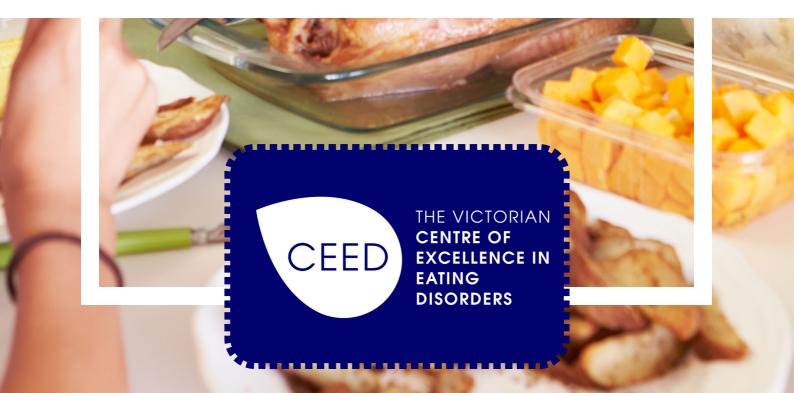


COMMENCING FAMILY LED REFEEDING AND RECOVERY







EATING DISORDERS EXPLAINED

What is Anorexia How does a young person develop anorexia 9 truths Advice from other families

WHAT YOU NEED TO KNOW

Why family led refeeding and recovery is best option Faster is better Going to be tough Look after yourself Sibling

FAMILY MATTERS TIPSHEETS

Getting Started and Making a Plan At the Meal Table 100% of the food 100% of the time Phase 2- the Dance Telling people

RESOURCES

Guide to ensuring eating is non-negotiable Books Videos Recipe guide and nutrition information Distraction ideas

PEER SUPPORT OPTIONS

In person Online

CONTACTS





ANOREXIA NERVOSA EXPLAINED

What is Anorexia Nervosa

A person experiencing anorexia nervosa restricts their food intake. This results in weight loss and a body weight that is too low for their age, sex, stage of development and physical health. The person is terrified of gaining weight and will engage in various behaviours to avoid this. There will also be a disturbance in the way they perceive their body weight, shape or size, and they may experience very low self-worth as a result.

There are two sub-types of anorexia nervosa; people with the 'restrictive' subtype significantly reduce their intake of food (and/or increase their amount of energy output through means such as excessive exercise). People with te 'binge/purge' subtype/, may not have such a high level of food restriction, but will try to control their weight through excessive exercise or purging (e.g. by self-induced vomiting, laxatives use).

Another variation of this illness, atypical anorexia nervosa, occurs when a young person displays the features of anorexia nervosa, but without the low weight classification. People experiencing atypical anorexia nervosa may have lost weight quickly, but still be classified within the normal or overweight range. Recently, there has been a significant increase in the number of young people presenting with atypical anorexia nervosa.

How does a young person get an eating disorder?

No one is to blame for the development of an eating disorder in a young person. Parents do not cause eating disorders and young people do not choose them.

A combination of individual personality traits, genetics and environmental factors can contribute to a person developing an eating disorder. These are known as predisposing factors. The overall mechanism seems to be weight loss or an energy deficit over a period of time in persons who have a predisposition to anorexia nervosa.

The most prominent risk factor for an eating disorder is dieting. Dieting includes eliminating food groups, fasting or missing meals. In young people, food provides the nutrition required for healthy growth and development.

Genetics can contribute to a person developing an eating disorder, but this isn't well understood. For example, genetics may influence the way people perceive food (reward-pleasure responses), and their internal responses such as appetite and metabolism.

Certain personality traits are associated with an increased risk of developing an eating disorder. These traits include perfectionism, low self-esteem, rigidity, anxiety and/or being driven and high achieving, avoidant or impulsive. Obsessive-compulsive tendencies may also be a factor. Societal ideals and cultural norms may also have a negative impact.

"I feel pretty stupid for not spotting it earlier. I didn't see it as a problem until too late. Initially I thought that my daughter's sudden interest in good health, healthy eating and exercise was a great idea and that I could influence her making appropriate decisions. Pretty soon it became obsessional and I found it very difficult to influence her behaviour. I was expecting a rationale response and it took me a long time to realise she could no longer make rational decisions" - parent

NINE TRUTHS ABOUT EATING DISORDERS



Truth #1: Many people with eating disorders look healthy, yet may be extremely ill.

Truth #2: Families are not to blame, and can be the patients' and providers' best allies in treatment.

Truth #3: An eating disorder diagnosis is a health crisis that disrupts personal and family functioning.

Truth #4: Eating disorders are not choices, but serious biologically influenced illnesses.

Truth #5: Eating disorders affect people of all genders, ages, races, ethnicities, body shapes and weights, sexual orientations, and socioeconomic statuses.

Truth #6: Eating disorders carry an increased risk for both suicide and medical complications.

Truth #7: Genes and environment play important roles in the development of eating disorders.

Truth #8: Genes alone do not predict who will develop eating disorders.

Truth #9: Full recovery from an eating disorder is possible. Early detection and intervention are important

Produced by the Academy of Eating Disorders (www.aed.org) in collaboration with Dr. Cynthia Bulik, PhD, FAED, who serves as distinguished Professor of Eating Disorders in the School of Medicine at the University of North Carolina at Chapel Hill and Professor of Medical Epidemiology and Biostatistics at the Karolinska Institutet in Stockholm, Sweden)



WHAT YOU NEED TO KNOW

Why family led refeeding and recovery is best option

- Family based treatment options have the best evidence base compared to individual therapy approaches. Malnourishment compromises the ability of the person with an eating disorder to engage in individual led treatment because the brain is not cognitively able to engage.
- Family are best placed to lead treatment and sustain this support over time. The young person with an eating disorder will require this in order to overcome the illness.
- Remaining in the home allows young people to remain engaged or reengage with social life and school earlier
- Families know their child best and are able to tailor treatment to suit the preferences of their child e.g. use leverage which is meaningful for their child
- It is very unlikely that a young person can recover from this serious mental illness on their own

Weight gain is key

- Recovery is not possible without weight regain to a weight consistent with your child's weight trajectory prior to any food restriction.
- Weight regain and full nutrition for the brain is required to lessen the anorexia voice/compulsions, reduce anxiety and return your child back to their normal demeanour
- A useful concept in weigh restoration is "state not weight". It is important for families and teams to not fixate on a number that is viewed as the magical weight restoration number. This identified weight goal varies for different children and 'state' is a better indicator of recovery than a predetermined number. Your child will want to fixate on a number and strongly argue for not going past this particular weight, however you need to not attend to this eating disorder thought. "State" is specific to each child, but families have described the following examples:
 - Basic changes:
 - Eating Disorder symptoms lessen
 - Change in mood, behaviour, outlook
 - Reduced rigidity in thinking
 - Less obsessive thoughts
 - More amorphous but more meaningful changes:
 - Interest in life
 - Ability ride emotional waves
 - Tone of voice

- Absence or decrease in body image concerns
- Compliance with eating
- No fear foods
- Ease with clothing
- Return of sense of humour
- Diminished anxiety
- Ability to process joy
- Carefree
- Regained life



• For all adolescents, the final weight is a moving figure as adolescents should keep gaining weight throughout adolescence up until approx. 20 year.

Faster is better

- You can support slow or fast weight gain most families find minimal difference in the level
 of distress experienced by the child between the fast or slow approaches. Stretching the
 refeeding phase out over a longer period of time can lead to fatigue and exhaustion in the
 family.
- To gain 10kg at 100g a week will take just under 2 years. 1kg a week will get you there in 10 weeks.

It will be tough

- Anxiety is at an all-time high so extreme distress is the norm. Expect it.
- It is important for families to take steps to manage distress rather than avoid distress
- Actively managing distress with distractions and calm demeanour, and providing firm boundaries around the AN reduces anxiety. Reactivity from parents and loose boundaries increases distress.
- See our list of distraction techniques later in the folder for ideas

Look after yourself

- Having a child with a diagnosis of AN is extremely scary, daunting and exhausting. At times
 like this, our adrenaline will kick into gear and all of our efforts are directed at saving our
 child's life. Self-care can seem like an irrelevance.
- However, this illness can take a long time to resolve and it is vital to pace yourself so that you have strength and determination at later stages of the treatment path. You will need greater internal strength later in the journey, for example, \ just before weight restoration.
- Providing 24/7 care for your child can mean the opportunities for self-care are challenged. In the general community support for families supporting a young person with an eating disorder is less than for other conditions.
- For those families in which both parents or a single parent need to keep working, the challenges are even greater, but in many ways more critical to self-care.
- Self-care involve activities as simple as a daily walk, reading a book, watching an online TV show in the car when your child is in class, listening to uplifting music, parents taking in turns to get a decent break, asking for help from others outside the family, massages.

Siblings

- Siblings can react in various ways to the arrival of AN into the house, depending on age, own issues and personality. Include siblings where possible in treatment process
- Don't be afraid to ask for help with siblings from others



FROM CEED PARENT SURVEY (2015)

Advice from parents who have supported their children to recovery to parents new to this journey

"Love them but challenge the illness"

"Be prepared to do things way outside your comfort zone"

"Seek separate psychological help for yourself "

"Don't argue with the child. You're only arguing with the disorder"

"Don't give up. Listen and trust your instinct"

"Control all emotions. Remain in control and be consistent, firm and fair"

"It may be stressful and confronting for the whole family. You need to look after yourself as it can be very wearing"

"Work with your partner, you can't do it alone"

"You can insist on full nutrition each meal. You can stop all exercise immediately"

"Take control of the eating disorder - do not enable the disorder "

THE VICTORIAN
CENTRE OF
EXCELLENCE IN

DISORDERS

Knowing what they know now, what would parents have done differently?



Take a firmer stand on our daughter's eating and exercise right from the beginning

Stopped sport

Took control of eating earlier

Kept a very close eye on her after meals

Sought more help with friends and family, rather than just us parents doing everything

Not try to keep everyone happy because then nobody is Prioritised nutrition

Stop the excessive exercise regime

Tried to halt healthy eating sooner

Not worked

Been more insistent about food

Challenged her behaviour sooner

Kept a closer eye on her

Not agreed to minor diet changes

More calm approach

Encouraged open discussion

Taken authority as parent more confidently

Taken control earlier

Been more alert to the underlying anxiety problem.

Sought more information about refeeding program

Changed schools to a smaller school where they are better at pastoral care

Increase all positive feedback and feel-good

type activities with her

Not allowed her to make so many of her food

Removed scales from home

choices







Family Matters – Tips for families from families

Getting started and making a plan

Refeeding is a necessary part of recovery from an eating disorder and keeping your child safe from the effects of an eating disorder (and not a punishment, as it may feel like to your child). The way in which the parents go about this difficult but delicate task of refeeding does not differ much in terms of the key principles and steps that a competent inpatient nursing team would follow.

It may be helpful to re-frame the re-feeding process as a **medical protocol**. Your daughter/son is very ill with a life-threatening disease, and just like a cancer patient, she/he needs a treatment plan that will deliver the right medicine in the right quantities to beat the disease.

So how do we set up our home and routines to manage the care of our child at home? Each family and child is different but there are some key things you need to incorporate in a plan which everyone in the household/s understand and adhere to.

The easiest thing to remember in what you are about to undertake is that 'Life Stops Unless You Eat (or stop exercising or purging)". And that means life. Nothing trumps eating, weight restoration and reduction of compensatory behaviours - not school, not family commitments, not formals, not Year 12 exams, not anything. **ALL** of these are possible and encouraged as long as child is eating, and not exercising or purging.

Food/eating

For EDs, the *medicine is food*, and the quality and quantity of the medicine needs to *be non-negotiable*.

You need to be prepared to provide at least 3 generous meals & 2 / 3 snacks (including nourishing drinks at each meal & snack).

Eating at predictable times is helpful in the beginning and ensuring no more than 3-4 hours between any meal/snack.

The child is not involved in *any* choice or preparation of food. His/her only job is to turn up to meal table and eat. While it feels paradoxical, this reduces anxiety significantly. Keep him/her out of the kitchen.

Present food in dishes or containers so calorie information not available e.g. yoghurt tipped into bowl.

Plastic crockery can be handy if going to get thrown.

Make sure you have extra food at hand before meal to replace any food disposed of by child.

You will need a **back-up plan** for food refusal that everyone understands. This may vary from family to family and from service to service. You need to discuss your specific local options with your clinical team but the end goal is to make eating at home non-negotiable, in the same way it would be in the inpatient setting.

During meals, your child will require you to sit with them and *support or distract them*. Don't debate the eating disorder, rather games, light-hearted conversation, television, friends can all be useful distraction once child eating. You can even use pause button on TV/Video or next game move dependent on mouthfuls being taken.



Resource for families helping their young person with anorexia nervosa

Support outside of meals

Your child is going to be *very* unhappy as the eating disorder is challenged and eating required. Prepare a range of activities to distract them or soothe them when not eating (and that are relatively sedentary). They may also appreciate hot water bottles, warm blankets, baths (also helpful for soothing stomach discomfort), and massages to calm down their anxiety. This may also be the last thing they want! It is important to remember this process is distressing but *the only way out is through*. You may not be able to do much to alleviate distress.

Preventing exercising and purging

If exercise compulsion or purging is a component of your child's illness, additional boundaries need to be set up in your home.

You may need to provide 24/7 supervision of your child, including overnight while asleep. You can sleep with your child or they can sleep on mattress in your bedroom. At the minimum, supervision for an hour after meals is helpful as this can be when the urge to compensate for eating is the strongest.

Bathroom visits may need to be supervised, including door open. While embarrassing for all involved, it is important for the behaviour that can occur in bathrooms, whether purging or exercising, to be interrupted.

If any behaviour cannot be interrupted e.g. constantly standing, leg jiggling, food intake needs to be increased to make up for the calories burnt. Once your child realises he/she can't circumvent your attempts to ensure weight gain, many of the behaviours decrease.

Some other tips at the start

The distress is high and may lead to self-harm. Consider sources of harm in your house and remove e.g. lock up knives, sharp implements, medications.

You may need to do a regular check of your child's room for laxatives and evidence of purging. This is keeping them safe, not an invasion of their privacy. Locks to bedrooms should be removed.

Clothing can become an issue as they gain weight. For this gaining weight period, loose and stretchy clothing can be helpful. While at home and not at school, lounging around in comfortable clothing and even pyjamas is best, and would be what they would be wearing if in hospital. You will need to totally remove all clothing that fitted when at their lower weights.

Try to work out ways and means for each parent or family member to get a break from providing the care and supervision as you can get overwhelmed. Once overwhelmed it becomes more difficult to insist on the boundaries required.

The greater your belief that you are stronger, smarter, and have more staying power than the ED; the greater the chance your child will come to believe that too

Developed by Belinda Caldwell – CEED Carer Consultant, and the mother of a daughter with anorexia nervosa.

Tips collated from the lived experience and wisdoms of parents on the FEAST website (<u>www.feasted.org</u>) and other sources.







Family Matters – tips from families for families

At the meal table

Restoration of full nutrition is the first and most necessary step in recovery. But how do you do it? Following on from the first tip sheet, in this one we explore in more detail the ins and out of supporting our child to eat.

To achieve full weight restoration as efficiently as possible, you will need to feed your child a high calorie diet, ensure he/she eats everything you provide (no mean feat!) and prevent any compensatory behaviours (will be covered in a later tip sheet).

What to feed your child?

One of the key challenges for parents is working out how much to feed someone in order to gain weight. Common pitfalls for families is finding the volume of food required as 'too much', not being aware of which foods provide more calories, being used to cooking in ways which minimise fat content and having fixed ideas of what is 'healthy'. In many ways feeding someone with Anorexia Nervosa runs counter to all of our society's traditional norms on healthy eating. The key to success is minimising the 'footprint' of the food our children are required to eat. In order to do this, you will need to change the food you serve to include full fat products, plenty of fats and oils, foods rich in proteins and carbohydrates. Vegetables may become an optional extra for a while! You may also need to change your food preparation style e.g. sausages may now be fried in oil rather than grilled.

Families differ in terms of how they work out what to feed their child – some families are naturally very good upping the calorie density and portions by intuition. Other families may need to take a more structured approach. However, any measurement of food or calorie counting must not be done in view of the child.

Ideas for high calorie meals and food options can be found at http://www.bookemon.com/read-book/320399, http://www.maudsleyparents.org/learnmore.html or on websites supporting nutrition of children with cystic fibrosis or cancer.

How do we make them eat?

Many parents have found the term "Magic Plate" helpful in enabling them to conceptualise what they have to do. Magic Plate means that caregivers/parents make all decisions about food and nutrition until the sufferer is able to eat safely and appropriately him/herself. You plan the meals and snacks, you do the shopping, you do the preparation, you decide the amounts, you



Resource for families helping their young person with anorexia nervosa

put it on the plate and the sufferer must eat it. The only job for the child in all this for now is to eat what you give him/her. Most parents honour historical dislikes, but strive to reintroduce foods that were previously accepted but became "hated" or feared during the course of the disease.

Typically parents see fireworks at first, but this subsides once the ED works out your daughter/son has no choice in the matter. Counterintuitively, being relieved of the choice of what, when and how much to eat ultimately eases the sufferer's anxiety and they are able to eat what is presented.

Encouraging versus requiring

A key challenge for parents is to understand the difference between **encouraging** the child to eat and **requiring** him/her to eat. Understanding the difference can make all the difference

With *encouraging*, you leave the eating up to the sufferer. Dish up her food (not too much! you don't want her to freak out!) and hope she eats; try to say exactly the right thing that will support her in exactly the right way (not too pushy, mind you!). The truth is nothing you can say will overcome the loud voice of ED in her head that is stridently telling her NOT to eat. She has a loaded gun pressed to her temple telling her not to eat. Your words are not going to win that battle.

With *requiring*, you take the choice away from the sufferer. You dish up the food she needs and do not give her a choice about eating it. Food is her medicine; it's very important that the medicine be taken. **Sit with her until it is 100% gone.** Plan on *long* meals at first. Bring a book if you need to and settle in at the dining room table for a few hours. No phones get answered, no tv's get turned on...all other activities cease.

Research tells us that meals are more effective when families have a behavioural focus on eating (verbal and physical prompting) rather than trying to 'convince' the child to eat or provide child with choices. Verbal prompts may be 'keep eating', 'pick it up and eat it', 'you need to eat all the xxx". Non-verbal prompts can be pushing plate towards child, putting spoon into hand etc.

Useful things to say

Many parents have found the following mantras useful to say:

"We love you too much to let you starve."

"Food is your medicine; if you are too sick to take your medicine, you are too sick to _____" (fill in the blank: go to school, go to work, watch TV, text, listen to her iPod, etc).

"Eating is not a choice. You can eat here at home or you can eat at the hospital; but eating is not a choice."

Every meal that goes in moves your child closer to recovery; every meal that he/she misses, or every food group that she cuts from her diet, makes her sicker.













Family Matters – Tips for families from families

100% of the food 100% of the time

When parents are filled with self-doubt, when they shrink in the face of the eating disorders rage and resistance, when they vacillate around the imperative of **full** nutrition and enough time for complete medical recuperation; this can undo all your efforts. Your child will be uncertain about both the necessity and the efficacy of the treatment itself, and the eating disorder plays on this doubt. Backing of or wavering in treatment decisions is, by far, the surest way to prolong your child's suffering and this nightmare for your family.

While this applies to all aspects of looking after someone with an eating disorder, it is highlighted in getting them to eat. Eating is something that terrifies them. So what do we do when terrified of something? Calmly go ahead and do it? Not usually. We usually make every excuse under the sun, rational and irrational, as to why we can't do it, we refuse, and we might become violent even, if pushed. But usually we don't need to actually do the thing we are that afraid of because it is not threatening our life.

As families, we have to support our loved ones to eat when they are terrified. How do we do this? They have to know that there is no way out but through.

As one mother says "For us, nothing else happened until our daughter ate. Nothing. Nada. Zip. I sometimes think others don't fully understand the depth of that statement. We cancelled nearly every social engagement in our lives, stopped inviting friends and family over, stepped back from every outside charitable, civic or business activity association during the re-feeding. Once food was on the table, our daughter didn't leave until it was done. Then, we stayed with her for hours afterwards to support her. If it were breakfast and she didn't eat it, she didn't go to school. If she had an outside evening activity with either friends or a school group, then she didn't go if dinner wasn't done...no compromises, no exceptions. Our life literally centred around our daughter's dinner plate until the time she could do it herself (which is where she's at now)"

What can happen though is that parents buckle. They serve them a plate, but the child knows that if they just channel a little Gandhi-like passive resistance for an hour or two, then the parent will have to either go to work, go to class, meet a friend or do some other thing. This is the difficult part. Life not only stops for the anorexic, it has to stop for one of the parents as well.

Avoid the cajoling or "persuading". Return passive resistance with quiet, benevolent absolutism (a sort of Gandhi meets Edmund Burke). Bring a book if you need to and settle in at the dining room table for a few hours. No phones get answered, no tv's get turned on...all other activities cease.

At the meal table you can provide support for your child to eat through direct prompts such as "pick up the spoon", "have some x, y or z", "take another mouthful". The clearer the better. Once your child is eating, move to light conversation and distraction techniques. If they stumble or stop, return to the prompts and stop the chatter/distraction techniques until they are eating again. Once the meal is finished, switch moods and move to enjoyable and relaxing activities.

Resource for families helping their young person with anorexia nervosa

Some useful phrases may be:

"This is what we're eating for lunch/dinner/breakfast/snack"

"Yes, I'm sure you have to eat it"

"I know exactly what is required in your meal plan"

"The only way to get better is to challenge that thought"

"This is exactly what you need today, please begin eating"

"Let's pick up the fork and get started, sometimes it's easier to get going and get through this"

"I know this is super hard for you, this isn't easy. Let's get it going, and I'll be right here with you"

"Let's try a few of the coping skills you've learned" (deep breathing, hand fidgets, distraction with a game on my phone or funny animal video)

"You'll have to stay at the table, and I know you have better things to do, so let's get this done, so you can do them"

"I'm not going to let you do this alone, I will ALWAYS be right here, no matter how hard it gets. We can do this one bite at a time"

"I'm so sorry you feel that way about eating, but it's what we have to do so you can get back to being a normal kid."

Distraction techniques have been found to extremely helpful for anxiety and fear. These can include having friends over, playing games (verbal, board or iPad), watching TV. You know your child best here. We spent many meals playing iPad scrabble where being able to take a turn was dependent on eating steadily. Sometimes we watched TV episodes and with the advent of Foxtel IQ could pause the episode when eating stalled.

Once they are eating, you need to make sure they are not using restricting behaviours. Finding any restricting behaviours are dealt with by replacing not eaten food as soon as this is discovered. Common restricting behaviours you may see include:

- "Dropping food" onto the floor.
- Smearing food under chairs and tables, onto hands and clothes (particularly common with fats, sauces, dressing, peanut butter).
- Hiding foods in pockets, sleeves, hoods, pants, napkins, etc.
- Hiding foods under the plate.
- Leaving food on the plate (particularly common if food is cut up into small pieces first).
- "Chipmonking" the food in cheeks.

Finally, you should have a written plan agreed with your clinicians for what to do with complete meal refusal, with a plan A, Plan B and as many additional plans you need to ensure eating is non-negotiable.

"Your continued confidence in him/her and in his/her recovery is a gift you offer every single day, every meal, every bite"

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Family Matters – Tips for families from families

Phase 2- the dance

What does it actually look like

Yay - you are now in Phase 2! BUT many parents complain that this phase is harder in some ways than Phase 1. It is lot more gray than black and white and it is really difficult to hand over control, trust your child, stay vigilant about ED and do it methodically and carefully so it doesn't backfire. It is linear and don't expect perfection. Baby steps are advisable. As for your child, taking these 1st steps towards independent eating, "choosing" to eat, choosing to fight ED on their own rather than being told what to do, introduces a new level of guilt and anxiety. Your child may not be able to express this herself, but he/she is likely to be struggling with having to choose to eat rather than have it chosen for her.

Many parents transition into Phase 2 slowly and systematically. As one parent says "We started with 1 snack that D chose from a bag of other snacks - then we tried two snacks - and finally we tackled meals. It is frustrating! It takes patience and time. Good news is that my D can now feed herself and maintain her weight herself with me very much in the background"

Another parent described it as "There is also a lot of backtracking, when you realize that something isn't working or is too hard, you can always step back and say that she wasn't quite ready, let's practice and then next time maybe it will be easier. When it came time for my D to plate her own food - she would do it under our noses. We would tell her to add a little more or approve. If she added more and we still felt it was under, we could then take over and do the portioning. If she protested, we would just say that this may be too hard for her at this stage and we would go back to our portioning from the outset and removing that control temporarily. Kind of stepping back to Phase I for a bit and then moving forward again - it's a dynamic process"

How do we do it?

- Take baby steps, don't rush this phase, and accept that this Phase may take a long time. This process can be likened to making sure you put chocks behind each bit of progress to make sure you don't slide back.
- Accept and embrace the fact that Phase II poses an inherent risk.
- Have the child/young person practice choosing and preparing her food under supervision before she is permitted to eat unsupervised.
- Be systematic in how you approach introducing independent meals and snacks. Decide on the process and stick to it.
- Assess progress regularly. Weight needs to be monitored in this phase to ensure any lapses are picked up early.



Resource for families helping their young person with anorexia nervosa

- Take back control when necessary. It can be a 2 steps forward, one step back process. No blame should
 be attached to the child or on yourself if these backward steps occur. Remember that whatever happens
 is simply feedback, not failure.
- Some young persons need a gentle nudge to move forward as it can feel very safe to have no choice in what and when to eat. For some, this choice creates real anxiety which needs to be gently pushed through.
- Don't force Phase II into an external timeline. Trying to push independent eating to get to go on an
 overseas school trip or off to university etc won't work in general, although in the latter stages these
 opportunities can be used to get fully flexible eating of a wide range of foods bedded down.
- Keep things in perspective while it may feel to you at the time that this process is tortuously long, you will look back in 3 months, 6 months and be able to see clear signs of progress.

(some of above tips from Dr Ravin http://www.blog.drsarahravin.com/eating-disorders/navigating-phase-ii/)

What does it feel like for the young person?

Phase II is also the time when their brain starts feeling all of those emotions that restriction had suppressed. The primal terror of food is replaced by anxiety and thoughts that they are now actually processing but don't want to process. It can be a bit tumultuous and confusing for both the young person and their family.

The young person may send mixed signals – she/he may beg for the freedom to eat lunch in the school cafeteria and go out to dinner with her friends, but yet she is clearly unable to take a single bite of food that isn't "required" and "supervised." To outsiders, the young person seems normal – she/he looks healthy, she/he acts more or less like a typical teenager (in between mealtimes, at least), but appearances belie the at times still-raging battle in his/her head.

What does it feel like for families?

After having been on 24/7 hyper alert for the last number of months while in Phase 1, many parents find it hard to get the balance right between remaining vigilant and proactive in steering their young person to recovery, and not being hyper vigilant when it is not required. It is normal to have our own adrenal system still on full alert when it is not necessarily required, especially as you approach the end of Phase 2. We can often over-react to seemingly small glitches which seem the precursor to a dramatic slide back to the hell of the worst of this illness.

This is where serious self- care becomes imperative. As the burden of caring for our young person is lightened, we need to take time out for ourselves, address any ramifications of this incredibly stressful period of our lives and start to re-enter our normal lives. You can feel disconnected and even alienated from your previous life; feel like small chat is an irrelevance and many other manifestations of prolonged extreme stress, anxiety and fatigue.

Self care is very individual and you need to work out what works for you to re-establish your equilibrium. For some it is a return to work, taking up new hobbies or even careers, stopping all work and commitments for a while and just taking it easy, seeking counselling to process what you have been through and possibly medication where needed, time just with your spouse or other children, massages etc. Whatever heals you, do that. Don't expect healing to be quick or easy, so be kind with your own expectations of yourself

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Family Matters – Tips for families from families

Telling people

Eating Disorders are a disease of secrecy. The sufferer may have kept it secret for a while before diagnosis. Many families feel the need to keep the diagnosis of their child secret, either on request of the child, to protect the child or for fear of blame, stigma or judgement from others. Sometimes it feels too complicated to explain to others in a way that makes sense. And you are too tired to even just think how to frame it!

The reality is that there is a level of ignorance and misconceptions out there about eating disorders and there is always a chance that someone you tell will respond in a way that is not helpful.

However, there are some strong arguments for being more open about your child's diagnosis

- AN thrives on secrecy and the less people who know, the more opportunities there are for AN behaviours to increase in the absence of people to hold the AN to account
- Informed family and friends can provide a network of safe social opportunities and even provide respite
 for you as a family. As your child moves to more independent eating, it can be reassuring for them to
 know a couple of close friends or grandparents will keep an eye on them. It can make it easier to tell the
 AN voice, which by then is softer, to go away.
- Remaining connected to friends and extended family is key to avoiding or minimising the social isolation that frequently accompanies this illness.
- Finally, while not the responsibility of any individual family, the more families who are open and matter
 of fact about their child's eating disorder, the less stigma and misconceptions there will be for families
 following on.

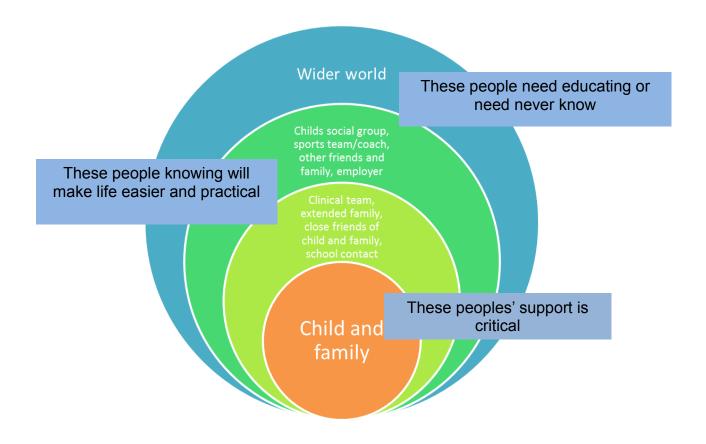
Developing a 'spiel' in advance can be useful for when you get caught unawares. This 'spiel' will be different for each family but it is good to

- 1. go on the front foot
- 2. address the possible misperceptions and/or correct any quickly
- 3. and then talk about what is involved in treatment.

I used to say something along the lines of "L has been unwell/off school etc as she developed anorexia nervosa a couple of months ago. Not sure how much you know about anorexia nervosa, I always thought it was a vanity thing or wanting to be thin but researchers in recent years have found that it is actually a brain based disorder which is triggered by weight loss (in our case L went trekking in Nepal) which for some reason causes the person to become phobic about eating and needing to exercise compulsively - bizarre. Anyway the most effective treatment involves us as a family making sure she eats 6 times a day and stops exercising until she regains the weight - which is pretty intense, I can't work at the moment unfortunately etc". You may be pleasantly surprised by the responses of people when it is framed like this – there is a level of uncertainty for other people in talking to families whose kids have a mental illness.

Resource for families helping their young person with anorexia nervosa

It can also be useful to think of who to tell by looking at the below diagram



Useful resources to point people to who want to know and understand more are

- www.feast-ed.org
- www.maudsleyparents.org
- Brave Girl Eating by Harriet Brown is an easy read for those friends and relatives wanting to understand what is going on

Below is a sample letter written by a parent prior to a family gathering. Some of it you could also use for a general email out to family and friends whose support would be helpful. If you ask for their support, be specific about the ways they can assist e.g. cook some high calorie meals, provide some respite for you between meals by entertaining your child, assist with other siblings by taking them for a few days or taking them on special outings, taking on some of the other tasks you need to do e.g. school stationery shopping, house cleaning etc. By being specific you can avoid well-intentioned but potentially damaging attempts at help.

Developed by Belinda Caldwell – CEED Carer Consultant, and the mother of a daughter with anorexia nervosa.

Tips collated from the lived experience and wisdoms of parents on the FEAST website (www.feast-ed.org) and other sources.



Resource for families helping their young person with anorexia nervosa

Sample letter to family and friends before a gathering (amend details as needed)

Dear

As you may know <child's name> is suffering from anorexia nervosa and will find the upcoming family gathering/shared holiday challenging. We hope this gives you an idea of what she is going through and how best you can support her.

Anorexia is a serious ILLNESS. It is not a personality trait or intentional stubbornness about food. This illness causes <child's name> very real anxiety and fears about eating. This can be confusing, since most of us struggle to not be overweight and have a hard time relating to a fear of eating the high-fat foods that most of us crave. As a result, we may trivialize or even joke about anorexic behaviours, without realizing this can be very hurtful.

To help put it in perspective: think of **your** worst fear (heights, claustrophobia, snakes, etc.) and being expected to face that fear (climb a tall ladder, ride in an elevator, encounter a snake) 6 times a day, every day. That would be really scary! That is what eating is like for <child's name> right now.

<child's name> is being treated with Family Based Treatment which is the current evidence based treatment for AN and involves us as a family requiring her to eat 6 times a day, eat enough to regain the weight loss and return to normalised eating. As a family, we receive support from <our local Child and Adolescent Mental Health Service> to do this. Currently we need to be with <child's name> 24/7 and supervise all meals, including those at school. We have to prioritise eating and not exercising over anything else in our lives currently until <child's name> is better.

We have all been learning a great deal about this illness. Anorexia causes sufferers to think about food almost constantly as a substitute for actually eating it. That is why we need to focus on activities and distractions that have nothing to do with food or physical exertion. <child's name> is taking up crocheting again; despite the fact that she has the LEAST crafty mother on the planet!

I realize everyone at the reunion cares deeply for D, and wants to assist in her recovery. Here are a few practical guidelines:

- 1. Do not comment or ask questions about her weight or what she is (or is not) eating.
- 2. Refrain from comments about your own weight and/or desire to be thinner. Many of us do this without even realizing it... usually in a self-deprecating way.
- 3. DO spend time with D as you normally would and include her in a variety of activities. One caveat is that we are restricting her physical activities. Other good options are Cards, crafts, talking, watching movies, playing games, playing with babies, etc. Please bring your favourite board games I will bring several!
- 4. Be aware and respect that D's meals and snacks will be prepared and monitored by me. That may or may not include items from the 'group' meal/s.
- 5. D is **not** allowed to participate in meal planning, food preparation or meal clean-up.
- 6. If you have questions about what she is (or is not) allowed to eat, please refer those questions to me. D is not to be consulted about food choices.
- 7. Do not ask 'why' or other questions designed to figure out how this happened. While I realize that these conversations would be initiated with good intentions, there simply is no good answer. Conversations about the root cause of the illness can cause feelings of guilt and stress. **Any 'blame' should be laid squarely at the feet of the illness itself.**

Ensuring eating at home is non-negotiable

Family

Parenting style
Personality
Confidence, hope and
expectancy
Leverage
Other family demands
Existing supports

Issues to consider when problem solving with families on how to make eating non-negotiable at home.

Troubleshooting these issues is critical to ensuring families are in control of intake rather than the eating disorder

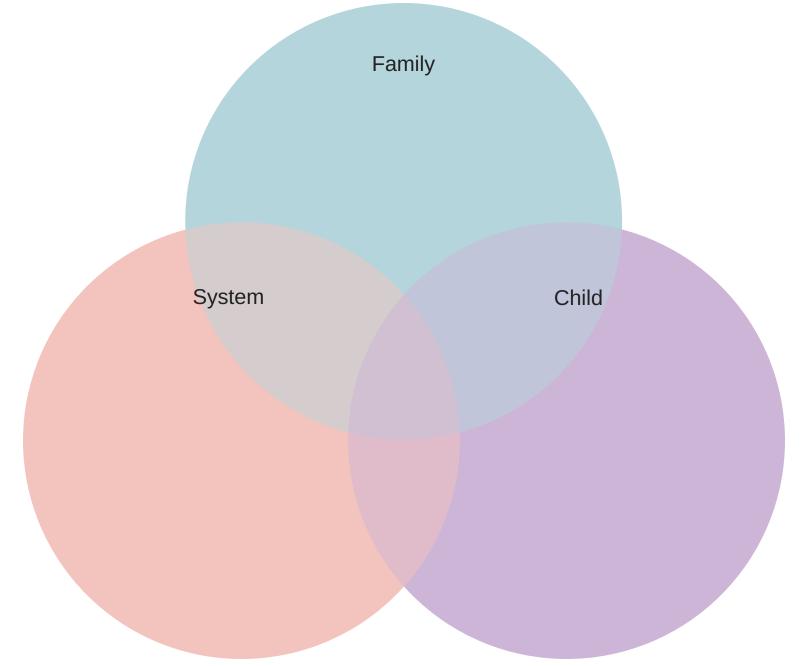
System

Back up options for meal refusal
Risk management plan
Collaborative mental health and medical care team
Consistency in team advice

Child
Severity of AN
cognitions
Level of distress
How resistance presents
Suicidality and self harm



Troubleshooting issues



Actions

Family

System

Child



Lisa

Banana Muffin

Ingredients

- 8 tablespoons butter
- 1.5 cups sugar
- 2 eggs
- 2 cups flour
- 1 teaspoon salt
- half teaspoon baking soda
- 1 cup mashed banana (I use 2 bananas)
- half teaspoon vanilla
- half cup sour cream
- plenty of chopped walnuts or pecans (I don't measure these, but probably put in at least 2 cups)

Mix together the butter and sugar, then the eggs. Mix together the dry ingredients first, then add to the butter/sugar/egg mixture. Next add the banana, sour cream, and vanilla. Last add the nuts.

I put all of this mixture into a non-stick pan that has 4 LARGE muffin tins (and cook at 180c for around 45mins till cooked). 4 Large muffin tins is key. Just make a huge muffin look like the normal size...none of this small cupcake sized muffin business!!! Each of these muffins should have about 1000 or more calories. And they are delicious! My d asks for them now even though she has moved on to less calorically dense breakfasts!

Susan

- 1. <u>Chinese food:</u> 2 cups of rice (about 450 cal) with stir-fried dish of veggies, tempeh (pressed soy beans minced and fried in olive oil first -- 1/3 package: 180 cal with 2 tbsp olive oil with garlic and soy sauce). That plus a glass of milk will get you between 8 and 900 cal.
- 2. <u>Pasta with pesto sauce.</u> This is a very easy quick meal. Again, big portion of pasta (about 2 cups cooked) with pesto (we used Buitoni with 300 cal per 1/3 cup?). Again, with a glass of milk and a hunk of bread, 120 to 160 cal, or one slice of Pepperidge Farm Texas Toast, 150 cal, and that's 8 to 900 cal.
- 3. <u>Pasta with homemade or store-bought sauce.</u> Add plenty of olive oil and parmesan cheese (shredded has more cal than grated). Eggplant will soak up lots of oil, so we often sauteed eggplant in olive oil and added it to sauces. We served milk and a good size piece of bread with every dinner just about. Sometimes we added a can of white beans to the sauce.
- 4. Lasagna and eggplant parmesan.
- 5. Peanut butter sandwiches: bread with 100 cal/slice plus 4 tbsp of peanut butter = 580 calories.

What worked for us was to increase calories with oil, butter, etc. and serve larger portions. Hope this is helpful. I could probably come up with a few more suggestions and can provide more specific recipes, if needed. I clearly remember that feeling of dread every morning when I woke up and wondered what I was going to feed my d that day or how she would receive the food. This got much better as she got healthier, so hang in there. Good luck!!!!

Nancy

Peanut, bacon and avocado sandwich

Ingredients

- 8 thick slices of wholemeal bread, buttered
- 2 tablespoons crunchy peanut butter
- 2 tablespoons mayonnaise
- 8 rashers bacon, grilled
- 1 ripe avocado, thinly sliced and sprinkled with lemon juice
- shredded iceberg lettuce
- freshly ground black pepper
- 1. Spread the peanut butter on four slices of bread and mayonnaise on the other four.
- 2. Place the bacon, avocado, lettuce and pepper on the peanut butter spread slices and top with the mayonnaise spread slices. Cut each round into four.

Karen

Cheesy Mac

This may sound odd, but check out the recipes on the Food Network website (www.foodnetwork.com) under "Paula's Home Cooking". Paula Deen is a southern style chef and I think she puts butter in practically everything. She has a recipe for cheesy-mac (this week) that has butter, cheese and sour cream in it:

Ingredients

- 4 cups cooked elbow macaroni, drained
- 2 cups grated cheddar cheese
- 3 eggs, beaten
- 1/2 cup sour cream
- 4 tablespoons butter, cut into pieces
- 1/2 teaspoon salt
- 1 cup milk

Preheat oven to 350 degrees F. Once you have the macaroni cooked and drained, place in a large bowl and while still hot and add the cheddar. In a separate bowl, combine the remaining ingredients and add to the macaroni mixture. Pour macaroni mixture into a casserole dish and bake for 30 to 45 minutes. Top with additional cheese if desired.

You can look up recipes from past shows. It may take a while to find what you want, but she really is the highest-fat chef I have ever seen. There is nothing low about her cooking! She also tends to use some ready-made items to make cooking easier.

Hot Cocoa

Ingredients

- 2 tablespoons butter
- 1 tablespoons cocoa powder
- 1 cup premium vanilla ice cream (substituted for the 1/2 c sugar in the original recipe)
- 1 cup whole milk (you could substitute 1/2 c cream, 1/2 c milk)
- 3 tablespoons Ovaltine
- 1 teaspoon vanilla (optional)

Melt butter, add cocoa stir. Add ice cream, melt & stir. Add milk, ovaltine and stir. I put it in the blender before it got really hot and returned it to the pot to heat. This made it creamier.

This is a total of 785 calories (more if you do the cream/milk combination).

You could add marshmallows if you like, too!

Rob

Porridge

Ingredients

- 1/2 cup oats
- 1/2 cup double cream
- 1/3 cup water (to make it less thick)
- 1/4 cup raisins
- COOK THIS 2-3 minutes in microwave

Add:

- 1/4 cup sunflower seeds or nuts
- 1/2 banana
- 1 scoop protein powder

Ripley

I'm cutting and pasting the following information from a diet article about 'foods that fool' people into thinking they're low-calorie and low-fat. I hope the author won't mind it being used by parents re-feeding their kids back to health! We didn't count calories during that phase, but many of these foods were on my d's menu:

- "Granola" -- Most brands are loaded with calories and sugar. In fact, granola is one of the
 most calorie dense cereals on the market. A typical "ø cup serving has 220 calories and 17
 grams of sugar that's more than 4 teaspoons of sugar. What's more, most people pour 2cup portions that's a whopping 660 calories and 51 grams sugar (12 teaspoons -- yikes!).
- <u>Chicken Caesar Salads</u> -- It's a salad, right? What could be unhealthy? Thanks to excessive dressing, croutons, and cheese, a standard chicken Caesar salad can total 1,130 calories and add more than 90 grams of fat to your diet!
- <u>Dried Fruit</u> -- All fruit is packed with nutrition; however, dried fruit is significantly higher in calories than fresh fruit when you calculate comparable amounts. That's because you're taking out all the moisture leaving a small piece of concentrated sugar (albeit "natural" sugar).

Consider this:

- 12 small pieces of dried mango = 320 calories
- 2 red apples + 15 grapes + "ö small cantaloupe = 320 calories
- Yogurt Covered Nuts -- This yogurt snack is strictly food for the soul! It's filled with calories, sugar, fat... and clearly NO active cultures. In fact, 20 yogurt covered nuts = 460 calories, 32 grams fat, 14 grams saturated fat, and 8 teaspoons sugar.
- Banana Chips -- Bananas fried in oil and sugar over the top! Consider that 1 cup typically provides 300 calories, 20 grams fat, 18 grams saturated fat (that's the artery clogging type), and 19 grams sugar (4.75 teaspoons).

- <u>Trail Mix --</u> Although packed with healthy nutrients and fiber, traditional trail mix is also loaded with calories that add up quickly. In fact, "ö cup typically equals 350 calories (that's the same number of calories as 11 cups of air-popped popcorn).
- <u>Fruit Smoothies</u> -- It's true, fruit smoothies can provide a lot of nutrition, but they pack in the calories as well. One 24-ounce smoothie provides about 450 calories. That's the same amount of calories in 10-12 doughnut holes! "

Megan

I don't really have that many new ideas, but I'll share what has been helping my daughter.

- 1. <u>Bagels and peanut butter & banana</u> can be up to 700 or more calories (depending on bagel size/type and how much PB you put on)
- 2. <u>Full fat yogurt</u>. It's not as scary as ice cream, but has PLENTY of calories. Make a healthy high calorie 'parfait' with 350ml full fat yogurt, 1/2 cup granola and some cut up fruit. It's delicious and high in calories.
- 3. <u>Starbucks</u>. It's always a treat and the drinks can be VERY high calorie.
- 4. <u>Trail mix</u> is very high calorie, and very nutritious. 1/4 cup can be around 160 and it's not very bulky so they can eat a lot.

Charlie

Mix n' match ideas for salads -

- avocado
- croutons
- bacon bits
- shredded cheese
- fried holloumi
- potato salad
- coleslaw
- olive oil, ceaser dressing
- pine nuts
- chicken/tuna mayo
- garlic sausage/salami/pepperoni
- Sour cream
- Pesto

Serve with thick buttered bread.

Elisabeth

Muffins

Ingredients

- 1.5 cups flour
- 1/2 cup cornmeal
- 2 tablespoons wheat germ
- 1 cup sugar
- 1/2 cup butter
- 2 eggs
- 1 tablespoon molasses (nutritious and great with cornmeal)
- 150ml sour cream
- one cup or so cut up peaches (PEACH season!)
- 1 cup sliced almonds

Follow directions for muffins at beginning of thread. Peaches and cornmeal are a great combo. I make one biggish one for you know who and 4 smaller ones for the rest of us in the same giant 6 piece muffin pan. Good eating days usually start with muffins. A muffin and a glass of milk are about 1/3 of daily calories (1100 cal). I have a hard time serving anything else for breakfast with that much of a punch. Other breakfasts look "too big" and have less calories.

Chelsea

Choc/banana drink

- 3 heaped tablespoons of Milo (drinking chocolate)
- 200ml full cream milk
- 1 large banana
- 3 tablespoons of double thick/rich cream
- 1 tablespoon honey
- total= 900cals

Barbara

<u>Pesto Pasta Bake</u> (This could be vegetarian but I added ground turkey so make that Turkey Pesto Pasta Bake)

- 500g ground turkey (not the lean kind)
- about 3/4 of a 500g box penne pasta (I used the Plus kind for more protein)
- 1 small onion, chopped
- 1 tsp garlic
- 1 tbsp olive oil
- 1 large can crushed tomatoes, not drained
- 1 tsp oregano
- 2/3 cup ricotta cheese (whole, of course)
- 2/3 cup mozzarella cheese
- 1/3 cup parmesan cheese
- 2/3 cup prepared pesto (I used basil pesto with the highest calories found)

- 1/2 cup mozzarella cheese
- 1/4 cup parmesan

Heat oil in skillet. Brown meat in skillet with onion, garlic. Once meat is cooked and onions are translucent, add tomatoes and oregano. Turn down heat and Let simmer.

In small bowl, mix together ricotta, mozzarella, parmesan cheese and pesto.

Cook pasta about 7 - 8 minutes. It will not be fully done. Drain, rinse with cold water, and drain again.

Oil a large baking casserole. Put about 1/3 of penne pasta in bottom of casserole. Layer about 1/3 of sauce. Add all of the cheese mixture in one even layer over this. Add layer of remaining pasta. Add remaining sauce on top of that. Top with remaining mozzarella and then parmesan.

Bake at 180for about 1/2 hour-40 min. until bubbly. Let sit for about 5 minutes after to set.

AND serve with garlic bread (of course using butter) and salad with dressing for a pretty high calorie/nutritious meal.

From a University of Chicago website for Cystic Fibrosis

Ideas on how to increase calories in foods

- Add butter, margarine, or vegetable oil to:
 - o breads, toast, crackers, or sandwiches.
 - o potatoes, hot cereals, rice, noodles, soups, or casseroles.
- Add sour cream to:
 - o potatoes, rice, pasta, or vegetables.
 - o use as a dip for vegetables, or chips.
- Add mayonnaise to:
 - o sandwiches or crackers.
 - o dips, salad dressing, or sauces.
 - o meat, fish, eggs, or vegetable salads.
- Add cream cheese to:
 - o fruit slices, raw vegetables, bread, toast, or crackers.
- Use double creams in:
 - o soups, sauces, batters, custards, puddings, shakes, mashed potatoes, or cooked cereals.
- Use whipping cream on:
 - o pancakes, waffles, fruit, ice cream, pudding, hot chocolate, or other desserts.
 - o mix in cream soups, hot cereals, mashed potatoes, pudding, and custards.
- Add brown sugar, maple syrup, or syrup to:
 - o hot cereals, cold cereals, fruits, ice cream, or puddings.
 - use as a glaze on meats, or vegetables.
- Add powdered milk to:
 - o cereals, potatoes, cream soups, eggs, puddings, gravy, and casseroles.

- add two to four tablespoons of powdered milk to one cup of whole milk to make "super milk."
- Add cheese to:
 - o sandwiches, burgers, toast, crackers, eggs, potatoes, noodles, and snacks.
- Add peanut butter to:
 - o sandwiches, crackers, toast, fruit slices, vegetables, ice cream, or milkshakes.
- Use high-calorie drinks such as:
 - homemade milkshakes, Carnation Instant Breakfast®, Scandishakes®, Pediasure®,
 Boost®, Boost Plus®, Ensure®, Ensure Plus®, etc (check Australian versions)

Also try other websites for conditions that require high calorie meals e.g. cancer and cystic fibrosis. Examples:

http://kidshealth.org/en/teens/about-cf-recipes.html

http://www.hdny.org/recipes.html



Minimum Food Needs for Ongoing Weight Restoration



Distraction ideas

- Funny YouTube videos <u>www.wimp.com</u>,
 http://www.cracked.com/funny-videos.html or just search!
- Play Pictionary on a wipe-erase board
- Board games- hard copy or on Ipad e.g. Scrabble
- Riddles (pre-plan them)
- Trivia cards,
- Worst case scenario cards (how would you handle the situation type questions
- Read jokes.
- Any type of whodunit scenarios that you can read and she can solve
- Any kind of car ride games like I Spy, 20 questions,
- Audible books
- IPAD/TV comedy or light-hearted often good and if a long series even better
- Games on the phone like quiz up, true or false, and taboo
- Solitaire with a pack of cards
- Puzzles: crosswords or perhaps jigsaw puzzles
- Colouring Sheets, colouring puzzles,
 http://www.mombooks.com/colouring.html
- Optical illusions http://www.michaelbach.de/ot/

"We watched episodes of 'Modern Family', so my d could drink the dreaded milkshake. It was the hardest thing for her to do, but watching the program together made it possible for her. She would lean into me, and we'd laugh together. I think the physical closeness was also important, as so much of the time she was angry and very prickly during refeeding. It was a chance to connect and positive for us both. Plus, the show is laugh-out-loud funny....and made our dysfunctional family life at the time seem just a tad more normal"

BOOKS AND VIDEOS

Books

- Surviving FBT Maria Ganci
- Brave Girl Eating Harriet Brown
- Eating with your Anorexic Laura Collins
- Anorexia and other eating disorders: How to help your child eat well and be well - Eva Musby
- Throwing Starfish Across the Sea: A pocket-sized care package for the parents of someone with an eating disorder - Laura Collins and Charlotte Bevan
- Parents Survive to Thrive Guide BC Childrens Hospital

Videos

- Go to CEED website and videos to see links to -
- Drive Series- Eating Disorders
- Stuck and not eating
- What paediatricians and parents need to know about eating disorders

ONLINE PEER SUPRORT



Our team

CAMHS
Phone
FBT Therapist
Phone
Email
FBT Therapist
Phone
Email
Psychiatrist
Paediatrician
CATT team
Local Emergency
GP
Others
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