



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.

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

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

