

Eating Disorder Handbook

for families of the Children's Ward

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Welcome to Townsville University Hospital

Having a child admitted to hospital can be a very challenging and stressful time. Our staff are here to support you and provide the best possible care. When a child with an eating disorder is underweight, malnourished or medically compromised, they require a hospital admission to support their treatment occurring safely. The focus is to restore the health and stability of your child's body. We will also provide you with advice and support to continue to care for your child into the future.

The impact of eating disorders

Eating disorders are a group of psychological conditions that have significant impacts on a person's physical and mental health and include anorexia nervosa, bulimia nervosa, binge eating disorder and avoidant restrictive food intake disorder (<http://thebutterflyfoundation.org.au/>).

Recovery from an eating disorder may be long and challenging. Recovery consists of several stages including an initial reintroduction of food (re-feeding stage). Your child may need to be admitted to hospital for the initial refeeding stage if they are medically compromised.

Eating disorders can lead to malnutrition which refers to when a person's diet does not provide enough energy for growth and health. This significantly affects the body and the mind. Your child needs to be closely monitored during this initial hospital treatment period, particularly for the effects of malnutrition on their heart, brain, liver, kidney, and hormones. The medical team will develop a treatment plan that is individualised to your child's needs.

Children and adolescents with anorexia nervosa experience intrusive thoughts about losing weight and being thin, which can be very distressing for them and difficult to understand for those supporting them. It is important to separate the eating disorder from your child and to acknowledge when thoughts and behaviours are being driven by the eating disorder rather than your child themselves. It is important to focus on food as medicine and remain positive to support your child, giving them confidence in themselves, their treatment, and their recovery.

Your child's recovery will include periods of struggle and pain, but also times of achievements.

Research shows that early intervention, such as this admission to hospital with supportive family engagement in therapy, results in better outcomes. It may be difficult to imagine how your child's future will look; remember that the treatment they receive here will assist them to have the greatest outcome possible.

Your child's care team

There are many different staff involved in your child's care who are committed to their recovery. The team will meet with you regularly to discuss goals and treatment plans. The team may include, but is not limited to:

- Child and Adolescent Psychiatrist
- Child and Youth Mental Health Service (CYMHS)
- General Paediatrician
- Clinical Nurse Consultant or Team Leader
- Nursing team
- Dietitian
- Psychologist
- Social worker
- Hospital schoolteacher (not academic focused – maintains contact with child's primary education facility)

What will happen on the ward?

The medical team admit your child under a paediatrician who will closely monitor your child during their re-feeding. The paediatrician will contact the Child and Youth Mental Health Service team who will see you and your child Tuesday mornings and/or Thursday afternoons. The focus during this initial treatment period is on re-feeding and managing medical compromise. The team will discuss with you the initial treatment plan; this consists of a nutrition plan, bed rest, supervision, observations, medications, and medical monitoring. These guidelines may appear

strict and sometimes hard to accept. They have been developed by Queensland experts in eating disorders and are essential for the treatment and recovery of your child. The team will meet with you regularly throughout the admission to discuss your child's progress. It is very important that the treating team and the family present a united front against the eating disorder and that they work together to strictly adhere to the plan. During your child's hospital stay, you may find that the eating disorder thoughts and behaviours are an attempt to create conflict and non-unity amongst the members of your treating team. Recognition of this and continuing to work as a team is integral to managing these thoughts and behaviours.

Nutrition plan

The nutrition plan for initial re-feeding will be based on how medically compromised your child is. The term "medically compromised" is used when people have an abnormal heart rate, body temperature, blood pressure and/or blood sugar/electrolytes as a result of their eating disorder. From admission your child will receive a nasogastric tube (NGT) which is a small tube that runs up the nose, down the back of the throat and into the stomach to deliver nutrition. The nutrition plan is prescribed by the dietitian to meet all your child's nutritional needs during this critical re-feeding stage. Your child may be prescribed medications that include a multivitamin and thiamine supplements that support their bodies health and reduce the risk of further medical compromise during refeeding and restoring your child's nutritional status.

Bed rest

Medically compromised children must avoid being physically active and are prescribed full bed rest (resting either in bed or a chair) and must only use a wheelchair around the ward on admission. Bed rest will be reduced when the medical team determines your child's physical health is able to mobilise without risk of significant deterioration. Any physical activity will increase the energy expenditure of the child and must be accounted for when determining their nutritional plan. Activities for your child to use during their stay on the children's ward will be available depending on the child's age and interests (i.e., jigsaw puzzles, boardgames and craft supplies). Please make sure your child has warm clothing in hospital as it gets cold due to the air-conditioning and the medical compromise associated with eating disorders.

Supervision

Close monitoring and supervision throughout the child's admission are essential for their recovery. To assist with this, their room will be located near the nursing station. Initially, all children will be placed in a multi-room bay to allow adequate supervision. Bed curtains are to remain open (excluding changing), and all meal and snack times are supportively supervised by parents and/or nursing staff. This provides role modelling of meal support to families and may assist in distracting your child from strong eating disorder thoughts. Post meal distraction and supervision is integral as the eating disorder thoughts and behaviours can become more prominent after your child has completed their meals.

Children will also be sensitively supervised during all bathroom visits by parent/carer or nursing staff (nursing staff are in the bathroom). Showers are to be limited to 5 minutes, so the body does not use up too much energy. Patients are not to have bathroom visits for an hour after main meals and half an hour after snacks; as such, attending the bathroom before meals is encouraged.

Monitoring

Your child will have regular heart rate, blood pressure (sitting and standing), blood tests and blood glucose monitoring. They are weighed twice a week on Mondays and Thursdays; this occurs before breakfast and after first wee (urine) of the morning in hospital gown on seated scales.

Nutrition

"Food is medicine" is frequently discussed with children with eating disorders, especially during the initial re-feeding treatment. This is because adequate nutrition is the most important treatment during this phase for malnourished patients. Depending on the child's level of malnutrition, consuming large amounts of foods (particularly compared to the volumes of food that they had been consuming at home prior to admission) can place them at risk of re-feeding syndrome. This syndrome causes rapid changes in fluids and electrolytes in the body and places the patient at risk of cardiac arrest. To prevent re-feeding syndrome the dietitian will prescribe specific meal plans that gradually increase over the admission to provide enough food to rebuild the body.

At the start of admission, to ensure the slow, continuous administration of nutrition and reduce the risk of complications, an NG tube is used.

When an NG tube is inserted, the team aims to reduce its use as quickly as possible, as your child increases their oral food intake. Some mealtime guidelines that help make mealtimes more manageable:

- Not allowed:
 - ‘outside’ food – even lollies
 - chewing gum
 - coffee / tea.
- The dietitian has the experience and expertise; they are the only person able to make changes to the meal plan
- Meals are to be supportively supervised by nursing staff and families
- All drinks should be decanted into a cup so as the eating disorder is not exposed to nutritional information/calorie contents
- It’s important that there are strict time limits on mealtimes which can help to reduce stress and anxiety around food as well as energy expenditure during the mealtime period. The following time limits are provided from when the food is placed in front of your child:
 - 30 minutes for main meals
 - 15 minutes for snacks.
 - Where meals are not able to be completed in full during these time limits, a meal supplementation will be provided

Meal size and individual item components may be confronting for not only the young person by the family supporting the child and the meal. The energy requirements have been individually determined for your child and discussion with your child and their eating disorder about meal constituents is discouraged and may negatively impact their recovery.

Managing mealtimes

Often, a family’s experience of mealtimes prior to admission has been highly stressful. Below is a list of strategies used to support your child during mealtimes on the ward.

- Remember that you are the parent. You need to take initiative to lead and support your child.

- It is important to validate how difficult the process may be for your child. Perhaps you could say, “I know this is hard, but we can do this together”.
- Use distraction at mealtimes such as talking about home life, friends, family, pets and get your child involved in conversation; this can reduce unhelpful thoughts or negative self-talk that avoids eating and may distract all from the task of completing the meal.
- It is helpful to have two supportive caregivers available to assist your child at mealtimes. Presenting a united front leaves less opportunity for your child’s eating disorder to take over at mealtimes.
- Limit the number of additional visitors present during mealtimes initially.
- If the eating disorder becomes stronger during meals, provide consistent messages to help remind them to focus on a meal. Prompt them to pick up their fork, pick up food and bring to mouth to start eating, then repeat this every few minutes. Phrases to use include “We love you and we want you to get better, please start eating now. Food is medicine.”
- Deep breathing might also be helpful to calm your child. Try encouraging your child to breathe into the count of three, hold their breath for two counts and breathe out to the count of three.
- Lastly, keep calm! Eating disorders thrive on panic and uncertainty. Eating disorders want you to escalate, become frustrated and walk away from the difficult situation. Do not give up. Remember, one meal at a time. Be persistent and patient during mealtimes with your child.

Post-meal support

The time after a meal can be some of the most stressful for your child as it is often filled with negative self-talk about eating or unrealistic consequences about food eaten i.e., ‘now I’m going to be fat’ which are not helpful for recovery. Post-meal support gives the families the opportunity to support their child to manage these emotions.

Having routines after a meal can provide welcome distraction from distressing thoughts and help your child focus on developing their skills to cope with stressful times for the future. The following are examples of helpful strategies which may support a successful transition back into your child routines following a challenging mealtime:

- Remove all food trays to create a safe place for your child that limits unnecessary exposure to food/ food related items that

may cause distress.

- Establish a post-meal routine filled with activities your child finds calming or enjoyable i.e., listening to favourite music, playing a favourite game/watching an enjoyable movie together, reading a book.
- Use controlled breathing exercises, mindfulness techniques, guided meditation, and grounding strategies to support your child's emotional state. Your child's psychologist has many helpful strategies that will be suited to the individual needs of your child.

Preparing for discharge

As your child moves through their admission, we start preparing and planning for discharge. To help a smooth transition back into home life, a gradual process of having some meals in the hospital grounds and at home will be organised. This will help to provide some normality around meals and allow families to practice the strategies they have learnt in practice with some of the pressures of normal life. You and your child will work closely with the dietitian to prepare for going home and continue to be followed up after discharge. Once home, you will have regular follow ups with your CYMHS case manager, your GP and your Dietician. The team will support you and your family to keep on track with your goals to avoid returning to hospital.

Caring for yourself and your family

It is very important that you look after yourself and your family while your child is fighting the eating disorder. Self-care does not have to be extravagant or involve costly activities but is a way to nurture your mind and body to support long-term coping and positive ways to manage stress. Below are some tips:

- 1. Acknowledge that not everyone will understand** your situation or eating disorders and that is ok. Maintain contact with people in your life who can support you through this difficult time.
- 2. It is important to be mindful of other siblings during your child's admission.** Siblings often feel left out and deprived of time with their parents as the primary focus needs to be on the child with an eating disorder. Where possible, make time for one-on-one time with your other children as they often need comfort and support to make sense of their siblings eating disorder and needs.

- 3. Maintain the basics!** Being on the ward can feel all-consuming; however, taking regular breaks to support your body's basic functioning is vital to maintain energy levels to support your child's long-term recovery.
- 4. You don't have to do this alone.** Where possible, tag team with other family members as this allows you to continue to complete parenting responsibilities or work commitments necessary to maintain your family life outside of the hospital. Remind your child that there is always someone on the ward willing to listen to them and help them (be this a family or staff member).
- 5. Recovery is a marathon not a sprint.** Fighting an eating disorder requires perseverance, bravery and resilience. There will be times during the re-feeding process where you want to give up, lose motivation or are feeling very overwhelmed or frustrated. This is ok and a normal reaction to an extremely challenging time for both your child and your family. Acknowledging that this progress is not always straight forward and comes with many setbacks helps to take the pressure off.
- 6. Ask for HELP!** Use your family resources / support networks for assistance where possible (so that you can continue putting your energy and focus into re-feeding your child). This may mean stepping outside of your comfort zone and seeking help and support from trusted others. It is ok to ask for help and this will also role model positive coping strategies to your child for the future.
- 7. Practise daily self-care strategies.** Self-care activities can be anything you find calming, relaxing, enjoyable or something that takes your mind off your child's eating disorder and the admission. This could include reading a book, listening to music or a gentle walk outside. Scheduling in daily activities that make you feel good is an important part of a family's ability to cope with their child's admission and can be a wonderful way to role model how to practice self-care to your child.
- 8. Learn emotional regulation and adaptive coping strategies.** Your ward psychologist has many useful strategies which will be offered throughout your child's admission.

More information

Eating Disorders QLD

Offer many different carers support services, over the phone and online. They are all based out of Brisbane but if you contact Eating Disorders QLD, they can assist you in connecting to different groups including:

- **Individual support** – phone or face to face – to help carers increase their understanding of eating disorders and ways they can support their loved one's recovery
- **Fostering Recovery Workshop** – workshop aims to provide carers with a tool kit of positive coping strategies and communication skills (runs 4 times per year in Brisbane)
- **Carer Connect Support Group** – a monthly support group with a different topic/focus each month and an opportunity to connect with other carers in a similar situation. Sharing is encouraged but not compulsory.
- **Carer Peer Mentor Program** – link in with a mentor who has supported a loved one to recover from an eating disorder

Website: eatingdisordersqueensland.org.au

Phone: (07) 3844 6055

Email: admin@edq.org.au

Websites

- **Maudsley Parents**
www.maudsleyparents.org
- **FEAST (Families Empowering And Supporting Treatment of Eating Disorders)**
www.feast-ed.org/
- **The Butterfly Foundation**
<http://thebutterflyfoundation.org.au/>
- **National Disorders Collaboration**
www.nedc.com.au/helplines
- **Around The Dinner Table**
www.aroundthedinnertable.org

Books

- 'Brave Girl Eating' - Harriet Brown
- 'When Anorexia Came to Visit' - Bev Mattock
- 'Help Your Child Beat an Eating Disorder' - James Lock & Daniel Le Grange
- 'Help Your Child Start to Recover from Anorexia Nervosa: A Practical Guide (Children's Ward book: Can loan to inpatients)
- "Unpack your eating disorder" – Maria Ganci and Dr Linsey Atkins

YouTube links

- **Medical complications of eating disorders** (10+ mins) www.youtube.com/watch?v=oHJLQTAa7nl
- **Understanding eating disorders** (2 mins) www.youtube.com/watch?v=KellmifQFQ4
- **Parents and eating disorders treatment** (4 mins) www.youtube.com/watch?v=axSo3aQdfvo
- **When your child refuses to eat** (6 mins) www.youtube.com/watch?v=of9gDhuOhnQ
- **Lessons for parents: the recovery process** (5 mins) www.youtube.com/watch?v=w4iUTPpoMZw
- **Supporting your child through recovery** (3 mins) www.youtube.com/watch?v=IHXePHIDIns
- **Eating disorder meal support** (30+ mins) www.ceed.org.au/video/eating-disorder-meal-support

If you have any questions or need further information please contact the Children's Ward on (07) 4433 2348.

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