expression of anorexia) can be a useful way of validating the young person’s account and at the same time altering the meaning of the behaviour for the parents in a similar way to externalizing conversations (described below).

Psychoeducation on the effects of starvation on physical and cognitive functioning

Clinicians should be familiar with the Minnesota Starvation Experiments (Keys et al 1950) which highlight the fact that many of the psychological phenomena associated with anorexia nervosa are the direct effect of starvation. Discussing with families the impact on healthy volunteers of being placed on a starvation diet over a period of 6 months provides a useful context for changing the understanding of many of the symptoms of the illness that the families are familiar with both physical (e.g. bradycardia, loss of muscles including heart muscle, loss of hair, dry skin, low blood pressure, reduced basal metabolism, feeling cold, having poor circulation and loss of libido) as well psychological (e.g. low mood, emotional distress, social withdrawal, development of suicidal ideation and self-harming behaviours and perhaps most strikingly increased preoccupation with thoughts of food and eating).

It is important to share this information with families because it emphasises the fact that starvation alone is likely to be causing many of the physical and psychological changes that the parents and patient have observed. Additionally it highlights why restoring healthy weight is a necessary precondition without which psychological recovery is not possible.

The most important message during the early stage of treatment, repeatedly emphasized to the patient and her/his family, is that food is medicine and that feeding of their child by the parents is an expression of caring rather than coercion. The therapist needs to be sympathetic to the young person’s

predicament but at the same time look for opportunities to emphasize that there is no recovery from anorexia nervosa without eating and re-gaining lost weight back to a healthy range.

An awareness that starvation has an impact on the functioning and "hard-wiring" of the brain means that reversing these effects is of prime importance. The longer the patient remains at low weight, the greater the impact on the brain and on positive treatment outcome.

The clinician explains that although the only solution to begin with is to re-nourish the young person, once a healthier weight is achieved it will be important to also attend to any residual difficulties which might prevail. (See below re psychological traits in anorexia)

Psychoeducation on the disadvantages of in-patient admission

Once the rationale for urgency of restoring nutrition is explained, the clinician needs to set out the rationale for parents managing the process of re-feeding in the patient's own home rather than on a hospital ward. Clinicians explain that research evidence has shown that whilst weight can be restored during a hospital admission, there is a 25-30% rate of relapse post-discharge which increases to 50-75% after repeat admissions (Lay et al 2002; Strober et al 1997)

The clinician may also explain the research evidence indicating that there is some evidence that admissions to hospital may themselves have a negative impact on the long term course of the illness (Gowers et al 2000). The clinician might explain to parents that whilst hospital staff can feed their child it is far more likely that their child will ultimately recover if they are supported to manage this process in their own home with the parents drawing on their strengths to find effective ways to help their child.

Psychoeducation on predisposing personality traits for the development of anorexia nervosa and comorbidities

Certain inborn personality traits like perfectionism, anxiety, obsessionality and rigidity seem to predispose young people to eating disorders. Scientists agree that probably 46-78% of the risk of developing an eating disorder is genetic and inherited (Scott-Van Zeeland, 2014).

Eating disorders often occur in young people with other mental health problems such as anxiety, depression, and obsessive compulsive disorder (OCD).

One of the most common conditions that young people suffer before developing an eating disorder is anxiety. In fact, anxiety disorders are often found in families and relatives of young people with an eating disorder. Many young people who go on to develop anorexia nervosa have a previous history of being anxious worriers, and shy overachievers who do not like to take risks. Young people at risk of developing anorexia nervosa are often extremely hard working and very anxious about making mistakes. They tend to put a lot of effort into academic performance and strive for perfection in their work and appearance.

Young people with anorexia are less likely than is commonly seen in their healthy peers to be driven by immediate rewards and are more likely than their healthy counterparts to be focused on long-term goals. Their anxiety usually worsens during puberty once they are faced with the complexity of new challenges and adolescent development.

Paradoxically, young people at risk of developing anorexia nervosa may feel less anxious when they restrict food, and feel more anxious when faced with eating the meal in front of them. Food restriction and starvation in young people at risk can reduce anxiety just at a point when they feel distressed and

overwhelmed by their emotions. Bingeing and purging can also provide physiological effects that blunt or temporarily reduce anxiety.

It is important that the clinician informs the young person and her/his family that though they will probably feel more anxious once they start eating an adequate amount of food, in other words ‘things will get worse, before they get better’, this is nevertheless, entirely unavoidable in order for them to re-gain health and achieve a fulfilling life.

Another common co-morbid condition with anorexia nervosa is depression. Similarly to anxiety, it is often hard to distinguish what came first - the eating disorder or the depression. Social withdrawal, lack of energy, poor sleep, and poor concentration can all be the consequences of starvation. In most instances a nutritional recovery alone will improve symptoms of depression, however not immediately. The clinician should make parents aware that typically it can take a number of months for the brain to recover and for depressive and anxiety symptoms to subside.

Patients and parents need to know that if personality traits like perfectionism, rigidity, obsessionality and anxiety were present prior to the development of the illness then they will most likely remain after weight is restored. However, the clinician should clarify with the young person and her/his parents that she/he will be offered support and coping skills that are geared towards helping them to manage these traits so that the impact on their daily living, relationships, emotional development and recovery is reduced. Young people and parents may also need to hear that some of these traits might be highly positive; maladaptive perfectionism can be channelled differently so that the young person can use it in a more effective way.

Use of externalisation including potential pitfalls

Externalisation can be an effective technique in the treatment of eating disorders, although (as with any powerful therapeutic technique) it has pitfalls that therapists need to be aware of. The notion of externalisation has its origin in projective psychology (Bellak, 1959) and Gestalt therapy (Perls, 1969) but has been most clearly developed conceptually by narrative therapists (White and Epston, 1990; White, 1995) for whom externalisation is a central concept and is used to separate problems from the individual, their actions, or effects of their actions, in order to facilitate conversations leading to new narratives, new meanings and new self-evaluations (White and Epston, 1990).

Externalising conversations, which label anorexia as a quasi-external force, gives new meaning to some of the physical, psychological and behavioural effects of anorexia. Used therapeutically as a metaphorical concept, externalising the effects of the illness can helpfully dilute the impact of conversations that focus on emotions such as guilt and blame, which are often present for families dealing with anorexia. Externalising conversations can be used in a variety of ways determined by the specific fit with the individual adolescent and her family and the particular stage of treatment. These will include:

- Externalising conversations about the nature of anorexia
- Mapping the effects of anorexia on the individual and the family
- Exploring beliefs about the impossibility of parental action (looking for unique outcomes and strengths)
- Externalising conversations about what happens at mealtimes
- Exploring the role that AN has acquired in the management of emotions, feelings and interpersonal relationships

Therapists will use a range of other interventions with similar externalising intent both in single and multi-family therapy contexts. These could include:

- Information giving and psychoeducation (e.g. describing the physical and psychological effects of starvation (Keys et al 1950) which gives a new meaning to many of the “eating disorders symptoms” as being physiological responses rather than volitional or willed behaviours.
- Motivational letters (e.g. letters to AN my friend and AN my enemy, letter from the future, letter from my body)
- Interviewing AN

Limitations and pitfalls in the use of externalisation

A significant minority of patients feel dismissed and patronised if externalising conversations are not qualified by a tentative exploration and description by the therapist. In all cases it is important to ensure that the language used to begin the externalising process is developed collaboratively; “does it sometimes feel as though anorexia is driving your actions and thoughts?”, “it might be as though your child has been taken over by an incredibly strong force”, “does it feel as if you cannot make choices that defy these strong impulses?”. In so doing the therapist is checking out with the family and patient the extent to which they can identify with these notions without insisting that anorexia is definitely and always in control and a totally separate entity. If used too liberally and without care, anorexia can become described in increasingly dramatic and fearful terms which for some patients cannot easily be separated from their core sense of self. Externalising is a useful therapeutic tool but can too readily become a description that cannot be separated from the patient’s self. When the metaphor becomes over-used and relied upon too readily as a vehicle for the distress and anger caused by the illness, delineation between overt blaming of anorexia and blaming of the patient can become blurred. Not enough is known about the particular impact of externalising as a therapeutic intervention and as such it should be used carefully, sensitively and collaboratively.

Additionally it is essential from the outset that the therapist is clear that an externalising perspective does not mean that the patient has lost responsibility for acting within acceptable limits. This is often achieved through conversations that focus on acceptable and unacceptable behaviours in their particular family, and conversations which invite the family’s ideas about “normal” adolescent struggles; which adolescent behaviours do they tolerate and which need clear and firm parental boundaries? Which behaviours are those of an adolescent and which are those of an adolescent being influenced by anorexia? This is particularly important with patients who become physically aggressive or behave in other unsafe ways. Parents need to have an opportunity to discuss how they might react and consider appropriate parental responses to these situations. Without the benefit of these conversations families might become muddled by a potential message through externalising conversations which could be heard as “she can’t help it, it’s the anorexia”

Phases of treatment

The treatment in this manual is described as having four phases but it should be recognised that these phases are not discrete time periods and are used more as a way of emphasizing the main focus of the work at different stages of treatment. Thus for instance we describe the *Family Meal* in the section on Phase 1 (*Engagement and development of therapeutic alliance*) because of the important role this session has in the establishment of a good therapeutic alliance although, clearly, it is also part of the work in Phase 2 (*Helping families manage the eating disorder*). Similarly, the focus of Phase 3 (*Exploring issues of individual and family development*) clearly overlaps with Phase 4 (*Ending treatment, discussion of future plans and discharge*), which in turn connects with previous phases with the family reflecting on the recovery journey they have been on as well as looking ahead to life without an eating disorder.

Phase 1- Engagement and development of the therapeutic alliance

The aims of the initial phase of treatment

The main aim during the first phase of treatment is to engage the family, including the ill young person, by creating a safe base and helping to build a shared sense of purpose for treatment (a key element of therapeutic alliance in family therapy). Families will vary in the extent to which they have been affected by the eating disorder but generally the family will present for assessment and the early stage of treatment in varying degrees of crisis. Typically they will be paralysed by high levels of anxiety and a sense of despair. Parents will often feel that they have failed and they may blame themselves (or sometimes each other) for their child's predicament. In some families feelings of guilt and blame may turn to criticism or in some instances hostility towards one another. The young person will often (though by no means always) wish to deny or minimise the illness but will also likely be experiencing a mixture of feelings including fear, guilt or anger.

The way in which the family is engaged from the start should reflect the gravity of the illness and the sense of crisis within the family. A number of general principles are important to keep in mind:

Treatment with the family as opposed to treatment of the family

Clinicians should be familiar with the empirical evidence showing that despite research efforts to prove otherwise, families that include a child with anorexia nervosa do not differ from control families (Konstantellou et al 2010). Clinicians should also understand that when families present for assessment and treatment, the way in which they communicate, behave and organise themselves and their family relationships are in large part likely to be the result of their managing the illness rather than signs of "family dysfunction"; the way in which families may become organised around illness and other persistent problems is helpfully described by Steinglass, 1998 and Eisler, 2005 (see above).

Many families are preoccupied with the question of *why* their child has developed an eating disorder, however from the very first contact with the family the clinician should explain the lack of evidence for families being the cause of the illness, the potential futility of ruminating on this concern and the need to turn this effort into supporting healthy change. It may be important to reassure the family that through the process of treatment, and especially in the third and fourth phases of treatment, attention can be focussed on the family's concerns relating to the history of the development of the illness but whilst their child remains in a starved state, the focus of attention must be drawn away from these issues and centred firmly on supporting their child's efforts to eat.

The clinician should reiterate that the reason for meeting with the family is not because they are assumed to be the source of the illness but because their strengths and unique knowledge of their child are needed to support the recovery process. From the start the therapist focuses on exploring these strengths and resources in the family and finding out what might get in the way of these assets being used to the maximum.

Owning expertise in eating disorders and providing advice and information

The expertise that the therapist, together with the rest of the team, has in eating disorders is an important factor in developing a sense of a safe base for therapy for the family. This will include providing information about eating disorders, the effects of starvation, giving advice on meal plans and discussions of how mealtimes can be managed as well as assessing and discussing medical and other risks. Therapists, of course, need to be aware of the potential pitfalls of being in the position of the expert (e.g. reinforcing a sense of dependency on professionals or allying more obviously with the parents, rather than the young person) but they should not assume that these pitfalls can be avoided by

simply adopting a more neutral position. In the early stages of treatment, particularly if the young person is severely underweight or medically compromised, the family's reliance on the team's expertise can be helpful, as long as it is clear that this is a temporary state and that there are limitations to this expertise. Thus from the start the expertise in eating disorders should be contrasted with the fact that the therapist does not have the answer as to what any individual family will need to do to overcome the illness, for example the therapist might say "*I don't know what is going to work for you because I have only just met you and I don't know what sort of parents you are; most families at this stage don't believe they can do it because anorexia has taken away their confidence in themselves as parents; we will work with you to work out what will work best for you and your daughter*". Therapists should be clear about the limitations of their knowledge and when they give advice or give examples of what other families have found helpful, they should invite families to consider how relevant the specific advice might be for their particular family. At other times, the therapist needs to take a clear and expert position and to make strong statements related, for example to safety or risk. Advice is offered, often in the context of what other families have found helpful or what research might suggest. This "expert" positioning is purposive and situated in a therapeutic context of high risk and therapeutic need.

"The situation is so dangerous right now that your daughter cannot survive for very much longer without your finding a way to feed her. We know from all the available research evidence that your daughter's best chance of getting through this illness is to have you feed her at home with our support and guidance. We know that if she doesn't begin to eat now she is likely to end up in hospital. One hospital admission reduces the chance of a positive outcome; two admissions makes the future look even bleaker. Of course we will admit her if that's what we have to do to keep her alive but we want her to have the best chance of getting over this which means her going home with you and your finding the strength and skills to feed her"

Here-and-now focus and illness orientation early on in treatment

The main focus for engaging the family in Phase 1 is very firmly illness/problem orientated. Assessment of the severity of the illness, its history and what the family has attempted to do to tackle it, is combined with giving information about the effects of starvation, including the physical and psychological risks (see section on psychoeducation above)

The family time frame is generally orientated in the present and congruent with this is the emphasis at assessment on physical risk and the need to implement step-by-step changes. The therapist holds a broader time frame based on the experience of having been through the process of therapy with other families, which extends to the future and includes an expectation of change. The therapist conveys this temporal context by describing the nature of treatment being offered; its duration and the part that families generally play in the process, emphasising that like they themselves, most families at this stage of treatment do not believe that they can be central in helping their child to recover.

Engaging the young person even though s/he may deny s/he has anorexia

Many, though by no means all, young people with anorexia nervosa deny or minimise their illness at first. Some may show reluctance to take an active part in the assessment, but will contradict parental accounts of how bad the problem is. They may say that they can easily regain any weight they have lost but don't see why this is an issue. At a surface level they may give every indication that they don't see a problem and/or that they are not motivated to change. Some patients attend for assessment in such a physically and cognitively compromised state that any attempts at engagement become impossible. In such situations the clinician should convey their empathy and concern and let the patient know that whilst they will continue to speak about her, s/he should listen, and if possible

interject if s/he feels that her parents or the clinician are getting anything wrong or if she has anything to add to the account. The clinician should also convey their trust that once her/his parents have found a way to support her/him in beginning to recover, s/he will be fully involved in the treatment and her/his thoughts and ideas will be a central and valued consideration in future sessions. The therapist will have to judge the level at which engagement is possible; sometimes this will be no more than fleeting eye contact by the patient or a smile or the expression of sympathy by the therapist at how hard it is going to be for the patient when explaining to the parents that they will have to take a strong stance against anorexia. The empirical evidence is that most adolescents with anorexia develop a positive therapeutic alliance in the context of family therapy (Forsberg et al 2013) and contrary to what might be predicted this appears stronger in those with high levels of eating disorder cognitions (LoTempio et al 2013). If the patient is cognitively able and willing to connect with and manage the information being discussed, the therapist needs to make sure that their side of the story is heard and taken seriously. The therapist should empathise with the difficulty of their predicament whilst making it clear that ensuring their health and safety have to be the priority for now and that when anorexia nervosa has taken a grip on her and her family, doing nothing is simply not an option. Often, broadening the conversation beyond eating and weight to other areas such as school, friendships or relationships within the family will allow the young person to acknowledge that there are many areas of life that have been affected and that change in these areas might be helpful.

It is sometimes helpful to offer an account of the different phases people go through during illness and recovery to broaden the time frame from the here-and-now which the young person (and the family) are likely to be orientated in; *“When you say you don’t have an illness, I don’t know exactly what I should make of it. I know from talking to young people who have recovered that often there is a phase when people become ill when they don’t themselves recognise what is happening; later they realise that things are going wrong but they find it difficult to let other people know and it is only when they begin to believe that others could help that they can start talking about it; I can’t tell the difference between the first two phases because I don’t know if ‘I don’t have an illness’ means ‘I can’t believe I am ill’ or ‘I don’t want to talk about it’”*.

Reframing feeding by parents as caring

Perception of control is very important for anorexia sufferers and they will often report that restricting their eating gives them the sense that they are in control of “at least something”. This may be understood in part as being related to a low tolerance of uncertainty which is characteristic of individuals who develop anorexia (Frank et al 2012). The meaning of placing the parents in the role of supporting an appropriate level of dietary intake has to be carefully explored with the patient so that s/he can genuinely accept that the parents’ role in increasing their eating is a reflection of the parents’ care for their wellbeing and not a hostile act of taking away control from them. This can happen all too readily because usually neither the young person nor the parents feel that they are in control of things and assume that the solution is to gain control (young person through not eating, the parents by getting the young person to eat). The choice of words and the manner in which this is discussed with the family is therefore of key importance. Therapists should try to avoid language that implies power and control but emphasizes care and love (*“you can’t expect your parents to sit back and watch you starve yourself to death; they care too much about you and need to help you to start eating again so that you can get your life back”*)

Earlier discussions of the effects of starvation and externalisation of anorexia are utilised to emphasise that due to their illness *“it is anorexia that is in control of their eating and not them”* and that parents need to find a way to support a regular, weight gaining food intake until anorexia is no longer in such dangerous control. At the same time, it must be clearly stated that the long term aim is for the young person to regain full control of the decisions they make in their life i.e. including making their own

choices about what and when to eat alongside the other age-appropriate choices they will have retained through the process of treatment. This is more easily achieved once their eating is less controlled by anorexic cognitions. For young people who have had a secure relationship with their parents prior to the onset of anorexia, it is easier to accept that their parents support for them in eating is an expression of good parental care and love rather than an act of wilful intrusion into their lives.

With prolonged and severe starvation, patients often become increasingly rigid and socially isolated. Additionally starvation often reduces or numbs feelings of anxiety, however, the anticipation of eating can in turn increase levels of anxiety. Correspondingly the need for predictability and certainty is increased. Parents therefore need to be aware of this phenomenon by introducing predictable rules around meal times, duration of meals and meal content. Parents should be advised not to enter into conversations or negotiations around food at the table and to reduce the scope of negotiation at other times. Parents can be helped to recognise when they are negotiating or talking to “anorexia” when any rational outcome is unlikely and when their child is present enough to talk about matters related to eating and food.

Parental pain and a sense of helplessness when observing the distress in their children affected by anorexia, can become too overwhelming and result in parents “giving in” to the anorexic demands. When the young person insists on eating less or threatens to stop eating completely if parents do not comply with these demands, parents may feel unable to resist the temptation to yield to their imploring child. Not being able to contain, process and manage their child’s and their own distress might result in parental inability to act. This may contribute to a prevailing sense of failure and feelings of self-blame and guilt which in turn can lead parents to verbally express their sense of negativity and to become overtly critical (Besharat et al 2001). The therapist should empathise with parental frustration and distress whilst also describing the counterproductive nature of hostility and criticism (See below: Individual work with the young person)

The use of externalisation in the initial stages of treatment

Externalisation during Phase 1 happens in a number of ways, a key part being the giving of information about anorexia and the effects of starvation. This gives new meaning to some of the behaviours and experiences accompanying the eating problems, reframing them at least in part as a physiological response to starvation. For instance describing the effects on healthy volunteers of being starved in the Minnesota Study (see section on psychoeducation) and the many parallels with someone suffering from anorexia nervosa; low mood, irritability, preoccupation with food, fear of losing control, can change the perception of the “anorexic behaviours” as being wilful and under the young person’s control to being common and expected behaviours which arise in response to anorexic cognitions which are reinforced by starvation that requires the combined efforts and support of the family to overcome.

This can be reinforced by the use of “externalizing conversations” in which anorexia is labelled as separate from the young person. Initially this may be no more than the therapist adopting a language that implies anorexia for many people is almost like a separate entity (“*When did you first begin to realise that anorexia was influencing your daughter; how has anorexia affected how you get on with your friends?*”). How the young person and the family respond to the idea that anorexia has an external controlling quality will determine how externalisation is best used with a particular family. Some families readily describe their child and themselves as being “taken over by anorexia” or the patient might describe an internal anorexic voice which controls her behaviour and which she struggles to defy. Others may not experience anorexia in this separated way or may not yet have reached an acceptance that they are unwell. Some simply need to clarify that they know this is not a

voice from outside but their own thoughts, but they will acknowledge that these thoughts are intrusive and difficult to resist.

Other adolescents, however, are clear that they dislike the idea of anorexia being described as separate from them, particularly if they feel this is being imposed or if they feel that it may give their parents licence to take control. Some may feel patronised or dismissed. It is therefore important that any exploration of the idea of externalisation starts by enquiring if it makes sense to the young person (*“Many of the young people I have worked with have said that anorexia is a bit like having a voice; they know it’s their own thoughts but they are difficult to ignore; for others it is different; what is it like for you?”*). Exploring with the young person what her own experiences are and acknowledging its uniqueness can be an important moment for connecting and strengthening the alliance both with the young person and the family as a whole who are often reassured when witnessing a developing conversation between their daughter and the therapist.

If the young person dislikes the idea of externalising, the therapist will need to be cautious in the way it is used in their work with the family. They might need to explain that whilst it might not fit for them, this way of talking may, nevertheless help their parents to understand the seriousness of what is happening and how powerful the effects of the illness can be.

Early on in the externalising process it is important to think with families about differentiating normal adolescent behaviour from anorexic struggles. Without such a conversation there is a risk that unacceptable behaviour is excused or anorexic behaviours go unchallenged.

The therapist must consider the age of the patient in exploring issues related to responsibility and adolescent development as younger patients might not yet see themselves as adolescent and might not relate to conversations that seek to separate adolescent from anorexic behaviours. However young the patient, a conversation about responsibility for managing and controlling some of their own, potentially risky behaviours will be appropriate.

By externalising the illness and diluting a sense of guilt or blame it becomes possible early on at assessment as well as later on in treatment to have conversations about the impact of the illness on family life, relationships, behaviours and beliefs. These externalising conversations should inform the formulation (see formulation section). Externalising conversations also offer opportunities to explore those areas of life that anorexia has failed to invade, leading to potential “unique outcomes”; those times when the patient has been able to defy anorexia because they remain able to tap into their “healthy mind”, or those times when the parents have been able support their child to eat despite their fear of doing harm by their insistence.

The initial session/the assessment

The first meeting, if the team structure allows, is a MDT assessment, which includes a meeting with the family, a separate meeting with the young person and a medical assessment and evaluation of risk as described earlier. While the primary aim of the medical and risk assessment, as described above, is to ensure physical safety it is also an important part of the engagement process that shapes the relationship with the therapist and the team. The family should be told in advance how long the assessment will take depending on the particular service assessment set-up.

The assessment starts with the family interview and will initially be similar to any other engagement of a family in therapy. The therapist engages the family by making contact with each family member making sure to include any children in the conversation. This may include brief conversations about school, parental occupations, interests etc. Enquiries are made about any absent members of the family. In keeping with the seriousness of the illness, the non-problem talk to engage with the family is generally fairly brief but gives the clinician an early opportunity to observe patterns of interaction

in the family, levels of anxiety, willingness (or lack of) to take part in the process etc. From the start the therapist should look for opportunities to connect with the patient while respecting that they may initially be reluctant to join in.

The therapist should not automatically assume that the person most ready to offer an account of what has brought the family to the clinic (usually one of the parents), should provide the initial information (*“who would be the best person to tell me about what brings you here today”*, turning to the young person *“should it be you or would you prefer one of your parents to start”*). The clinician will enquire about the nature of the illness (including details of weight loss, occasions of overeating and compensatory behaviours, excessive exercise, effect on mood, mental state, social functioning, school etc.) and the history of the development of the illness (including previous attempts at treatment). The assessing clinician should also ask questions that place the development of the illness in context; instead of simply asking *“when did the eating problem first start?”* one might ask *“who first noticed that you were losing weight?”*, *“who worries about it?”*, *“who else worries?”* If the young person denies there is a problem it is useful to explore the extent of this e.g. by asking if she can see why others are worried.

It is important that the therapist explores the various narratives that different family members have about their experience of the illness, including narratives that are not at the forefront of the family's presentation. The therapist should ask questions which may enable or highlight alternative narratives or meanings to those which the family automatically presents. This establishes that the therapist is interested in everyone's point of view, that family members might have different beliefs or ideas and that these may all be valid in their own right. The therapist should pay attention to particular cultural beliefs around physical and mental health, the effect of restricting eating on participation in cultural or religious activities and how this might impact on relationships in the family.

This is followed by an exploration of family perceptions of the illness and its development, and a discussion of the effects of the eating disorder on the family as a whole. If there are absent members the therapist should include them in the conversation, asking what they might say if they were there for example. If only one of the parents is at the assessment, the reasons for this should be explored in a way that makes clear that there is an expectation that both parents have a role to play in the treatment. Often there is a simple explanation accompanied by a statement that the absent parent is expecting to attend next time. When this is not the case, the discussion needs to go beyond the surface explanation of the absence and the clinician should explore some of the underlying or unstated narratives. An example might be the following questions exploring why only mother and daughter came to the assessment even though the invitation had been for the whole family.

“You told me that your father couldn't come today because he was too busy and that in any case he doesn't understand your problems with eating and food. Do you think he believes he can be of help? If he did believe that he can help you, and if he thought that coming here could make a real difference would he want to come? If coming here would help him understand you at least a little bit better would you want that?” Often this conversation and exploration is enough to ensure that the absent parent joins the next session.

The attendance of siblings raises different issues and needs to be negotiated with the family taking into account their age, the nature of their relationship with the patient and other factors such as school attendance etc. If the reason given is that the sibling(s) are too young to understand this should be explored, with the therapist pointing out that usually even young children are aware of what is happening, that they get worried and that talking about such worries is usually helpful. The family should be given a clear message that attendance of the siblings is useful not only for the patient but usually for siblings too. The parents however should be given the final decision on sibling attendance in treatment sessions. If the parents decide not to bring the siblings the therapist should accept this

whilst making clear that this question might need to be revisited if issues arise that are of relevance to the siblings. Often, once parents feel more confident and comfortable with the ongoing therapy they may revise their view about whether their other children should attend.

As families attending for assessment are often in crisis, it is important to consider how to respond in a helpful, therapeutic way when strong emotions are expressed during the assessment. The therapist needs to be confident in managing and containing these emotions; validating strong feelings whilst reframing negativity are important skills; *“I wonder if fear and dread of what might happen if things don't change can easily look like anger, does your family know how frightened you have been for your daughter?”* Showing empathy whilst also sometimes having to be firm that *“turning down the volume on emotions”* might be more helpful in enabling family members to listen and hear what's being said. Psychoeducation around the way family relationships and behaviours adjust when a dangerous illness comes into the family can be used to demonstrate an understanding that the family are doing their best but may have become stuck and hopeless in the face of the illness and that this is often expressed in difficult ways when under pressure.

Separate meetings with parents and the young person

As a part of the assessment separate meetings with the parents and young person should be undertaken. Time alone with the clinician is important especially for older teens as well as for those whose participation is minimal with their parents present when the therapist can test out if they are more forthcoming when seen alone. Any separated conversations should occur following an agreement about what will and will not be shared with parents. Any issues of serious risk for example, which require risk management or the involvement of other professionals, will be highlighted as issues that cannot be kept between the patient and therapist.

Couples who attend together but are unable to collaborate together, possibly because they have separated and have never had to manage this type of co-parenting situation at close quarters, might need separate time with the assessing therapist, especially if arguments are close to the surface and the patient is being exposed to too much expressed emotion.

Addressing any safeguarding concerns

As with any CAMHS assessment, attention must be paid to any pre-existing Child Safeguarding concerns or any such concerns that should arise through the process of assessment and treatment. Mental health difficulties in a young person can increase the potential for abusive situations to occur in families. The stress associated with being an unwell child, the stress of parenting an unwell child and the expectation that parents will have a central role in restoring healthy nutrition in their child, all hold the potential for exacerbating any existing family tensions and increasing the potential risks for that child. Therapists and their teams should be flexible in their approach to treatment when there is a known history of abuse, where abuse is being investigated or where abuse is suspected. Local child safeguarding procedures must be followed and appropriate referral and risk management observed and applied. It is crucial that therapists seek advice from their safeguarding leads and liaise closely with local authority safeguarding professionals should they already be involved with the family, or if a safeguarding issue emerges in the course of treatment or where parents are unable to engage in a treatment plan, thus placing their child at risk.

Self-Harm

As part of the assessment the patient's general mental state should be explored and the therapist should pay attention to any concerns related to low mood, suicidal ideation and self-harm. If a risk-

management plan has not already been agreed this should be contracted at assessment in order to lessen any risks and in acknowledgement of the potential increased risks once treatment commences and the illness is challenged.

On-going issues of self-harm must be addressed and monitored throughout the treatment process in order to ensure firstly that the child is kept safe and secondly so that this can be worked with effectively alongside the eating disorder.

Medical assessment

(see also Appendix A – Medical assessment and management in outpatients)

Alongside the meal plan, the clinicians wherever possible should request an ECG and blood tests to be undertaken the same day. This has the double role of both ensuring that potential medical risks are addressed but also of conveying a sense of urgency in the required parental action. It is hoped that this offers parents some reassurance that over the coming days, when their strengths and efforts will likely be tested to the limit, they have a clear rationale for acting in ways that are likely to have become alien to them over the course of the development of the illness.

End of assessment feedback

Feedback to the family following the assessment should be given straight after the medical examination and any separate conversation with the young person or parents that have taken place. It is helpful for the assessing clinician to be joined by the doctor who has conducted the medical examination. Because of the central importance of the emerging therapeutic relationship, the visible presence of the multidisciplinary team can reinforce the sense of a secure base for treatment. The presence of a senior member of the team during the feedback to the family can also reinforce this. While the initial engagement of the family may be as much with the MDT as with any individual clinician, the importance of the development of the therapeutic alliance with the therapist should be kept in mind and, wherever possible the assessing clinician should also be the clinician who takes on responsibility for the treatment of the patient. If this is not possible, the next best option is for the treating therapist to join the feedback section of the assessment. Again, if this is not possible, the treating clinician should commence their contact with the family at the earliest opportunity (typically within a week of the assessment session) to start the process of treatment.

The clinicians feeding back to the family will offer their diagnosis/es and give information based on other patient's recovery trajectories, about likely length of time that treatment (usually from 9 to 12 months). They will continue with appropriate additional psychoeducation and present the family with a treatment plan.

The plan will outline who will be taking on responsibility for treatment and additional treatment options including Multi-Family Therapy if this is available.

The plan will usually also include an appropriate meal plan, which will be presented by the assessing or treating therapist as a "prescription". The therapist tells young person and their parents that the meal plan is a prescription and food is a medicine. Beforehand, it is helpful to ask parents if they would find a meal plan helpful or the are confident enough about the amounts of food their child needs to gain weight. The majority of parents will readily acknowledge that they would find meal plan helpful. If the child is physically compromised the therapist will need to be very active in encouraging the urgency of parental support for feeding their child an appropriate level of dietary intake. In the early phases of treatment parents should avoid any negotiations with their child about food and avoiding anorexic traps such as giving in to an anorexic idea that as long as their child "eats

something” this is better than nothing. They should not be tempted to add “extras” (this runs the risk of losing trust and it should be explained to the parents that building parental trust is as an essential part of early treatment). See below regarding meals at assessment.

Feedback to the family should include a description of the phases of treatment with an emphasis on the “just for now” nature of parental interventions in the early stage of recovery. This is extremely important for both parents and patients to hear. They should be reassured that although in the process of refeeding, their child they may find that they are acting in ways reminiscent of their parenting strategies for a much younger child, this will not continue, but until a regular pattern of intake and subsequent recovery of physical health is achieved, this may be what is required of them. The patient will hear that the therapist understands how difficult this may be for them to tolerate, especially for an older patient, but that until they discover ways of managing their anorexic thoughts, behaviours and compulsions with the support of their family and the MDT, their best chance of managing will be to allow their parents to support them in eating more and managing the emotions this elicits.

Parents will often request an individual intervention from the outset believing that their child needs individual psychological help to overcome their illness. It is hoped that for many parents they will understand the rationale for a family approach, but for some the idea of family therapy may feel alien for a number of reasons, for example, because they feel helpless. Psychoeducation, reference to the research and NICE guidelines in the UK, have an important role in explaining the rationale for this treatment approach. Patients and parents should be reassured that once weight has risen to a healthy level an individual intervention may well be warranted but whilst at a low weight, their child will struggle to connect with and engage in an individual intervention that requires a good level of cognitive functioning. Moreover, feedback should include the relationship between low weight and anxiety, low mood, irritability, emotional lability, emotional disconnection etc. By providing this information, the major message can be reinforced that, for now, the primary urgency is in refeeding and commencing eating regularly and other issues will be addressed along the way.

Use of food in Phase 1

Using food in the initial assessment as an intervention - “the mini meal”

With a proportion of patients it may be appropriate to ask the child to have something to eat/drink during the first session. The purpose as well as the intervention itself is different from the planned Family Meal session described below.

The mini meal is not a routine intervention and should be used only when warranted by the clinical condition of the child i.e. when the child is seriously unwell, possibly becoming medically unstable and if s/he is unable to eat. Mini meal (coined “milk and biscuit test” by our paediatrician) is to test out the possibility of avoiding a hospital admission by restarting eating during the assessment feedback. The therapist needs a clear contingency plan in case the child does not eat (including checking the availability of paediatric beds should an admission be needed). This should always be congruent with the specific clinical situation and any additional action be clearly seen as a consequence of the child being unable to eat and the increased risk that this entails. This may require asking the family to return to the clinic the following day for further medical review and monitoring or that an immediate paediatric admission is necessary.

The responsibility for both introducing the idea that this is needed and helping the young person to eat rests with the therapist who should avoid getting into a confrontational position and should carefully describe the rationale for what they are suggesting and doing.

Unlike a planned family meal the mini meal is an intervention by the therapist directly with the child. The therapist is responsible for the choice of food (although it may include a discussion with the child

offering two alternatives). The choice should be realistic (e.g. a glass of milk and a biscuit) but with a clear expectation that there is no ongoing negotiation and what the child eats is not just symbolic. The therapist takes an active role, brings the food, uses their authority, and models for the parents how to stay firm and calm.

When to do it:

- The patient is visibly unwell (probably because of dehydration or very low blood sugar levels) and immediate nutrition can make a difference to their response in the assessment
- There is an expectation on the part of the family that outpatient treatment is not going to work and admission will be necessary. The aim is to show that the young person can eat outside of hospital. The therapist models how best to do it.
- The physical condition of the child is such that unless she starts eating, a hospital admission is unavoidable. The intervention may be seen as part of the assessment of whether outpatient treatment is possible because if the patient cannot eat even in this context, a hospital admission is going to be necessary.

There are two common pitfalls for this intervention. The first is that the child eats but the parents feel that they will not be able to do the same at home (“*S/he ate for you but s/he won’t do it for me/us*”). It is important that the therapist acknowledges that s/he is in a different position to the parents and expresses an understanding of the fact that the parents feel that this may not translate to the home setting, whilst emphasizing that this is how most parents feel at this stage. It is key that the therapist avoids judging parental competence on the basis of this early interaction and remains respectful of the parents (a useful analogy can be to think of the therapist as being in a grandparental role, i.e. early on grandparents can have a useful role in supporting parents with advice as long as it is clear to both sides that this is not a permanent state of affairs and that the grandparents will quickly back off and let parents find their own way of parenting – similarly in the early stages of therapy it may be reassuring for parents to be given clear advice/guidance but always accompanied by a clear expectation that this is only one small part of the solution that families have to find).

The second pitfall is that the child does not eat, everyone (therapist included) feels disempowered. In order to avoid this the therapist first has to decide carefully if the intervention is warranted. Second, they should go for a reasonably “soft option” in terms of choice of food i.e. one that can make a difference but is not unrealistically challenging. Third the therapist needs to be self-reflexive about why they are doing the intervention (e.g. is it really because there is a high level of risk or is it out of frustration that the parents are not responding to cues from the child that she wants the parents to be more firm). The therapist needs to be confident and generally a degree of experience/seniority is required. If the therapist is uncertain (and if they don’t have a team to back them up) it is safer not to introduce the intervention.

In most cases the child will respond to the therapist’s calm firmness and will eat. S/he may be upset and the therapist should encourage the parents to comfort her/him. The therapist should avoid praising the young person for doing well but may briefly empathise with how s/he must be feeling (“*that must have been really hard for you*”; “*I think it was brave to face up to this*”). The therapist may also express a hope that this is a good first step towards being able to avoid a hospital admission.

This intervention can help immensely in engaging families and gaining their trust. They witness that therapeutic team is not avoiding and is not evasive of the situation that is most difficult and challenging for them – the young person eating. For some parents witnessing that their child can eat with adults who are caring and firm gives impetus and motivation to start managing their child’s eating at home.

Managing eating if the patient has been admitted to the paediatric ward

If the patient is admitted to the paediatric unit, the eating disorder team who is treating the patient should support meal supervision.

The lead therapist for the family should attempt to meet with the family on the paediatric ward as soon after admission as possible and preferably at a meal time. If the patient is being fed by NG tube, then as soon as the patient is able to feed orally the therapist or ED team member should be present when a meal is being served. Whilst on the ward the therapist can continue to make an engagement with the patient and their family and begin the process of coaching the parents to help their child to eat. Parents need to begin as soon as possible to take on the task of supporting their child to eat. This can be done at their bedside or if a private room is available then the meal can be undertaken there. The therapist/ED team member utilises the skills already discussed above in the description of the family meal although following an admission, this may be the first opportunity the parents have had to attempt this process following assessment. The therapist will therefore need to judge if the parents need to see modelling from the therapist or encouragement and exploration of the attempts they make to feed their child. The therapist, if modelling the parental role should hand back responsibility to the parents for feeding their child as swiftly as possible during this first meal. Whilst undertaking this intervention, the therapist can continue to encourage parental efforts with more psychoeducation; repetition of key messages and themes following the assessment and an admission may be really important as both parents and patient may have forgotten much of what was discussed at assessment if the admission was sudden and alarming. Even without the crisis of an admission, therapists generally need to repeat these key ideas during the early weeks of treatment.

The family meal

The family meal is usually the second session with the family (the exception is if the initial assessment is carried out by another member of the team, in which case the family should meet with the allocated therapist and assessing clinician just prior to the family meal. The assessing clinician should then join the allocated therapist for the family meal as a way of handing over care and supporting the engagement with the new team member).

The family meal has a number of aims. First, it is an opportunity for the therapist to show willingness to share some of the most difficult experiences the family has to face. There is some preliminary evidence that the family meal intervention strengthens the therapeutic alliance both with the parents and the young person (Assis de Silva 2013). Second, it provides an opportunity for the therapist to observe how the family functions around food in a way that a narrative description by the family cannot capture. Third, it offers an opportunity to help identify in real time the moments when things are happening differently, which might counter the dominant narrative of failure. In this way, the focus of the family meal is not wholly concerned with whether or not the child eats, but it is far more concerned with the process of the meal.

Although the therapist should set up the family meal session with the expectation that the parents will succeed in helping the young person to eat, it should not be the aim of the family meal to “find the solution” or to try to ensure that the parents “win the battle” and manage to overcome the daughter’s resistance and make her eat. While in the majority of cases the parents manage to support their daughter or son with their eating of the meal, the main aim is to encourage the family to try new approaches to dealing with food without being paralyzed by the usual fear that ‘doing something different could make things worse’, or with the idea that ‘something is better than nothing’. It is important to emphasise that the parents can only do this if they accept that some of the things they try will not work but also that some things may need to be tried repeatedly before they become part of the solution. The meal should be a useful experience whatever the outcome. It is therefore important to

always have time with the family to process what happened during the meal. If the meal went well or exemplified the changes the family are already making, it provides an ideal opportunity to think about “unique outcomes” and explore the strengths that have led to such important changes. A reflection by an observing team or colleague is a useful way of opening the discussion in this way and supporting the family to talk about their experiences of the meal; what does this say about them as a family, as parents, as a young person? What will they do more or less of over the coming weeks? What does this say about their ability to adapt and adjust their skills to meet their child’s needs? etc.

The meal is introduced to the family as a routine part of treatment to help the therapist understand how anorexia has affected meal times, behaviours and relationships. The setting up of the family meal is itself an intervention forming an important part of the engagement process.

The therapist should give clear instructions about the meal and agree explicitly who should attend. Parents are requested to bring food for everyone, and for the young person. If the young person is on a meal plan they should be asked to bring what the meal plan stipulates for lunch. If they are not on a meal plan, the parents should bring in what they think their child needs at this stage rather than what they think she can manage. The discussion of the family meal is itself an opportunity to emphasise the role that the parents are going to have to take on in order to manage their child’s eating.

The therapist sets the rules for the session; they set the scene for the meal by preparing the table before the family arrive, with plates, cutlery, and water so it is ready for them, like an empty canvas. The parents are asked by the therapist to plate up the food. The setting for the family meal can be introduced as an “unusual experience” for the family (eating being observed by others), which can facilitate conversation about maintaining factors, obstacles to change but also identifying positive differences or unique outcomes that can be built on.; *“At the moment it might feel like an unusual thing to do, eating like this in the clinic with people observing behind the screen/in the room; we do a lot of unusual things here, and I will check with you in a minute how this fits with what happens at home, but we hope that all of you, six months down the line will be able to look back at this family meal and say I understand why we did this, or I am glad we did it...”*

It is recommended that clinicians do not undertake meals alone and have at least one other team member join them either behind a screen if available or in the room offering reflections to the therapist. The families will by now be familiar with the idea of having a team involved, as they had experienced this at the initial assessment. A small team (1-2 therapists if possible) are behind the screen/in the room to support the lead therapist with the intervention and also to keep an external perspective of what is happening in the room as the lead therapist becomes part of the system in the room (e.g. Andersen, 1993).

The therapist might also need to set up the expectation for the time frame of the meal:

“We have 90 minutes for this session and we need to have time to talk after the meal so we expect that you finish your meal within an hour...”

The family meal also provides an opportunity to explore what happens at meals at home and an opportunity for trying out what it would be like if different things are tried. We might start with questions that resemble a behavioural analysis interview.

“How did you decide what to bring today, who prepared this, is this what normally happens at home...do you eat as a family? Do you sit around the table like this?”

Direct observation and circular questioning are used at this stage to see how families communicate both verbally and non-verbally. Observation can also highlight stuck patterns of interaction that may have become part of the maintenance of the illness.

“I noticed that when you do X your mother responds in X way. Dad, have you noticed that as well? Is that what happens at home? Do you think this is helpful? How can you help your wife with this? How would it be if you tried Y?”

The therapist does not sit around the table, or eat with the family. S/he remains active for the duration of the meal and is looking for what the family is already doing that is working. Any small “success” or change can be highlighted as a positive step forward which the family can build on at home.

“(To a parent) you are doing great, do more of that...”

During the meal the therapist also provides structure and supports the parents by reinforcing their supportive parental role. It is also important to avoid making the young person constantly mindful of eating and it is often useful to enquire about what kind of distraction techniques the young person finds helpful.

“It feels like we are doing a lot of talking about eating and not much eating...I will let you get on with what you are doing, I noticed that your mum is really good at distracting you when you struggle, by talking about things other than food...I noticed that that is helping you, I will let you do more of that”.

The team behind the screen can call in with observations or questions, but generally it is more useful for the family and the lead therapist to wait until the meal is finished and to offer reflections by the team of what they observed (Andersen, 1993) in front of the family with the family observing.

Possible pitfalls of the family meal

There are possible pitfalls in this process; the family might bring very little food, or forget the food and leave it at home. In such an instance the therapist will ask the parents to get more food, explicitly agreeing what would be appropriate. Another pitfall is that during the meal the situation escalates either with the parents becoming angry or the young person acting out and perhaps throwing the food on the floor. In such situations it is the therapist’s responsibility to maintain boundaries. This may include pausing things and perhaps getting the young person to imagine looking back on the way home and reflecting on how things went (see section on “Working with time”). If the young person throws food, the therapist should intervene, firmly but calmly (*“we don’t allow food to be chucked around here, please pick it up”*). Later, after the meal has finished, this may need to be followed up with conversations about how boundaries are set at home, what is and what is not acceptable and how anorexia might have changed or inhibited what parents would normally do in such situations.

The timing of the meal should not exceed the agreed limit so that there is sufficient time to hear reflections from the team and for the therapist to discuss with the family what they have learned. The key thing for the therapist to remember is that whatever the outcome of the family meal there are always things to learn from it.

Learning points resulting from different outcomes of the family meal

a. The parents have tried hard and the child eats

When this happens the family meal can be very important in helping the family reflect on their positive qualities as parents, their strengths and those of their child. The therapist can begin to support the family to develop a new narrative that fits with this development. The conversation can focus on family relationships and what each appreciates about the other. The therapist might also tentatively explore how these strengths might be harnessed as the recovery process unfolds; *“what are the*

strengths that you have shown today that you will most likely need to draw on when things become harder or when anorexia becomes even louder and stronger?”, “what is it about your relationship with your mum and dad that means they have been able to help you eat even when anorexia was yelling in your ear?”, “what does this say about your strengths as a young person?”

b. The parents have tried hard and the child does not eat

When this happens, the therapist should support the parents to reflect on the process; *“how difficult was it to try this strange thing?”, “I now know how far you are prepared to go to support your daughter, do you think there might be a healthy part of her that desperately wants to be able to take up all that support and move on?”, “Of all the things you tried today, which are the ones that you might try again at home?”, “does your daughter know that you will not give up on her?, I wonder if what you have done today is a really important way of showing her just how hard you will keep trying to help her?”*

Of course the team may also need to consult together. If the parents report previous good intake at home following the assessment there may be no need to escalate the situation. The parents should be encouraged to ensure their child eats when they return home, even if this means one meal running into another. However if this is how things have been since the assessment, which for most families should be no longer than a week ago, decisions will need to be made on the basis of the level of physical risk this poses e.g. if weight has fallen to a dangerous level and physical observations suggest the patient may become physically compromised then consideration will have to be made for a hospital admission. If the patient is not physically compromised, then the patient should be allowed to return home with an increase in clinical monitoring, possibly seeing the patient up to 3 times a week or with increased telephone contact to monitor progress.

c. The child eats without the parents having to try

In this instance the therapist should ask lots of questions to assess whether or not this is how things usually are, or if this is a new behaviour. If the patient has managed her meals in this way at home, then the therapist can focus on the patient’s motivation, strengths and relationship with her/his parents. If this is a recent development the parents should again be encouraged to reflect on how they have influenced this change and what strengths this implies in their relationship with their daughter. Sometimes the family will say that the daughter just did this to get the therapist off her back. The therapist should explore what was so specific about this situation to allow the daughter to eat. The behaviour in the family meal should be seen as a unique outcome and the therapist should ask questions that explore what this means and how this change can be replicated at home.

There is a danger that if taken on face value without searching questions being asked, this intervention will become a missed opportunity whereby the reflective space for the family will not be optimised in order to draw out potential strengths and resources should things become more difficult in the future.

d. The parents don’t try and the child does not eat

The therapist will have to explore what is inhibiting parental action and whether or not this is what is happening at home. If the child is also not eating at home then the measures described above relating to increased risk will have to be activated. If, however the parents and child report something very different and are positive about behaviours at mealtimes at home, it might be important to explore the therapeutic relationship and the family’s understanding of the treatment alliance. If this position appears to be very stuck and the parents and child are unable to derive support from the therapist and the team, there will need to be a very frank discussion about the potential for a severe decline in the

patient's physical and mental health. The therapist should attempt to elicit the parents' understanding of what is happening and their views on the possible future outcome if they do not find a way forward.

Weighing the patient

A regular routine of weighing the patient must be established by the clinician from the outset of treatment. This routine of weighing is an essential part of the engagement process and should not be carried out by anyone else or at a different time; without knowledge of the current weight the treating clinician has no focus for the session especially in the early phases of treatment; how are parents managing to support their child to eat? Is reported progress evidenced in a good level of weight gain? If there is a disparity in the positive reports by the parents or patient but no corresponding weight gain, what might be getting in the way? Have the parents made appropriate arrangements with the school in order to ensure that their child has a good level of support at lunch time? Have parents managed to understand the high level of support that they need to provide in this critical early stage?

Some patients express a fear of seeing their weight each week. If this is the case it is essential that this is explored and linked to underlying issues e.g. anticipatory anxiety. In the early stages of weight restoration, it may be helpful for the young person not to see their weight but the therapist needs to be clear that this is a temporary arrangement. Later in treatment the therapist will need to address the links between knowing their weight and relearning about appetite, hunger, natural fluctuations, effects of more physical activity on weight gain/loss etc. If the young person shows no concerns about knowing their weight each week, this should be acknowledged and discussed in terms of how they will let their parent or their clinician know if knowing is becoming harder for them or less helpful.

The scales offer a really helpful measure of progress in the early stages but the clinician must be mindful of the need to adjust their own and the patient/parents' reliance on the scales as treatment progresses through to phases 3 and 4. Patients and parents may need encouragement to begin trusting their own instincts and relying less on the physical evidence of weight gain on the scales. If parents are able to observe positive behaviours and the patient is displaying evidence of taking responsibility for managing cognitions and eating well, there is an opportunity to step away from the scales as a sign of life getting back to normal and trust becoming well established. Therapists need to establish collaboratively with the young person and their parents who should go to the weighing room with the therapist. This may change as treatment progresses and a young person who had previously wanted a parent to accompany them will be happy to go alone. The young person should be weighed in light clothing (not underwear), without shoes and jewellery and with empty pockets. Taking the patient to the clinic room to be weighed will often offer opportunities for useful conversations "outside of therapy". For instance if the patient has lost weight unexpectedly a conversation about how s/he thinks parents will respond to this and how best to handle this. In one such situation the patient and therapist agreed that she would go in to the therapy room and role play the therapist, which she did admirably, commenting on the need to break patient confidentiality and expressing both concern about the weight loss and a conviction that the patient could turn things round. The parents were completely disarmed by this (and had of course been expecting the weight loss) that the subsequent conversation was much more productive than had been the case in the past in similar situations.

Developing a systemic formulation

After the assessment, family meal and subsequent one or two sessions it is useful to begin to develop a systemic formulation that can be shared with the family and MDT. In developing the formulation the following should be born in mind:

- Families presenting for assessment and treatment of anorexia are likely to have developed a number of explanations for the development of the illness
- Explanations for the development of the illness are likely to be both shared and individually held within the family
- The formulation should convey that whilst there might be predisposing, precipitating and maintaining factors, the family remain the greatest source of action for the treatment of the illness rather than being to blame for the development of the illness
- The formulation should be a systemic description
- The formulation should be developed collaboratively between the therapist and the family members
- The formulation can be seen not only as a helpful clinical tool for thinking and planning by the therapist and the clinical team but also as a potentially powerful therapeutic intervention
- Certain areas of the formulation may remain constant; goal for ultimate recovery for example, whilst other areas may be less concrete and will necessarily develop over the course of treatment and as the needs of the family and its members change over time
- Development of a systemic formulation should commence on assessment but should also be informed by subsequent sessions with the family
- The thinking behind the process of developing a formulation can be a helpful tool in supporting the therapist to make clinical decisions, especially when they begin to feel stuck or are considering a change in pace or positioning to move recovery forwards.

The formulation should address the following points:

The nature of the problems/illness that the young person and the family are struggling with

This should include the goals expressed by different family members – acknowledging potential benefits and disadvantages; the main aspects of constraints to change, family adjustment to the eating disorder and where these adjustments have become problematic in their own right.

Reorganisation of the family around the illness

Evidence of reorganisation around the illness should be included in the formulation. This description should be informed by the discussions with the family and re-framed as the family's attempts to manage the illness; families presenting with a family member who has developed anorexia will have attempted to instigate many solutions. Some of these attempted solutions will have served to perpetuate the course of the illness and served to render a sense of helplessness and hopelessness in family members.

Problem narratives beliefs and cognitions

A formulation should include both individual beliefs related to the illness as well as shared family beliefs. Attention should be paid to discrepant beliefs that either the family members or the clinical team feel need to be challenged, deconstructed or questioned. Consideration of how these beliefs might be related to the maintenance of anorexia will be helpful. Beliefs about parenting will need to be addressed early on in the course of treatment and should be addressed within the formulation. The formulation should also include particular family or wider context/cultural/religious values that can be seen as supportive/constraining in the process of recovery.

Emotions and feelings that may be connected to the illness

Where anorexia nervosa has developed alongside a pre-existing anxiety, depressive, obsessive-compulsive or other mental health disorders some people describe a numbing of difficult feelings when at a low weight whilst others describe an escalation of these feelings as their weight increases. Any such phenomena should form a part of the formulation especially in relation to the impact this might have on the relationships the young person has with parents and other family members. The formulation should address minimising risks associated with both anorexia and self-harm and the extent to which parents' fear of an escalation is inhibiting parental action.

Mapping significant patterns

The therapist will be organised by a central need to ensure that the patient can be supported to increase their dietary intake and to refrain from any activities to reduce weight gain (over exercising, purging through vomiting or use of laxatives etc.). Significant family patterns are likely to be elicited from the first meeting and should be explored from a position of curiosity. The therapist should re-frame potentially blame-ridden descriptions of behaviours whilst also exploring alternative actions or exit points for potentially dangerous interactions. The therapist should again be alert to unique outcomes within the family description of the illness.

In mapping significant patterns, the formulation should address specific feedback loops that reinforce or maintain the illness. The therapist should identify with the family, particular areas of conversation that need to be supported in future therapy which should be reviewed as new information arises and as the family needs to change and develop through treatment and over time.

Strengths, resources and resilience factors

Specific accounts of individuals' personal attributes, supportive relationships both within and outside the family, examples of capacity to change and areas of life not adversely affected by anorexia should be noted.

This is a context where therapists can usefully comment on their knowledge drawing both on clinical experience and research. Therapists should be familiar with the empirical evidence of factors that predict positive outcomes and use this in a purposeful way to guide their exploration of strengths/resilience factors in the family.

Appendix H gives an example of a fictional formulation as it would be developed at the beginning of treatment and modified over the four phases of treatment.

Phase 2- Helping the family to manage the eating disorder

The second phase of treatment is primarily concerned with dealing with eating behaviours. In some families this happens fairly rapidly and dramatically but more commonly this is a gradual step-by-step process. There is a great deal of variability in the way families respond to the idea that parents should have a key role in dealing with the illness. For some, particularly if the illness is of relatively short duration, it is reasonably easy to accept that the parents and the adolescent are jointly fighting something that has invaded their lives and even though the patient may at times feel cornered and frightened when facing food, s/he may herself (outside of mealtimes) encourage her parents not to back off.

In other families there may be initial protracted negotiations which, if they take place during therapy sessions, may require the therapist to repeatedly question whether the negotiation are with the

“anorexic voice” or a discussion with an adolescent about reasonable alternatives of food choices for example. In such situations parents often rely on the therapist to be the voice of authority of what their daughter needs. This may include repeatedly referring back to the meal plan the family was given at assessment. In accepting such a role it is often helpful to acknowledge openly the intentional aspect of the clinician’s expert stance; *I’m sure you know what someone of your daughter’s age needs to eat to gain weight but I am more than happy to give you a meal plan if it is going to help you not to listen to the anorexic voice speaking for your daughter*’).

If the anorexia has been present for a long time and particularly if attempts at confronting the illness have led to overt criticism, hostility or even violence, the family may feel paralyzed, frustrated and angry with the therapist for not helping them avoid conflictual situations. If the level of criticism and negativity is high it may be helpful at least during the early stages of treatment to have separate sessions with parents in parallel with sessions with the adolescent on her own (Eisler et al 2000; 2007).

Exploration of what happens at mealtimes

It is important from early on to get a detailed description of what happens at mealtimes, who makes decisions about food, who prepares it, who serves it and how much is put on the plate. Much of this exploration can happen during the family meal, however these conversations are usually on-going and form a central part of the discussions in both Phase 1 and Phase 2.

The interactive processes around food should be discussed in a matter-of-fact non-judgemental way with the therapist asking how things used to be in the past and how this evolved to the current patterns. The aim of these discussions is to emphasise that all families get caught up in the processes around anorexia, which has the effect of preventing them from using their strengths. The aim of the therapy is to understand the particular way in which this happened and how this might need to change in order to start the process of recovery. This should include how different family members respond which the therapist should do in a way that emphasizes the value of difference – *“it may be helpful at this stage that your Dad doesn’t understand you as well as your Mum does, it might help him to be tougher with anorexia”*. At the same time the therapist needs to be on the lookout for opportunities to suggest trying out doing things differently. “Dad, if you find you dislike being bad cop all the time, then maybe you and Mum could swap from time to time.

Continuing to provide information about anorexia and the effects of starvation

Much of the groundwork for this will have been laid down in Phase 1 at assessment and during the family meal, however therapists should be prepared to continue to provide further information that may help to explain unwelcome and sometimes puzzling aspects of behaviour or physical response. This may include explaining large fluctuations in weight that could be due to loss of fluid resulting from minimal carbohydrate intake leading to the depletion of carbohydrates in the body that normally bind fluid and the rebound effect on fluid that happens when the minimal carbohydrate store is replenished. Similarly, during discussion of changes in mood it may be useful to return to the findings of the Keys Minnesota starvation experiment.

When weight gain has been established parents may need repeated reassurance that their observations of continuing anorexic cognitions are to be expected because of the demonstrable time lag between changes in eating behaviours/weight and psychological changes. It may be helpful to use analogies such as “money overdrafts” or “bank loans” from the body that people pay back with interest and that become like bottomless pits until the overdraft is completely cleared.

Families will often come up with their own analogies in which case the therapist should use the families' own idea of e.g. Having a balance sheet from which anorexia can take away and to which recovery can bring positive assets.

Challenging beliefs about the impossibility of parental action

Typically parents will profess that it is not possible for them to get their daughter to eat, that she is the one who is in control. This should be met with showing an understanding that most parents at this stage feel this way. The therapist should convey a wish to understand what kind of parents they are, what works for them, what their customary parental roles are and how these have been undermined by the eating disorder. It is important that such discussions explore how parents work together, how they deal with differences between themselves, emphasising that all parents have different perspectives but when faced with something as serious as anorexia they may need to develop a more united stance than would normally be the case to prevent anorexia from splitting them. The differences between parental positions should at the same time be explored as a potential resource. The conversation might include examples of what parents might do in unusual situations that require a strong parental response.

Suggesting options and examples of what other families have done

Parents at this stage often express a wish for detailed instructions of how they should manage meal times. The therapist needs to find a balance between being clear that s/he does not have the answer as to what is going to work for their particular family but also a willingness to give advice based on what other families have found helpful in similar situations. When giving examples of what has worked or what has not worked for other families, it needs to be made clear that what works for one family does not necessarily work for everyone. It is sometime easier to give advice about what does not work e.g. *“most families find it is unhelpful to discuss food at mealtimes, you might try to have a rule banning such discussions”*.

It can be useful to include accounts of some of the more unusual things other families have done (e.g. setting up a 'hospital at home' environment, father taking sabbatical leave from work, putting burglar alarms on bedroom and bathroom doors to prevent the young person from secretly vomiting). These stories should not be given as instructions and it can be helpful if they are presented in a serious but fairly light hearted way. The aim is not to suggest that the family should adopt one of these but rather to challenge them to think about the “impossible” things they may need to consider in order to meet the challenge of anorexia. The aim is for parents to feel that they have new options to try out in order to find out what works for them.

Exploring the role that anorexia has acquired in the management of emotions, feelings and interpersonal relationships

This is particularly important if there are difficulties in establishing systematic progress early on in treatment. Again, such explorations should focus on how these difficulties have developed around the attempts to manage anorexia rather than on what role they may have played in its development. The interactive, interpersonal nature of these processes also needs to be highlighted together with an exploration of alternative or unexpressed meanings and narratives. Where there is a high degree of negativity or hostility, parallel sessions with parents and the young person may be helpful (see above). This may include explorations with parents about their own experiences of being parented, their beliefs about themselves, attachment experiences etc. parallel individual sessions can be used to explore motivation to change.

Phase 3- Exploring issues of individual and family development

Phase 3 is the least structured and least predictable phase of treatment. It starts at the time when the concerns around eating and weight begin to recede and parents can hand back control of eating to the young person. The timing of the transition is variable and is influenced by a number of factors such as the young person's age, her level of motivation to change, the stability of weight progress so far and how the family have re-negotiated their roles and relationships in the recovery process. Throughout this period the focus of sessions become much broader, exploring consequences of being better on the activities and relationships of the whole family.

Moving to Phase 3 is often tricky and complex but a necessary part of real recovery. It can be influenced by the parents' anxieties about the impact of the devastating changes that the illness might have inflicted on their child and their own level of confidence. Parents are often organised by a fear that they may be again "caught unaware" by the illness. Similarly the clinicians' own anxiety might result in a protracted delay in encouraging the young person to begin taking responsibility, making their own mistakes, navigating normal adolescent developments and taking responsibility for their eating and good health. This is a phase where therapeutic transparency and risk-taking are essential in driving this necessary step in the recovery process. Transparency in the use of therapeutic stories from the therapist's previous clinical experience can be an invaluable resource in helping to make it okay for families to consider the pros and cons of trying to achieve a position of "safe certainty" (Mason, 1993) (meal plan, weight checks, being back home for meals etc.) or moving towards safe uncertainty where unpredictability and risk-taking as a normal part of adolescent development can be better tolerated. Transparency might also include statements by the therapist about their dilemma *"I notice that when we have these conversations about moving forward, we can all become caught up in trying to make everything as safe as possible, I include myself in this pattern and wonder if we all need to be taking some risks now to move this forward"*

At this stage of treatment, families vary considerably in terms of what they need or want to get out of continuing treatment. For some there is a relatively brief process of adjusting to life with a well daughter or son. For others, issues that have been obscured and or intertwined with the illness come to the fore and become the focus of the therapeutic work. Sometimes these issues are most usefully addressed in the family context but for others, focusing work on specific individual issues with the young person on their own is more relevant.

Throughout this period the focus of sessions becomes much broader, exploring consequences of being better on the activities and relationships of the whole family.

When to move to Phase 3 and managing changes in responsibility around eating

The "right timing" to move to Phase 3 of treatment is variable for each family and is influenced by a number of factors, such as the parents' anxiety and fear of relapse, young person's age her/his level of motivation to change, the stability of weight progress so far, parents' willingness to take risks and how the family negotiated their roles in the recovery process. Many of the young people are well ahead of their parents in their readiness to take the therapeutic risks entailed in Phase 3. With such families it is helpful for the therapist to highlight this disparity and remind them that this is a predictable stage, which most families go through. Most parents are relieved to hear that it is normal for them to feel anxious about this new direction and they may need to come back to their most feared anxiety (of relapse or allowing more freedom etc.) repeatedly during the process of letting go and backing away. In other families parental uncertainty and a reluctance to let go of the safety of control of eating and weight of their daughter is matched by the daughter's own fears and uncertainties of what life without anorexia is going to entail. Exploring issues of independence, adolescent identity

and self-esteem as well as addressing issues of how parents meet their own needs take on a more central focus during this phase.

There are pitfalls in both encouraging the family to step back too early and in them staying heavily involved for too long. If we consider when this “move” needs to occur we need to also consider the stage that each family has reached just before this move is made and work around these issues collaboratively

From an eating point of view, a move into Phase 3 is more likely to work when physical stability and steady weight gain over a number of weeks or months has been achieved. Most patients are more cognitively available for negotiation and more able to have sensible and rational conversations that are less clouded by the illness. Carefully pacing the handing over of responsibility from parents to young people is safer and less overwhelming on both the adults and youngsters. Allowing the young person to make snack choices for example, rather than parents/clinicians is also a useful testing out of the patient’s readiness for taking on independent eating. Involving the team Dietitian as a Consultant on dietetics - giving guidance and advice about options in the patient’s individual choices is often a very helpful intervention at this stage. This should ideally be done with the patient in the presence of the parents and the therapist. It is also often helpful for patients to take charge of choosing and feeding themselves during one of the meals in the day, usually breakfast, or deciding whether they move to re-joining their friends for lunch at school.

Questions such as:

“How will your parents know that anorexia is no longer too strong for you and that it is safe enough for them to begin to step back a bit?” “Will they be more reassured by the weight that you have gained or by the way that you eat and the choices of food that you are able to make?”

Throughout this period the focus of sessions becomes much broader; exploring consequences of being better on the activities and relationships of the whole family. Discussion and negotiations about returning to exercise should also form part of these conversations.

Moving to positions of safe uncertainty

According to Mason (1993) when people first come into treatment they are either at a stage of “unsafe uncertainty or unsafe certainty”. During the early phases of therapy they may have moved into a position of “safe certainty”. The important shift during treatment but specifically for Phase 3, is moving towards a position of “safe uncertainty”, where the “comfort blanket” of a structured meal plan with clearly defined calories and predictable weekly weight gain has to be slowly pulled away. and some risk-taking experiments with meal plans, trusting of the patient to gradually take more responsibility for choosing and eating in an age/development appropriate way has to be considered by all.

Uncertainties about weight and eating, while often continuing to be part of the conversations, sit alongside adolescent issues (exploring relationships, sexuality, school, achievements, friendships, growing up and managing anxieties about growing up without resorting to restricting food as a way of coping with anxieties around exams, friends and social acceptance). For parents it is also about reconnecting with each other as a couple, reclaiming the time they have lost to the illness where their own life-cycle developmental issues were perhaps put on hold. Examples of this are parents returning to working-full-time/part-time, studying, taking care of themselves - exercising, socialising, reconnecting with extended family, taking up a previously enjoyable hobby etc.

At this stage, everyone, including the therapist might be in a position where a routine has been established and individuals feel safer; negotiating decisions that might challenge this sense of safety

can cause anxiety. A useful example to conceptualise these processes is the meal plan. After a few months of hard work in implementing and negotiating what is sufficient for the stage of recovery for each young person and how the family is going to work as a team with the support of the therapist to implement this, it is to be expected that initially parents will continue to have anxieties about any changes in eating patterns and may be reluctant to reduce their vigilance at meal times. Many patients at this stage are also able to understand these parental anxieties and tolerate what they would have previously experienced as intrusive behaviour. In such cases the discussion of such issues can become fairly light hearted with humour and laughter helping to break the tension. Creative techniques and experiments might be used to test the fears that individuals might have about change at this stage (challenging rigidity around certain aspects of the meal plan for example).

Another example is exercise and participating in sports. At the beginning of treatment and as part of creating a secure base and medical stabilisation, most parents will have had to take charge and support the young person to stop exercising. Entering Phase 3 opens up the possibility of reintroducing exercise and collaborative conversation with the young person. Conversations need to focus on experimenting with exercise and taking responsibility for being more flexible with re-introducing exercise in a safe way. Collaborative conversations need to take place to support parents in working with their son or daughter on how to manage exercise safely and also on how to be flexible with any consequent changes which may need to take place to increase their nutritional intake in response to the energy being used in exercising.

The use of externalisation in later stages of treatment

Having developed an externalising language that fits for the patient and their family, it becomes possible to continue with the use of externalising as a metaphor when the treatment emphasis moves through the later stages of treatment to a focus on increasing flexibility, independence and responsibility for recovery. As the patient and family develop their understanding of the illness and learn that it is possible to change their behaviour and beliefs in relation to the demands of the illness, externalising can continue to be used therapeutically in relation to moving towards recovery.

Externalising conversations might helpfully focus on the extent to which anorexia has become less of an influence and on the strategies the family have developed in the process of recovery. Conversations will continue to focus on individual strengths that have been called upon to minimise the control that anorexia now has. It may be important to use externalising conversations to explore the losses when anorexia is no longer so present; *“How will life be filled now that anorexia is no longer so present?”*, *“With anorexia less present how will relationships in the family look?”*, *“Will we stay as close?”*, *“How can we remain attached with anorexia gone?”*, *“If anorexia has managed to disrupt the life-cycle transition from childhood through adolescence and towards adulthood, how can you all be helped to reflect on this disruption and regain a sense of responsibility for gaining appropriate independence?”*

With some families it is important to revisit earlier externalising conversations and explore how relevant this metaphor remains. Is it a help or a hindrance now that the initial crisis is over? Would it be more helpful to move on and shift the focus to individual and shared responsibility for recovery and relapse-prevention? Has the family developed an understanding of anorexia such that continuing to externalise makes sense to them and provides a helpful shared understanding? Often parents and the adolescent take different views with the young person increasingly wishing to reclaim her own sense of herself and objecting to parents labelling any behaviour they find difficult as “anorexic”. In other instances the young person also finds it reassuring to keep the externalised anorexia around. Therapists will often need to demote the idea of externalisation by exploring differences between

adolescent and anorexic behaviours and the importance for the adolescent to take increasing responsibility for her behaviours, emotions and feelings.

Change in the relationship between therapist and family

The move to Phase 3 is marked by an important shift in the therapist's position. As was discussed above, in the early stages of treatment the therapist/team expertise provides the "safe base" that allows the family to believe that change possible. Phases 1 & 2 can be characterised by the way the therapeutic process enhances predictability and reduces uncertainty. Central to Phase 3 on the other hand is a move away from this position to one where increasingly the expectation is for the family to take more responsibility, just as there is an expectation that parents start stepping back and encourage the young person to take responsibility for her life. This does not mean lack of expertise on the therapist's part but an increasing move towards a position of collaboration, what Mason (1993) calls "authoritative doubt, one that encompasses both expertise and uncertainty". This opens up the possibility of a move away from certainty and opening up more negotiation through collaboration and curiosity around possible solutions that fit with each family, allowing the therapist to work alongside and collaboratively with the family to allow space for new meanings to emerge and the opportunity for new preferred stories and narratives (i.e., White, 1990).

Discussions about "healthy weight" as an example of addressing uncertainty

A good example of the changing nature of the therapeutic relationship is illustrated by discussions about weight. It is understandable that many patients and their parents will want to know the weight that they should be aiming for. The therapist's response to these questions should be informed by several factors. The therapist should be mindful of the inherent uncertainty as to what weight any one individual should be to be healthy (see Appendix E – A paediatric perspective on healthy weight) but will also need to consider the phase of treatment the patient is at, the patient and family's engagement with the therapist, their response to treatment and the context in which the question arises.

In the early stages of treatment, the therapist should have explained that the goal of weight gain is to reach a point where both the physical and psychological effects of starvation are reversed, the most tangible aspect being that a weight has been achieved which is most likely to prompt the resumption or onset of periods (in young women) and/or a return to the expected growth trajectory for those whose growth has ceased as a result of starvation. The therapist should emphasise that it is not possible to know the exact weight that a patient may need to achieve for this to happen although there will be some broad indications such as the weight at which periods were regular before the patient became unwell or in the case of a patient with primary amenorrhea or males, premorbid weight trajectories or the median BMI for their age and sex (but note the limitations of each of these as discussed in Appendix E). These conversations will have included broader discussions about the need to reverse the effects of starvation and the differential rates at which these often happen as weight is restored.

During Phase 1 the therapist's response will be strongly informed by the fact that the young person needs to put on a significant amount of weight and consideration of how much weight they need to gain overall is of secondary importance. Similarly, if the patient has not lost her periods but remains preoccupied with anorexic cognitions when the question of healthy weight arises, regular (3 meals and 3 snacks), balanced (all food groups), structured (use of meal plan if this reduces anxiety around meals), sustainable (aiming for no days when patient restricts food) eating becomes the treatment target. Reduction of cognitions, increased flexibility and independence in eating would all indicate that the patient has achieved a weight that is healthier for them.

When the question about healthy weight arises later on in treatment the therapist's response will be different for a number of reasons. First, the certainty about the need to gain weight from earlier in treatment will be replaced by the uncertainty about the point at which a "healthy weight" is achieved. Second, at this stage of treatment the goal is no longer to contain anxiety by reducing uncertainty but to increase tolerance of uncertainty. The need to tolerate uncertainty applies not just to the young person but also the parents and in important ways also to the clinician as part of the move away from the more dependent relationship characteristic of the early stage of treatment.

In responding to questions about healthy weight (or "target weight" – an unhelpful term that itself connotes that there is a number to aim for) the therapist will need to reflect on the reasons behind the inquiry, the extent to which the question is driven by the need for certainty and consider their response accordingly. The therapist's response at this stage of treatment will of necessity be more varied and tailored to the individual patient and the family and the progress that has been achieved.

For example, if the question arises in the context of good weight gain the therapist should be alert to patient and parental preoccupation with target weights. It will be important for the therapist to explore whether or not there are signs of flexibility emerging in the patient's behaviour e.g. in relation to trying different foods, eating with others, eating without supervision or the patient being able to take more responsibility for making good choices; in other words, is the patient managing the anorexic cognitions or are the cognitions reducing? If the patient is managing well and is able to take responsibility with little or no supervision, the therapist can remind the family that weight on its own provides limited information about health and have a broader discussion about indicators of health and how the parents and the young person will make decisions about when to stop focussing on weight. A response might be as follows: Turning to the parent who asked the question *"I can see why you might want me to tell you when it is going to be OK for you to back off – I wish I had the crystal ball that would allow me to do that – but as you know being well is not a number on the scales"*. Turning to the daughter *"I wonder how you will you know when you are healthy. Whose responsibility is it going to be to decide how long you hang on to a bit of anorexia and keep your weight at the lowest possible level compatible with health and what will need to happen for you to want to just get on with life. How will you negotiate this with your parents and how will they know when it is safe for them to back off"*.

If however despite achieving steady weight gain the patient remains controlled by anorexic thoughts e.g. is rigid, cannot eat unsupervised and is unable to take responsibility for their recovery, then questions about healthy weight might signify that anorexia remains unhelpfully central in organising parental and patient responses. In this situation the therapist should offer expertise in suggesting that the parents and patient may need to start taking more "risks" alongside more non-expert initiated conversations about what independence and responsibility mean for the recovering patient (see also general principles in Phase 3 above). Therapists need to be aware that a decrease in anorexic cognitions does not necessarily run parallel with weight gain. In fact, for some young people, these may become more powerful as weight increases, causing distress to both them and their families and thus increasing the need for certainty. For some young people in this situation there may be benefits from offering a targeted individual therapy at this stage taking in to account the presence of any comorbid anxiety disorder, OCD or depressive disorder which does not resolve with weight gain. There are a range of individual treatments that could be potentially beneficial e.g. systemic individual treatment, adolescent focused therapy, CBT-E, CBT for comorbid disorders, or RO DBT. While therapists should always remain sensitive to parents' need for certainty in the face of coping with a potentially a life threatening illness, they should also reflect on how the changing nature of the therapeutic relationship to a more open and more collaborative one impacts their own need for certainty.

Another time the question of healthy weight may arise is in the context of poorer weight gain and raised anxiety on the part of the young person or parents who are seeking reassurance through the certainty of a number. The young person may be experiencing particularly powerful anorexic cognitions as a result of weight gain, manifesting in significant distress which parents understandably wish to relieve. Here the therapist should be cautious in their response, and address the dilemmas that ensue when “target weights” are given and then need to be changed as a young person gains height and grows older.

It is important to note that weight or weight gain itself should not determine how they respond. If a patient is menstruating at 87 %mBMI for example, but is otherwise recovered in relation to cognitions, flexibility and taking responsibility, there is no strong argument for increasing their weight further. If, on the other hand, they are menstruating but are driven by anorexic cognitions such that they cannot take responsibility for managing their intake it may be an appropriate time to have a full review of the treatment plan with the team, young person and family in order to fully explore what might be most helpful to promote engagement and enhance motivation for a full recovery at this stage.

There will be situations when, in spite of good progress in the areas described above, there may be legitimate questions whether further weight gain is needed (e.g. the patient has returned to her pre-morbid weight or is near the median BMI for age but her periods have not returned or there is concern about growth) in which case a consultation with the paediatrician may be recommended.

As engagement develops and trust is established in the therapeutic relationship, these questions can be approached with curiosity and collaboration. Without good engagement and trust it is far harder to hold more helpful explorative conversations, which attend to the meanings and beliefs about “certainty” as regards these issues.

Addressing family life-cycle issues post anorexia

For the majority of the families that we see when they initially come to the service the illness is seen as a central organising principle (Steinglass et al., 1987) as discussed earlier in this manual. At this stage it might be useful to reconsider with the family the stages that led to the family reorganisation around the illness and some of the parallels that might be present when we think in terms of possible changes to the family reorganising around treatment. At the initial stages of treatment there is a shift from accommodating the illness needs to accommodate the treatment needs. Parents take time off work, the adolescent as a result of being ill often missed school, might have experienced social isolation (the same might apply for other family members) and has been dependant on his/her parents and other family members. This might have caused a change to parenting styles, might have focused the decision making to the here and now, disrupting family rituals, distorting the family identity and slowing down adolescent development. Furthermore, the experience of psychological distress both of the adolescent and the family may have negatively affected adolescent development but also a development necessity going through one's life cycle, the need for flexibility and taking risks. It is also important to take into consideration individual developmental needs and personality traits, and to have conversations which open up possibilities for future preferred stories.

Exploring issues of individuation and adolescent development

Because for some time anorexia has acted as a mediator of relationships in the family, the parents may find it difficult to deal with normal adolescent issues. If they have disagreements or clashes with their daughter/son they may find it difficult to differentiate between ‘adolescent’ and ‘anorexic’ behaviour. They may continue with the process of externalisation and label all difficulties and negative behaviours as due to the illness. Parents may find themselves tolerating behaviours such as bad

language, aggression or violence, which they would ordinarily find intolerable and unacceptable; *'she wouldn't normally behave like that, it is the anorexia that makes her do that'*. They may dismiss their daughter's dissatisfaction, irritation or complaints as just being due to anorexia. The earlier process of externalisation needs to be reversed by demoting externalisation through conversations that emphasise volition on the part of the young person;

'how do you tell if it is anorexia shouting at you or just your daughter being irritated with what you are doing'; 'have you found ways of winding up your parents other than by not eating'; 'if your daughter continues to behave in such a violent way, at what point would you call the police'.

The therapist and the family work together towards the creation of a central understanding of areas to focus upon. This may include repeated stuck patterns of circular behaviour that might maintain the illness, links between shared or individual beliefs about what it means to grow up as an adolescent while in the process of recovering from anorexia, separating the "ill behaviour" from "typical adolescent behaviour".

Parents may find it difficult to manage the essential transition from parents of a dependent ill child to parents of a recovering adolescent requiring opportunities to explore the world, develop their own personality and make mistakes from which they learn about themselves and the world. Similarly adolescent development is likely to have been interrupted by the effects of the illness; normal teenage experiences will have been missed out on and opportunities to express their developing personalities may have been lessened. Against a backdrop of parental fear of relapse and adolescent anxiety, opportunities to begin regaining an appropriate level of autonomy may need to be encouraged by the therapist. The family may need some coaching in experimenting with new experiences; parents may need to be encouraged to leave their child overnight or adolescents may need encouragement to socialise or have sleepovers. Sometimes therapy sessions may focus on parental experiences of adolescence in order to reconnect parents with their own needs and wishes as teenagers in order that they may more readily connect with their child's developmental needs.

Finally, throughout our work with families we should not forget that the overarching framework is of supporting individuals and families to re-discover their strengths, utilise their resources and develop a positive family and individual identities. This may include conversations about coping strategies that have been effective, good communication, their commitment to seeking help and support and making use of all the resources available. Again, therapists can draw from their clinical experience, describing what we know can be helpful but also sharing our knowledge of research evidence. Broadening the time frame from the here and now to the future can open up important conversations and themes that may seem difficult to talk about or open up areas that may previously have felt threatening.

The move to Phase 3 can create an opportunity to revisit the formulation and explore with the family any changes they would want to make to the initial ideas they held about themselves and their family. Conversations may focus on any changes they notice in their family relationships, beliefs or behaviours. This conversation can include a reflection on their strengths and their ability to meet the challenges of the illness. Connections can be made with positive family traits and different generations from whom these positive traits might have been inherited. Such conversations can expand the family's sense of efficacy and hope for positive change in the future whilst also acknowledging any continuing difficulties.

It is important that we do not convey a sense that this exploration is somehow related to ideas of family dysfunction underlying the eating disorder rather the focus of the discussion should encompass normal developmental issues that have affected the family or been put on hold by anorexia. Families will often themselves say that they feel family life was put on hold and time came to a stand-still. As anorexia loses its grip they may initially tend to look to the past to a time before anorexia. Looking

ahead to the future may feel less certain and requires a degree of self-reflection from the family which in normal circumstances they may not have had to undergo. Families sometimes comment that having had to struggle with anorexia has already forced them to look at themselves and decide what aspects of their relationships they like and what they want to change. Such changes may have taken place anyhow under normal circumstances due to the usual demands of the family life-cycle transition but they may have happened more gradually and in a less overt way.

Separated parents, reconstituted families, single-parent families and other family forms

Clinicians will have been meeting with families with a wide range of family constellations and by Phase 3 should have established a collaborative and effective treatment plan involving appropriate significant others. For example, where parents are separated/divorced therapists might have seen the young person with one or both parents together, with a parent and step-parent, or perhaps with a parent and grand-parent or other family member, initially focusing on the best sub-group to enhance weight restoration. The therapist would have in most circumstances have met/had contact with the other parent in order to keep them fully involved. When working with step-families the therapist would have been mindful of the way parent and step-parent had developed a pattern of parenting and how this had been impacted on by the development of the illness. The therapist must be particularly mindful of the pros and cons of anorexia – perhaps a previous conflictual relationship between divorced parents has been replaced by collaborative co-parenting and the young person is fearful that conflict will resume once anorexia has gone; perhaps the illness has had the effect of distancing the step-parent from the parent – a possible positive for the young person but not for the parent.

Phase 4- Ending treatment, discussion of future plans and discharge

Like the transition in treatment to Phase 3, the timing of the transition to Phase 4 will vary from one patient/family to another. As with other therapeutic interventions the inevitability of an ending to therapy should be addressed in different ways and for different purposes throughout treatment. There should be discussions right at the start in Phase 1 explaining that treatment usually takes up to a year, and the likely duration of treatment should also be addressed at review meetings so that both family and therapists are clear what work remains to be done. In the middle phases of treatment, when considering the future without anorexia in Phase 3, the therapist may already have begun talking about life without the therapist and treatment. When discussing issues of flexibility and independence the therapist is also likely to have talked about a time in the future when the family and patient will have developed their own ability and skills in experimenting with change and tolerating the uncertainty these experiments will engender. Conversations throughout treatment which focus on family and individual strengths can support a meaningful and authentic reflection on these positive family characteristics when the prospect of ending treatment is discussed.

Exploring issues about ending of therapeutic relationships

Families will have different responses to the idea of ending treatment and ending their relationship with their therapist. Some will embrace and even celebrate the notion whilst others may feel unsteady, reluctant and scared at the prospect of life without their therapist and the team. Work carried out in therapy during Phase 3 needs to have addressed the potential barriers in moving towards an ending and discharge. Work which has explored the family, their wider network and their family contexts will have often touched on issues of attachment and loss and experiences of other endings in different contexts. If not addressed prior to beginning the ending phase of treatment, it may be helpful to think with the family and individual family members about their responses to equivalent or similar endings. The therapist may then talk with the family or patient individually about the particular challenges

these experiences might mean for the ending phase of treatment. Whatever these experiences the therapist will need to remain alert to their own and the family's potential reluctance to end. Repeating conversations centred on Safe Uncertainty (Mason, 1993) will be helpful in addressing some aspects of the worries associated with ending.

Reviewing the family journey through treatment and turning points

The ending phase of treatment offers an opportunity to reflect with the patient and their family on what they have achieved over the course of treatment. These therapeutic conversations are most helpful when the family and patient can assume some ownership of the work and gain a sense of increased agency in terms of their capacity to influence future events and crises. Changes or particular turning points that have seemed significant to the family can be explored in an attempt to elicit family beliefs about these changes and to highlight any interpersonal processes that may have contributed positively to these changes or turning points.

It is sometimes helpful for the therapist to reflect on their own observations of the family journey through treatment. Families will often express surprise at some of these recollections which can highlight how radically different things are now in comparison to the beginning of treatment. In the midst of the anorexic crisis families can sometimes forget the detail of events as they struggle to survive. Where appropriate, the therapist can engage in carefully judged humour as a way of marking an important shift from the seriousness of the early phases of treatment to this ending point when previous anorexic behaviours can be examined with the distance of time. Patients are often able to express their incredulity when reminded of how different things were when anorexia was so much more in control of their lives; reflection on these differences can underpin a sense of agency, resilience and competence in the family and its members.

Discussing issues of responsibility for management of any remaining/future difficulties and seeking help if needed

Discharge from a specialist eating disorders service will often happen before the patient has recovered completely from anorexia. Weight will generally have reached a healthy maintenance level and anorexia will have lost its central organising role in the family. However, many patients will continue to experience anorexic cognitions. These will be increasingly under the control of the patient and will have less influence over their behaviour. Waiting for menstrual periods to return is not always appropriate or practicable.

The age of the patient will often influence conversations focused on responsibility for management of any remaining or future difficulties. A younger patient and their family will be encouraged to identify both parental and individual strengths in managing any on-going difficulties, whilst an older adolescent may need to be supported in thinking about their personal responsibility to seek support in an age-appropriate way. Family beliefs about independence and adulthood might influence these conversations, as well as maturity and level of independence of the patient.

Exploring current/future family life without anorexia

Anorexia will have changed family relationships, beliefs and behaviours in response to the needs and stresses of the illness. Exploration in Phase 3 of treatment will have addressed family life cycle and individual developmental issues which might have become distorted or changed by the illness. Phase 3 will have also focused on changed relationships and beliefs influenced by the illness. Where parent/child relationships have become unusually close and dependant, conversations about closeness and distance in relationships will be highly important especially if the closeness has been a secondary

gain of the illness; how can the patient and parent be reassured that a new relationship without anorexia can be maintained in a mutually helpful way? How will future family crises affect relationships? How will other members of the family adjust to life without anorexia? How will siblings negotiate new relationships with their sister/brother/parents?

Tackling anxieties around discharge

The experiences associated with managing anorexia will invariably impact on individual and parental beliefs about their ability to cope with future difficulties. Fears will often be related to the possibility of relapse or re-emergence of co-morbid disorders such as OCD, depression or anxiety. Parents and patients are likely to have differing feelings about discharge with many patients expressing an eagerness to move on whilst their parents express reservations about the future without the safety of the therapist and the team.

Open conversations about the fears and anxieties associated with ending treatment can be a helpful way of exploring potential ways of managing future crises. Drawing on conversations that have focused on family strengths can elicit the generation of the family's own problem-solving strategies. Reflecting on past crises and how these were managed can increase parental and patient confidence in their ability to manage future difficulties. Normalising parental fears associated with the transition from childhood to adolescence and adulthood can be helpful in reminding them that anxieties and worries are inevitable factors in family life. Talking about the therapist's experience of other families managing the ending process might also be helpful; reflecting on families who expressed similar worries but nevertheless found that they were equipped to cope when difficulties arose.

Families for whom the ending of therapy feels intolerable can sometimes benefit from an ending that is paced more slowly. Although the message needs to be clear; that the therapist believes they can manage on their own, where the service provision allows for a protracted ending with ever increasing gaps between sessions, families can be helpfully held until a point where their anxiety has reduced and a discharge becomes more tolerable.

Sometimes it is important to focus on practical issues associated with referral pathways and other resources for treatment (when co-morbid disorders might need future attention but not in a specialist eating disorders service) or the clinic-specific re-referral process in the event of relapse.

Discussing post-discharge plans and ending of therapy

Patients and their families need to know the formal arrangements for their discharge. In some instances the patient will be discharged to the General Practitioner, sometimes they will be discharged to another mental health professional or team to address on-going difficulties related to co-morbid disorders.

Relapse prevention

Separating difficulties associated with anorexia from those that would have arisen in other families unaffected by the illness can be a helpful way of thinking about how future difficulties might be addressed and managed. In the ending phase of treatment it is important to discuss what the patient has learned about themselves and their relationship with the difficulties associated with adolescence and those they associate with anorexia; can they tell the difference? What informs them that the problem is not about anorexia? When they sense that anorexia is becoming stronger what do they notice about the anorexic voice/thoughts? When does it become louder and more influential? Are they more vulnerable to the influence of anorexia when other life stresses are around? What do they notice about their thoughts and behaviour when anorexia is becoming more apparent? What do people

around them notice and know about the influence of the illness? What permission can the patient give to those around them for openly recognising when behaviours seem influenced by anorexia? Are they able to seek support when anorexia is becoming too influential? What measures can the patient/parents/other important people take to ensure that support is available?

Individual work with the patient

Assessment

As a standard part of the assessment, a young person is seen without their family present. The purpose of this is to explore areas that she/he may have found difficult to talk about in the presence of her/his parents (we routinely ask '*is there anything you were not able to say in front of your parents?*'). This is also an opportunity to ask more about risk issues (suicidality, self-harm, abusive experiences, alcohol and drug use) if it hasn't been covered already or if the patient indicates that there is more to say but they are not able to open up with their parent/s in the room. It is important that this meeting should start with a discussion of confidentiality and its limits; the young person should be fully aware that if they share information suggesting that they or anyone else is at risk then this will have to be shared with either their parents and/or with other professionals.

How much time is allocated to the assessment is informed, in part, by the age of the young person. Older teenagers (16-18 years old) are generally offered more individual time at assessment, as are those whose referral and/or assessment questionnaires suggest risk issues are present.

Individual Work as part of ongoing treatment

Individual work is an important part of treatment for many young people; however, the timing of individual work is carefully considered and the focus of the work is in line with the themes of FT-AN.

Timing of Individual Work

In Phase 1 and 2 the focus is on creating a family environment where the young person can begin the process of weight restoration. Generally speaking, individual therapy is not considered at these stages for the following reasons:

1. When a young person is highly malnourished they may have limited motivation or poorer cognitive capacity to benefit from an individual therapeutic intervention such as CBT.
2. In the early stages, many parents feel demoralised and often do not believe that they can help their child. They are likely to see the therapist as the expert who is better equipped to support their son/daughter than they are as parents. In this context it is important to highlight the evidence that the family is usually the best resource for recovery and therefore it is vital to support the parents through family therapy.

In Phase 3 the focus shifts towards exploring issues of individual and family development. These issues are explored in a family therapy context; however, it is during this phase that individual sessions can be a useful addition. This is particularly true for older teens for whom it is developmentally appropriate to have time away from parents to support the individuation process.

Some families will request individual therapy for the young person before phase 3. It is vital to listen to and respect these requests, exploring the meaning behind them and understanding who is asking for therapy (parents, young person or both). Sometimes, as mentioned above, parents can be motivated by a sense of powerlessness in the face of the anorexia and therefore see individual therapy as the 'fix'. A common misconception is that the anorexic cognitions need to change before a young person can

eat normally. It is very important to explain that cognitive improvement tends to lag behind physical improvement and that there can be little cognitive improvement without weight gain; weight gain is the first essential step for recovery. We share research evidence with the family that demonstrates the importance of adequate nourishment for therapeutic work to be successful. We emphasise the crucial role of the parents in the re-nourishment stage of recovery and highlight that individual work is an adjunct - not an alternative - to family involvement in treatment. We then think collaboratively with the family about when the best timing for individual work might be.

Focus of Individual Therapy during Phase 3

Individual work during Phase 3 can be a useful, and should be offered and discussed with a young person in addition to the family work. The focus of individual work mirrors the themes covered in the family work but by offering a separate space to the young person, aims to further support their individuation and motivation for recovery.

Individual exploration of motivation to change

The purpose of this is to strengthen engagement with the young person and to explore their motivation to complete recovery. In the initial stages of treatment a young person will often acquiesce to changes either for the benefit of their family or because they feel they have no choice; however, if the young person is to navigate Phase 3 successfully they need to develop internal motivation for recovery. Exploration of motivation may include homework tasks (e.g. writing letters to “anorexia my friend” and “anorexia my enemy”) and exploring the pros and cons of recovery from AN. Internal motivation is crucial at a stage when they need to reclaim responsibility for food.

Identity and Individuation

One of the key tasks of the life stage of adolescence is individuation from parents. Anorexia can place a hold on emotional and social development for many young people, with parents having had to reclaim full control of feeding and to re-institute high levels of observation and responsibility for their child. Phase 1 and 2 can promote regression in the family relationships as a young person can start to welcome the sense of safety and certainty that this offers.

In Phase 3 it can be helpful to explore issues of separation from the family on an individual level, especially for those young people who have very close relationships with their parent or parents.

An important part of individual work during this phase can be to help the young person to re-widen their perspective on life outside of the minutiae of food related issues. Focus on *perceived* control over food, weight and shape may have served the function of deflecting attention to other areas of life which may have been highly anxiety-provoking. Supporting young people to think about how to reconnect with their peers, develop interests outside of the family and begin to re-introduce ‘fun’ back into their lives is key in Phase 3. Older adolescents in particular benefit from space to explore issues of identity, fears and expectations around growing up, the future, and sexuality.

Factors that may require greater focus on individual work

High levels of criticism or hostility in the family.

When there are high tensions, a history of or suspected child maltreatment, overtly negative or critical family relationships, separated systemic work is advisable from Phase 1 onwards (see section on safeguarding when safeguarding concern and referral to the local authority social services department). The focus of both individual and parent sessions mirror the standard family therapy

themes for each Phase with periodic family review sessions in order to join up the work (see Simic et al 2016 for modification with emotionally dysregulated adolescents). In some instances co-facilitation can be a useful option here, with one therapist working individually with the young person and another therapist with the parents. Family reviews are then conducted jointly by both therapists.

In Phase 1 and 2, both individual and parent sessions are working on the same theme of parents being supported to feed their child. However, given that in these families issues of trust and control tend to predate the Anorexia, there is likely to be a lot more ambivalence within the relationships; parents being the role of supporting their child to eat often brings an oppositional response from a young person and an increase in hostility can arise. A young person may therefore need individual space away from their parents where they can be supported to understand the importance of weight gain. These sessions are also an opportunity to explore issues of trust and control, i.e. helping the young person to understand that at this stage of recovery they are not able to be in control of food, and that it is therefore essential that they give permission to their parents. At this point it is helpful to draw a distinction between their parents taking a lead in managing food (as a temporary measure in order to support them) as opposed to them taking control over their life in general. A key part of these individual sessions needs to be motivational work in order to help the young person accept both weight gain and the need to grant their parents the permission to support them around food.

Older Teens

It can sometimes be harder for parents of older teenagers (16-18) to take over responsibility for food. If the young person is motivated, the introduction of individual work in Phase 2 can be helpful usually with the proviso that they have to be able to demonstrate their ability to manage progress in a reasonable way. The focus is the same as in described in the previous section.

Lack of progress

Individual work may also be indicated if there is not the expected treatment progress. The focus of this work would be to better understand and enhance the young person's motivation for recovery and address any obstacles preventing progress towards recovery.

Comorbidities

Sometimes when a young person becomes well-nourished, difficulties with low mood or anxiety may resolve, either through being addressed in the family work or through the effects of re-nourishment *per se*. However, if comorbid OCD, anxiety or depression remains in the later stages of treatment individual CBT based work targeted at the specific comorbidity / comorbidities should be considered. Important consideration should be given to young people who experience anorexia and comorbid self-harm. A thorough functional analysis is required to ascertain to what extent the difficulties with eating are serving as a means to self-harm. This may well be adequately addressed in family work but sometimes a young person may feel more able to openly address this through individual sessions (see also Simic et al 2016)

Integration of Individual Therapy with Family Therapy Sessions

It is important that any individual work that occurs is re-integrated as much as possible to the four stage model of family work. This may be mitigated to some extent by the permission given by the young person to share specific information from their individual work but the young person is encouraged to feedback to their family as much as they feel comfortable from any individual work they have undertaken.

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Appendix A

Medical Assessment and management in outpatients

Initial **Physical Health** Check List

Initial Assessment date:

Trust ID no:

Name:

Date of Birth:

Initial Assessment:

%mBMI: ____% weight loss: __kg/wk over ____weeks

Days < 500kCal/d: ____days

Phosphate: __mmol/L White Cell Count: ____10⁹/L IGF 1 (nmol/L): _____

Examination

Muscle wasting: YES/NO Lanugo hair: YES/NO MUAC:
_____cm

ECG

Performed: YES/NO Findings: _____

Refeeding Risk Given: _____ **Meal Plan Given:** _____

	Day	Date	BP (lying)	BP (standing)	HR	Temp	PO4	WCC/ Neuts.
Assessment	0							
Visit 1								
Visit 2								
Visit 3								
Visit 4								
Visit 5								
Visit 6								

Baseline Results

IGF-1 (nmol/L)		LH (IU/L)		Coeliac	
Free T4 (pmol/L)		Prolactin (mIU/L)		Ferritin	
TSH (mIU/L)		B-HCG(kIU/L)		B12	
Estradiol (pmol/L)		AFP (IU/L)		Hb	
FSH (IU/L)		Vitamin D (ug/L)			

Initial Assessment

Meal Plan Guidance and Follow Up Schedule

Risk assessment Tool

	HIGH RISK 2 CRITERIA REQUIRED	MODERATE RISK	LOW RISK
%BMI	<70%	70-80%	>80%
Weight loss	1kg/wk for 4 weeks		
Period of abstinence (< 500 kCal/d)	>=5 days	3-5 days	<3 days
Plasma Phosphate	<0.8 mmol/L		
White cell count	<3.8 10⁹/L		

Blood Tests and Meal Plan Schedule

Risk	Week 1		Week 2		Week 3	
	Meal plan (kCal)	Bloods & Clinical Review (No of Days after Introduction of week 1 mealplan)	Meal Plan (kCal)	Bloods & Clinical Review (No of Days after Introduction of week 2 mealplan)	Meal Plan (kCal)	Clinical Review
High	1500	1,3,5	2500	1	2500	x
Moderate	1500	1,3	2500	x	2500	x
Low	2500	2	2500	x	2500	x

Clinical

Full clinical examination to include lying/standing blood pressure, SUSS, Height, Weight

Investigations

FBC/Ferritin/film

U&E/LFT/Bone/Mg/ CK(if exercising)

IGF-1/HbA1c

Glucose (*if hypoglycaemia <2.6mmol/L, also plasma
Betahydroxybutyrate/Nonesterified fatty
acids/Cortisol/Insulin/CPeptide/Acyl
carnitines/urine organic acids, ketones (dipstick)*)

B12/Folate/Vitamin D

Chloride/Bicarbonate/Potassium *if history of vomiting*

Amylase/lipids *if history of vomiting/abdominal pain*

TFT

*If amenorrhoea present: Prolactin, FSH, LH, Estradiol, AFP,
BHCG*

Coeliac Screen

12 Lead ECG: *clear documentation of the corrected QT is
essential (QT/\sqrt{RR}): note that a prolonged QT_c can be associated
with cardiac arrhythmia. It is sex-dependent. (See Appendix 1
for criteria)*

Subsequent review

Clinical

HR, BP, Temperature, Weight

Investigations

ECG if previous abnormalities or change in cardiac

status

FBC/Ferritin/film

U&E/LFT/Bone/Mg

IGF-1

Glucose

Physical Risk Criteria		ALERT Admit	CONCERN Regular review Admit if Non-Adherent to meal plan
Nutrition	%m BMI	<60%	<70%
	Skin	spreading	Areas of breakdown
	Rash (purpuric)		Present
Circulation	Systolic	<80	<90
	Postural drop (mmHg)	20 or rise in pulse >30 or syncope	10 mmHg or presyncope
	Heart rate	<40	50
Temperature		<34.5°C	<36°C
Musculo-Skeletal	SUSS	0	2
Gastrointestinal		abdominal pain involuntary vomiting	
Metabolic	Glucose	< 4.0 mmol/L <u>AND</u> drowsiness/non-anxiety- related jitteriness/pallor	<4.0 mmol/L
Bone Marrow	WCC		
	Neutrophil count	<1.0 and fever/unwell	<1.0
	Hb	<9 g/dl and tachycardia	
	Platelets	<100	
Salt/ Water balance	Na	<130 mmol/L	130-139
	K	<3 mmol/L	
	Mg	< 0.6 mmol/L	
	Ca	< 2 mmol/L	
	PO4	<0.8 mmol/L	
ECG	QTc	>440 in boys >460 in girls	

Appendix B

The Role of the Paediatrician in the Multidisciplinary Team

The Role of the Paediatrician in the MDT

Young people presenting with eating disorders are often very unwell. As a consequence of their calorie restriction and purging behaviours, often over many weeks and even months, many will have slipped into a decompensating starved state, which has short-term consequences for their physical and psychological well-being, potentially longer term consequences for their skeletal health and in some cases pose life-threatening risks. The priority of the paediatrician in this context is to exclude all other physical causes of weight loss, quantify the degree of risk associated with malnutrition, and to support the “prescription” by the treating therapist of a robust and safe refeeding plan for the family to follow to allow the young person physically to rehabilitate. An additional but no less important role of the paediatrician is to communicate their findings and their concern in a supportive but objective way illustrating how the specific medical findings are consistent with what is known generally about the effects of starvation. These psychoeducation inputs will often most visibly galvanise the parents to redouble their efforts to bring about change although the impact on the young person, whilst not always immediately apparent, should also not be underestimated. In order to understand the effects of malnutrition, it is important to know the biology that underpins it:

The Biology of Starvation

The pathophysiology of starvation is complicated, partly because it is not always clear at what point normal physiological compensation to fasting stops and the pathological state of starvation begins. Starvation is perhaps the oldest condition in human experience and one of the few conditions we have in common with other vertebrates. Our capacity to adapt to low calorie environments for weeks to months and yet maintain some form of cognitive functioning has undoubtedly been key in the success of our species as a whole. Our brains, after all, are our metabolically the most expensive organ. When calories are sparse, the body adapts in four ways:

Metabolic adaptation. The human body derives the bulk of its energy from the breakdown of the glucose molecule, itself released from food containing carbohydrates. When food is abundant, eating leads to storage of surplus glucose in liver cells in the form of glycogen, which is gradually released into the bloodstream between meals to maintain a constant glucose concentration [4-6 mmol/L]. Levels are continuously measured in the pancreas and the brain by ‘glucoreceptors’ which stimulate release of hormones (insulin, glucagon, cortisol, growth hormone) to ensure glucose levels never stray beyond tight margins. In the fasted state, however, when liver stores of glycogen begin to dwindle, fat stores begin to release energy in the form of glycerol and fatty acids. These latter molecules can be converted to ‘ketones’ which can be used as a supplementary fuel in some particularly metabolically active cells (notably brain and heart) – in effect taking the pressure off glucose as the sole fuel. In other words, the fat that is laid down in times of plenty can be used as energy when times are lean.

‘Slowing it down’ When calorie intake is restricted, one of the earliest compensatory mechanisms is for metabolism to slow, in an effort to reduce all energy outgoings. For metabolism to slow, cells must perform less work, and the body, and therefore the patient, ‘slows down’. This manifests as symptoms: people feel tired and cold; they get light-headed when they stand up; movements are often slower. Any cells with an intrinsic ability to be pulsatile (cardiac muscle, smooth muscle of the stomach and gut) do so more slowly – leading to slow heart rate (bradycardia), constipation and delayed gastric emptying. In addition the skin and gut cells turn over more slowly, leading to delayed healing and hair loss.

Either as cause, or by effect, using muscles less causes them to waste more, and this is true of cardiac as well as skeletal muscle. As skeletal muscle wastes, so the tension they exert on bones declines and this has a knock on effect for bone strength.

Prioritisation. Certain non-essential biological processes, largely to do with fertility and growth, can be temporarily arrested as they consume calories that could otherwise be diverted for survival. Thus a female with a normal menstrual cycle will lose her periods as starvation takes hold and similarly a child or young person may find their growth rate slow or stop. In principle these are reversible states and resumption of growth and puberty can be seen as the herald of a return to a healthier state.

'The late effects' The growth of children and young people is intimately tied to their stage in puberty – prior to the pubertal years, growth is principally driven by growth hormone, and beyond infancy, usually occurs at around 5 cm/yr. The onset of puberty (testicular volume > 4ml in boys, or breast bud in girls) marks the involvement of other hormones which both lead to changes in body composition as well as faster growth. These (especially oestrogen both in boys and girls) act also on the bones. Oestrogen deficiency coupled with lack of nutrition at a particularly vulnerable time (peak growth velocity in boys is mid-puberty, whilst in girls it occurs in early puberty) contributes to the possibility of reduced bone mineral density in adult life. Poor bone mineral density is associated with length of amenorrhoea, length of treatment for anorexia, and low body mass index (BMI).

Management of medical risk

Managing severely ill young patients in a safe way requires expertise and the level of specialist medical expertise within the team will impact thresholds for safely managing patients outside of an inpatient medical setting. Ideally all specialist ED teams should include a medically qualified member of staff rather than relying on such input coming from outside the team. This not only provides a better and more immediate access to specialised medical knowledge but also strengthens the family's sense that outpatient treatment can be provided in a safe and expert way.

The following assumes that a paediatrician on the team provides this role.

A paediatrician typically approaches a consultation by taking a history and performing a physical examination. The purpose of the history is to identify the key concerning problems (the 'presenting complaint'), quantify their impact and severity and identify the cause. In the context of eating disorders this involves focussing on how much the young person is restricting and for how long, and to identify any symptoms which might suggest a slowing metabolism. The assessment is both to rule out the possibility of coexisting conditions that lead to weight loss, as well as to assess and quantify the risk of medical instability from malnutrition and to advise on the safest way of re-establishing regular eating in the short term.

The purpose of the clinical examination is to find evidence for the findings in the history. It should therefore be thorough and detailed, and involve top to toe assessment to exclude all issues.

Clinical signs of malnutrition include:

1. Carotenaemia - the sallow complexion that often accompanies malnutrition
2. Bradycardia (heart rate below 60 bpm)
3. Prolonged capillary refill time (on depressing the nail for 5 seconds, the capillaries should refill within 3 seconds)
4. Postural hypotension - the blood pressure drops >15 mmHg on standing
5. Cool hands/feet
6. Muscle wasting: this is most noticeable in the upper arms and thighs ('thigh gap'), and if severe, is the basis for proximal muscle weakness, which leads to failure of the Squat, Sit up and Stand ('SUSS') test. Equally muscle loss is seen in the face (sunken eyes and prominent cheek bones), the spine, ribs and pelvis. Hands can be very telling: malnourished hands have visible tendons, are cold and have poor capillary return.

7. Lanugo hair - fine, downy hair that appears on the trunk (abdomen, back and face particularly) only found in malnutrition
8. Constipation (palpable loading in the lower abdomen)
9. Gastritis (tenderness just below the breastbone)
10. Breast atrophy (this examination must be done sensitively, with a chaperone, and with full consent of the young person and carer) which is a manifestation of low oestrogen that comes as a result of starvation - its utility is that Tanner staging can help chart stage of puberty.

The importance of identifying these features is both to document the degree of malnutrition, but also to quantify the degree of physical instability and the level of risk.

Charts

When working with young people with an eating disorder it is important not to become too drawn into discussions about numbers (either about weight or calories), charts can be a useful tool in getting across the physical effects of malnutrition. Serial heights can show if height velocity has been affected, serial weights can show how that young person is managing with their meal plan. BMI corrected for age and sex is the most useful measurement. With children and adolescents it is normally expressed as a percentage of the median (50th centile) value, which means that young people can be shown how their weight compares with other young people the same height, age and sex as them. Values typically (though not always) below 85% (approximately 9th centile) represent “underweight”.

Early Refeeding and the ‘Refeeding Syndrome’

It has been well known since at least the early 19th century that reintroduction of nutrition in patients where malnutrition is profound can lead to serious, even fatal, consequences. Now more is known about the ‘refeeding syndrome’ and its causes, however it is still not clear for certain which patients are at risk, or indeed how best to manage them if identified in time. The basis of the condition is thought to relate to an exaggerated and uncoordinated surge in insulin following realimentation: insulin is an anabolic hormone, a chemical message released from the pancreas when food is ingested, even from the moment food is smelt and tasted, whose function is to drive the chemical building blocks of food into cells for storage. In a state of profound starvation insulin is switched off, functioning only at the lowest levels. When food is finally introduced, the insulin response has been shown in studies to be quite different to that seen in control subjects. The effect of this disordered insulin surge is to cause fluid and electrolyte shifts (in particular phosphate ions) which can interrupt cellular function of key organs, in particular brain cells leading to seizures, and cardiac muscle cells, leading to abnormal heart rhythms.

The common thread of all guidance in the management of refeeding is that it must be cautious; that calorific intake initially should be low (though the literature disagrees what is the optimum level at which to start), and increased slowly with close clinical and biochemical monitoring. The true incidence of refeeding syndrome is not known, though it is low, and often over-stated, and known to cause clinicians often to be overcautious in what has now been described as ‘underfeeding’.

It is important therefore to walk a line between being cautious whilst refeeding young people with malnutrition, and, whilst counselling them with this information, not reinforcing a fear of food that already exists. Studies have shown (Whitelaw, 2010) that 80% of hypophosphataemia (the biochemical hallmark that accompanies refeeding syndrome) occurs within 4 days of starting to refeed, and therefore in practical terms this risk has all but gone by the end of the first week.

Quantifying risk

Guidance is now available nationally on how to decide whether children and young people are sufficiently physically unstable to require admission to a Paediatric Unit (<http://www.rcpsych.ac.uk/files/pdfversion/CR168nov14.pdf>). The Junior Marsipan Group, a collaboration of different professionals experienced in Eating Disorders, supported by the Royal College of Psychiatry, have produced a risk assessment tool specifically for this purpose (<https://www.rcpsych.ac.uk/pdf/CR189checklistXX.pdf>). The tool, which identifies certain objective parameters, in particular identifying cardiovascular, hydration and electrolyte findings, which can be used to attribute levels of risk and therefore decide if early refeeding should happen within hospital rather than at home.

The paediatrician and psychoeducation

Psychoeducation forms an integral part of treatment of ED and the paediatrician's contribution has a key role in its delivery. This is partly due to their experience in the diagnosis and management of malnutrition in other organic disorders, and their knowledge about growth, puberty and emotional/psychological development. Importantly though their experience of assessing and talking to families when children are unwell conveys the strong message that the young person is ill and needs special care from the parents. The presence of a paediatrician at the initial assessment of the young person therefore both serves to ensure that assessment and early management of risk is safe, but also consolidates the process of engagement with the team and shapes the direction of future therapy.

During the early phase of the illness, where engagement is key, the paediatrician can become the voice of concern, and the meal plan and clinical health surveillance measures become the metaphor for the path to recovery. Along the way, issues relating to growth and puberty, fertility, menstrual health, bone and skeletal health, can all be brought back to nutrition.

Paediatric admissions

Practice varies internationally with regard to the medical stabilisation of malnourished children. Most agree with a comorbidity-oriented hospital-admission strategy, rather than one purely based on arbitrary weight cut-offs. The threshold for medical admission is based on the findings of the medical assessment which has four objectives. It must:

1. attribute a risk of physical instability (a measure of frailty)
2. attribute a risk of developing the refeeding syndrome (which dictates how cautious and closely monitored reintroduction of nutrition should be),
3. exclude other medical cause of weight loss
4. serve to reinforce the psychoeducational messages to the young person and the family

The role of the medical admission is first and foremost about safety: identification of the malnourished and ill young person, and management of the refeeding and stabilisation process with maximum support and monitoring. If handled well, it has a secondary benefit of containing anxiety for the young person and their family through the early steps towards recovery.

A further important role of a medical admission, however, is in engaging the young person. At assessment many young people come across as reluctant participants, passive and even hostile recipients of care, and frequently, at least overtly, in denial of their frail physical state. The explicit concern of medical professionals towards their physical well-being can be a powerful motivator in helping them see how ill they are. This is unavoidable during a medical admission, as busy medical

wards are staffed by large numbers of teams who change shifts twice a day - the medical concern is reinforced by every new shift arriving, and the physical state can be clearly charted for all to see with the observations: heart rate, temperature and blood pressure.

By its nature therefore a medical admission should be practical and short - it is there to stabilise and support to such time as acute risk has passed and the real work of recovery can begin in earnest. It is important therefore that the medical admission is not a disconnected event from the rest of the treatment process. During the time of admission there are often unique opportunities for the therapist to engage with the young person and her family in a way that is very different from what happens in sessions in the clinic. There will also be opportunities for the therapist to note changes in the young person's attitude and the family's perceptions that can be referred to and built on in subsequent treatment sessions

Risk of Physical Instability

Parameters of physical instability are related to findings on assessment, both on history and examination. Risk assessment tools from around the world identify cut offs in heart rate and blood pressure, level of hydration, or investigation findings (ECG or electrolytes) below which risk is deemed unacceptable to tolerate as an outpatient. This is because they represent decompensation in what is a chronically compensated state. As described earlier the UK national group Marsipan has formalised this risk assessment process providing a framework to assess malnourished young people and decide on medical admission (<https://www.rcpsych.ac.uk/pdf/CR189checklistXX.pdf>).

Risk of Refeeding Syndrome

This remains a controversial area, with advice in some quarters suggesting cautious and very low levels of calorie reintroduction at the outset with slow incremental increase, while other centres have published more aggressive refeeding guidance (Madden et al, 2015). It is known that those at risk tend to be those with lower weights, a longer period of abstinence, and those for whom plasma phosphate, and white blood cell titres are low before starting the refeeding process. Low body temperature is an important physical sign.

Calories should be reintroduced carefully and with close clinical and biochemical monitoring. The literature disagrees on the optimum - some advocate nasogastric feeding at the outset, the suggestion being that it smooths out surges in various regulatory and counter regulatory hormones (such as insulin and glucagon) implicated in the steps leading to the refeeding syndrome. Others advocate starting with food, as this releases energy slowly and has the benefit of being a more active process: the young person taking an active step towards recovery by eating. Meal plans should be consistent and unchanging, limited choice and no discussion or negotiation with regard to amount or content (with some minor flexibility only). Food should be provided regularly across the day, in the form of up to 6 separate meals or snacks. Bathroom visits should be curtailed around meal times, which should have explicit times and durations, with clear plans for meals left uncompleted. Meals should be supported at all times by staff, with encouragement from families and or the therapist where possible.

Exercise and activity should be discontinued, and strict rest advised (though bedrest is rarely essential). If marked bradycardia is present a cardiac monitor is indicated and correction of electrolytes, with regular observations. Hypothermia should be corrected as it adds further metabolic stress, and fluids may be given intravenously in the short term if necessary (though the intention should be to rehydrate and refeed gradually).

Calorie-targets should be set each day, with blood monitoring to inform decisions. Supplementation of phosphate and B vitamins (with thiamine) may be necessary, as well as vitamins D and K and zinc.

Resources required for a Paediatric Admission.

Managing profoundly underweight young people with eating disorders in medical inpatient settings is challenging. Their medical care requires access to specialist dietetics, gastroenterology, endocrinology, cardiology and high dependency. They need supportive and understanding nursing, and the medical ward staff need confidence in handling young people who are often distressed by eating. All medical and nursing staff need clear guidelines and protocols in place. The psychological care of the young people equally requires access to psychiatry and child and adolescent eating disorder expertise (see Use of Food in Phase 1). In setting up a service therefore it is essential to have locally agreed pathways and robust joint working across mental and physical health to ensure the different needs of the young people are met.

Refeeding syndrome

At presentation the young person is assessed for their risk of medical instability (using Junior Marsipan criteria) and their risk of developing the refeeding syndrome. At the Maudsley Hospital, patients who are deemed very high risk of refeeding syndrome are admitted to King's College Hospital and refeed cautiously with low calorific rates (See above), regular review and incremental calorie increase with close monitoring according to national guidelines. Factors which influence this include period of abstinence, rate of weight loss, body mass index corrected for age and sex and certain clinical, biochemical and ECG findings.

The majority of young people however can be managed on an outpatient basis. At the outset they are given a standardised meal plan of 1500 kCal/d (known as the 'soft meal plan' and entitled 'Establishing regular eating') by the assessing therapist. This is dairy-rich (and therefore phosphate-rich) and comprises 3 meals and 3 snacks divided across the day. It is prescriptive, with clear amounts and only two to three choices per meal or snack, to avoid confusion and conflict. Depending on their level of attributed physical risk, young people are encouraged to remain at home for the first week with minimal exercise, and undertake 3 visits to the clinic over that period for blood tests and clinical monitoring. Any concerns raised at those reviews, or by families at other times lead to reassessment.

If by the end of the first week all blood tests and clinical monitoring have proven normal, 1500kcal/d is changed by the treating therapist, for a 2500kcal/d plan (known as a 'weight restoration plan' or 'Working towards a healthy weight'). Blood and clinical monitoring is performed one further time following introduction of this new plan and generally thereafter medical investigations are relaxed if there is evidence of weight gain and clinical improvement is observed.

Meal plans can be tailored to specific requirements as necessary (e.g. in demonstrated food allergy where certain foods must be avoided) or if weight gain is not observed in a concordant young person. Generally though only limited negotiation is permitted over the content of the meal plan as this can often be divisive in the first two phases of treatment. The standardised meal plan can therefore be introduced as such to all families, and has the benefit of being available in acute hospital also should one be needed at short notice to staff less familiar with the management of eating disorders.

Supplementation

There is no evidence for regular supplementation beyond the meal plan itself. At presentation clinical assessment is made for evidence of nutritional deficiencies and blood tests are taken in order that specific supplements may be prescribed if necessary. Only if sufficiently ill to be admitted to hospital are patients routinely started on vitamin B and thiamine as well as a multivitamin. Inpatients also routinely receive up to 5 days of oral phosphate prophylactically. Outpatients however are not routinely started on supplements unless clinical or biochemical evidence exists. This helps also to reinforce the notion that food itself is medicine.

Appendix C

Medical management on a paediatric ward

This Appendix contains a document that has its own
Appendices identified by numbers 1-12

Child and Adolescent Eating Disorders – Guideline for the Medical Assessment and Management at King's College Hospital

Child and Adolescent Eating Disorders Service (CAEDS)

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Publication Date: 3/12/2014

Revision Date:

This guideline is for clinicians assessing *the medical risk* of children or young people 16y and under with Eating Disorders in the Emergency Department and continuing their medical management as in-patients at King's College Hospital NHS Foundation Trust.

This guideline provides a framework for the clinical assessment and early medical. It draws heavily on recently published consensus-based national guidelines ('Junior Marsipan'). Clinicians are encouraged to assess the risks of:

1. Medical instability
2. Refeeding syndrome

These two categories have a colour-coded 'traffic-light' system, with guidance on early management (assessment, investigation and treatment). There is guidance also for ongoing inpatient management on Toni&Guy and transfer between King's and South London & the Maudsley (SLaM).

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Introduction to the Child and Adolescent Eating Disorders Service (CAEDS)

Background

Child and Adolescent Eating Disorders Service (CAEDS) comprises 3 sites:

The Michael Rutter Centre: an outpatient service and principle location for presentation

Snowfield Adolescent Unit: an inpatient general psychiatry unit for young people and children who are medically stable but unable to be managed on an outpatient basis. It has two beds for young people with eating disorders and has facilities for nasogastric feeding.

Kings Variety Club Children's Hospital: the stabilisation of chronically malnourished children

CAEDS is a pioneer of family therapy for anorexia nervosa (FT-AN) an evidence-based based intervention for eating disorders, now replicated across the world, and the cornerstone of the NICE guidelines. It is still referred to as the 'Maudsley Model'.

The Patient Journey

Children in the main present to CAEDS and are managed here. CAEDS comprises a multidisciplinary team of specialist Consultant Psychiatrist, Psychologists and Family Therapists, specialist Dieticians and a Consultant Paediatrician. Occasionally the young people are sufficiently unwell to require stabilisation and may attend King's, either for admission, or for further assessment. A recent BPSU survey suggests that the younger children (9-12y) tend to present directly to paediatric clinic/A&E. These children tend to be more unwell. Most will be managed as outpatients or in the Maudsley day programme (Intensive Therapy Programme). If sufficiently unwell, however, they will require admission. If stable but requiring inpatient Child & Adolescent Mental Health Services (CAMHS), they may be admitted to Snowfield Adolescent Unit. The Liaison psychiatry team, in conjunction with CAEDS would need to be involved for this to happen.

Referral Pathway

As a general principle, the management of each case should not vary from site to site and where possible the guidance here should be followed irrespective of which part of the service is managing the case.

Any child or young person (< 16 years) requiring medical assessment should be discussed with the Paediatric Registrar on call at King's (020 32999000 bleep 424), who will discuss it with the Consultant of the Week. Where available, Dr Chapman should be informed of their attendance. Children can be reviewed in the Emergency Department initially if unstable, or accepted directly to Toni and Guy if felt appropriate, as determined by the Paediatric Registrar and Consultant on Call. They coordinate any admission with the bed manager (bleep 295).

Any transfer from the Maudsley (either from Snowsfield Adolescent Unit or from CAEDS Outpatient Service) into KCH should be accompanied with:

- **documentation** regarding assessment, management and observation of the young person
- **nursing** and **drug** charts as appropriate.
- Relevant entries on the **electronic Patient Journey System** (SLaM electronic patient record) should also be printed out
- Any mental health issues that might impact on the management of the child at King's should be discussed at referral and the liaison psychiatry team at the Belgrave made aware.
- If RMN support will be necessary the logistics of this should be discussed at the point of referral.

Any transfer from King's back to South London and the Maudsley should be coordinated by Dr. Chapman, or following discussion with either Dr. Mima Simic at the Michael Rutter Centre, or Dr. Richard Corrigan at Snowsfield Adolescent Unit.

The child should be discharged back with:

- a **full summary of inpatient care** with photocopies of **nursing and weight charts**, as well as **meal plans**.
- **Drug chart(s)/EPMA Printout**. For any drugs still prescribed, date of starting and number of days treatment to date
- **ECG** copies
- a print out of the **clinical notes from the EPR** system at Kings, as well as any **blood results**.

Nasogastric Tubes

Children/young people who are outpatients with the Intensive Therapy Programme will on occasion require one-off nasogastric tube feeds. This should happen only in working hours (9-5) on Phillip Isaacs Ward with prior agreement. A separate protocol for this is in place.

Children/young people who are inpatients on SAU may occasionally require nasogastric tubes to be passed, or have problems with existing tubes becoming blocked or dislodged. If this occurs in working hours, arrangements should be made with staff on Phillip Isaacs Ward to attend at an agreed time for this to happen. If this occurs out of hours, this service will be provided by staff on Toni & Guy ward. SAU staff will attend with the young person/child and bring the malfunctioning NG tube with them.

Indications

This guideline applies to the medical management of all children and young people under the age of 16 years.

Medical Management of the patient with eating disorders

The Initial Presentation

The key outcomes of the **Initial clinical assessment** must be to:

1. Assess degree of **medical instability** (*see Appendix 1 for criteria*),
2. Attribute a **risk of developing refeeding syndrome** (*see Appendix 2 for criteria*).
3. Identify psychiatric and medical comorbidities
4. Identify child protection issues

Medical Instability

Starvation and malnutrition in Eating Disorders depletes reserves. Acute decompensation can therefore occur quickly. This is likely to be seen most in those who are the most malnourished (lowest %BMI – see *risk of refeeding* below for definition) but may occur at higher weights if weight loss has been rapid. **Please see summary chart for absolute criteria for admission – Appendix 1: those with high risk (red column) will need admission. There should be a low threshold for admission of those children with moderate risk (orange column).**

Please note – severity of risk is determined by the highest scoring criterion.

Risk of Refeeding Syndrome

Refeeding is a clinical syndrome of encephalopathy/cardiac arrhythmia associated with endocrine, electrolyte and fluid changes following the reintroduction of nutrition in the profoundly malnourished (**see Appendix 10 for a summary of pathophysiology and principles of management**). Risk of refeeding increases with fall in BMI (***expressed as percentage of actual BMI /median BMI for age and sex***), with greatest risk at BMI < 70% expected. The presence of oedema is an associated sign. (**see Criteria for Assessing Risk of Refeeding Syndrome – Appendix 2**). Those with high or moderate risk may not necessarily need admission if presenting to CAEDS. If presenting initially to the Emergency Department or Paediatric clinic there should be a lower threshold for admission for controlled reintroduction of nutrition.

Please note – severity of risk is determined by the highest scoring criterion.

The Initial Clinical Assessment (In or Outpatients)

Initial clinical assessment should comprise:

- **clinical exclusion of organic causes of cachexia**
- **Degree of Medical Instability (see Appendix 1 for Criteria)**
 - **assessment of malnutrition:**
 - **weight (thin clothing only) and %median BMI**
(actual BMI/50th Centile BMI) x 100 – see chart for 50th centile values
 - **body temperature**
 - oedema
 - pallor
 - lanugo hair/carotenemia/acrocyanosis/thin hair and skin
 - muscle wasting
 - clinical evidence of specific deficiency (eg angular cheilitis)
 - evidence of delayed healing
 - sit up squat and stand test (“SUSS” – see **Appendix 11, p32**)
 - **assessment of dehydration/cardiovascular compromise (see Appendix 1 for criteria):**
 - blood pressure (postural drop) [hypotension and presence of syncope/presyncope]
 - heart rate [bradycardia]
 - capillary refill time
 - mucous membranes, skin turgor
- **evidence of purging (if applicable)/deliberate self-harm:** parotid hypertrophy, dental enamel erosion, calluses, scars
- **Assessment of growth and puberty:** anthropometry, pubertal staging [this may reasonably be left until later]

Initial Investigations

All patients should have the following investigations:

FBC/Ferritin/film

U&E/LFT/Bone/Mg/CK/IGF-1

Glucose (if hypoglycaemia <2.6mmol/L, also *plasma* Betahydroxybutyrate/Nonesterified fatty acids/Cortisol/Insulin/CPeptide/Acyl carnitines/*urine* organic acids, ketones (dipstick)

B12/Folate/Vitamin D

Chloride/Bicarbonate/Potassium if history of vomiting

Amylase/lipids if history of vomiting/abdominal pain

TFT

If amenorrhoea present: Prolactin, FSH, LH, Oestradiol, AFP, BHCG

Coeliac Screen

12 Lead ECG: *clear documentation of the corrected QT is essential (QT/VRT): note that a prolonged QT_c can be associated with cardiac arrhythmia. It is sex-dependent. (See Appendix 1 for criteria)*

Outpatient Management

Children and young people who present through Accident and Emergency or Paediatric Clinic and;

- are deemed to be **medically stable** (see *Appendix 1* for criteria)
- are deemed **low risk of refeeding syndrome** (see *Appendix 3* for criteria)
- are likely to tolerate a meal plan

should be referred directly to the Child and Adolescent Eating Disorders Service (CAEDS). A written referral will be necessary, though cases can be discussed with the doctor available in working hours (see **contact sheet** for fax and telephone numbers). Any associated mental health issues or concerns about the immediate safety of the child or young person should be discussed with the on-call psychiatrist.

They should receive a meal plan from the dietician prior to discharge (the dietetic team will provide this).

Reasons for Admission to Inpatient Services

Most young people with eating disorders will be managed on an outpatient basis. However, on occasion inpatient facilities may be necessary. The criteria for this fall into three categories:

1. **Medical Instability**
2. **High risk of refeeding syndrome**
3. **Ongoing weight loss in spite of outpatient support** (this latter would typically be to the Snowfield Adolescent Unit, unless risk of refeeding syndrome were felt likely or the young person had medical instability)

The management of both **Medical Instability** (see *Appendix 1 for criteria*) and **High Risk of Refeeding** (see *Appendix 2 for criteria*) are broadly the same: gradual and controlled reintroduction of nutrition. Refeeding is initially attempted using meal plans obtained from dietetics. If this is refused, nasogastric feeding should be used. **Note that a key part of assessing risk involves calculating the Percentage Median BMI (%mBMI) – see p41 for guidance.**

Acute Medical In-Patient Management

All admissions should be discussed with the Consultant Paediatrician on call. Consent from the child and family should be sought actively. If consent has not been gained, Psychiatry opinion should be sought at that stage to assess the child's capacity to refuse treatment, and if necessary, invoke the Mental Health Act. Any decision to impose treatment requires involvement of all professionals at senior level and the family.

Initial Management

Initial management should address hydration status, rewarming and appropriate correction of electrolyte and glucose abnormalities.

Initial Investigations

See *Initial Clinical Assessment* (p.6)

Hypoglycaemia

While hypoglycaemia is often seen in starvation, this should not be assumed to be the cause until investigated. These patients are rarely symptomatic as ketones produced in prolonged fasting can be used instead of glucose by the brain. A low capillary glucose (<2.6 mmol/L) should always be checked with a laboratory (oxalate) sample. If never previously investigated, blood and/or urine should be checked for the presence of ketones, and plasma sent for glucose (oxalate sample), cortisol and insulin. Other metabolic investigations (lactate, urine organic acids, ammonia, plasma amino acids, Growth hormone, C-peptide, acyl carnitines, synacthen test) should be considered based on the clinical picture.

In this context, hypoglycaemia is a marker of chronic malnutrition and represents decompensation. Its longterm effects are not known. It is an indication for escalation of nutritional intervention (increasing the meal plan

If ketones are present AND the child is asymptomatic, hypostop should be avoided. Blood sugar should be corrected with food, continuous nasogastric feed or iv fluids.

Thiamine deficiency

Thiamine is a cofactor important in carbohydrate metabolism, particularly in the glycolytic pathway and the pentose phosphate shunt. It is present in foods derived from animal sources, as well as bread which is fortified. Stores deplete within two weeks of reduced intake. Its biochemical hallmark is lactic acidosis.

Features include:

- **Muscle pain** – typically in the calves due to rapid accumulation of lactic acid after slight physical activity
- **Congestive cardiac failure** – shortness of breath, fluid retention and a rapid and sometimes bounding pulse: known as Wet Beriberi
- **Peripheral neuropathy** – loss of sensation and sometimes strength in the hands or lower limbs
- **Wernicke's Encephalopathy** – ataxia (unsteadiness), impaired consciousness and problems of eye movement

- **Korsakoff's Psychosis** – loss of memory for both new (anterograde) and past (retrograde) events together with confabulation, making up a version of events to cover for the loss of memory
- **Other features** – hypothermia, hypotension (low blood pressure) and autonomic neuropathy

Treatment is with iv thiamine (as Pabrinex) [**see medicines below for dosing**]

Nutrition

Graded reintroduction of nutrition should be seen as a treatment of urgency and introduced at the earliest practicable opportunity. Supervision of refeeding should be coordinated by the senior ward clinician, in association with a dietician. For medical inpatients, the default treatment is a meal plan. If this is refused, continuous nasogastric feed should be used to provide continuous infusion over 20 hours of calories, and blunt the late rise in insulin associated with reintroduction of carbohydrate. If tube feeding is required, a meal plan should be offered at the earliest possible opportunity. Initial calorific intake should start at **1200 kCal/d**, increasing in daily steps:

- Day 2: **1500 kCal**
- Day 3: **1750 kCal**
- Day 4: **2000 kCal**
- Day 5: **2250 kCal**
- Day 6: **2500 kCal**

If nasogastric feed is used, a low carbohydrate high calorie formula, such as TwoCal, should be used: (*see Appendix 6 for details of feed and meal plan*). **Note: a more cautious dietetic plan may be necessary if:**

- **plasma albumin is low**
- **%mBMI is <60% or weight is <30kg**
- **the child is under 12 years**

This should be discussed with the Paediatric Consultant prior to starting. Although under no obligation, the child or young person should be encouraged where possible to take small amounts of drink or soft food by mouth. Excluding gains from correction of rehydration, a gain in weight of between 0.5 and 1 kg per week would be expected once 2500 kCal/d has been achieved³.

Children and young people should be weighed twice weekly, on set days, before meals and preferably after voiding. They should wear light clothes/pyjamas, or preferably underwear only.

Once the nasogastric feed is safely established, reintroduction of oral diet should be considered as early as possible. The KCH & SLaM teams will decide and plan the reintroduction of food on a case by case basis. In some cases oral diet will only be reintroduced once full requirements have been achieved via NG feed, whereas in other cases it may be appropriate to introduce oral intake at an earlier stage. A series of bespoke meal plans at different calorific levels are available within the dietetic service for the purpose.

³ NICE guidance

KCH catering services (Medirest) have agreed to provide menus that conform to the nutritional requirements specified by KCH and SLAM dietetics teams. **Select an appropriate meal plan from Appendix 6 based on advised starting calorie content as guided by Consultant or Dietitian. Three copies are required: provide one copy to the diet kitchen (ext. 32613), one copy to the ward hostess and one copy should be kept in the bedside notes.**

Meal and snack times can be very distressing for the young person with anorexia and one-to-one supervision will be necessary for all meals and snacks and for a period of 30 minutes to one hour afterwards (30minutes for snacks, one hour after meals). Meal supervision can be difficult and stressful and the KCH and SLAM care teams will agree on a case by case basis who is best placed to manage this. In some cases SLAM staff may be able to assist, or health care assistants or ward nurse may be used. Registered Mental Health Nurses (RMN) may be required if a Mental Health Section is in place. Some basic guidelines for meal supervision are provided in **Appendix 5**

Medicines

All children should be supplemented from the outset with: (they can be given via NG or orally if tolerated):

phosphate sandoz 500mg bd (32mmol/d)

vitamin B complex strong (contains B₁ [thiamine] and B₂ [riboflavin], nicotinamide, B₆ [pyridoxine]))

2 tablets TDS

or if liquid used (Vigranon B)

age: 1-12y 10ml TDS

12-18y 15ml TDS

multivitamin. (*sanatogen* or *forceval* one tab od)

NB: if strong suspicion of thiamine deficiency

Pabrinex

Vial 1 (contains B₁ [thiamine] 250mg and B₂ [riboflavin] 4mg, B₆ [pyridoxine] 50mg))

Vial 2 (contains C [ascorbic acid] 500mg, nicotinamide 160mg, Glucose 2000mg)

Pabrinex is also available as an Intramuscular High Potency Injection. Therefore before administration, ensure that both the Summary of Product Characteristics and ampoule labels refer to the INTRAVENOUS injection.

- 1) The preferred method of administration of Pabrinex Intravenous High Potency is by drip infusion. Equal volumes of the contents of ampoules number 1 and 2 should be added to 50ml to 100ml physiological saline or glucose 5% and infused over 30 minutes (see "Special Precautions for Storage" section).
- 2) For a combined injection volume of not more than 10ml (e.g. the contents of one 5ml ampoule number 1 and one 5ml ampoule number 2) the contents of the ampoules are drawn up into a syringe to mix them just before use, then injected slowly, over a period of 10 minutes, into a vein.

ADULT DOSE: 10ml of each ampoule diluted with 50-100ml of (0.9% saline or 5% dextrose) given over 30 mins

CHILD DOSE:

6 - 10 years	third of the adult dose
10 - 14 years	half to two thirds of the adult dose
14 years and over	as for the adult dose

Monitoring of medical instability following refeeding

For the first 48 hours the young person should remain on bed rest/limited activity, with cardiac monitor and 4-hourly temperature, pulse, respiratory rate and blood pressure. If parameters are stable by day 3, aspects of this can be relaxed on a case by case basis. Capillary blood glucose should only be monitored if previously low, and monitoring discontinued when 2 successive values are above 4 mmol/L in the absence of symptoms.

Electrolytes, especially phosphate, should be carried out on admission and daily following refeeding. For those who have additional risk factors (hypoalbuminaemia) or oedema, electrolytes should be measured up to 8 – 12 hourly.

Children should be weighed twice weekly

Hypophosphataemia

Studies suggest that 80% of hypophosphataemia occurs in the first 4 days of refeeding. If plasma phosphate falls below reference range, doses of oral phosphate should be increased, or intravenous phosphate be considered (<0.4 mmol/L). In the context of other parameters of physical instability (*see Appendix 1*) HDU should be informed. Feed rates should not be increased. Close clinical and biochemical monitoring is essential with early supplementation or correction of electrolyte abnormalities.

Myelosuppression

Children and young people with malnutrition typically have low total white cell and neutrophil counts. The clinical significance of this is uncertain. Neutropenia can be racial and it is important first to ensure normal haematinics and blood film. **If the neutropenia is < 1 10⁹/L AND associated with a fever > 38°C, young people should receive broadspectrum intravenous antibiotics pending cultures.**

Mental Health Issues and Supervision

Many children and young people with eating disorders will have comorbidities such as depression or anxiety disorders, obsessive compulsive symptoms or personality disorders. They commonly have marked anxiety around food and meal times, which they convey to those caring for them. This anxiety may cause some to be evasive about their food intake, and even hide food to give the impression it has been eaten. Equally, young people may surreptitiously drink large amounts of water ('waterloading') in order to make their weight appear higher than it is. It is essential therefore

that a parent or member of staff is able to sit with the young person during mealtimes to offer them support. If there are other psychiatric comorbidities, or suspicion of purging behaviours (tampering with the NG tube, occult exercising/vomiting, hiding food), 1:1 supervision by an appropriately trained person who has built up a rapport with the child or young person will be necessary. Strict boundaries should be given for mealtimes, with clear guidance to the young person of plan should a meal not be completed within the allotted time:

45 hour for meal-times (30 mins for breakfast)

30 minutes for snacks

No access to the toilet should be allowed for 30 minutes after each meal or snack.

Children and young people should remain on the ward during the admission. They may be allowed negotiated periods away as part of their therapeutic plan, but these must be agreed in advance.

Mental Health Act

For some children who do not consent to treatment, it may be necessary to use the Mental Health Act. Admission for most children should have been negotiated with them at the outset and on the whole most will consent. For those where consent cannot be obtained, early psychiatric opinion and advice on the use of the Mental Health Act should be sought, in the first instance from the on-call Child and Adolescent Mental Health team at the Belgrave, with early input where available from the Eating Disorders Service.

Discharge

Most admissions will be for 5-7 days as calorie intake is gradually increased with appropriate monitoring. If physical observations and biochemical parameters are stable, transfer to SAU may be considered. If the child or young person is already known to CAEDS, CAEDS should organise this with SAU. If CAEDS have not hitherto been involved in the management of the child or young person, the liaison psychiatry service at the Belgrave must be involved early on to facilitate any assessments necessary or onward transfer to other CAMHS services.

It is essential that all documentation including meal plans, drug charts, blood results and ECGs be transferred with the young person.

Appendix 1 Assessment of Medical Stability

All children at high risk of medical instability will require admission to King's for stabilisation. There should be a low threshold for admission of those at moderate risk.

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% [Approximates to below 0.4th BMI centile]	Percentage Median BMI 70-80% [Approximates to between 2nd and 0.4th BMI centile]	Percentage Median BMI 80-85% [Approximates to between 9th and 2nd BMI centile]	Percentage Median BMI >85% [Approximates to above 9th 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 <0.4th centile (84-98mmHg depending on age and sex[2]) Diastolic <0.4th centile (35 -40 mmHg depending on age and sex1)	Sitting Blood Pressure Systolic <2nd centile (88 - 105mmHg depending on age and sex1) Diastolic <2nd centile (40 - 45mmHg depending on age and sex1)	Normal sitting blood pressure for age and sex with reference to centile charts1
	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-syncopal symptoms but normal orthostatic cardiovascular changes	Normal orthostatic cardiovascular changes
	Irregular heart rhythm (does not include sinus arrhythmia)			Normal heart rhythm

Hydration Status	Fluid refusal Severe dehydration (10%): Reduced urine output Dry mouth Decreased skin turgor, sunken eyes Tachypnoea Tachycardia[1]	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
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	<35.5oC (tympenic) or 35.0oC axillary	<36 oC		
Biochemical Abnormalities	Hypophosphataemia Hypokalaemia Hypoalbuminaemia Hypoglycaemia Hyponatraemia Hypocalcaemia	Hypophosphataemia Hypokalaemia Hyponatraemia 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	

Appendix 2 Criteria for Assessing Risk of Refeeding Syndrome

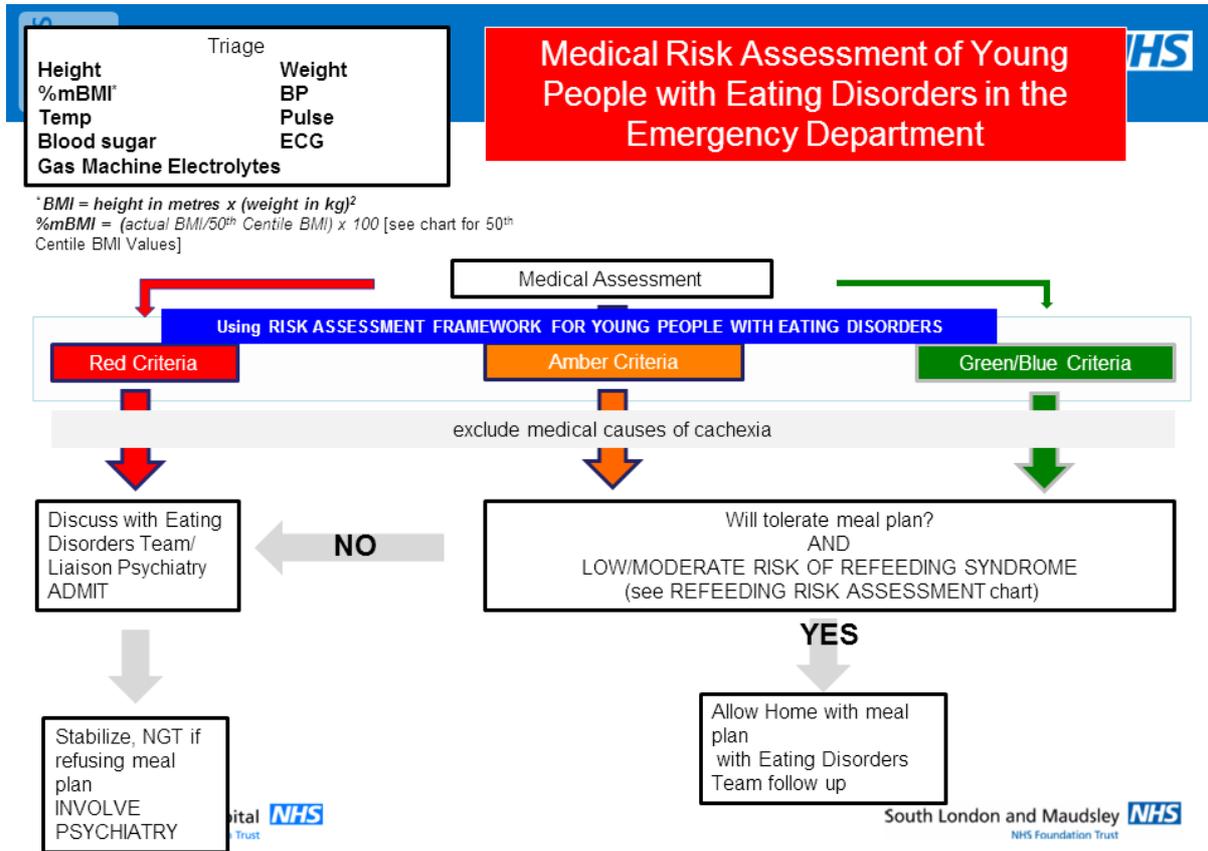
	HIGH RISK	MODERATE RISK	LOW RISK
%BMI	<70%	70-85%	>85%
Caloric restraint	Abstinence > 5days or <1000kCal/d	Abstinence 3-5 days or 1000 – 1500kCal/d	>1500kCal/d
Plasma Phosphate	<0.9 mmol/L		
WCC	low		

Only one feature required to dictate risk

Note: If the any of the following are present, urgent medical review is mandatory, and threshold for admission should be low:

- **hypoalbuminaemia is present (<40g/L)**
- **Total abstinence for 5 or more days**
- **medical comorbidity (see appendix 3)**

Appendix 2 Emergency Department Flow Chart



Appendix 3 Inpatient Management Chart

King's
King's College Hospital 
NHS Foundation Trust

Avoid treating hypoglycaemia with hypostop unless symptomatic or nonketotic

Initial Investigations
FBC/Ferritin/film
U&E/LFT/Bone/Mg
Glucose (if hypoglycaemia <2.6mmol/L, also plasma Betahydroxybutyrate/None sterified fatty acids/Cortisol/Insulin/CPeptide/Acyl carnitines/urine organic acids, ketones (dipstick))
B12/Folate/Vitamin D
Chloride/Bicarbonate/Potassium if history of vomiting
Amylase/lipids if history of vomiting/abdominal pain
TFT
 If amenorrhoea present: Prolactin, FSH, LH, Estradiol, AFP, BHCG
Coeliac Screen
12 Lead ECG: clear documentation of the corrected QT is essential (QT/RR): note that a prolonged QTc can be associated with cardiac arrhythmia. It is sex-dependent. (See Appendix 1 for criteria)

BEDREST (consider RMN)
 Rewarm
 Correct Electrolyte Abnormalities
 Cardiac Monitor (if prolonged QTc)

NOTE: 80% of hypophosphataemia occurs by Day 4

EARLY REINTRODUCTION OF NUTRITION (meal plan or NGT)
 DAY 1: **1200**KCAL/24H
 DAY 2: **1500**KCAL/24H
 DAY 3: **1750** KCAL/24H
 DAY 4: **2000** KCAL/24H
 DAY 5: **2250** KCAL/24H
 DAY 6: **2500** KCAL/D

Involve Child and Adolescent Eating Disorders Team early to plan transfer
 IN HOURS: 020 32282545
 OUT OF HOURS: Child & Adolescent Psychiatry On-Call

MONITOR GLUCOSE,
 U&E, MAGNESIUM,
 PHOSPHATE daily

Medicines

phosphate sandoz 500mg bd (32mmol/d)
vitamin B complex strong (contains B₁ [thiamine] and B₂ [riboflavin], nicotinamide, B₆ [pyridoxine]))
 2 tablets TDS
 or if liquid used (Vigranon B)
 age: 1-12y 10ml TDS
 12-18y 15ml TDS

multivitamin. (*sanatogen* or *forceval* one tab od)
NB: if strong suspicion of thiamine deficiency
 Use **Pabrinex** instead of Vitamin B complex
Vial 1 (contains B₁ [thiamine] 50mg and B₂ [riboflavin] 4mg, B₆ [pyridoxine] 50mg))
Vial 2 (contains C [ascorbic acid] 500mg, nicotinamide 160mg, Glucose 2000mg)
 ADULT DOSE: 10ml of each ampoule diluted with 50-100ml of (0.9% saline or 5% dextrose) given over 30 mins
 CHILD DOSE:
 6 - 10 years 1/3 of the adult dose
 10 - 14 years 1/2 to 2/3 of the adult dose
 14 years and over as for the adult dose

Appendix 4 Nursing Care Plan for admission of patient with Eating Disorder

On admission

- Allocate bed in open bedded bay, ideally Bed 4
- Obtain weight and height
 - Calculate BMI (kg/m^2)
 - Plot on growth chart
 - **%median BMI** - $(\text{actual BMI}/50^{\text{th}} \text{ Centile BMI}) \times 100$
- Confirm medical monitoring requirements – this may include cardiac monitor 4-hourly temperature, pulse, respiratory rate, blood pressure and blood glucose

Feeding

- Contact ward dietitian – aircall KH4434
- Confirm with medical team or dietitian method of feeding – oral or enteral
- Enteral feeding
 - Insert nasogastric tube and follow feeding plan as per **Appendix 7** for highest risk patients (low plasma albumin, %BMI less than 60%, weight under 30kg or under 12 years old) discuss with dietitian (or outside working hours Consultant)
 - Feeding plan uses Ensure 2kcal, this can be found in the SFU in 200ml bottles. If not available, nutrison energy can be considered.
 - Feeding plan does not provide full fluid requirements – ensure fluid needs are met though oral fluid intake, regular water boluses or discuss need for IV fluid with medical team
- Oral intake
 - Select appropriate menu plan from **Appendix 6**
 - Go through menu plan with patient
 - Three copies of menu plan required for:
 - Beside notes
 - Diet kitchen (ext. 32613)
 - Ward hostess
 - Supervision is required at all mealtimes, please refer to **Appendix 5** for guidance
 - Monitor and document oral intake of food and fluids

Appendix 5

Meal Supervision Guidelines

Meals and snacks must have clear time boundaries and the patient should be reminded of these at the start of each meal/snack and if necessary at intervals though the meal.

Breakfast 30 minutes

Snacks 30 minutes

Lunch and dinner 45minutes (30mins main course, 15 mins dessert)

Offer the young person the opportunity to use the toilet prior to meals and snacks. The toilet should not be used during the post-meal supervision period (1 hour after main meals, 30 minutes after snacks). If it becomes imperative for the young person to use the toilet they must be under eyesight observation as these are very high risk periods for over-exercising or vomiting.

What is served is what is to be eaten – no swaps, negotiations or substitutions to be made. Anorexia may cause the young person to seek to engage a meal supervisor in negotiations about portion size, the fairness or otherwise of the meal plan etc. Avoid any discussion or negotiation, simply advise the patient that the food is provided according to the plan specified by the dietitian and that they are required to eat what is provided. Swapping food, reducing portions or trying to be helpful or 'kind' in other ways will not aid the young person's recovery and will make future meal supervision harder.

Young people with anorexia who have eaten poorly for a period of time often experience unpleasant gastro-intestinal symptoms once they start to eat again. They may feel bloated and nauseous and may suffer constipation. These sensations can be distressing, particularly as they may be interpreted as evidence of over-eating by the anorexic patient. It is important to reassure the young person that although it can be uncomfortable and distressing that these symptoms are normal and to be expected. The best method of alleviating the symptoms is to continue building up their oral intake as this will enable their gut to adapt. The symptoms will diminish over time. Reducing oral intake simply perpetuates the problem.

Be supportive and firm at mealtimes. Acknowledge how hard it is for the young person but remain calm and firm in encouraging them to complete the meal or snack. Be cautious about offering praise – some young people with anorexia perceive eating as failure and praise can exacerbate their sense of shame and guilt at their perceived failure. If unsure, ask the young person what they would find helpful. In some cases distraction may be helpful – e.g. chatting about neutral (i.e. non food/weight/shape

related) topics, but in other cases the young person may prefer to eat quietly focusing on the task at hand.

Challenge eating disordered behaviours such as cutting food into tiny pieces, pushing food around the plate, eating one pea or raisin at a time, or smearing food. Prevent excessive use of salt/vinegar/ketchup by limiting access to condiments.

Be alert for possible attempts to dispose of or hide food. Napkins or serviettes should only be given once a meal is complete as they may be used to hide food if provided during a meal. Sometimes a young person may smear food in their hair or under the table, hide food in clothes, or drop it on the floor. Point out that you have observed this and explain the lost or spoiled food will be replaced. Where possible replace the lost food. If this is not possible add the equivalent amount to the NG feed.

Keep an accurate food and fluid chart so that oral intake and NG feeds can be correctly calculated to meet nutritional and fluid requirements.

Appendix 6

Meal Plans

Day One - 1200kcal meal plan – nursing copy

Meal	Options	Calorie Content	Equivalent Fortisip compact
Breakfast	Cereal (variety box on ward) with 200ml semi skimmed milk Orange Juice fruit cup	200	84ml
Morning Snack	Three digestive biscuit Or Custard pot Or Ginger cake Or St Clements cookie Or Full fat yogurt Or 200ml semi skimmed milk with a piece of fruit	150	63ml
Lunch	Half jacket potato with tuna, baked beans or cottage cheese And yogurt Or ice-cream Or rice pudding Or Any sandwich	300	125ml
Afternoon Snack	Three digestive biscuit Or Custard pot Or Ginger cake Or St Clements Cookie Or Full fat yogurt Or 200ml semi skimmed milk with a piece of fruit	150	63ml
Supper	Half portion of: Beef lasagne Or Salmon Jambolaya Or Chicken tikka Or Tomato and basil pasta Or 5 bean chilli and half jacket potato Or Macaroni cheese Orange Juice	300	125ml
Evening Snack	Hot chocolate (made with 150ml of semi skimmed milk)	100	42ml

Day One Meal Plan – patient copy

Meal	Options
Breakfast	Cereal (variety box on ward) with 200ml semi skimmed milk Orange Juice fruit cup
Morning Snack	Three digestive biscuit O Or Custard pot Or Ginger cake Or St Clements cookie Or Full fat yogurt Or 200ml semi skimmed milk with a piece of fruit
Lunch	Half jacket potato with tuna, baked beans or cottage cheese And yogurt Or ice-cream Or rice pudding Or any sandwich
Afternoon Snack	Three digestive biscuit Or Custard pot Or Ginger cake Or St Clements Cookie Or Full fat yogurt Or 200ml semi skimmed milk with a piece of fruit
Supper	Half portion of: Beef lasagne Or Salmon Jambolaya Or Chicken tikka Or Tomato and basil pasta Or 5 bean chilli and half jacket potato Or Macaroni cheese Orange Juice
Evening Snack	Hot chocolate (made with 150ml of semi skimmed milk)

Day Two - 1500kcal meal plan – nursing copy

Meal	Options	Calorie Content	Equivalent Fortisip Compact
Breakfast	Cereal (variety box on ward) with 200ml semi skimmed milk And one slice toast with margarine/butter and jam And Orange Juice fruit cup	300	125ml
Morning Snack	Three digestive biscuit O Or Custard pot Or Ginger cake Or St Clements cookie Or Full fat yogurt Or 200ml semi skimmed milk with a piece of fruit	150	63ml
Lunch	Half jacket potato with tuna, baked beans or cottage cheese And yogurt Or ice-cream Or rice pudding Or any sandwich	300	125ml
Afternoon Snack	Three digestive biscuit Or Custard pot Or Ginger cake Or St Clements Cookie Or Full fat yogurt Or 200ml semi skimmed milk with a piece of fruit	150	63ml
Supper	Half portion of: Beef lasagne Or Salmon Jambolaya Or Chicken tikka Or Tomato and basil pasta Or 5 bean chilli and half jacket potato Or Macaroni cheese Orange Juice	300	125ml
Evening Snack	Cheese and crackers Or Hot chocolate (200ml semi skimmed milk) and one digestive biscuit Or Fruity flapjack	250	105ml

Day Two Meal Plan – patient copy

Meal	Options
Breakfast	Cereal (variety box on ward) with 200ml semi skimmed milk And one slice toast with margarine/butter and jam And Orange Juice fruit cup
Morning Snack	Three digestive biscuit O Or Custard pot Or Ginger cake Or St Clements cookie Or Full fat yogurt Or 200ml semi skimmed milk with a piece of fruit
Lunch	Half jacket potato with tuna, baked beans or cottage cheese And yogurt Or rice-cream Or rice pudding Or Any sandwich
Afternoon Snack	Three digestive biscuit Or Custard pot Or Ginger cake Or St Clements Cookie Or Full fat yogurt Or 200ml semi skimmed milk with a piece of fruit
Supper	Half portion of: Beef lasagne Or Salmon Jambolaya Or Chicken tikka Or Tomato and basil pasta Or 5 bean chilli and half jacket potato Or Macaroni cheese Orange Juice
Evening Snack	Cheese and crackers Or Hot chocolate (200ml semi skimmed milk) and one digestive biscuit Or Fruity flapjack

Day Three - 2000kcal meal plan – nursing copy

Meal	Options	Calorie Content	Equivalent Fortisip Compact
Breakfast	Cereal (variety box on ward) with 200ml semi skimmed milk And two slice toast with margarine/butter and jam	350	146ml
Morning Snack	Oatmeal cookie Or lemon muffin Or 200ml semi-skimmed milk and one toast with margarine/butter and jam Or three digestive biscuits	200	84ml
Lunch	All jacket potato with tuna, baked beans or cottage cheese Or any sandwich And yogurt Or ice-cream Or rice pudding	500	208ml
Afternoon Snack	Oatmeal cookie Or lemon muffin Or 200ml semi-skimmed milk and one toast with margarine/butter and jam Or three digestive biscuits	200	84ml
Supper	Beef lasagne Or Salmon Jambolaya Or Chicken tikka Or Tomato and basil pasta Or 5 bean chilli and half jacket potato Or Macaroni cheese Orange Juice	500	208ml
Evening Snack	Cheese and crackers Or Hot chocolate (200ml semi skimmed milk) and one digestive biscuit Or Fruity flapjack	250	105ml

Day Three Meal Plan– patient copy

Meal	Options
Breakfast	Cereal (variety box on ward) with 200ml semi skimmed milk And two slice toast with margarine/butter and jam
Morning Snack	Oatmeal cookie Or lemon muffin Or 200ml semi-skimmed milk and one toast with margarine/butter and jam Or three digestive biscuits
Lunch	All jacket potato with tuna, baked beans or cottage cheese Or any sandwich And yogurt Or ice-cream Or rice pudding
Afternoon Snack	Oatmeal cookie Or lemon muffin Or 200ml semi-skimmed milk and one toast with margarine/butter and jam Or three digestive biscuits
Supper	Beef lasagne Or Salmon Jambolaya Or Chicken tikka Or Tomato and basil pasta Or 5 bean chilli and half jacket potato Or Macaroni cheese Orange Juice
Evening Snack	Cheese and crackers Or Hot chocolate (200ml semi skimmed milk) and one digestive biscuit Or Fruity flapjack

Day Four - 2500kcal meal plan – nursing copy

Meal	Options	Calorie Content	Equivalent Fortisip Compact
Breakfast	Cereal (variety box on ward) with 200ml semi skimmed milk And two slice toast with margarine/butter and jam	350	146ml
Morning Snack	Cheese and crackers Or Two slices of toast with margarine/butter and jam Or Fruit flapjack Or Lemon muffin Or 200ml semi skimmed milk and two digestive biscuits	250	105ml
Lunch	All jacket potato with tuna, baked beans or cottage cheese Or any sandwich And Packet of crisps And yogurt Or ice-cream Or rice pudding	700	292ml
Afternoon Snack	Cheese and crackers Or Two slices of toast with margarine/butter and jam Or Fruit flapjack Or Lemon muffin Or 200ml semi skimmed milk and two digestive biscuits	250	105ml
Supper	Beef lasagne Or Salmon Jambolaya Or Chicken tikka Or Tomato and basil pasta Or 5 bean chilli and half jacket potato Or Macaroni cheese Crumble Or Sponge pudding	700	292ml
Evening Snack	Cheese and crackers Or Hot chocolate (200ml semi skimmed milk) and one digestive biscuit Or Fruity flapjack	250	105ml

Day Four Meal Plan – patient copy

Meal	Options
Breakfast	Cereal (variety box on ward) with 200ml semi skimmed milk And two slice toast with margarine/butter and jam
Morning Snack	Cheese and crackers Or Two slices of toast with margarine/butter and jam Or Fruit flapjack Or Lemon muffin Or 200ml semi skimmed milk and two digestive biscuits
Lunch	All jacket potato with tuna, baked beans or cottage cheese Or any sandwich And Packet of crisps And yogurt Or ice-cream Or rice pudding
Afternoon Snack	Cheese and crackers Or Two slices of toast with margarine/butter and jam Or Fruit flapjack Or Lemon muffin Or 200ml semi skimmed milk and two digestive biscuits
Supper	Beef lasagne Or Salmon Jambolaya Or Chicken tikka Or Tomato and basil pasta Or 5 bean chilli and half jacket potato Or Macaroni cheese Crumble Or Sponge pudding
Evening Snack	Cheese and crackers Or Hot chocolate (200ml semi skimmed milk) and one digestive biscuit Or Fruity flapjack

Appendix 7 Nasogastric Feeding Plan for Refeeding at KCH

- Supplementation of the following should commence prior to starting nasogastric feeds
 - **phosphate sandoz** 500mg bd (32mmol/d)
 - **vitamin B complex strong** (contains B₁ [thiamine] and B₂ [riboflavin], nicotinamide, B₆ [pyridoxine])
 - **multivitamin.** (*sanatogen* or *forceval* one tab od)
- Biochemistry including potassium, phosphate, magnesium and calcium should be checked and supplemented as required prior to commencing nasogastric feeds
- Ensure the nasogastric tube is correctly placed using a pH strip before feeds commence
- Flush NGT with sterile water before and after use

THIS ENTERAL FEED REGIME IS NOT SUITABLE FOR PATIENTS AT THE HIGHEST RISK OF PATIENTS (THOSE WITH LOW PLASMA ALBUMIN, %BMI LESS THAN 60%, WEIGHT LESS THAN 30KG OR UNDER 12 YEARS – CONTACT WARD DIETITIAN FOR GUIDANCE

FEED: ENSURE 2KCAL	Provides/day	Rate	Notes
Day One	1200kcal in 600ml	30ml/hr for 20hrs	
Day Two	1500kcal in 750ml	37ml/hr for 20hrs	
Day Three	1750kcal in 875ml	44ml/hr for 20hrs	
Day Four	2000kcal in 1000ml	50ml/hr for 20hrs	
Day Five	2250kcal in 1125ml	56ml/hr for 20hrs	
Day Six	2500kcal in 1250ml	63ml/hr for 20hrs	

NB: Please be aware the above regime does not meet fluid requirements, ensure fluid needs are met either by oral fluid intake, additional water boluses via nasogastric tube or IV fluids

x 8 **Comparison of Feeds**

	Energy (kcal/100ml)	Protein (g/100ml)	Carbohydrate (g/100ml)	Fat (g/100ml)	% energy from protein	% energy from CHO	% energy from fat	Phosphate (mg/100ml)
Standard	100	4	12.3	3.9	16	49	35	72
Energy	150	6	18.3	5.8	16	49	35	108
Standard gen n plus 75 500kcal	121	3.8	11	7	12.6	34	52	68
HN	200	8.4	21.9	9	16.7	41	40	106
	150	6.3	10.5	9.4	16.7	27	56	106
are	150	6.3	10.6	9.3	16.7	28	55	106
tion ents								
o	150	6	18.4	5.8	16	49	35	78
mpact	240	9.6	29.7	9.3	16	49	35	174
ole)	66	3.3	4.5	3.9	20	26	53	93
immed)	46	3.4	4.7	1.7	29.6	38	33	96
rison								
st milk	72	1.3	4.3	4.1	7.2	22	59	106

Appendix 9 Contact Names and Numbers

Dr Simon Chapman, Consultant Paediatrician (available through switchboard)

Dr Mima Simic, Consultant Child and Adolescent Psychiatrist, Michael Rutter Centre

Dr Richard Corrigan, Consultant Child and Adolescent Psychiatrist, Snowsfield Adolescent Unit

Kings College Hospital Switchboard:	020 32999000
Paediatric Registrar on call:	bleep 424
Paediatric SHO on call:	bleep 495
Bed Manager:	bleep 295
Toni & Guy Ward:	extension: 4401/3102
Phillip Isaacs Ward:	extension: 4200
HDU:	extension: 3660
Paediatric Accident & Emergency:	extension: 3139
Dietician:	aircall through switchboard: KH4434

Snowsfield Adolescent Unit:	020 32282208 (ward)
	020 32282223 (fax)

Michael Rutter Centre:	020 32282545 (departmental secretary)
	020 22285011 (departmental fax)
SHO/Registrar:	020 32282545 (via departmental secretary)
Michael Rutter Centre (Dietician):	020 32283302

Kitchens

KCH	extension 32613
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Appendix 10 Refeeding and Refeeding Syndrome Background

Refeeding syndrome is a clinical syndrome characterised by cardiac arrhythmias, encephalopathy or seizures following reintroduction of nutrition in the profoundly malnourished. Its biochemical hallmark is hypophosphataemia, often associated with other electrolyte abnormalities (hyponatraemia, hypokalaemia, hypocalcaemia and hypomagnesaemia).

Pathophysiology

In starvation, catabolic pathways dominate, mediated by catabolic hormones - these include cortisol, glucagon and growth hormone. They promote gluconeogenesis, glycogenolysis, lipolysis and ketogenesis. They also confer a degree of resistance to insulin. In the chronically starved state protein and fat catabolism lead to a negative nitrogen balance, decreased lean body mass and a metabolic adaptation to starvation - glycerol from lipolysis and glucose from gluconeogenesis continue to be used but some tissues switch over to partial use of ketones: the brain, a major user of glucose is able to do this. Peripheral tissues are also able to use fatty acids as a fuel source. In this way carbohydrate is supplanted by protein and fat as the principle energy source.

In addition to the metabolic adaptation, substrate use is also reduced: cardiac output and muscle mass fall, as does body temperature.

Following reintroduction of nutrition, in particular carbohydrate, there is a switch back to glucose metabolism. This causes insulin release which also drives intracellular movement of glucose, potassium and phosphate, as well as water. Magnesium and thiamine are both key cofactors/coenzymes.

Rapid refeeding, especially with carbohydrate, following prolonged starvation therefore can lead to an exaggerated insulin surge with a subsequent hypophosphatemia and the associated clinical manifestations of this.

Anorexia Nervosa and Refeeding

Hitherto the risk of refeeding syndrome and its clinical management has been extrapolated from what is known in other contexts - particularly malnourished infants in the developing world, or malnutrition through other causes where comorbidities exist. This has been emphasised by case reports of cardiac or neurological sequelae during refeeding of anorexic patients on hospital wards. Clinical management in these situations has tended to follow national guidance (NICE) which

advocate a reduced calorie intake (10-20 kCal/kg/d) with small incremental increases at daily intervals with daily measurement of electrolytes and plasma phosphate.

A number of centres however have noted this approach can be counterproductive and even lead to the 'underfeeding syndrome', where reintroduction of nutrition is excessively cautious. It is likely, also, that as a population, anorexic patients are not easily comparable to the groups on which the above guidance is based. Patients with anorexia on the whole have no comorbidity. To compound this, many case reports documenting refeeding syndrome have occurred on the reduced calorie intake⁴.

Experience of refeeding young people with eating disorders at higher rates has also been published showing more aggressive feeding regimens:

Author	No of patients	Age (mean)	%IBW	Starting kCal/d	target kCal/d	Hypophosphat aemia cases	Notes
Whitelaw et al. ⁵	46	15.7	72.9	1900	2700	38% mild	same protocol used in 309 children with similar results
Kohn et al. ⁶	'over 400'	13.8	mean BMI 14.1 kg/m ²		3000		letter to editor only
Ornstein et al. ⁷	69	15.5	72.7	1200		5.8%	
Gentile et al. ⁸	33	22.8	<12	28kCal/kg	32kCal/	0	EDU Italy

⁴The refeeding syndrome and glucose load, O'Connor, Goldin, International Journal of Eating Disorders 44:2 182-185 2011

⁵Whitelaw et al., Does aggressive refeeding in hospitalized adolescents with anorexia nervosa result in increased hypophosphataemia? Journal of Adolescent Health 46(2010) 577-582

⁶Kohn et al. [letter], Journal of Paediatrics and Child Health 43[2007] 318-321

⁷Ornstein et al. Hypophosphatemia during nutritional rehabilitation in anorexia nervosa: nutritional implications for refeeding and monitoring, Journal Of Adolescent Health 2003;32:83-88

⁸Specialised refeeding treatment for anorexia nervosa patients suffering from extreme undernutrition, Clinical Nutrition 29(2010);627-632

⁷Garber et al., A Prospective Examination of Weight Gain in Hospitalized Adolescents With Anorexia Nervosa on a Recommended Refeeding Protocol, Journal of Adolescent Health 50 (2012) 24-29

			kg/m ²		kg		
Garber et al. ⁷	35	16.2	80.1%	1205	2668	20%	California USA
Gaudiani et al. ⁸	25	Adult (26y)	13.1kg/ m ²	990	2000	45%	Denver USA
Vignaud et al	68	31+/-12	12 +/-3 kg/m ²	22.3+/- 13kcal/kg		16% (10)	ITU France

Rationale for re-feeding protocol for young people under 18 years old – Dietetic Perspective

Re-feeding may be by oral feeding with food, liquid oral nutrition supplements, tube feeding, or a mixture of these methods. During nasogastric feeding, if at all possible, some oral intake, at least of water, should be maintained, as it may be very difficult to re-establish later.

Young people should be assessed and assigned a risk level. There should be a standard protocol for each level of risk.

Risk is primarily assessed on the basis of %BMI. Physical co-morbidities such as diabetes should be taken into account.

There is rarely justification for giving less energy than resting energy expenditure, as this perpetuates a deficit and increases risk. Beginning at 1200 calories per day is considered safe on current research evidence. Refeeding can be managed safely if blood electrolytes (Na, K, PO₄, Mg, Ca) are monitored daily, and replaced as needed.

⁸Gaudiani et al., Severe Anorexia Nervosa: Outcomes from a Medical Stabilization Unit, Int J Eat Disord 2010; 00:000-000

As carbohydrate is the macronutrient most likely to cause metabolic disturbance, a relatively low carbohydrate to fat ratio is safer. Tube feeding formulae such as Pulmocare or Oxepa might have some advantages here, but may not be readily available. Otherwise, a standard feed plus Calogen would be possible. TwoCal HN also has a suitable nutritional profile and where available may be the most straightforward option.

High intake of phosphate may be helpful. This can be achieved with normal food by using a milk-based diet (see below). It is more difficult to achieve using oral nutritional supplements or tube feeding formulae, so routine supplementation may be appropriate.

Ratio of phosphate to carbohydrate may also be relevant; feeds with a higher ratio of phosphate to carbohydrate may be preferable, although there is insufficient evidence to provide a target ratio.

For further details of feeds and their nutritional composition, and sample meal plans please refer to

- **Blood Pressure Reference**
- **Sit Up, Squat and Stand Test**
- **Clinical Features**

Blood pressure centiles for Great Britain

Lisa V Jackson, Nandu K S Thalange and Tim J Cole

Arch. Dis. Child. 2007;92;298-303; originally published online 11 Aug 2006;
doi:10.1136/adc.2005.081216

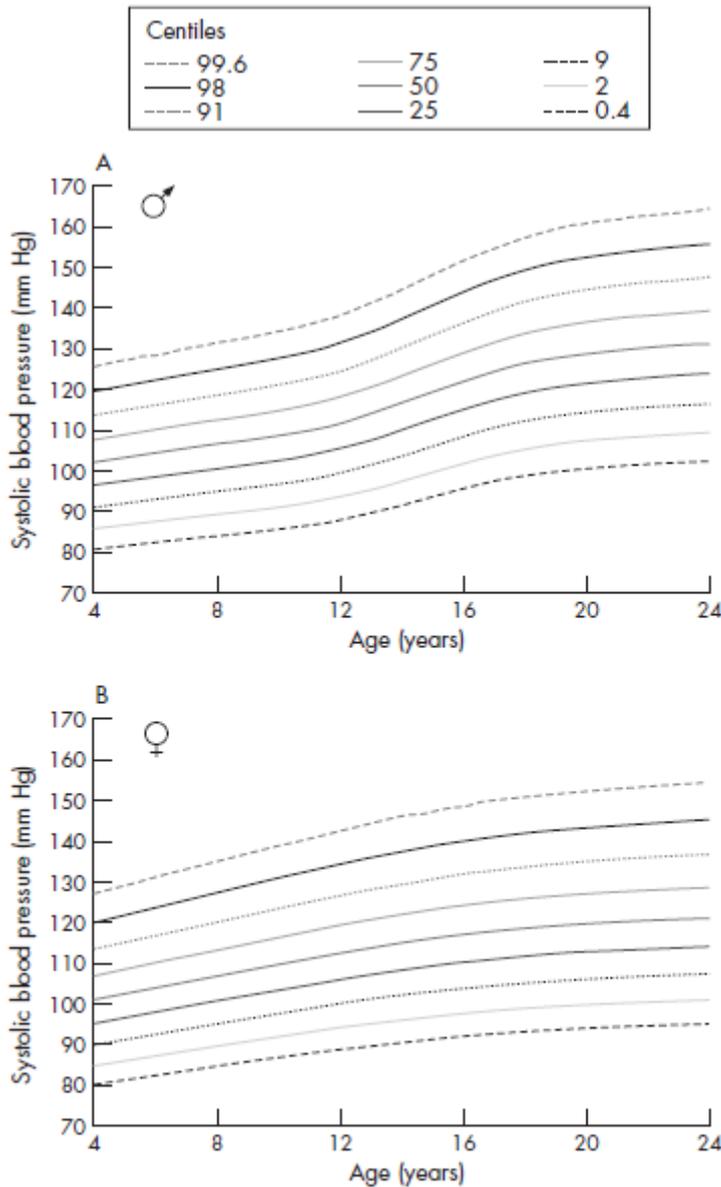
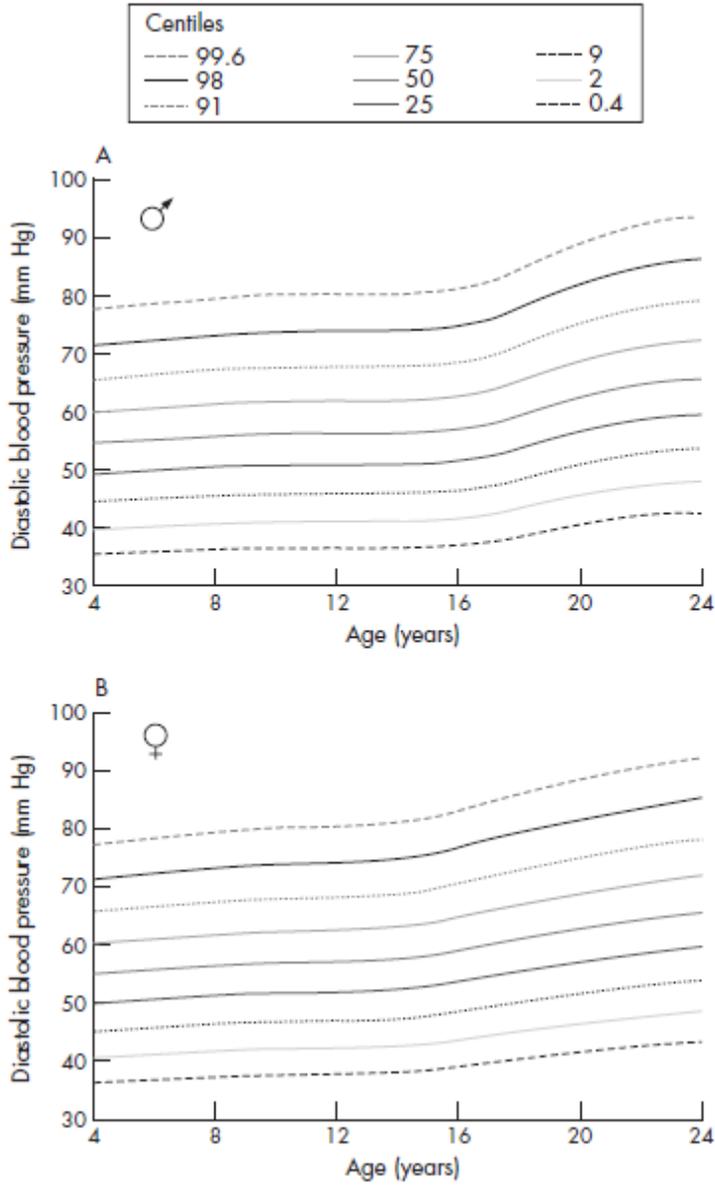


Figure 1 Systolic blood pressure centiles in male (A) and female participants (B). The centiles are spaced two-thirds of a standard deviation score apart. Systolic pressure rises progressively with age, but rises more steeply in puberty, particularly in boys.



The sit up, squat, stand (SUSS) test

Sit up

The patient is asked to sit up from lying supine on a flat surface without using the hands, if possible.

Squat

The patient is asked to squat and to rise without using the hands, if possible.

Rating

The scale used for rating both squatting and sitting is as follows:

- 0 completely unable to rise
- 1 able to rise only with use of hands
- 2 able to rise with noticeable difficulty
- 3 able to rise without difficulty.

Clinical Features of Eating Disorders

Table 2 What to look for on physical examination

Bradycardia	Cold extremities/acrocyanosis/
Orthostatic changes in pulse or blood pressure	weak peripheral pulses/reduced
Hypothermia	capillary refill time
Dull, thinning hair	Muscular weakness and
Sunken cheeks, sallow skin	peripheral neuropathy*
Lanugo hair	Cutting/self-harm
Signs of malnutrition, angular stomatitis, pallor	Callous on third finger
Atrophic breasts	(Russell's sign)
Pitting oedema in peripheries	Dental erosion
Carotenaemia (yellowing of palms)	Parotidomegaly
Infection	Signs of vomiting
Thyroid (for differential diagnosis)	Signs of substance abuse

*The SUSS test: Sit up: The patient is asked to sit up from lying supine on a flat surface without using the hands, if possible. Squat: The patient is asked to squat and to rise without using the hands, if possible. Rating: 0 completely unable to rise; 1 able to rise only with use of hands; 2 able to rise with noticeable difficulty; 3 able to rise without difficulty.

Nicholls D, Hudson L, Mahomed F. *Arch Dis Child* (2010). doi:10.1136/adc.2009.177394

How to calculate the Percentage Median BMI

King's

King's College Hospital 
NHS Foundation Trust

50th Centile BMI values

age	boys	girls
years	Kg/m ²	
9	16.037	16.399
9.25	16.125	16.515
9.5	16.219	16.637
9.75	16.318	16.765
10	16.423	16.898
10.25	16.533	17.036
10.5	16.648	17.179
10.75	16.768	17.327
11	16.892	17.478
11.25	17.02	17.634
11.5	17.154	17.793
11.75	17.291	17.954
12	17.433	18.117
12.25	17.579	18.281
12.5	17.729	18.446
12.75	17.881	18.61
13	18.037	18.772
13.25	18.194	18.932
13.5	18.354	19.09
13.75	18.514	19.244
14	18.675	19.395
14.25	18.836	19.542
14.5	18.997	19.684
14.75	19.158	19.822

age	boys	girls
years	Kg/m ²	
15	19.317	19.955
15.25	19.475	20.083
15.5	19.632	20.206
15.75	19.786	20.324
16	19.938	20.438
16.25	20.087	20.547
16.5	20.234	20.652
16.75	20.378	20.751
17	20.519	20.847
17.25	20.656	20.938
17.5	20.791	21.026
17.75	20.923	21.11
18	21.052	21.19
18.25	21.178	21.267
18.5	21.301	21.342
18.75	21.422	21.413
19	21.54	21.482
19.25	21.655	21.548
19.5	21.768	21.612
19.75	21.878	21.674
20	21.986	21.735

BMI = height in metres x (weight in kg)²

%mBMI = (actual BMI/50th Centile BMI) x 100 [see chart]

Example

14.5 year old girl,

Weight: **30kg**

Height: **158cm**

BMI: 30/(1.58x1.58) =

12kg/m²

50th Centile BMI: **19.684**

kg/m²

%mBMI = (12/19.684 x100)

= 61%

Appendix 12

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Appendix D

Outpatient meal plans

DAILY MEAL PLAN

Restoring regular eating

Name:	Date:
BREAKFAST	
<ul style="list-style-type: none"> • 100mls fruit juice • With 30g cereal eg porridge <i>or</i> rice krispies <i>or</i> cornflakes made with 150mls full fat milk 	
MID-MORNING	
<ul style="list-style-type: none"> • 200mls full fat milk • With 2 x digestive biscuits • <i>Or</i> 2 x crackers with ONE of the following: 20g cheese <i>or</i> 40g avocado <i>or</i> 15g nut butter (without added sugar). 	
LUNCH	
<ul style="list-style-type: none"> • 100mls of fruit juice • 1 slice of bread with 1tsp of butter • With ONE of the following: 2 slices of turkey/ham <i>or</i> 20g of cheese <i>or</i> hummus <i>or</i> 1 x egg • Include some salad • And a 125g pot of full fat yoghurt 	
TEA	
<ul style="list-style-type: none"> • 200mls full fat milk • With 1 x large piece of fruit e.g. banana/apple <i>or</i> 2 x medium e.g. kiwi/plums/satsumas. 	
DINNER	
<ul style="list-style-type: none"> • 100mls of fruit juice <p>Choose ONE of the following:</p> <ul style="list-style-type: none"> • 50g of cooked pasta/noodles/couscous with 50g of meat or fish. • <i>Or</i> 100g of shepherd's pie/ fish pie/ spaghetti bolognaise. • Include approximately 50g of well cooked vegetables. <p>Dessert:</p> <ul style="list-style-type: none"> • With 125g full fat yoghurt 	
SUPPER	
<ul style="list-style-type: none"> • 200mls full fat milk with 1 x digestive biscuit 	
DRINKS	
Plus additional 500mls, spread throughout the day, to be provided by non sugar containing fluids.	

Why you need this plan

This menu is planned for you to use for a few days only, while you get used to eating regularly. If you have not eaten very much for some time, it may be difficult for your body to deal with food at first. This meal plan is designed to give your body a gentle re-introduction to food, so that all the body systems that deal with food can gradually return to full normal working. It will help to correct any abnormalities in your blood tests.

The most important things that you need most as you begin to restore healthy eating are:

- **Phosphate.** You need a high phosphate intake as you slowly increase the amount you are eating. It is important for keeping muscles working, especially the heart muscle. Milk and foods made from milk, like yogurt, custard and cheese, are high in phosphate. (Note: some brands of soya milk are very low in phosphate, so it is not a suitable substitute)
- **Calcium.** Calcium can help protect and strengthen your bones. Milk and foods made from milk, like yogurt, custard and cheese, are high in calcium.
- **Potassium.** Blood potassium may be low if you have not been eating well. Like phosphate, it is essential for muscle function. Fruit, fruit juice and vegetables are high in potassium.
- **Fluid.** Every cell in your body needs water to work properly, so being dehydrated can make you feel quite unwell.

You will see that the meal plan has a lot of milk and milk-based food, fruit juice and fluid, to make sure you get these essential elements in your diet.

You will also need a vitamin and mineral supplement.

The meal plan suggests having regular small meals and snacks, so you do not have to eat too much at one time. The foods are easy to eat and digest, to help make sure eating them is not too tiring or stressful.

DAILY MEAL PLAN

Restoring a Healthy Weight

Name:	Date:
<p>BREAKFAST</p> <ul style="list-style-type: none"> 40g serving of muesli <i>or</i> cereal with 150mls full fat milk and 100g fruit e.g. berries With 1 x slice of toast with 2tsp of peanut butter <i>or</i> chocolate-hazelnut spread <i>or</i> butter and jam With 200mls fruit juice 	
<p>MID-MORNING</p> <ul style="list-style-type: none"> 1 x large piece of fruit e.g. banana/apple <i>or</i> 2 x medium eg kiwis/plums/satsumas. <p>With ONE of the following:</p> <ul style="list-style-type: none"> 2 x digestive biscuits/ 3 Jaffa cakes/ 1 x regular sized bag of crisps/ 10 dried apricots/ 1 x slice of bread with thickly spread peanut butter or cream cheese/ 1 regular sized pot of full fat yoghurt 	
<p>LUNCH</p> <p>Choose ONE of the following:</p> <ul style="list-style-type: none"> 1 x bagel/2 slices of bread/1 x pitta/1 x wrap or 1 x roll 1 x palm sized jacket potato 180g cooked pasta/couscous/rice or similar grain <p>To have with either:</p> <ul style="list-style-type: none"> 1 x egg <i>or</i> 3 slices of meat <i>or</i> 1 heaped tbsp hummus/nut butter. <p>Include a small side salad/vegetables and 2tsp of butter <i>or</i> mayonnaise <i>or</i> salad cream</p> <p>Followed by 1 regular sized pot of full fat yoghurt and either a snack size chocolate bar/ small bag of popcorn/ yoghurt covered raisins <i>or</i> packet of crisps.</p> <ul style="list-style-type: none"> With a 200ml glass of smoothie <i>or</i> fruit juice 	
<p>TEA</p> <p>Choose ONE of the following:</p> <ul style="list-style-type: none"> Breakfast bar, regular packet of crisps, 2 digestive biscuits, 30g of nuts, 40g dried fruit or 35g popcorn. 	
<p>DINNER</p> <p>Choose ONE of the following:</p> <ul style="list-style-type: none"> 180g of cooked pasta/ rice/bulgur wheat or similar grain 1 large jacket potato (approximately palm sized) <p>To have with either:</p> <ul style="list-style-type: none"> a 150g fillet of meat/fish <i>or</i> 2 large eggs <i>or</i> 100g of cooked minced meat /lentils/ Quorn <i>or</i> beans <p>OR choose:</p> <ul style="list-style-type: none"> 350g lasagne/spaghetti bolognese / shepherd's pie/ cottage pie / risotto <i>or</i> ½ a 12 inch pizza <p>Include salad or vegetables with the meal and 2tsp (used in either cooking or as a condiment) of salad dressing/mayonnaise/butter or oil.</p> <p>Dessert:</p> <ul style="list-style-type: none"> Choose ONE of the following: 125g full fat yoghurt, custard <i>or</i> rice pudding <i>or</i> 2 scoops of ice cream. With ½ a tin of tinned fruit/ 25g dried fruit/ 2 tablespoons of fruit compote. 	
<p>SUPPER</p> <ul style="list-style-type: none"> 200ml mug of milk <i>or</i> hot chocolate made with full fat milk. <p>With ONE of the following:</p> <ul style="list-style-type: none"> 2 x digestive biscuits <i>or</i> cereal bar <i>or</i> 30g of nuts <i>or</i> 1 x slice of toast with 2tsp of peanut butter <i>or</i> chocolate-hazelnut spread. 	
<p>DRINKS</p> <p>Aim for 1500-2000mls of fluid per day i.e. 6-8 glasses.</p>	

Appendix E

A Paediatric Perspective on Healthy Weight

A Paediatric Perspective on Healthy Weight

The concept of a ‘healthy weight’ is frequently encountered in eating disorder literature, and preoccupies families and patients with eating disorders, though medical professionals have yet to agree on a formal definition. This is because there is an inherent inaccuracy in the term – it relies on a common understanding of the word ‘healthy’, and also assumes that weight is itself a concrete entity. The definition of ‘healthy’ is also open to different interpretations. The medical-model of disease would describe health only as absence of disease, whilst other concepts of health go to the root of the word suggesting a more holistic definition – that of achieving full physical and psychological potential. Body weight itself is tricky to ascribe value to. It represents the added masses of all the tissues in the body (including the skeleton), as well as all ingested food and fluid, and all waste products, and therefore says nothing about body composition. Equally, ‘normal’ body weight in children is a moving target, as it will by definition increase as children grow, and children grow at different speeds at different timepoints in childhood.

Given the differences in stature and growth patterns between children of different ages and sexes therefore, weight has been abandoned as too blunt an instrument, in favour of body mass index (BMI). BMI is also not without its problems, but it has certain benefits over weight as a measure alone. First, it is normally distributed (unlike weight). Second, if one uses published growth charts, reference values exist that allow one to correct weight for height, age and sex. This is more accurate therefore, but still fails to take into account puberty and body composition. Furthermore, charts will only describe the variation in normal BMI in a population – they will say nothing of where that individual actually belongs. For example, according to UK-WHO reference data, a healthy 10 year old boy of average height (138.4cm) can have a body weight of anywhere between 26 kg and 41.6 kg. This assumes 2 standard deviations above and below the mean and therefore describes 95% of the population. This is a huge range, with the majority (50%) having a weight of 31.5kg and heavier and lighter boys are found less frequently in the same population. Knowing the weight of a 10 year old boy, tells nothing of how healthy he is. A child with coeliac disease may be 31.5 kg, for example, but have fallen a centile on his growth chart over the preceding 6 months. By contrast, a boy who has always been on the low centiles and is 26 kg on his 10th birthday, in the absence of any illness and normal growth, cannot be said to be unhealthy.

Public health programmes typically use growth charts as screening tools: they use the concept that any children identified below or above a particular centile cut-off increases your chances of identifying illness. For example, given that only 3% of the population should be below the 3rd centile, it is more likely that any child found at this weight does not belong there. Such a screening programme as a minimum would still identify the 3% who do. Screening tools are only useful for identifying illness that has yet to cause symptoms and where intervention at this early stage may help.

When identifying illness, doctors usually focus less on charts, and more on symptoms (what patients describe) and signs (findings doctors make when they examine patients). For patients who have symptoms, low charted weights therefore carry much more significance.

This is the context in which ‘healthy weight’ should be seen. The best definition therefore of a healthy weight is:

1. Absence of symptoms of malnutrition
2. Absence of signs of malnutrition
3. Normal growth
4. Normal puberty/fertility

Children and young people with malnutrition have evidence of a slow metabolism (low pulse, blood pressure, temperature), and typically have cognitive or psychological symptoms also. When examined they will have evidence of muscle wasting, possibly lanugo hair, as well as evidence of specific nutritional deficiency (vitamin, iron and so on). If still in puberty they will have delayed or arrested findings (for example breast atrophy or regression in ‘Tanner’ stages), and if they have already had their first period (menarche), will no longer be menstruating regularly (amenorrhoea). On a growth chart they will have slowing in their growth pattern.

At its simplest definition, ‘healthy weight’ represents an absence of all these. Driven by the need for certainty, patients may ask professionals occasionally for a ‘target weight’ at which point they will be ‘recovered’. In these circumstances clinicians may use population growth charts, previous growth data of the child or young person, findings on physical examination, as well as blood hormone levels and xray or ovarian ultrasound results as surrogate measures to predict ‘healthy weight’. In isolation, none of these measures are sufficiently sensitive or specific but together can go some way to providing some prediction of what might be the lowest weight that that young person can function at without being malnourished. It is arguable that living at this threshold is truly healthy, and of course this definition does not take into account psychological recovery at all. It could be said that a single-minded drive to maintain one’s weight at this low but ‘healthy’ level is not very different from the single-minded drive to maintain weight at a lower level when in the powerful grip of anorexic cognitions seen at presentation.

In summary, it is not possible to fully know what weight any one individual should be to be healthy and conversations about this are driven by the wish for certainty and reassurance for the parents (and ourselves) that if the young person gets to their “right” weight they will be OK. Objectively the most one can say about where a particular person’s healthy weight is likely to be based on

1. what tables say - and the example above is a prime example how misleading this can be
2. individual weight trajectories – but these are not always very good predictors at an individual level as these can change during adolescent development
3. premorbid weight or weight at which an individual was menstruating – again many for whom this can be misleading
4. ovarian scans, hormones etc – these may tell us something about whether an individual is at a healthy weight or not, but does not tell us if they are recovered or not
5. other physical (or psychological health) features such as menstruation, not feeling cold, normalizing cognitions etc – again these tell us when someone is at a healthy weight but because there is a time lag between achieving individual healthy weight and re-starting the period, this does not always tell us whether someone is already at the weight that is healthy for them or not.

The bottom line is that all these things work at a group level but at an individual level they are uncertain. At the stage of treatment when these conversations are coming up they are good opportunities to address tolerance of uncertainty.

In later stages in treatment the main focus should be responsibility and flexibility that a patient has for her/his own eating. If someone is menstruating regularly but remains highly preoccupied, there is no evidence that increasing their weight will change their ED cognitions. If therapist is pushing for a higher weight it is probably because professionals think that if we give patients a weight “cushion” this will allow them in the future to drop a bit of weight without relapsing. Intolerance of uncertainty and wish for more certainty influence both therapist and young person’s and their family instance of knowing the one and only target weight.

Appendix F

Family Therapy Intervention Techniques

A brief overview of family therapy intervention techniques

Interventions can be divided along a number of hypothetical dichotomies; influence on the client and influence on the therapist; reflective and action oriented; support and challenge (Tomm 1987a; 1987b; 1988; Dallos & Draper, 2005; Eisler & Lask 2007). Therapy is of course a mutually influential process and such dichotomies are always relative. They are used for the purposes of the manual as a descriptive tool and not as a way of identifying specific interventions. In general there will be a shift in focus throughout therapy, with a greater balance of relational and reflexive questions as therapy progresses. However, the therapist will be purposive in their questioning style and will be guided by both the focus of their intervention and intention at any one time and by the needs of the patient and their family.

Questions that inform and influence the therapist

At assessment the therapist will ask questions in order to better understand the presenting difficulties and in order to arrive at a diagnosis and appropriate treatment plan. Questions on assessment and during the engagement phase will include both questions for information and questions of perspective. Questions for information will include information related to the age, school / work, relationships and interests of the patient and family members. Questions will also be used to gather information related to the general history of the family, information about the history of the eating problems, and to the different perspectives related to maintaining and contributing factors and the resources available to the family to begin overcoming the illness. Initial questions are important to the joining process and in the development of the therapeutic relationship, so that less anxiety provoking and more competence evoking questions should be asked initially in order to help engage the family.

However, in the treatment of anorexia nervosa the therapist should keep this phase of engagement in the assessment fairly brief as it will be important to convey some sense of urgency in attending to the nature of the difficulties that have brought the family and patient to the assessment; too much emphasis on "getting to know" type questions might detract from the seriousness of the situation and the need for urgent action later on following the feedback stage of the assessment process.

Questions that aim to influence the family

Change during the course of treatment for anorexia will develop from many elements, but the use of particular questions form a significant amount of the work of the therapist. Questions may be intended to track patterns and interactions; mark differences in beliefs and behaviours, map the effects of the illness, support the development of unique outcomes, deconstruct constraining discourses, amplify solutions, imply suggestions and consider potential futures.

Once the family and patient have been engaged by their treating clinician and have begun the process of re-feeding, the therapist can expand the repertoire of questions to encompass more relational and reflexive questioning styles.

Questions may be used to encourage fuller descriptions of people's experiences. They are also used relationally to engage clients in collaborative participation related to the direction or themes of therapy. The questions that the therapist asks should be informed and structured by the therapist's hypotheses and evolving formulation and help shape new narratives (Brown, 1997; Tomm, 1987b; White 2007). The therapist will constantly gauge, session-by-session and sometimes moment-by-moment where appropriate emphases should be placed. Decisions will be made on the basis of stage of recovery, risks, current information, current concerns of patient or family members etc. The following are some examples of different types of questions that therapists will use:

Mapping the effects of the illness

These questions attend to the nature of the illness in relation to the client and their family or system. *“What problems has the anorexia brought to you, as an individual, and to your family?”*, *“What would you be able to get on with, if anorexia were out of your life?”*, *“How does anorexia influence what you believe about yourself?”*, *“What impact does anorexia have on your school life or friendships?”*, *“How has it influenced your hopes and dreams for yourself?”*, *“What does anorexia do to the relationship you have with your parents?”*, *“How has it affected their view of themselves as parents?”* *“What would your life be like if anorexia were to be less of an influence on you and your relationships?”*

The “miracle” question (De Shazer, 1988) or other hypothetical, future oriented questions might be used to generate a detailed discussion of life without anorexia. A discussion about the pros and cons of anorexia can generate both future oriented conversations but also conversations about the dilemmas involved in making changes. The process of painting such a picture of a different life without anorexia may then be used to consider the necessary steps to achieve that new life. *“If you were to wake in the morning and discover that anorexia has completely gone, what would be the first thing you noticed?”*, *“How would other people know that things are different?”*, *“How would you feel, what would you notice in yourself and others?”*, *“When it is gone, what will you be able to do that you haven’t been able to do while it is around?”*

Tracking patterns and interactions

There are numerous routes to tracking patterns. While this line of questioning provides information to the therapist, it also provides new information to the family as a result of the emerging detail and sequential connections. An event might be described by the family and the therapist then slows down the process. Tracking questions such as: *“what happened when your parents showed you how far they would go in fighting anorexia? How did they decide at that moment that they would not obey anorexia's demands? What did this tell you about their strengths in the face of such tension and anger? How did your dad know that your mum was serious about making sure you ate enough? How did your dad support your mum's efforts?”*

An alternative is the use of narrative questions. These question trace the influence of the illness on the client and their family or significant others on the seriousness and severity of the illness. For example: *“When does anorexia get loudest in your head? Are people around you able to tell how loud anorexia has become? Do they know what they can do to help you when the voice is drowning out all other sounds and thoughts? What have you noticed about those times when anorexia seems to be weaker? Whose voice are you more likely to hear when anorexia seems quieter?”*

Attending to Beliefs, Behaviours, Emotions and Feelings

Circular questions draw on the assumption that individual problems are connected or embedded in patterns of relationships, and the aim of these questions is to illuminate how these patterns may be understood. Examples might include, *“How would different people in the family describe the problems the illness brings?”*, *“Who worries most? ”What’s the difference between the way your mum and your dad show their worries?”*, *“When people get worried about you, does it make you feel better or worse?”* Other questions might require family members to describe what they make of behaviours that they observe, or speculate about thoughts and feelings of others. Questions might be asked about the way different people in the family responded to the illness and what interactions this might lead to.

Circular questions provide a basis for describing the illness in a contextual way and allows for alternative descriptions to emerge. For instance, the family may have a narrative that *“mum worries a lot while dad does not show his feelings”* implying that mother is too anxious and father too detached. Useful questions to develop alternative aspects of this might be *“Does your dad not worry or is he better at hiding his worries?”*; *“How do you know when your husband is getting worried?”* and *“When your dad tries to reassure your mum, what effect does it have on her worry”*.

Similarly, circular questions that draw out differences in parental or family roles can be extremely useful when the therapist is trying to support parents in finding their strengths. For example, during early stages of treatment the therapist might ask questions about parental roles and strengths; to mother *“Has anorexia allowed your husband to support you in feeding your daughter or does he feel pushed away?”* *“If anorexia were not so in charge, what are the strengths you know your partner has that we might see more of?”*, *“when you try to help your daughter to eat, what do you think your partner would like to do to help you both?”* *“How good is your wife at asking for help when she needs it?”*

This may lead to a discussion of the differences between experiencing and showing feelings and the interplay within the family between behaviours and emotions of different family members. It may also be an opportunity to talk about individual and gender differences and perhaps the different expectations that each parent brings with them from their own family of origin (Penn, 1982; Tomm, 1988).

Strategic questions are used with the specific aim of influencing the family in a particular way. They will often be analogous to giving instructions or may include an implicit assumption (e.g. that change will happen). For example *“What will be the first thing that people notice when you and your Dad are little less angry with each other”*, or *“Have you reached the stage yet when you can sometimes laugh about your Mum worrying about you or does it still always irritate you?”*, which might be followed by a comment *“It is important that you notice when this happens, because it will make it easier for you to deal with similar situations in the future”*. These are also referred to as embedded suggestion questions in that a possible solution is built into the question. Strategic questions can be used to invite a change in behaviour *“How are you going to let people know that you are struggling so that you don’t have to lash out and hurt your mother?”* or more generally to challenge the status quo. As discussed earlier, therapists need to be mindful of the potential pitfalls of using their therapeutic authority in this way (Tomm, 1987a).

The therapist’s activity of noting and evoking details of *unique outcomes*, exceptions or the ‘absent but implicit’ alternatives can also be considered strategic in terms of the intention to influence. Again, this is done with careful consideration of the client’s agenda, pace and therapeutic context (Carey, et al., 2009). It may be that the therapist simply chooses to lean forward and ask for more detail that connects to an alternative identity. *“You just mentioned that you want to get back to seeing your friends and having sleepovers, tell me more about that”* as an augmentation of narrative of self-value or personal agency. Or there might be questions that might pick up on a moment when the urge to restrict was resisted. *“What helped you to resist the voice of anorexia on this occasion?”*, *“What ideas or feelings made it possible to express your fear of having to eat rather than getting in to a fight with Dad?”* To the parent: *“What ideas or experiences did you draw on, that supported your response of listening to your daughter’s distress rather than experiencing it as criticism or anxiety?”* Supporting the changing perceptions of the individual often means searching for indications of this identity in the past and developing more detail (Freedman & Combs, 1996). For example, questions about the existence of self-value prior to anorexia will strengthen its validity. *“What is the earliest sign of self-value you can imagine?”*, *“Who would have seen this in you? What would you have been*

doing that would have contributed to this awareness in them?”? ” What are the kinds of things your friends have liked about you?”

Solution focused questions are designed to note small changes and work toward specific goals. These might be used at assessment when focusing on motivation to change or through the processes of therapy that require changes in emphasis from, for example, eating to a meal plan to increasing flexibility and responsibility. At assessment it might be helpful to rank the level of worry *“If you are ranking the level of worry other people have about your weight loss and difficulties in eating how would your mother/father/sister/ grandma rank their worry”, “You say you can't eat in the dining hall at school, what's the first step towards being able to do that? Would it be enlisting the help of a trusted friend to sit and eat with you or would it be trying to eat in front of others somewhere less threatening as a first step?”*

Future oriented questions invite thinking about possible future alternatives. These questions may be more acceptable to clients who have settled into therapy rather than in the early stages (Penn, 1985). For example, a future orientated circular question would be *“Who will be the first to notice that you are managing to ignore the anorexic voice?”* A narrative question that follows an exploration of how a sense of isolation resulting from anorexia may be followed by possible future developments in this area; *“As, as you begin to appreciate the importance you place on being connected to people close to you, what will you do to support this commitment to developing your relationships?”*

Reflexive questions require family members to reflect on how things might be different under changed circumstances, or if they took a different course of action: *“What would you need to do for your mum to know that you recognise her worry rather than just her irritation with you?”* Reflexive questions will typically introduce an alternative way of framing a particular behaviour, opening up new possibilities and challenging the assumptions that may underlie a particular pattern of behaviour. *“Having an adolescent with anorexia can make parents pull together or pull apart; which would be closest to your experiences?”* They may address an emotion or an aspect of behaviour that is not being expressed overtly and may only be guessed at. Therapist to adolescent; *“When you say ‘I don’t know’, does this mean you would rather not say because it is upsetting, that you are angry or bored, or that you really don’t have an answer?”*

Reflexive questions, like circular questions, assume that behaviours and the meanings that we attach to them are part of the relational context of the family and that there may be more than one meaning that might be attached to a particular behaviour. The aim is for the family to reflect on this context and to explore the way in which thoughts, feelings and behaviours of different family members connect and how they might change (Tomm, 1987b). *“Many parents feel scared when they first find out their child has anorexia. Sometimes they also feel angry. Some parents feel they should take more control over the child when they find out about anorexia and others feel they should back right off in case they make their child eat even less than before”. “Can you tell how this applies to your parents?”*

Reflexive questions may also include the therapist’s own self reflexions: *“I am wondering whether it’s best to consider the worry or irritation, which line of questioning would be most useful?”, “We seem to be at a crossroads, what would be the most important direction to take?”, “Am I asking you the right questions?”, “I find myself feeling increasingly worried about Sophie’s safety, I wonder if you as parents are feeling the same? I wonder if you, Sophie, also feel worried? When I tell you I feel worried, does that make you more or less concerned for yourself?”, “I am aware that I have not asked the most obvious question about because it is quite a difficult thing to talk about. Do you think this is what stops other people from talking about it? Is it helpful if people back off or would you prefer if they found a way of being more direct with you?”*

Deconstructing constraining discourses or contexts

These discourses may be embedded in conversation as unquestioned assumptions about the nature of humankind or how best to live life. These deconstructive questions are aimed at challenging the overarching discourses and beliefs that place the relevant aspect related to the problem in a particular frame (White, 1992; 1993). The ‘deconstructive attention’ can be on the ideas around eating disorders or other central themes in the therapy. For example, “*When you say that women feel things more intensely than men, where did that idea come from?*”, “*What has gone into making you feel that there is greater shame connected to anorexia than other kinds of responses to stressful circumstances?*”, “*There are a lot of expectations of how young adults are meant to become independent; how do we think about their needs for protection and closeness to their parents?*”, “*Some people see anorexia as a way of avoiding growing up, others see it as a way of taking control, some see it as a response to the pressures in society to look perfect, what descriptions fit for you and which are so wide of the mark they might make you feel angry because they really fail to describe what's going on for you?*”, “*This therapy is all about anorexia because that is so dangerous but in focusing so much on that, do you think this might eventually distract us from seeing or thinking about something else that is very important about you as a person?*”

Statements or comments

Statements or comments made in systemic work tend to be made in the form of hypothesis, metaphors, reflections on process and emotional responsiveness. Therapists may provide an account of what they recall from a previous session or offer an observation of some aspect of the session in progress. Generally, these ‘statements’ are offered in a tentative manner and should be followed by a ‘goodness of fit’ question and a further exploration of whether this is the way the family wants things to be and hypothetical questions about who/what would need to do something different for things to change. Asen (1997) suggests the following sequence when commenting on process:

1. Describe process (*I have noticed that...*)
2. Check if description fits (*does this make sense / have I got it right / do you agree that's what happens?*)
3. Ask if family wants it that way (*is it helpful if things are like this or would you prefer it if things were different?*)
4. What would need to happen for things to change, (*who is the most likely to respond differently when this happens again / what effect would this have?*)
5. What if ... (*if next time your son and his father are having an argument you decide not to help them resolve this, how would it pan out?*)

Establishing a safe environment

It is the therapist’s responsibility to ensure that the therapy environment feels safe even when difficult issues are being addressed. The therapist may, therefore, need to actively intervene in situations of high levels of hostility or criticism. This may include a reframe, for example “*I wonder if you are saying that out of fear or love as much as frustration*” or direct intervention “*Could you tell me what you have felt like rather than your son, it might be easier for him to hear that way and feel less attacked?*” or even very directly stopping an escalating, repetitive sequence “*This sounds like one of those situations that you have described where you go round in circles. Let's try to have a different kind of conversation.*” It may be useful to suggest taking a short break if people feel too emotional and therapy can either continue with the person re-joining or can stop for a bit.

Additionally, there are numerous intentional therapeutic communications that are more subtle. Affirmative responses, encouraging utterances (tell me more etc.), body posture are all included in the repertoire of therapist activity.

Emotional connection

The therapist will consider the emotional responses of family members in their treatment sessions. Emotions can be understood both as a reflection of the feelings experienced by individuals and as a communication, in that they become part of the narratives told and demonstrated by other family members as well as to the therapist and observing team (Flaskas, 1989; Fredman, 2004). They may also be understood as strongly felt experiences with a validity of their own. One of the themes often encountered in adolescent mental health difficulties is that of difficulties in emotional regulation. Developing the capacity for expression of emotions may be central to the work, both for the young person and the parents. Discussions of feelings may be supported by the use of non-verbal techniques such as drawings or the use of questions seeking concrete descriptions of body awareness of emotional reaction and therapists offering possible descriptive words. For example: *“Where does the numbness start, does it spread, some people would call that feeling fear, does that fit?”*, *“What would you, mother / brother call this, if they were feeling the same thing?”* (White, 2007) *Exploration of how different family members show their feelings may also be useful. “You say your Dad does not do feelings. Can you tell if he is upset? What are the signs?”*

Therapists may respond to expressions of emotion by joining and witnessing and ‘being with clients’ or they may make use of such situations to explore the experience of difficult feelings and sharing them in the sessions as having the potential for movement and greater understanding. It may be useful on occasions to reflect with the family on their experience of such situations and their preferred response.

Attachment patterns may be problematic and often, an expression of fear, rejection and hopelessness sits on a foundation of a wish for a better relationship. The discussion of these feelings needs to be done without creating further blame. The process should result in the discussion moving from a sense of anger and resentment to an appreciation of the less obvious but essential caring elements. Current conflict may have its base in a long standing sense of not being sufficiently cared for and it may be important to follow the theme from its origins, so that it may allow a new narrative to emerge with a different understanding both emotionally and cognitively. The parents’ own patterns of attachment and their own experiences of being parented may be important topics in some families, particularly where there are high levels of hostility or negativity. In such situations exploring these may first need to be done in separate sessions with parents or in contexts that reduce the immediacy and lower the intensity of feelings such as genogram work or discussions that are not focussed on the here-and-now.

Positioning and pacing

The movement from reflective to active positions is also a concern of the therapist. The therapist may ask questions at a very slow and thoughtful pace, creating space for contemplation and listening. The therapist may also take an active stance. This might be quite literal in terms of directing and interrupting, active reframing, using play techniques with young children or movement (sculpting). The therapist may include the intentional use of her body or posture to support particular intentions. The therapist may also write down significant words to create an emphasis.

Active support and challenge – support may be offered in explicit or subtle ways. Support may be communicated through eye contact and a nod, a brief ‘tell me more’ or more obvious questions that clearly imply therapist's positive connection to that idea or development. Support will often involve more focused questions related to developing a fuller account of, for example, how progress was made. More direct challenging, though respectful, interventions may be possible in the context of a strong therapeutic relationship. This may involve deconstructive questions exploring and undermining the strength of constraining beliefs, interrupting unhelpful patterns, offering a tentative hypothesis.

Focus

Focus of the session will vary along the lines referred to in the previous section on theories of change. Therapists may shift attention from individual beliefs, emotions or behaviour to the relationship level or broader contextual / meaning level. The focus may be directed to observable behaviour in the session or to past or future events. Therapists may move questions around to include all members or may focus longer conversations with an individual before linking back to others as audience. Some families or family members may make more use of a concrete orientation, while others may prefer more abstract concepts. Therapists assume ultimate responsibility for the therapeutic quality of the questions and the direction of the session, but this should also be done in relation to feedback and collaboration.

Working with time

Anorexia may have a long history or alternatively it may be a development over recent months. The family will come to therapy with a temporal reading of the presenting issues as well as having a family orientation to time. Individuals and families as a whole have their preferred time frames and pace, which may change depending on the life cycle stage of the family (e.g. families with infants tend to be present oriented, while families with adolescents are often more future oriented and families in post parenting stages more past oriented). These time frames are also influenced by any ongoing problems; anxiety provoking or life threatening problems often tend to orient families to the here-and-now while feelings of guilt and blame will have the effect of orienting towards the past. Families also have a preferred temporal focus as a result of individual member's orientation and cultural influences (Boscolo et al, 1993).

During the engagement phase therapists need to be mindful of the time frame that is most salient for the family while at the same time indicating that s/he has a broader time frame (based on the experience of having been through the process of therapy with other people), which extends to the future and includes an expectation of change. The therapist conveys this by describing the nature of treatment being offered and the significant part that families play. At this point the therapist may notice the look of incredulity on the parents' face when they realise that they are expected to take on the task of managing their child's eating and might say *"You probably think that it is a crazy idea that parents are the ones who can best help a young person with anorexia to recover; in my experience most parents at this stage"* [acknowledging the here-and-now time frame] *"tend to think that but most parents when they have looked back a year later with me"* [implying the therapists broader time frame] *"have said yes you were right we were able to do it."* The therapist's broader time frame and experience with other families through treatment makes it possible to express hope whilst acknowledging that the family's sense of hopelessness and failure is understandable because most families at an early stage of treatment feel the same. Future orientated statements may be particularly useful in the engagement phase especially in the form of reassurance that things are likely change and that the therapist has seen this process unfold many times before.

During middle and later stages of therapy there will be many instances when introducing a different time frame can be used to open up new areas of conversation for the family, increase or decrease the level of emotional intensity, change the pace of conversation or allow a discussion of painful issues that are otherwise too difficult to talk about. The following two examples will illustrate some of the above:

During an escalating argument between mother and daughter in which the mother becomes increasingly defensive and the daughter responds more and more angrily, the therapist interrupts the argument turns to the daughter and in a voice that initially matches the intensity of the argument but is quickly modulated down and says to the daughter: *"This sounds like a well-rehearsed argument that you and your Mum have had many times; I'm not sure that it's leading anywhere. Let me suggest*

something. I want you to imagine that we have wound time forward for about an hour when you are on your way home and I want you to imagine that the argument today had a different outcome from the usual one where you get more and more angry because you feel that your mother is not listening to you and your mother gets more and more defensive because she feels that you are taking things out of context. This time you have somehow managed to end the argument differently and you both feel good about it. Who would have been the one to break the usual vicious circle, you or Mum? Don't tell me just run it through your mind. What do you imagine happened next? And then what." After a while both Mother and daughter started talking about their usual argument in a different way, each acknowledging their own part in keeping things as they are. The brief time shift allowed the breaking of the intensity of the emotions that was escalating the argument while allowing mother and daughter to continue discussing the issue (previously the only way of stopping the argument was for them to drop the subject completely).

Another example was a conversation between therapist and a father who had been accused by his 16 year-old daughter of having been physically abusive in the past. Father denied that he had ever been excessive and when the daughter tried to get her mother and brother to support her, they both equivocated (although both had previously, in father's absence, been openly critical about his temper). At that point the therapist turned to the father and asked him to imagine a time when his daughter was grown up and had a family of her own: *"What sort of stories do you think she will tell her children about their grandfather."* Father went quiet and after a while said in a sad voice: *"I hope she doesn't talk about me the way I talk about my Dad. He was a brute and beat us mercilessly. I never forgave him till the day he died."* Little more was said on the topic until several sessions later when the therapist commented on the fact that the daughter seemed much less angry with her father, to which she replied: *"I just needed to hear him say I wasn't making it up."*

Child and adolescent centred interventions

Younger siblings will sometimes be present during therapy sessions and some pre-adolescent patients will be referred for treatment. It is extremely important for therapists to keep in mind the developmental needs of both children and adolescents within family therapy sessions (Strand, 1997). Interventions will need to be tailored to fit both their cognitive and emotional capacity (Lund, Zimmerman, & Haddock, 2002; Wilson 1998).

The process and implicit rules of therapy may be confusing and anxiety provoking for young children. It may also be necessary for therapists to clearly explain parts of the therapeutic process. Therapists need to make sure the room is conducive to work with a wide age range. With younger children this includes toys suitable to different ages (usually puppets, dolls, plastic animals, building materials, drawing paper and washable pens, books, toys and puzzles, etc.) (Cooklin, 2001; Imber-Black, 2009; Wilson, 1998). In the introduction to the therapy, the therapist needs to help the child and parent feel comfortable with the discussion of basic ground rules within the session. The therapist may say *"Young people may find some of the chat boring and if they wish to play, these toys are here to play with and you can help yourself or even some times, I may play with you. If you wish to bring anything to play with the next time, that's ok and if you want to bring a snack that's ok too. We will make time to clean up at the end. If you need a loo break, we will stop and wait, just let us know"*.

Involvement of young children in the initial stages of therapy may be complex in terms of balancing their awareness and reactions to the anorexic behaviours. The therapist and parents/carers may need to have a discussion about the potential for either over exposure or avoidance of significant material in the early stages of treatment when psychoeducation and information giving might provoke an inappropriate level of anxiety in younger siblings. Many siblings however, express great relief in being able to participate in some aspects of therapy, often describing an urgent wish to know how to respond to their sibling's needs and a worry that they may be doing "the wrong thing".

The young child's awareness of family difficulties may be communicated by agitated, avoidant or clingy behaviour. The therapist will consider the parental understanding and response and may ask about the meaning placed on the behaviour (Dallos, 2001). This may be helpful in supporting the notion that a family is a system of mutual influence and that emotions can be communicated through behaviour as well as words. For example *"If your little one could show you she was noticing you were worried about your older daughter, what would she be doing?"* Older children may be more directly connected to the sessions through encouragement and developmentally tailored questions or use of supportive materials. The therapist may say *"Sometimes brothers and sisters can know some special things about each other that even the mum and dad might not know, is there something that your brother does that makes you happy?"*

Young children may require simple choice questions, props or examples. It is important for therapists not to rely solely on verbal channels in communicating with children. Drawings, play and puppetry may all be helpful in enabling children to communicate their ideas, and therapists should be comfortable in using these methods with children (Irwin & Malloy, 1975; Lerner, 1996).

During the assessment and very early stages of treatment, engagement with the parents may be more visibly achievable than engagement with the patient, with the young person often protesting their disagreement with the goal of gaining weight or indeed any need for change. Nevertheless, developing an effective therapeutic alliance with the young person is an important early goal (LoTempio et al 2013) and clinicians need to actively look for opportunities to connect with the young person albeit in ways that are in tune with their overt reluctance to take part in the treatment.

Adolescents may adopt various age appropriate positions in the sessions; dependency/ autonomy, active participation / withdrawal, empathy and self- centeredness (Werner-Wilson, 2001). Adolescents suffering from an eating disorder will sometimes experience shame, anger and intense concern for privacy. For example, when faced with a question from the therapist, the adolescent may appear uncomfortable and look to a parent as if searching for the right answer and then object strongly if the parent offers one on their behalf.

Adolescents may demonstrate needs to be either central or at times peripheral to the family discussions and the therapist should be sensitive to differing levels of discomfort and engagement. Adolescents may require "context warming" work by the therapist prior to becoming a willing participant in the conversation. Questions that bring forth descriptions of areas of the adolescent's life that are more satisfying are important prerequisites to discussion of more difficult topics. Additional attention needs to be given to the adolescent's life beyond the family and the way in which this boundary is managed within the family. School issues and vocational / academic pathways are often significant. Peer and intimate relationships may need to be included in the discussions, sometimes as part of whole family conversations, although some adolescents may wish to have an opportunity of discussing this individually.

The therapist needs to attend to the physical and biological changes occurring with the adolescent and how these are understood and responded to by the individual and the family members. Moments of egocentricism and heightened emotionality may be related to developmental changes and may need to be normalised or reframed as important and transitional. High levels of expressed emotion may be connected with early attachment difficulties or traumatic experiences and the associated feelings of guilt and blame (Besharat et al 2001) and may need careful containing and structuring. Sexual issues may be significant and difficult to discuss. There may need to be parallel sessions with parent/carer and adolescent with an agreement of bringing significant themes back into the family sessions.

Team reflections

There are a number of ways in which reflections from team members can become a direct part of the treatment process. This will range from exchanges between team members who have joined the family as part of the feedback process after the initial assessment, exchanges in the room between co-therapists when there is a need for co-working, conversations with a dietitian in front of the family or a more formal “reflecting team” intervention when the therapist is working with an observing team behind a one-way screen (Andersen, 1987; Friedman, 1995; Perlesz, et al 1994). When done in this more formal way, families are asked if they would like to listen to the team conversation about the session and then they are invited to comment on the fit and usefulness of the ideas.

The reflecting team may consist of some or all of the observing therapy team as seems appropriate relative to the size of the team and wishes of the family. The team may join the family or switch places from observation room to therapy room. All team reflections should be respectful of family, therapist and team members, hold a tentative and curious stance, stay connected to the ideas of the previous contributor, stay connected with the language used by the family, use age appropriate language, and restrict the number of themes and length of time the reflections take. The therapist should take responsibility for monitoring the effect of the team reflections on the family by asking for thoughts / reactions from family members after the team reflections and observe any changes in subsequent conversation that appear linked to the content of the team intervention. Direct and indirect feedback needs to be considered, as some families will only protest through a lack of responsiveness.

The idea of listening to team reflections can be introduced early on in the work with the family as something that may be helpful at different points in treatment but especially when the therapist or the family might need a change in direction of therapy or need support in thinking about ruts that may be impeding progress. Families will often find the initial suggestion somewhat strange at first but once they have experienced the process they will often express appreciation of an opportunity for others to witness and comment on their struggle or celebrate their achievements. Families are often more willing to take part if the rationale has been clearly explained; *“we often ask colleagues to help us think about what to consider next for therapy or to help us when things begin to feel a bit stuck. The best way to do this is to have a colleague/s join us behind the screen (or as an observer in the room), they will be there as another set of eyes and ears, to maybe pick up on things we have missed or maybe avoided. They won’t join in the conversation but part way through the team will talk amongst themselves in the room so that we can take time out to listen to what ideas they have had whilst we have been talking. Does that sound like something that might be helpful?”* Any explanation should position the therapist as part of the dilemma rather than implying failure on the part of the family or patient.

Sometimes the therapist might be drawn into too long a conversation with the family following the reflecting team’s conversation; this lengthy inquiry may dilute the intensity of the process. It is therefore necessary for the therapist to both seek the brief responses from family members whilst also encouraging the family to reflect on what they have heard when they leave the session.

Appendix G

Comparison of three family therapy treatment manuals for child and adolescent anorexia nervosa

Comparison of three treatment manuals for child and adolescent anorexia nervosa

To date a number of family therapy manuals have been used in the evaluation of treatments for child and adolescent anorexia nervosa. Three of these can be described as eating disorder or anorexia focused family therapy manuals (FT-AN) (the history of the development and comparison of the three treatments is described in more detail in Eisler et al 2015). The first is the (unpublished) manual by Robin & Siegel used in studies by Robin et al (1994; 1999). The second is the manual published by Lock et al (2001) and revised by Lock and Le Grange (2013), developed to provide a manualized version of the therapy used in the early Maudsley studies (Dare et al 1990; Dare & Eisler 1995; 1997). This manual (often described as Family Based Treatment or FBT) has been influential in the field of eating disorders and has generated discussion in relation to how manualized approaches can be used in the field by a range of clinicians with differing levels of experience and expertise; this debate is especially significant in those instances when complex presentations warrant a critical and clinically experienced approach based on more than can be contained within a treatment manual (Strober, 2014; Lock & Le Grange, 2014). This manual has also been modified for the treatment of adolescent bulimia nervosa (Le Grange et al 2007)

The Maudsley Service Model manual is the third of these treatment manuals and includes treatments for both anorexia and bulimia nervosa and describes the range of treatments applied to these disorders including group treatments offered on the Maudsley Intensive Treatment Programme. Two other family therapy manuals have been used in the evaluation of adolescent anorexia nervosa (Agras et al 2014; Godart et al 2012) but these are more generic family therapy manuals without a specific focus on anorexia nervosa and are not considered here.

The similarities and differences between the three manuals for anorexia nervosa are of interest as they highlight key areas of consensus but also show some of the variability of treatment approaches that are worthy of future investigation and theoretical developments. All three manuals share certain fundamental principles.

The first is related to the way in which families are seen as holding important resources, which can be promoted and enhanced in therapy and supported to help the child recover. Linked closely with this view is the fundamental understanding that families do not cause the illness.

Secondly, all three manuals emphasise the importance of supporting parents to have a central role in managing their child's eating from the outset of the treatment process whilst also holding the longer term understanding that this strong parental role will have to change through the process of recovery which requires the young person to reclaim developmentally appropriate individuation and independence.

The ways in which each of the respective manuals achieves this are subtly different as can be illustrated in the use of giving dietary advice or the use of a family meal as part of treatment. Robin/Siegel took a highly behavioural approach using structured behaviour modification interventions, including a behavioural contract and also used dietitians in regular parallel sessions to provide dietetic advice with the aim of establishing regular eating over 6 to 8 sessions. In contrast Lock/Le Grange emphasise the importance of intensifying the crisis to effect change far sooner in treatment, using a therapeutic family meal routinely in the second treatment session to help unite the parents in a joint effort to oppose the child's illness. They avoid giving specific dietetic advice and try to support the parents' own sense of competence in knowing a young person's normal nutritional needs although the authors' emphasize the need for therapists to be careful not to collude with the family if the food being offered is inadequate to achieve weight gain. This does not mean that the therapist avoids giving advice but this is focussed more on coaching parents on how to take a strong

stance against the eating disorder, what to say, how to work as a team or reassuring them that they are on the right track when they insist that the young person has to eat.

The Maudsley manual puts a strong emphasis on reframing the meaning of the parents' task as being one of caring for an ill child and away from notions of being in control. We also use a family meal early on in treatment but we have also developed the use of a "mini meal" at assessment to test out the possibility of allowing severely malnourished patients to be cared for at home. We will generally offer the family a meal plan, particularly if the child is very underweight as part of emphasizing that we are an expert multidisciplinary team (MDT) and that while we expect the family to be the main vehicle of change, we provide the expertise for this to be done in a safe way. We recognize that the readiness to provide this kind of expert advice is likely to foster a dependency on the therapist (and/or the team) but see this as an appropriate aspect of the early stage of treatment albeit with potential pitfalls that therapists need to be aware of and have to address as treatment progresses. Unlike Robin/Siegel we would therefore generally provide dietetic advice directly by therapists in sessions or occasionally inviting the team dietitian to join the therapist and family if more complex or unusual dietetic issues need to be addressed.

All three manuals externalise the eating disorder as a central therapeutic intervention but describe different technique to achieve this. Both Robin/Siegel and Lock/Le Grange use physical health analogies, whilst the current manual recommends the use of externalising conversations to access or reinforce the sense of the patient's identity (her own as well as her family's perceptions) separate from the illness and we also emphasize the role that the use of psychoeducation around the effects of starvation has to support these externalising conversations.

All three manuals emphasise the importance of addressing normative life-cycle challenges for both adolescent and parents later on in treatment but again the specific techniques they use differ in and are derived from a range of models. For example, unlike the other two manuals, Robin/Siegel use behavioural, problem solving and communication skills training. They also use cognitive restructuring to address cognitive difficulties in later stages of treatment. In the Maudsley manual there is a greater emphasis on using concepts and techniques from systemic therapy including addressing changing family life-cycle issues (Carter & McGoldrick, 2003), notions of safe uncertainty (Mason, 1993) but also drawing on other concepts such as mentalization (Asen & Fonagy, 2012) or attachment (Diamond 2005; Vetere & Dallos, 2008)

All three manuals set out the treatment in phases with the Maudsley FT-AN manual describing four phases and the other two describing three. The description and names of phases varies between the manuals and place a different emphasis on the tasks in each phase (this manual e.g. highlighting the importance of engagement and the therapeutic alliance or the ending of treatment and discussion of future plans). There are more similarities related to these phases than differences; all emphasise broadly similar concerns and attend to the importance of certain transitions in treatment, for example handing back responsibility to the patient or moving the focus away from a focus on eating issues.

The differences between the manuals are, nevertheless, important. They act as a further reminder, that our knowledge of how treatments work is still very limited and that in applying manuals to practice, therapists need to understand the concepts that underpin the interventions. They also highlight, that families vary and that what may suit one family well may be a poorer fit for another family and that clinical flexibility and respect for the families' own view must not be lost when treatment is informed by a therapy manual.

Appendix H

A formulation for a hypothetical case and its development over the four phases of treatment

Example of a formulation in Phase 1

A fictional formulation is described below (and then following each section of the 4 phases of treatment below). The example illustrates how the formulation might develop through the treatment process and is presented arbitrarily in this way to provide a clear narrative for the purposes of However, a formulation in clinical practice might change at any point in treatment as new information and interactions are elicited and explored. A formulation should be seen as a helpful tool that evolves over time and therefore subsequent sessions with the family should alter the formulation as new information becomes available.

Background information gathered from referral and at assessment session

Rachel is a 14 year old white British girl. She lives at home with both parents; her father David, her mother Ann and her younger brother Alex aged 11. David is employed as a solicitor and Ann is a primary school teacher. Both sets of grandparents are in contact with the family, David's parents more so than Ann's as they live close by and have always been involved in looking after the children in school holidays and also after school. Rachel is very close to her paternal grandparents although recently she sees less of them as she pursues her interests and hobbies. Alex goes to his grandparents after school most days. He is described as somewhat anxious and clingy. He has friends in school and enjoys football, he is bright and doing well academically. His father says that he and Alex are a bit similar in temperament.

Rachel achieved all developmental milestones early and made the transition from home to nursery without significant difficulty. She made friends easily in primary school but towards the end of Year 6 she experienced some bullying from a group of girls in a different class. She was very distressed by this experience and did not disclose her upset to her family until the school made contact with her parents to express their concern that she had become withdrawn and anxious in school. Rachel appeared to overcome this problem with the support of her parents and the school, however she became very anxious as the transfer to secondary school loomed. This transfer coincided with her mother's diagnosis of cancer when her paternal grandparents stepped in to support the family through this time of crisis.

Rachel is a bright student and she excels in all her subjects. Her ambition is to become a vet. She had been a strong athlete competing at county level and she is also a good musician and plays for the school orchestra. She has a large group of friends and one "best" friend.

Two years ago Ann was diagnosed with cancer. At the time of referral she had successfully undergone treatment. Ann says that David and the extended family all rallied round and without their support she would not have managed to keep going. David kept the home going when she was undergoing treatment and that in this time he became closer to both the children.

Ann says that her relationship with Rachel was a very close one and so both she and David were mystified when Rachel did not seek their help when she was experiencing bullying at school. Looking back, both parents think that Rachel may have been reluctant to add any more worry to an already difficult period for the family when Ann was undergoing tests and subsequent treatment for her illness. David describes himself as usually "laid back" but currently worried and overwhelmed by what is happening to Rachel. He says he feels a little less close to Rachel as she gets older although he believes they had a good relationship up until she became so unwell. Rachel says that she and her dad now have less in common which makes her a bit sad. David sees himself as the firmer parent as the children were growing up, however he expresses respect for the way Ann has managed work, parenting and family life, especially when she was unwell.

Rachel was referred to the Specialist Eating Disorders Service by the family GP. Her parents had noticed a change in her behaviour around meal times; leaving food, becoming very picky, eating slowly and sometimes refusing meals completely. She had developed an interest in cooking and shopping and was choosing “healthy” food options which she researched on-line. She rarely ate the food she prepared but as she seemed to enjoy cooking her parents were happy to see her mood lift and allowed her to continue. They were aware of a change in Rachel’s general demeanour; she was spending more and more time in her room, seeing less of her friends and her mood was rapidly shifting from apparently happy to extremely distressed and tearful from one hour to the next. When they were on holiday recently they noticed that Rachel had lost a lot of weight. They then began to realise that something was very wrong. Her parents believed that if they thought back very carefully these changes may have started developing up to 6 months earlier but had become very obvious in the last 6 to 8 weeks.

When they met with the GP the parents were shocked to learn that Rachel had stopped menstruating 3 months ago, she was found to be significantly underweight (76% median BMI) and she disclosed symptoms of anxiety, depression and self-harm (cutting), which she describes as all worsening over the past 4 months or so. She estimated that she had lost 10kgs over this 4 month period. She is described as never having been overweight although Ann says she did have “puppy fat” when most of her friends had lost theirs. Rachel’s hands and feet are now often blue and cold. Her sleep is disturbed by the discomfort she experiences when lying down and her spine and hips protrude.

Since their visit to the GP 2 weeks prior to the specialist assessment, her parents have attempted to follow the advice given by the GP to increase Rachel’s dietary intake. Since attempting to enforce this, Rachel has become more irritable, aggressive and secretive (They suspect she is exercising in her bedroom at night but she won’t admit it). She appears frightened at the sight of food and she is significantly more angry and distressed after eating any amount of food. Her parents had been weighing her at home after they visited the GP and to their distress her weight was continuing to fall. Rachel had also been sent home from school the previous week as she had appeared pale and “wobbly” in class. Her parents have never seen her so consistently distressed before and at meal times emotions become particularly fraught such that David and Alex are now eating separately from Rachel and Ann. Alex has tearfully confided to his father that Rachel frightens him when she gets angry at meal times and he is scared that “something bad” is going to happen to her.

Rachel confirmed at assessment that about 7 months ago she had begun to feel dissatisfied with her size and body shape, she perceived her friends as being slimmer than her but coupled with this she felt that they were somehow more popular and successful. Some of her friends had started dieting and skipping school lunch. Rachel joined in and despite her friends giving up their diets quite quickly, she continued and became more and more obsessed with losing weight. She describes being “taken over” by strong thoughts and what she described as a “voice” that was now persistently present and directing much of her behaviour. Rachel also describes her thoughts as being 90% taken up with thoughts of her size, her shape and with food.

The initial formulation based on the information gained at assessment.

The nature of the problems/illness that the young person and the family are struggling with

Rachel has a diagnosis of anorexia nervosa and is likely to have begun developing the illness about 6 to 8 months ago. She is significantly underweight which is impacting on her cognitive functioning. Her mood is low and she feels anxious, consistent with the effects of starvation. She describes an “anorexic voice”, which she feels controls her behaviour.. Rachel is self-harming and says that this is her way of managing the overwhelming feelings of anger and guilt that she is currently experiencing. As a result of the effects of the illness, family relationships are becoming strained; Rachel’s parents

have rarely needed to challenge her behaviour so directly and this change in their daughter has made them question their ability as parents. Alex is becoming distressed, sad and worried.

Both parents work long hours and are beginning to doubt if they can continue to help their daughter at home. They are frightened that she will continue to lose weight and their worst fear is that she could end up in hospital or that she could die. This fear means that they are now in a position where they accept Rachel eating very small amounts of food “as long as she is eating something”. This is maintaining a downward trend in her weight and maintaining the illness.

Reorganisation of the family around the illness

Rachel and Ann are now spending most evenings locked in disputes over how much she will eat. Meals are lasting late into the night and Rachel and Ann are becoming exhausted and more irritable with one another. David is trying to minimise the effect of this upset on Alex by spending time with him in the evening and at weekends and so they are living a somewhat separated life from Rachel and Ann.

David and Ann have been uncertain whether they should tell his parents about the difficulty, which is uncharacteristic as in other situations they have shared major concerns and have seen them as a source of support. They believe they know that something is wrong but they have wanted to honour Rachel’s wish not to tell other people. The parents are making excuses not to visit around meal times and David’s parents have begun to ask questions and seem worried.

Alex feels he cannot say anything to his grandparents or to any of his friends; he used to have friends over for sleepovers but he is now embarrassed by the daily arguments so no longer asks for his friends to visit.

Ann has had to take time off work due to exhaustion and also last week she took a call from Rachel’s school asking her to take Rachel home.

David very rarely spends time now with Rachel as she is spending so much time occupied with Ann around mealtimes.

Problem narratives, beliefs and cognitions

David and Ann are losing confidence in their ability as parents. They feel guilty because they believe that they should have noticed something was wrong far sooner. They wonder if they have done something wrong as parents to cause the illness.

Because Rachel is now self-harming they believe that pushing her too hard to eat could result in her hurting herself more seriously. Anorexia and self-harm now interfere with both parents’ ability to feed their daughter and to take a firm approach against the illness. Their belief, “eating something, even a small amount is better than nothing” makes them feel they are fighting a losing battle as Rachel continues to deteriorate on the tiny amounts of food she is consuming.

Rachel’s strong anorexic cognitions are preventing her from thinking rationally. At times she appears to be able to argue rationally, eloquently and vociferously against her parents’ views and concerns. This confuses her parents who now feel totally deskilled in the face of anorexic negotiations. Rachel had always been a well-behaved and compliant child as she grew up. Now her parents feel they no longer understand her or can respond to her in ways that in the past seemed straightforward, supportive and intuitive.

Rachel seems convinced that losing weight will be protective against further bullying as she believes she will become more popular when she is thinner.

Rachel may feel that at a time when she needed parental support she could not seek it as they were preoccupied with Ann's illness and treatment. It is also possible that she has developed a sense that she must manage her difficult feelings on her own for fear of overburdening her parents. This should be explored in future sessions especially as this potential belief could prevent her from letting her parents know if she were to feel unsafe in relation to self-harm.

Emotions and feelings that may be connected to the problem

Rachel feels frightened and overwhelmed by the attention she is receiving. She feels misunderstood and attacked by her mother's efforts to feed her. Sometimes she is aware that she is unwell but when faced with pressure e.g. when she is expected to eat, she cannot access these healthier, rational thoughts and anorexia then takes over. She might worry that causing stress to her mother by not eating could cause Ann to become unwell again; this would clearly be extremely frightening for her.

David and Ann are frightened by what is happening to their daughter but their fear that she may do serious harm to herself has added to their difficulty in acting firmly. Since they discovered 2 years ago that she had been bullied and then when they learned she had been cutting their view of her changed and now they feel protective and wary of causing her emotional distress. Before she was bullied and before the anorexia and self-harm, they believed she was resilient and tough as she had always appeared quite fearless, happy-go-lucky and had apparently managed her mother's illness so well.

As Alex sees less of his friends outside of school and because he feels unable to tell them what is happening he sometimes feels lonely, angry and sad.

Mapping significant patterns

The feelings described above have led to a pattern of parental uncertainty and fear of doing more harm, which in turn has meant that anorexia has taken hold of almost all aspects of family life.

The more malnourished Rachel becomes, the stronger are the effects of the illness on her ability to defy the anorexic voice.

David is less and less available as a resource to support Ann's efforts to feed Rachel. He has tried to support Rachel and Ann in the past but this has usually resulted in an escalation of arguments around food when he has intervened and tried to help. He now mainly stays away when Ann is trying to support Rachel to eat as he feels less and less equipped to help and he now believes that he is making things worse. He feels more confident in spending time with Alex when he tries to compensate for all the distress that is around.

Ann is becoming exhausted as she spends vast amounts of her time occupied in her attempts to help Rachel eat. She appears to feel guilty about her daughter being unwell and as a result she says she feels very responsible for making Rachel better. The ever-increasing time she spends in trying to support Rachel has affected her relationship with both David and Alex; they are all becoming less connected to one another. As a marital couple the parents are becoming less available to one another for mutual support.

The family are spending less time away from home because of the trauma around food and eating. They cancelled a family holiday recently and they rarely see family or friends. They have not yet spoken to friends or family about the illness, which isolates them from potential sources of support.

Rachel is no longer seeing her friends out of school. She feels totally taken over by anorexia which occupies so much of her thinking that sometimes she feels she no longer needs these friendships. The more alone she becomes with the anorexic thoughts, the less she feels able to reconnect with others. She is also too drained to bother with anything beyond school.

There have been times when Alex has felt responsible for helping to feed his sister; his mother has said that in her desperation she has sometimes asked him to try and encourage Rachel to eat. This has affected his relationship with Rachel who now sees him as a threat and so she lashes out at him as well as her parents. Alex now stays away from Rachel when his mother is trying to get her to eat.

Strengths, resources and resilience factors

The family have faced adversity in the past and they have managed to overcome their difficulties by reorganising family life to cope e.g. with the crisis of Ann's illness.

Both parents are thoughtful and sensitive people. They appear to be loving and warm and their sense of loyalty to one another is apparent. They understand that Rachel cannot manage to overcome the illness on her own and they are prepared to do anything they can to help her recover. They are also eager to accept any advice and support that is offered to them. They readily accepted the advice given to them at the assessment that their daughter cannot recover without firstly restoring her weight and reversing the effects of starvation.

Both parents are able to request time off work although Ann is worried as her illness 2 years ago meant taking time off. Despite this Ann is prepared to put Rachel's needs first. Financially they are fortunate in being able to take this possible option if necessary. David wants to be able to help as much as possible and plans to be at home more.

Rachel is motivated to do well in school and would like to regain her strength so that she can pursue her hobbies. Although she does not currently believe that her athletic ability has been affected by the illness there are times when she realises that she cannot carry on functioning at a good level if she continues to feel so lifeless. These motivators are likely to be helpful to both Rachel and her parents when they face the task of helping to increase her intake. She is a bright student and has ambitions for the future.

Before the illness took hold Alex and Rachel had a good relationship. He wants to see his sister get better and he is pleased that his parents no longer ask him to intervene. His brotherly love is likely to be invaluable when Rachel begins the treatment process and he can help to take her mind off anorexia by playing on the computer or watching TV like they used to do together.

The extended family have been a great source of support in the past. If the parents become more confident that telling some family and friends might help to fight the illness, these other adults can become a potentially vital source of support.

Example of development of formulation from Phase 1 to Phase 2

Development of formulation following assessment, Family meal and follow-up appointment

Two weeks on from the initial formulation further information is available and some initial changes have begun to take place.

The nature of the problems/illness that the young person and the family are struggling with

Both parents accepted that Rachel needed their support to eat everything suggested on the meal plan provided by their therapist. They understood that they had fallen into a dangerous anorexic trap which fooled them into thinking that a small amount of food was better than nothing. They were now willing to believe that anorexia was not caused by them but they continued to experience feelings of guilt and fear. Following the assessment Rachel felt fearful of the fact that she would be expected to gain weight and initially protested at the amount of food she was expected to eat. This meant that for several days following the assessment she continued to take a long time to eat her meals. However,

during the Family Meal, it emerged that with the support of her parents she had stopped protesting and had responded to her parents setting timings for each meal and snack. They had not allowed Rachel to leave or hide any food and because they were consistent, patient and firm, she realised they would not give in to the demands of the illness at meal times. The family developed a routine of distracting Rachel from the anorexic thoughts both during the meal and afterwards when guilty thoughts plagued her. Alex found ways of entertaining Rachel by showing her card tricks and watching episodes of their favourite TV show together.

Both parents were aware that there may be an increased risk of Rachel self-harming during this time and had therefore negotiated an agreement that she would tell them if thoughts of self-harm had increased. They had agreed that they would support her to spend less time alone in her room but that if she needed time away she could only be alone for extended periods if she agreed to her parents checking up on her from time to time.

In negotiating this agreement Rachel initially experienced the plan as intrusive, however the increased time spent with her parents had begun to build increased communication and trust between them all.

Alex continued to feel anxious, especially as there were still tensions around but he began to feel less excluded and worried.

The family have thought through the practicalities of allowing Rachel to return to school. They are exhausted by the focus on helping Rachel to eat and are beginning to realise that they will have to make big adjustments to their daily lives until Rachel is able to take responsibility for eating and keeping herself well.

Reorganisation of the family around the illness

Since the assessment and Family Meal, a clear routine has been introduced around meal and snack times, these events have become less fraught and lengthy. David and Ann try to have some mealtimes as a family so they can both support Rachel and one another. This is not always possible due to their work commitments; David has temporarily negotiated a shorter working day so he is available after school but Ann is involved as much as possible and both are there for weekend mealtimes. This has meant that a new predictability has entered the family's life which has lessened their anxiety around food and eating. Rachel is now resigned to eating what her parents prepare for her. She will sometimes protest but now with less aggression and any arguments are more swiftly resolved as her parents firmly refuse to give in. Rachel is clear that without the presence and support of at least one of her parents she cannot manage mealtimes on her own. This means that the parents have had to make a decision about how Rachel is supported in school. They have spoken to the head of year and now Rachel goes to a member of staff who sits with her whilst she eats her lunch. There is also an agreement that if Rachel has any difficulty finishing her lunch, the school will e-mail the parents and let them know. So far Rachel has managed to eat her morning snack and lunch with this help. She eats her afternoon snack with David as soon as she gets home from school.

The family are not yet able to break their routine and eat away from home. For the time being they are happy to keep to this routine but know that this will have to change as treatment progresses.

Problem narratives, beliefs and cognitions

As her eating improves and her weight increases, Rachel is becoming more aware of the anxious thoughts that had been around before the illness emerged. There was a time when she first began losing weight when anxiety seemed to have improved. It is possible that she had become numbed to anxiety at that point. The predictability of mealtimes and the fact that her parents refuse to negotiate issues around food has helped her to feel some comfort in knowing that she just has to eat what they

serve for her. However, there are times when she becomes highly distressed and believes that she has lost all control over her body and her life. At these times, thoughts of self-harm are more present but she now believes that she does not want self-harm in her life and that by confiding in her parents, they can support her to manage these feelings by communicating her distress through talking and feeling validated. Rachel feels guilty for the changes that have happened in her family because of the illness. There are times when this can give her a sense of motivation to overcome the illness, but at others she feels overwhelmed with guilt and shame for the distress the illness has caused to everyone.

David and Ann are exhausted, however they are also relieved that they have managed to achieve what they believed was impossible; Rachel is eating, she has increased her weight and she has begun to look physically better. This renewed hopefulness drives them to continue but they remain on edge and are unable to make any changes to the predictable routine in case this should upset Rachel and fuel anorexia. They see anorexia as something that is somewhat separate from Rachel and influencing all of them. Anorexia's influence sometimes catches them off-guard when they find themselves suddenly uncertain in their decision-making or confused by Rachel's reactions to seemingly straightforward situations. This leads them to wonder how they will continue to manage. Both parents have now spoken with their close extended family who have responded with concern but also confusion; David's parents have been researching the illness and keep asking when "therapy" will start; Ann's parents have offered to come down to the family home to be a support to them all. David has tried to explain to his parents that Rachel must first regain weight before individual therapy can be considered a helpful intervention. Both parents are thinking about Rachel's parents visiting and are uncertain if they can cope with this yet even though they feel they need some respite.

Alex feels angry towards anorexia; he has been told that his sister cannot help the way she feels about food and eating but he still doesn't like it when she snaps at him. Sometimes he thinks that anorexia is a big excuse for Rachel being mean to him and he would like his parents to tell her off when he believes Rachel, rather than anorexia is being unkind to him.

Emotions and feelings that may be connected to the problem

Rachel's emotions are less volatile and when she becomes distressed she knows that her parents are able to listen and support her. This new emotional closeness is something Rachel likes, especially the closeness she feels to Ann, although it also worries her because when her mum was unwell Rachel feared that her mum might die and that if she caused any difficulty at home she might be responsible for making her mum more unwell.

Rachel is confused about her friendships and feels isolated from the other girls in school. Since being unwell she has isolated herself off from her friendship group and she's not sure if they want her around anymore. She has not wanted to tell anyone about the illness and so now she worries that people are talking about her behind her back, especially as she goes elsewhere for her lunch and at breaks. These thoughts remind her of how it felt when she was bullied and felt very alone in school.

Alex feels relieved that he is now getting a bit more attention. He had felt left out but didn't want to let his parents know so he kept quiet. He still thinks that sometimes he should stay out of the way but nowadays this happens less often.

David and Ann feel relieved that things are getting a little better but they also feel anxious a lot of the time, wondering where the next crisis will come from. They sense now that they can pull together as a parental couple whereas prior to coming to therapy they had felt useless and hopeless. Although this experience is putting a strain on their relationship they are working together well but they know they have a long way to go.

Mapping significant patterns

As both parents now understand their central role in supporting Rachel to recover, they are working more as a team. This collaboration has helped to calm the atmosphere in the family home as there are less disagreements about how to cope and what to do to help Rachel; they now know what they have to do and feel more able to do it. However, as Ann and David now work together to support Rachel they have noticed that when David is on his own at mealtimes with Rachel, there is more likely to be a protest about eating. However David is now more confident in his role and is able to be firm whilst also being able to distract Rachel and show his care, love and concern; before he would often feel frustrated, fearful and angry. David is now more hopeful that Rachel will be able to accept his parenting as coming from a place of love rather than control. Parental feelings of guilt re-emerge from time to time but they are now less caught up in negative cycles of self-blame and guilt which has opened the way for hope and efficacy in their parental role.

Rachel and Alex are spending more time together, initially this was after every evening meal when Alex realised he could support his sister. He is doing this less as he feels his parents are coping and the atmosphere has relaxed a little bit in comparison to their contact before diagnosis.

Rachel continues to isolate herself at school but one particular friend now knows what is happening as Rachel managed to confide in her. A pattern of believing that she is not good enough or different, continues to isolate Rachel from others in school.

Strengths, resources and resilience factors

The parental couple relationship has many strengths; they are resilient and supportive of one another. They appreciate one another's attempts to support Rachel and there is now less criticism when things go less well. David and Ann have embraced the idea that they can help Rachel and both now feel they are beginning to learn the skills to adapt to the demands of the recovery process. Although they still worry much of the time, they are committed to keeping Rachel out of hospital and managing her recovery at home.

Rachel has begun to defy anorexic demands and to communicate more openly with her parents. This is an important strength coupled with her emerging willingness to let her parents know when she is struggling more. This also seems to be an example of good communication in the family now that the initial crisis has begun to pass.

Alex is a caring and empathic young person who has shown great loyalty and concern for his sister. This may need attention as treatment progresses as it seems likely that concern may be closely related to feelings of anxiety. It is possible that as he sees his parents continuing to manage the recovery process, his anxiety may subside.

The family may be able to consider accepting support from the extended family but this may take some time as the parents need to feel more confidence that they can coach other members of the family in the demands of recovery and the demands of the illness.

Development of formulation in Phase 3

After 7 months in treatment, Rachel is now within the healthy weight range.

The nature of the problems/illness that the young person and the family are struggling with

As Rachel has begun to take more responsibility for eating and managing anorexic thoughts, her parents feel less anxiety about allowing her a little more freedom. She has achieved steady weight gain over the past 7 months with one significant weight loss (1.5kg over 2 weeks), when she first

started eating unsupervised in school. Rachel is now weight restored and has had one light period. Both Rachel and her parents can acknowledge the dramatic difference in her emotional and physical well-being when they look back over the past few months of treatment.

Rachel has begun to spend more time with her friends at weekends, she has been doing PE at school for the past 2 months and she is going on a school trip, away from home for a week. Her parents now sometimes struggle to differentiate between behaviours driven by anorexia and behaviours that are typical in adolescence; Rachel becoming moody for no apparent reason and wanting to spend more time in her bedroom on her own for example. They also tend to assume that when Rachel asks for a smaller portion or says she feels full and cannot eat dessert, this is an anorexic decision rather than Rachel expressing a healthily considered preference. Rachel sometimes feels resentful that her parents do not seem to trust her and feels that she is being treated differently to her friends who she thinks have more freedom than her. Being weighed in the clinic has become over relied upon by the parents and they cannot imagine not knowing Rachel's weight.

Reorganisation of the family around the illness

Since Rachel has managed to consistently gain weight and her parents' have begun stepping back from their role in supervising every meal, family life has begun to change; although parents continue to notice and sometimes challenge what they believe is anorexic behaviour, this is happening less frequently as the illness holds less control over Rachel. Both parents remain vigilant and this is a cause of frustration to Rachel as she feels this is now not necessary.

Family activities are now more focused away from home; David has resumed full-time working, Ann has been working away from home every couple of months for a few days which was unthinkable to her when Rachel was very unwell. Alex has had friends over to play and the family have been seeing extended family more regularly. Rachel is going away from home for a school trip which marks an age-appropriate change that was not previously thought possible.

Problem narratives, beliefs and cognitions

Rachel views herself differently now and sometimes when she thinks back to the early days of treatment she cannot remember much of what happened then. She recalls some of the strong emotions that were present but when her parents talk about those times, she sometimes can't believe they are talking about her life. Rachel now knows that she has plans for her future which have no place for anorexia. She feels mostly strong in the face of the demands of the illness and sees herself as almost fully recovered. She believes that her parents will never trust her and that she will be held back by their worries.

Both parents talk about the recovery process as an experience that has changed them as individuals but also as a parental couple. They feel they have pulled together well and they see their relationship as having become stronger despite the pressures that are still on them. David feels closer to Rachel although he knows that their relationship is inevitably changing as she matures. Ann thinks that her relationship with Rachel is now based on a deeper understanding of one another.

Like the rest of the family, Alex sees things getting better and so rather than thinking his family is full of problems he now thinks they're just like other "normal" families. He thinks his sister is better now and that his mum and dad should "give her a break".

Emotions and feelings that may be connected to the problem

Many of the worries that were originally influencing the family have changed; whereas both parents felt hopeless and anxious they now have a different more positive view of themselves as parents. They remain worried about Rachel but increasingly realise that their worries are similar to those of other

parents they know who have teenage daughters. However they still get caught up in making decisions based on the illness rather than on Rachel's current strengths and changes in behaviour.

Rachel has noticed that she is less anxious lately and her mood has improved. Anxiety still increases when she is challenged, especially in new situations or when faced with eating "fear foods". She knows that anxiety reduces after a while and that she has found ways of distracting herself when anxiety is around. Rachel sees herself as almost totally separate from and in control of anorexia now. This sometimes makes her feel very strong and at other times she can feel almost as though she has lost something; a little like losing a friend who became disloyal and undermining.

Alex feels like his family is safe now. He likes his sister better now that anorexia is not so obvious. He still worries sometimes when there are arguments because he's not sure if the arguments are normal ones or ones about anorexia.

Mapping significant patterns

Whenever Rachel is faced with a new challenge or situation which involves eating, food or new social situations, anxiety re-emerges. Rachel usually manages the challenges, sometimes with her parents' support and sometimes without it. There is often tension when Rachel believes she can manage a new situation or challenge but her parents "interfere". This causes friction and leads to arguments. It is at these times that Rachel feels that her parents do not realise how well she is managing to overcome the demands of the illness. When these arguments occur, David and Ann feel they have to be very firm in case anorexia takes hold again. They know on the one hand that they have to let Rachel try things on her own but they are sometimes compelled to intervene for fear of her relapsing.

Strengths, resources and resilience factors

The family has shown tremendous care and love for one another. They have shown resilience in the face of difficulties and flexibility in adapting to changing needs of all family members. They will need to use all these resources and strengths to take the next difficult steps to encourage more independence in Rachel and show her that they trust her to get back on track when setbacks arise.

Development of the formulation in Phase 4

The nature of the problems/illness that the young person and the family are struggling with

Rachel went on the school trip and ate flexibly and regularly and despite extra activity whilst she was away she managed to maintain her weight. She is now very keen to develop her social life and doesn't like to be told that she cannot go to sleepovers every weekend.

David and Ann are uncertain what rules there should be for a teenage girl who has had a serious mental illness and life-threatening symptoms. They talk to family and friends who have similar concerns, especially those who have not parented a teenager before. They sometimes argue with Rachel but this now feels more normal and they are less preoccupied with the possibility that an argument might result in her restricting her food intake.

Alex is annoyed that his sister is allowed to do things he is not allowed to do.

Reorganisation of the family around the illness

The family is increasingly organised around the needs of both children; taking them to after-school activities, picking them up from friends' homes and ensuring they have a healthy routine during the school week.

David and Ann have been able to go out together and have been asking grandparents to baby-sit the children.

The family is no longer organised around the illness

Problem narratives, beliefs and cognitions

David thinks that Ann might be too stressed but puts this down to the demands of work rather than worries about anorexia. Ann believes that her better understanding of Rachel means that future problems will be easier to recognise and overcome.

Rachel sometimes worries about her weight but so do lots of her friends who then go on “diets” for a couple of days and then go back to normal eating. She wishes she could make them understand how risky it is to focus on this so much.

Alex wants to be able to play on his Xbox most evenings instead of going to bed at the right time. He thinks it’s unfair that Rachel gets to go to bed later than him.

Emotions and feelings that may be connected to the problem

Increasingly “the problem” is hard to define. David and Ann no longer believe that anorexia is “the problem” although they have a number of problems, which are similar to those of many people they know; arguments about bedtimes, can they afford a family holiday? Will Rachel manage her GCSE coursework? Will Alex become addicted to his Xbox? Will Ann’s next scan be clear?

Mapping significant patterns

When worries and problems become overwhelming, Ann and David can become tense and this effects everyone. Rachel gets quite argumentative when she doesn’t get her own way and then this can escalate into a family row. Both David and Ann are now very firm with Alex before bedtime and have set a clear rule for when he can and cannot play on his Xbox.

When the family spend time together at weekends they can have good fun together if they find something that suits both of the children. At these times they feel they have a happy and content family life.

Strengths, resources and resilience factors

The family have reached a point where they can look back with relief at their achievement in overcoming a dangerous illness. David and Ann often feel competent in their judgements as parents even if this is not always the case. Communication in the family has improved to the extent that Ann and David now trust both Rachel and Alex to tell them if something is bothering them. Despite having been severely unwell Rachel is a bright child and is doing well in school. This gives her confidence and a strong belief in her own ability to manage the demands that are made of her.

Alex plays less on his Xbox now and is reading more in the evenings, which he actually enjoys.