Paediatric Eating Disorders

Information for Parents & Caregivers

Developed by the Nurse Consultants for
Eating Disorders at WCH and FMC 2021

Government of South Australia
SA Health

Background

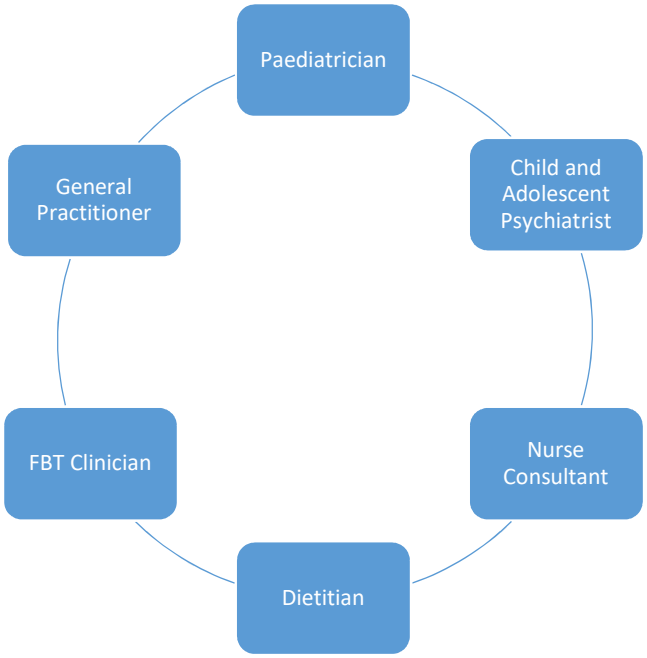
Eating disorders are serious life threatening illnesses and need to be treated quickly to:

- provide medical treatment
- reduce the risk of further malnourishment
- ensure a full recovery.

Eating disorders affect children and adolescents of all age, gender, ethnicity, culture and family backgrounds.

We have a treating team who specialise in eating disorders in children/adolescents and will work together with you to treat the eating disorder. As a treating team we share the same beliefs, values and treatment goals. It is very important that both parents/caregivers and the treating team are consistent in the messages we give to the child/adolescent about the eating disorder as consistency will be key in recovery.

Your child/adolescent will have a specialist team to help with recovery:



Outpatient based appointments are the usual way we treat and monitor children and adolescents with eating disorders. Sometimes, an admission to hospital may be required for medical instability. A hospital admission is not viewed as a failing and does not result in a worse outcome for recovery but rather, helps to get families started on the road to recovery.

We would like to reassure you that:

- We believe you are not to blame for this illness
- We believe in you
- We are here to support you
- We are always here for you.

What is an eating disorder?

If you are ever concerned for any reason, please bring your child/adolescent to the nearest Emergency Department or call an Ambulance for a medical assessment. Your concern is taken seriously.

An eating disorder is described as a severe illness that causes disturbances in thinking and behaviour around food, eating, body weight or shape. There are different types of eating disorders which are outlined in the table below.

Common types of eating disorders

Eating disorder	Description
Anorexia Nervosa (AN)	Is a serious illness associated with significant morbidity and mortality. The illness is characterised by a refusal to maintain a minimally normal weight for age and height, intense fear of weight gain and body image disturbance or lack of recognition of the seriousness of low weight.
Atypical Anorexia Nervosa	Is diagnosed when all the criteria for anorexia nervosa are present except that weight has not yet dropped far enough to qualify for Anorexia. Despite significant weight loss, the individual's weight is within or above the normal range. The treatment with the associated medical and other risks with Atypical Anorexia are the same as for Anorexia Nervosa so it is best considered as the same illness.
Bulimia Nervosa	Is predominantly characterised by recurrent episodes of bingeing and purging behaviour.
Other Specified Feeding or Eating Disorder (OSFED) or Unspecified Feeding or Eating Disorder (USFED)	Describes conditions that meet some but not all characteristics of another Eating Disorder.
Avoidant Restrictive Food Intake Disorder (ARFID)	Is an eating or feeding disturbance as manifested by persistent failure to meet appropriate nutritional and/or energy needs, which results in significant weight loss without the disturbance of body image.
Bingeing	Is the act of eating abnormally large amounts of food in a short period of time.
Purging	Is the use of vomiting or other methods, such as laxatives in an attempt to neutralise caloric intake.

The factors that contribute to the onset of an eating disorder are complex. No single cause of eating disorders has been identified however known contributing risk factors include:

- genetic vulnerability such as family genetics
- socio-cultural influences such as media
- psychological factors.

Extreme weight loss behaviours

Prior to the onset of an eating disorder, there is often a development of abnormal behaviour around eating and we explore these in the table below:

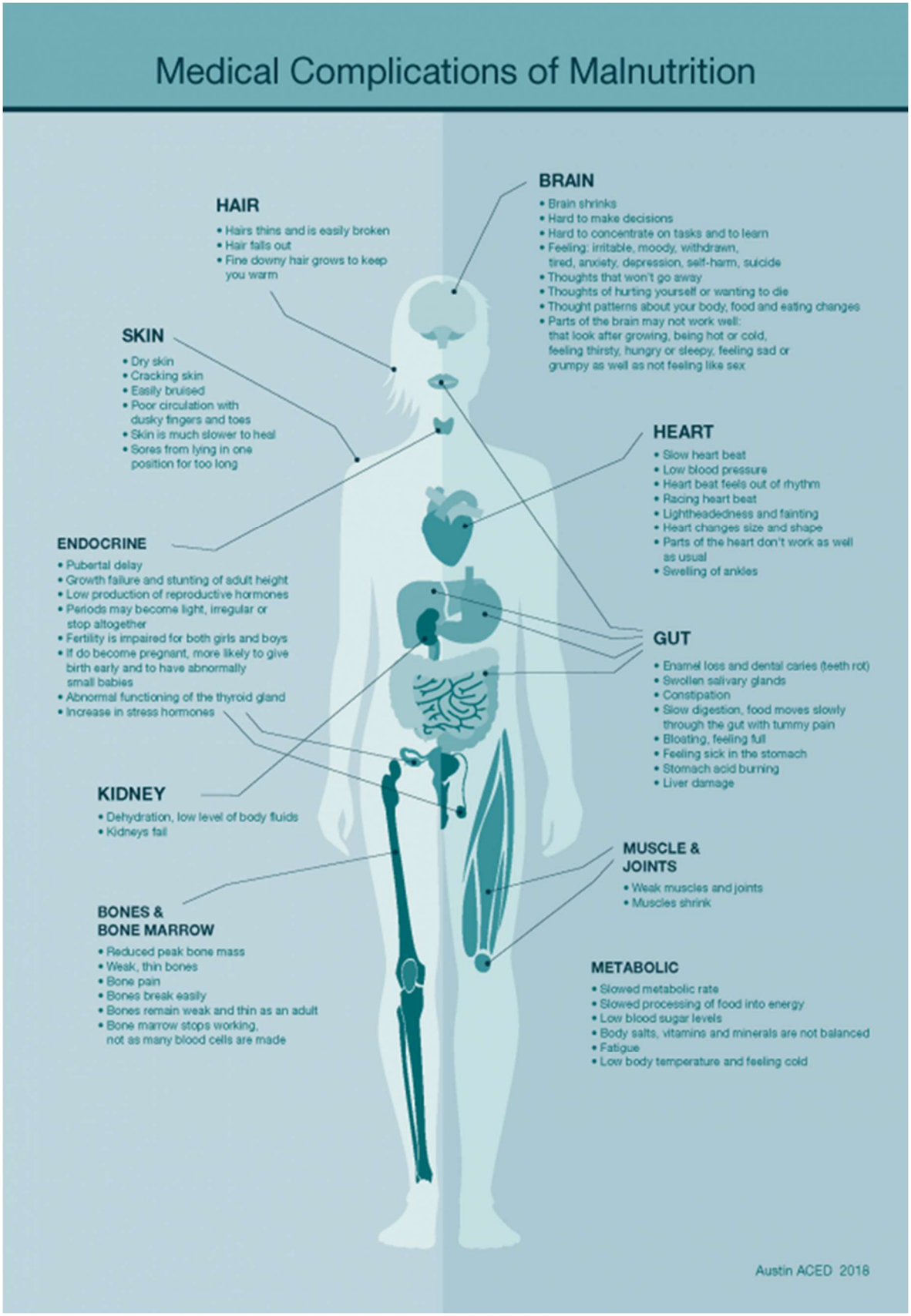
Behaviour	Description
Disordered eating	Disordered eating is the single most important indicator of onset of an eating disorder. Disordered eating is a disturbed pattern of eating that can include fasting and skipping meals, eliminating food groups, restrictive dieting accompanied by binge eating and excessive exercise. Disordered eating can also include purging behaviours such as laxative abuse and self-induced vomiting. Disordered eating can result in significant mental, physical and social impairment and is associated with not only eating disorders but also health concerns such as depression, anxiety, nutritional and metabolic problems and weight gain.
Dieting	While moderate changes in diet and exercise have been shown to be safe, significant mental and physical consequences may occur with extreme or unhealthy dieting practices. Dieting is associated with the development of eating disorders. It is also associated with other health concerns including depression, anxiety, nutritional and metabolic problems, and, contrary to expectation, an increase in weight.

Monitoring physical symptoms of an eating disorder

Eating disorders can impact many systems of the body. When caring for a child/adolescent with an eating disorder, Paediatricians and General Practitioners (GPs) take care to assess patient's health and some of the areas are outlined in the table below.

Test / Measurement	Reasons why
Blood pressure and pulse (lying and standing)	Blood pressure and pulse rates are measured after lying for 5 minutes and again after 2 minutes of standing. This assists doctors in measuring how much work the heart has to do to maintain normal blood pressure. Big changes in pulse and blood pressure can result in dizziness, feeling faint or fainting.
Temperature	Temperature is checked as when the body has reduced energy and insulation, children and adolescents can have a lowered body temperature. Temperature needs to be monitored closely as extremely low temperature (such as hypothermia) can lead to health problems.
Blood tests	Blood tests are essential to help doctors assess what is happening within the body. Some blood tests can test for any potential underlying conditions and others assist in monitoring the child/adolescent's health. Blood tests can be worrying for children and adolescents. Please speak to your doctor if this is a concern.
Bone Density Scan	Without adequate nutrition (usually calcium and vitamin D), bones can become weak. In children and adolescents it is particularly important to maintain good bone health for growth.
Re-feeding syndrome	The complex of potentially severe metabolic complications that can occur when re-feeding a malnourished person. Close medical monitoring is required.
ECG	An ECG is performed to check the heart for any abnormalities. This is assessed by measuring the electrical activity produced by the heart. The test involved electrodes (sticky dots with a wire attached) being attached to the chest, arms and legs.
Height and weight	It is important that weight is measured by a nurse or doctor regularly to check for progress toward re-nourishment. Measuring height is equally as important as it assists to measure growth and to calculate healthy weight.

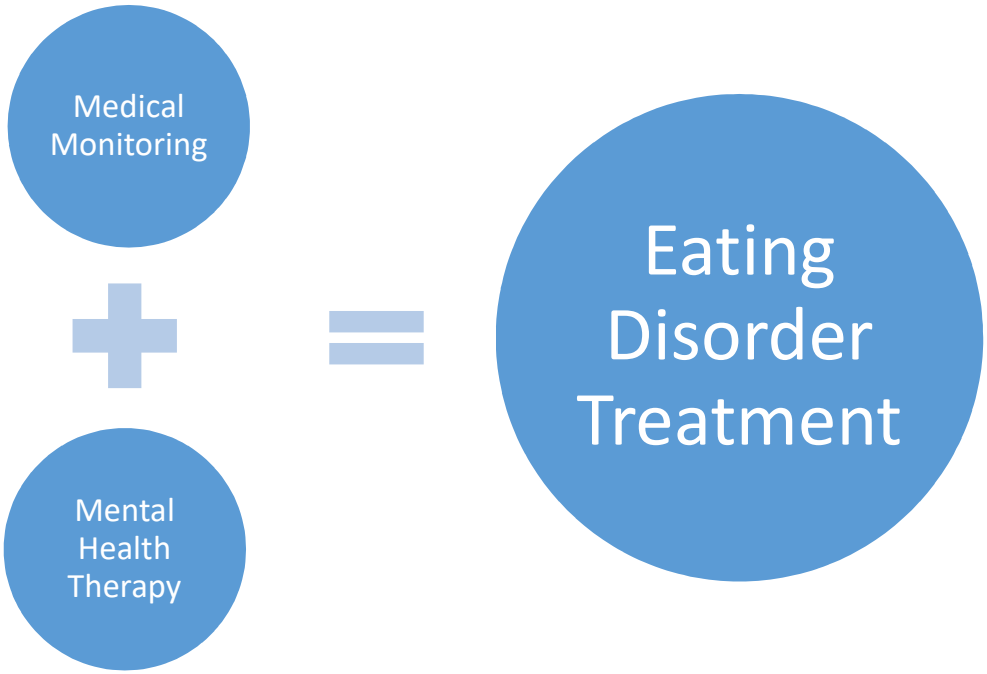
Eating disorders can affect many body systems and functions



Reference 1: nedc.com.au/research-and-resources

Treating an eating disorder

There are two parts to treating an eating disorder:



Medical Management

Medical monitoring is essential in ensuring that children and adolescents are safe from a health perspective. Medical check-ups are made in partnership between the Hospital Outpatient Clinic or Private Paediatrician and your family GP. We will communicate with your GP to provide them with the information about what tests and observations we require to be measured.

Mental Health Therapy

There are different forms of therapy which can be used to treat eating disorders and the Paediatrician or Psychiatrist will provide opinion into which therapy is best suited to the child/adolescent.

Generally, Family Based Treatment (FBT) is the first line form of therapy for children and adolescents with Anorexia Nervosa.

The core principles of FBT are:

- No one is to blame for the development of the eating disorder
- The eating disorder needs to be talked about as separate from the child/adolescent
- The family are viewed as the best resource to help the child/adolescent recover
- Hospital admissions are short term solution for medical stabilisation.

FBT aims to assist the parents/caregivers to:

- Help restore their child/adolescent's weight to normal levels expected given their age and height
- Eventually hand the control over eating back to the child/adolescent
- Encourage normal child/adolescent development.

There are public options for FBT through Child and Adolescent Mental Health Service (CAMHS) and private options through a variety of providers. There are Medicare rebates under an 'Eating Disorder Care Plan' which can reduce fees when accessing private providers. Your doctor will discuss these options with you. All clinicians in the public and private sector are equally skilled to treat eating disorders. You may find that there are wait lists, however we will equip you with the principles of FBT so that you can start treatment at home.

FBT consists of three phases:

Phase One – Weight Restoration	Parents/caregivers take over the full responsibility for all decisions relating to meals, meal preparation and quantity of food provided. 3 meals and 3 snacks are to be provided and fully supervised each day. 30 minutes after snacks and 1 hour after meal time should be supervised to ensure meals remain within the body and excess energy is not expended. 100% of the food needs to be eaten at each meal/snack 100% of the time. Stop exercise and sports, reintroducing under medical direction.
Phase Two – Weight Stabilisation	Transitioning to Phase Two is not a decision made just about weight but there should also be reduced eating disorder thinking. Parents/caregivers start to give some control back to the child/adolescent with support of the FBT therapist. 3 meals and 3 snacks per day should continue to be provided and supervised in line with FBT therapist guidelines.
Phase Three - Recovery	When the child/adolescent is able to make decisions about food and eating without support and they don't have any eating disorder thinking or behaviour, they will moved to Phase Three. This is a relatively short phase that focuses on normal issues of child/adolescent development.

PHASE ONE: REFEEDING AND WEIGHT RESTORATION

The parents/caregivers are given the responsibility of re-feeding their child/adolescent and containing eating disorder behaviours. The clinician coaches the parents/caregivers to manage problematic eating disorder behaviours and brainstorm barriers to refeeding.

In Phase One, also referred to as the weight restoration phase, the therapist focuses on the dangers of severe malnutrition associated with AN, such as hypothermia (low body temperature), growth hormone changes, cardiac dysfunction, and cognitive and emotional changes. They also assess the family's typical interaction pattern and eating habits and assisting parents/caregivers in re-feeding their child or adolescent. The therapist will make every effort to help the parents/caregivers in their joint attempt to restore their child/adolescent's weight.

A family meal is typically conducted during this phase, which is helpful because:

- It allows the therapist to observe the family's typical interaction patterns around eating, and it provides the therapist with an opportunity to assist the parents/caregivers in their endeavour to encourage their child/adolescent to eat a little more than they were prepared to. The way in which the parents/caregivers go about this difficult but delicate task does not differ much in terms of the key principles and steps that an inpatient nursing team would follow. That is, an expression of

sympathy and understanding by the parents/caregivers with their child/adolescent's predicament of being ambivalent about this debilitating eating disorder, while at the same time being verbally persistent in their expectation that starvation is not an option.

- Most of this first phase of treatment is taken up by coaching the parents/caregivers toward success in the weight restoration of their child/adolescent, expressing support and empathy toward the child/adolescent given their predicament of entanglement with the illness, and realigning the child/adolescent with their siblings and peers. Realignment with ones siblings or peers means helping the child/adolescent to form stronger and more age appropriate relationships as opposed to being taken up into an adult relationship.
- Throughout, the role of the therapist is to model to the parents/caregivers an uncritical stance toward the child/adolescent. FBT adheres to the belief that the child/adolescent is not to blame for the challenging eating disorder behaviours, but rather that these symptoms are mostly outside of the their control (externalising the illness). At no point should this phase of treatment be interpreted as a green light for parents/caregivers to be critical of their child/adolescent. The therapist will work hard to address any parental criticism or hostility toward the child/adolescent.

PHASE TWO: RETURNING CONTROL OF EATING TO THE CHILD/ADOLESCENT

The child/adolescent's acceptance of parent/caregiver demand for increased food intake, steady weight gain, as well as a change in the mood of the family (i.e. relief at having taken charge of the eating disorder) all signal the start of Phase Two of treatment.

In Phase Two, the parents/caregivers gradually hand back control of eating to their child/adolescent whilst managing any lapses. Family issues and relationships are simultaneously addressed as the focus slowly moves away from weight and food.

This phase of treatment focuses on encouraging the parents/caregivers to help their child/adolescent to take more control over eating once again. The therapist advises the parents/caregivers to accept the main task is the return of their child/adolescent to physical health and that this now happens mostly in a way that is in keeping with their child/adolescent's age and their parenting style.

Although symptoms remain central in the discussions between the therapist and the family, weight gain with minimum tension is encouraged. In addition, all other general family relationship issues or difficulties in terms of day-to-day parenting concerns that the family has had to postpone can now be brought forward for review.

Issues which are addressed in this phase are those which have an impact on parents/caregivers in their task of assuring steady weight gain. For example, the young person may want to go out with their friends to have dinner and a movie. However, while the parents/caregivers are still unsure whether their child/adolescent would eat entirely on their own accord, they might be required to have dinner with you and then be allowed to join friends for a movie.

PHASE THREE: ADDRESSING CHILD/ADOLESCENT ISSUES AND TREATMENT COMPLETION

The final phase assumes that the child/adolescent is weight restored and in control of their eating behaviours. The focus is on addressing normal child/adolescent issues and strengthening a sense of identity without the eating disorder.

Phase Three is initiated when the child/adolescent is able to maintain weight above 95% of ideal weight on their own and self-starvation has stopped. Treatment focus starts to shift to the impact the eating disorder has had on the individual establishing a healthy self-identity. This entails a review of central issues of childhood/adolescence and includes supporting increased personal autonomy for the child/adolescent relevant to their developmental stage, the development of appropriate parental boundaries, as well as the need for the parents to reorganise their life together after their children's prospective departure.

Nutritional guidelines for families

Malnutrition has devastating psychological as well as physical effects. Learning about the impact of starvation on the mind may help parents/caregivers understand why restorative nutrition is crucial for complete mental and physical recovery.

The Minnesota Semi-Starvation Study (Minnesota starvation study) offers insight into the ways in which inadequate food intake influences mental as well as physical health and there is a link to this study in the reference section of the handbook. Many of the psychological symptoms commonly seen in Anorexia Nervosa, including depression, anxiety, social isolation and obsessionality, are the result of malnutrition.

In the earliest phase of FBT, parents/caregivers work together to make sure their child/adolescent regains weight to a healthy level. Once weight restoration is accomplished, a recovering child/adolescent is better able to return to healthful independent eating and get on with their normal life. Good nutrition over the long term will help reverse both the physical and the psychological effects of starvation.

Many parents/caregiver feel unsure or nervous to take on the responsibility for the nutrition for their child/adolescent with an eating disorder. However, it is important to remember that up until the point your child/adolescent had an eating disorder, your child/adolescent was getting adequate nutrition and you were doing a great job in this regard. Nutrition can be a science but it need not be so difficult, humans and families have naturally provided balanced nourishment to their bodies and their child/adolescent's bodies for thousands of years for survival, and nutrition has always had other important roles e.g. for social interaction and celebration. The eating disorder in your family's life has upset the natural balance and enjoyment in eating for your child/adolescent. However, as parents/caregivers (with support of your family therapist) you do have the knowledge, skill and ability to know what to feed your child/adolescent and find strategies to work against the eating disorder and ensure that this food is consumed.

A meal plan set by a health professional can have negative consequences for a child/adolescent with an eating disorder and we recommend normal family meals.

This is because sticking to a rigid meal plan is not normal eating, and one of the important goals is for the child/adolescent to be able to eat a normal range of family foods. Also, the rigidity of thinking that occurs in a sufferer of an eating disorder can be exacerbated by a rigid meal plan. Coping with foods not on the meal plan, such as running out of a particular food, can become extremely challenging in the future if you follow a set meal plan each day.

Parents/caregivers should discuss between themselves what they believe are appropriate meals and snacks and the volumes of food to be served. They can then plan to make sure they have the food available. However, variety by not having the same thing for a particular meal or snack each day is important, as is flexibility by being able to change if circumstances change.

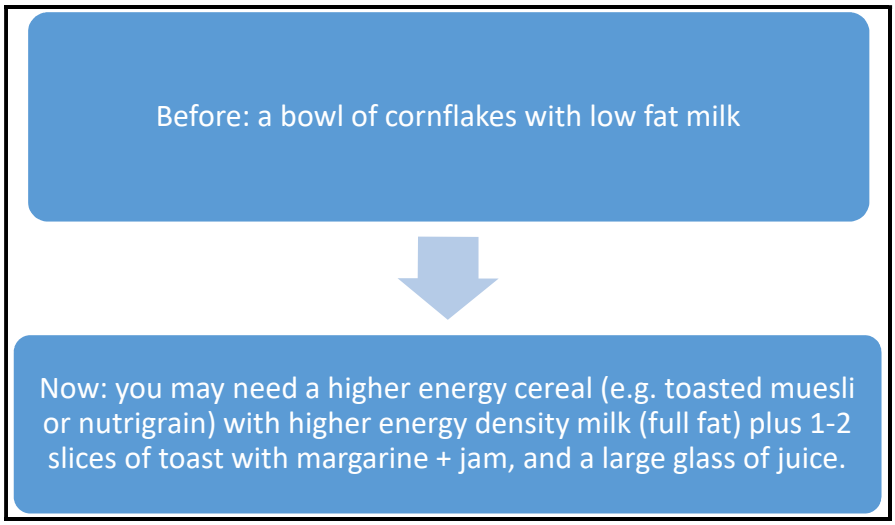
It can be confusing about what constitutes balanced nutrition as information about healthy eating are often targeted towards overweight adults, or in preventing obesity in people vulnerable to this condition. This advice can be unhealthy for children and adolescents who are still growing and can be extremely detrimental for someone recovering from starvation.

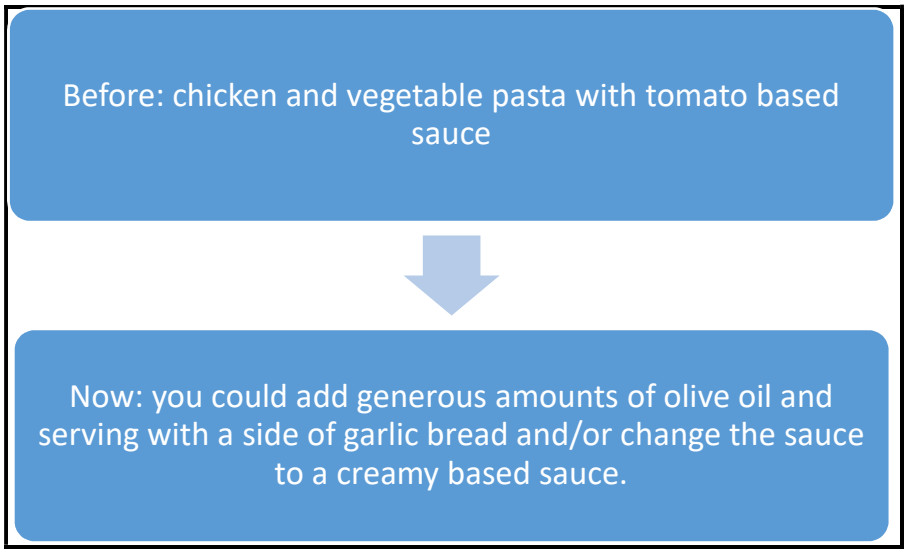
There are a few special considerations for nutrition in recovery from an eating disorder, and the following points will help you meet your child/adolescent's needs:

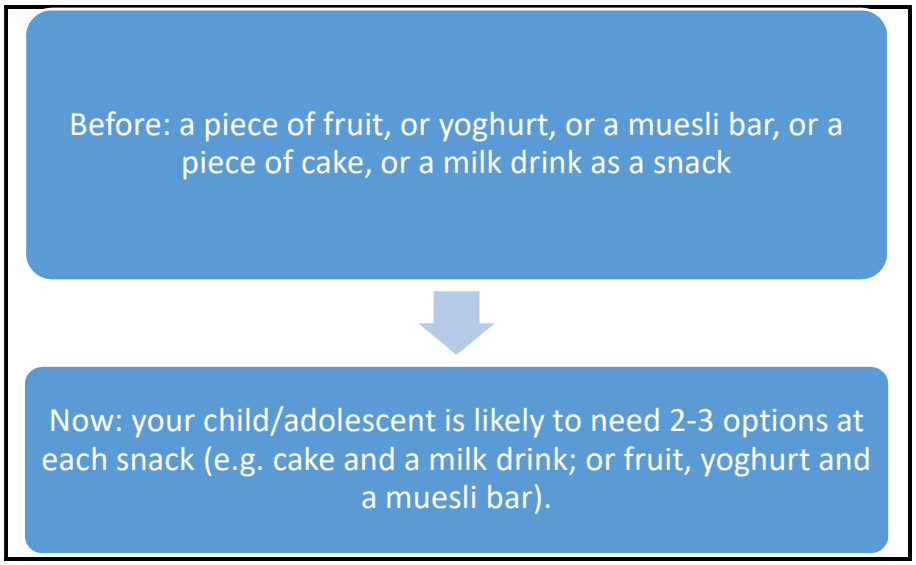
- Your child/adolescent has been starving. To help the body recover its bone mass, muscle mass and heal from the acute medical stress, your child/adolescent's nutritional requirements are higher than other healthy active children/adolescents.
- Teenagers naturally have very high energy (calorie) and nutrition needs as their bodies grow and mature rapidly. The typical healthy teenager should be eating more than the typical adult.
- Serve 3 meals and 3 snacks every day. Your child/adolescent is unlikely to be able to help themselves to snacks with the eating disorder present, so you will now need to ensure they are served to your child and they are supported in eating it.
- Iron deficiency is a common problem in teenage girls in Australia. Good sources of iron include red meat, chicken, fish, eggs and in lesser amounts green leafy vegetables and legumes. Have 1 to 2 generous serves of one or more of these foods daily.
- Bone health can be negatively affected by eating disorders. Ensuring adequate calcium intake is very important. The best natural source of calcium is dairy foods (e.g. milk, yoghurt, custard, cheese). Alternate sources include calcium fortified soy milks and products or calcium fortified rice milk or oat milk (note that calcium fortified rice and oat milk have much less protein and fat than standard milk). Your child/adolescent needs a minimum of 3 serves (where one serve equals 250ml milk, custard, yoghurt or 40g cheese) per day to meet their calcium needs. However, you may like to give them more than this as it is also a good source of energy and protein.
- A balanced diet of carbohydrates, proteins and fats is important by eating foods from all the food groups i.e. cereals (includes bread, breakfast cereal, rice, pasta, noodles), vegetables, fruits, dairy, meat/meat alternatives and fats.

Having a wide variety of food and being able to eat foods normally consumed at home or in the social context is important for your child/adolescent's health, as is being able to eat feared foods (e.g. foods containing fats or sugars).

It can be hard to meet these very high nutrition needs. You need to consider volume of food as well as energy density of food. Some examples include:







Tips and ideas

- We think of food as medicine. The 'dose' of food is different for every family member meaning that everyone does not have to eat the same 'dose' as the child/adolescent.
- When you leave the kitchen with a meal, do so feeling confident that you have prepared what the child/adolescent needs.
- Do not use diet, low fat or skim products.
- Use fats (oils, margarine and butter) or foods high in fat (avocado, cheese, cream) generously when preparing meals and snacks.
- Including desserts and high energy foods like chocolate regularly can be part of a balanced diet and will be important as you try and meet your child/adolescent's very high nutrition needs.
- Adding high energy drinks such as fruit juice, flavoured milk drinks, soft drink and cordial, rather than water (which has no energy) can be an easy way to boost up your child/adolescent's energy intake further.

Your Family Therapist will help you develop strategies to deal with eating disorder behaviours. The eating disorder may be intent on you not feeding your child/adolescent adequately, however together the family, child/adolescent and therapist can beat the eating disorder. The approach to eating and other behaviours may need to be altered weekly or more, based on how your child/adolescent is going regarding weight and their overall physical and mental health status.

Can I make my child want to get better?

We wish there were "magic words" that would inspire your child/ adolescent to eat. Children/adolescents haven't chosen to be unwell and similarly cannot 'choose to recover' while they're unwell with an eating disorder. You can help your child/adolescent in their recovery by providing support.

Often children/adolescents tell us they feel nervous and worried after meals and snacks. A helpful way to support your child/adolescent is by offering 'distraction' for during or after meal and snack times as this is when the eating disorder thoughts are their loudest. Distraction can assist your child/adolescent in tolerating the anxiety of eating. Below are some ideas but the most important thing is that the activity is with other people and is engaging enough to be a positive distraction:

- family members talking about things other than food
- listening to music
- detailed colouring in
- watching television
- going for a drive after a meal
- quiz questions
- craft projects or jewellery making
- playing a game or working on a puzzle.

Parents/caregivers have told us that once their child/adolescent was weight restored, psychological recovery followed. The brain is part of the physical body and when it is malnourished, it does not work right. When the brain is well-nourished over a period of time, rational thinking usually resumes. For some children/adolescents the change happens fast and for others weeks or months of full nutrition pass before cognitive and emotional responses improve.

Recommendations for recovery

The role of parents/caregivers is critical during this time to provide ongoing support to your child/adolescent both physically and emotionally. Your support may help to reduce the likelihood of admission however, we are here for you in hospital if an admission is needed. Your child/adolescent will need to go to hospital if their medical safety is seriously at risk or risk related to psychological factors including suicidal thinking as this must be taken seriously and managed.

Outpatient treatment involves regular medical and psychological reviews. Your family will have intensive support from your mental health clinician (FBT therapist). This will involve appointments with the treating team (Family GP, Paediatrician, your mental health clinician and sometimes a Psychiatrist) until your child/adolescent has achieved a healthy weight. It is understandable that you might feel worried about your child/adolescent being at home.

How can parents/caregivers work together to help?

The Family Based Treatment approach is suitable for all family groups. In FBT, parents/caregivers are a major asset in supporting recovery. The key to success is for all the adults in a recovering child/adolescent's life to deliver consistent messages, follow the same rules, and communicate with each other. It is important that you work together to get on the same page. It is important that any disagreements are discussed away from your recovering child/adolescent. For example, you may need to put aside any former disagreements on discipline, lifestyle, and past events. If the eating disorder sees that there is room for it to intervene (such as if adults are not in agreement), the eating disorder will likely increase behaviours to seek power or control over the child/adolescent.

Some parents/caregivers have found the following helpful:

- Present as a united front. Consistency from parents/caregivers is the way to beat eating disorders.
- Troubleshoot and plan privately, not in front of your child/adolescent.
- If a mistake occurs or tempers are high, make the repair/apologise and move on. Everyone makes mistakes.
- Use each adults' strengths: one parent/caregiver may be better at supervising mealtimes, and the other at cooking. One parent/caregiver may be good at research, the other at communicating with clinicians.
- Prioritise your own relationship by taking the time to talk and concentrate on each other.
- Remember that a threat to the family is also an opportunity to demonstrate love and commitment.
- Keep siblings' in mind when making decisions.

My child/adolescent looks at eating disorder websites. How should I handle that?

We recommend that parents/caregivers keep children/adolescents away from all eating disorders websites. Internet use needs to be closely managed, particularly in the early stages of recovery to make sure that the child/adolescent is safe and protected from the eating disorder.

Many eating disorder sufferers look at eating disorder websites. This includes both “pro-ana” (for pro anorexia), “pro-mia” (for pro bulimia), and “pro-recovery” sites. The pro anorexia and bulimia sites can hold a strong appeal to sufferers and cause untold damage. Other sufferers might do a lot of research on celebrities and their appearance. Caregivers should know that even sites promoting recovery can have unintentionally destructive consequences.

Medication

There is no medication cure for anorexia, but medications can be helpful for accompanying anxiety, depression or agitation and stress at meal time. Antidepressants can be helpful with bulimia.

We recommend that parents/caregivers develop a strong partnership with their child/adolescent’s prescribing doctor. Good communication is important. If medication is being considered, your child/adolescent’s doctor should take a careful personal and family history, explain options, and answer any questions you have. Parents and caregivers need to be informed advocates for their child/adolescent.

Since responses and reactions to medications vary among individuals, careful observation is important. You may find it helpful to keep a dated written record with all medications, dosages and reactions. This can help in sorting out a complicated situation later. Parents/caregivers should also remember to note any eating disorder behaviours—restricting, eating on an irregular schedule, purging, water loading, and dehydration—that may influence your child/adolescent’s mental state and potentially on the absorption of medication.

One common medication question is whether oral contraceptives should be prescribed for amenorrhea (absence of menstrual periods) to treat the side effect of bone loss. While this practice used to be common, recent research shows that oral contraceptives are not helpful for increasing bone mineral density for people with an eating disorder. Normal hormonal function typically returns with the restoration of healthy body weight. Oral contraceptives make it impossible to tell whether normal menstruation is occurring, an important measure of health. Parents/Caregivers should be sure to ask the child/adolescent’s doctor about current research if oral contraceptives are being considered or prescribed.

School

We suggest a minimum of staying at home for two to four weeks after diagnosis before returning to school. This is designed to help the parents/caregivers assess and organise the level of support that your child/adolescent needs to eat and put on weight, as well as to consolidate eating patterns. School work may be completed at home via correspondence/online learning at the discretion of the parent/caregiver and treating team.

It is important to note:

- It is the parent/caregiver's responsibility to ensure that their child/adolescent eats during the school day. You will need to go to school initially to eat recess and lunch with your child/adolescent or to take them home for recess and lunch. Some schools can supervise your child/adolescent if you are unable to do this. Some children/adolescents spend half a day at school initially to reduce the anxiety about eating at school.
- School counsellor support around other child/adolescent issues (such as peers and school work) should occur as normal. However, the psychological treatment of the eating disorder should be primarily addressed by family therapists.
- Discuss with the teacher about keeping things as normal as possible in the classroom, but be aware of the emotional and cognitive effects that an eating disorder has on academic and social performance.
- A revised workload and/or exam schedule will be helpful to the child/adolescent in managing the return to school as they are vulnerable to stress secondary to their high expectations.
- Some subjects may be triggering to a young person with an eating disorder and may need to be changed, such as PE, some health topics, and food and hospitality/cooking.
- Your health care team can provide a medical certificate for your child/adolescent and parents/caregivers to cover this leave of absence.

Physical activity

Your treating doctor/therapist will recommend no exercise initially. It is important to discuss exercise with your child/adolescent's doctor and to follow their recommendations around when it is safe to begin. Later, supervised activity can assist in restoring and retaining bone mass, joint flexibility and muscle strength.

Appropriate activity levels for your child/adolescent should be decided by the treating doctor/therapist and a graded approach to gradually re-introducing physical activity is often useful.

It is important that you monitor physical activity for eating disorder behaviour:

- Monitor for incidental exercise such as bending down to pick up dropped items repeatedly, putting items away one by one across the room, appearing to be hovering over a seat rather than sitting or repeatedly going up and down stairs.
- Your child should not be allowed to perform solitary exercises (e.g. running, star jumps, pacing up and down the hall, standing for long periods of time, or using a treadmill). The treating team can give guidance on how to deal with these activities if they occur.
- Be aware that exercising may occur at night time when everyone is asleep.
- Avoid bargaining and negotiating around physical activity.

Returning to normal healthy levels of physical activity can be permitted once the child/adolescent has been stable at/or above minimum healthy weight for a minimum period of 3 months or otherwise directed by your doctor.

Socialising

Friends play a large and important part of children and adolescent's lives. It is the parent/caregiver and child/adolescent's choice about how much information they provide about the eating disorder to friends. Contact with friends is at the parent/caregiver's discretion however, your therapist can give you support to guide your decision. Parents/caregivers should use their judgement about what is likely to be helpful and unhelpful in the early stages of recovery. When commencing contact with friends at home, it is important that the contact does not interfere with meal or snack times and adult supervision may be required.

Some parents/caregivers may help their child/adolescent arrange friend/s visiting the home for a sedentary activity (such as a movie night or game night, outside of meal times) to help their child/adolescent stay connected with peers.

Communication tips

Communicating with your child/adolescent is extremely important however it can be challenging when facing discussions about food and eating.

It is helpful to remember that we see the eating disorder and the child/adolescent separately when addressing eating disorder behaviour.

Sometimes, it is helpful to think of the eating disorder as a bully that you can't see. As the parent/caregiver you will need to protect your child/adolescent from the bully. Your actions of being calm, consistent and taking charge of all food related decisions help to show the bully that you are in charge and that the eating disorder has no place in your child/adolescent's world.

It is important that parents/caregivers do not enter into conversations with the eating disorder as these conversations will likely not be rational and might lead to an unhelpful discussion. Eating disorder conversations might be about food, a meal, exercise or another boundary placed on the eating disorder. Some families have told us that a phrase can be helpful to close these difficult conversations such as *"I hear what you have said, however we are not going to talk about that now*".

Similarly, if a parent/caregiver becomes aware of an eating disorder behaviour it is important that it is addressed. It is important that eating disorder behaviour is addressed in the moment as not doing so can lead to behaviours becoming bigger and more difficult to manage. Challenging eating disorder behaviour is something that needs to be done with care and consideration. The child/adolescent may be embarrassed about the eating disorder behaviour and it is important your child/adolescent knows you are not upset or angry with them, but with their eating disorder behaviour.

Be patient – recovery takes time.

Useful phrases to use when talking to someone with an eating disorder about your concerns:

Address the eating disorder behaviour whilst showing the child/adolescent compassion	"I noticed that your eating disorder was (insert behaviour). I care about the (name) part of you and we need that behaviour to stop"
Normalise mixed feelings	"Part of you feels…, yet part of you wants to…"
Describe the facts as you see them calmly	"I see you think… I think you said… I noticed that…"
Listen carefully to the answers	"Sounds like this might be the way you see things… Have I got that right?"
Listen without judgement	"I can see you feel differently to the way I do. That's ok, everyone has different views; I accept that you feel differently. I want to help the (name) part of you through this"
Offer support	"Is there anything I can do to help?"
Express all positive thoughts and comments as often as possible	Genuine support, love, kindness and respect can make a difference "Thanks for… I like it when…"
Phrase comments on negative eating disorder behaviours in non- judgemental tones. Sandwich such comments between reassurances that it is the behaviour that you dislike and you still love the person	"I care about the (name) part of you. I don't like it when... I understand that this is difficult for you"
Offer alternate activities to alleviate distress or to prevent boredom	"I noticed that you seem (observation such as upset, worried, bored). Can you help me with/Would you like to (activity – such as puzzle/drawing/painting/sedentary task)."

Being Aware of Risky Behaviour

This is a difficult topic, however your therapist has experience in assisting parents/caregivers in managing your child/adolescent's changes in their behaviour. This can be a result of eating disorder thoughts and can be challenging to manage in the home environment.

Some of these challenges are outlined in the table below.

Eating disorder behaviour	**Action**
Exercise at night time when the family is asleep	In order to keep your child/adolescent safe, it may be necessary to increase supervision levels

	at home. Some families have moved their child/adolescent into their bedroom to ensure their child is safe and not exercising or leaving the home at night. Your doctor/therapist can discuss this further with you should you require further support.
Outbursts at meal times when at home	Some parents/caregivers have purchased plastic plates and cups when this has occurred and also made sure that there is always a spare meal or snack accessible should it be discarded.
Suicidal thoughts can occur in young people with an eating disorder	Your doctor/therapist would recommend that if medication (including paracetamol, ibuprofen, vitamins or prescription medication) is in the home that these are locked away. This is to prevent accidental or intentional ingestion of medication. If you suspect that medication has been ingested, please seek urgent medical assistance. As a part of suicidal thoughts, some young people may cut their body with a sharp object. Consider safe storage of sharps or when using sharps (knives/scissors, blades out of pencil sharpener etc.) and if self-harm is a concern, please speak to the doctor and mental health clinician for support.

If you are concerned about your child/adolescent in any way, you can present to any Emergency Department at any time. You may need to increase the supervision and support you provide as parents/caregivers until further medical review.

Financial Support

There can be a financial strain when caring for a child or adolescent with an eating disorder. Support options include:

- You may be eligible for a carer's allowance through Centrelink and your treating team can help with the application process for this.
- Your child/adolescent's treating team can complete a carer medical certificate if required for parent/caregiver leave from work. Social work support is available through hospitals and we can arrange a referral for you.
- SA Ambulance Cover for your child/adolescent to avoid large call-out costs should an Ambulance be called.
- Low cost food stores in Adelaide and some community/council groups offer free or low cost food to families. Contact your local council or search 'free food + your suburb' for assistance.

Parent/caregiver education workshop

Twice a month, there are parent education workshops run by a FBT therapist and are held at the Glenside Campus Learning Centre.

These workshops are open to parents/caregivers as well as family members that you feel would benefit from eating disorder education. The group covers treatment principles of FBT, gives the opportunity for parents/caregivers to develop a peer network and helps build your confidence in managing your child/adolescent at home.

Your doctor/therapist will support you in enrolling in this education workshop.

Resources

- **Victorian Centre for Excellence in Eating Disorders**

  ceed.org.au
- **The Butterfly Foundation**

  National charity that supports people with eating disorders

  butterfly.org.au
- **ED HOPE (Butterfly Foundation's National Helpline)**

  Free, confidential service that provides information, counselling and treatment referral for people with eating disorders, and body image and related issues

  1800 33 4673 (8am-midnight AEST/7 days a week)
- **The Centre for Clinical Interventions, Western Australia**

  cci.health.wa.gov.au
- **Beyond Blue**

  Increases awareness of depression and anxiety and reduce stigma

  1300 22 4636 (24 hours/7 days a week)
- **Headspace**

  Provides mental health and wellbeing support, information and services to young people aged 12 to 25 years and their families

  1800 650 890 (9am-1am AEST/7 days a week)
- **Kids Helpline**

  Free 24/7 confidential and private counselling service specifically for children and young people aged 5 to 25

  1800 55 1800
- **Lifeline**

  Provides 24-hour crisis counselling, support groups and suicide prevention services

  13 11 14
- **Suicide Call Back Service**

  Provides 24/7 support if you or someone you know is feeling suicidal

  1300 659 467

School Resources

> Practical measures schools take to support pupils with an eating disorder

https://anorexiafamily.com/meals-anxiety-school-eating-disorder/?v=6cc98ba2045f

> Schools health promotion, body confidence, diets, disordered eating and obesity: What to do?

https://anorexiafamily.com/health-promotion-ED-prevention-body-obesity-school/?v=6cc98ba2045f

> Is your school supporting lunch? For pupils with an eating disorder, it must.

https://anorexiafamily.com/legal-school-plan-eating-disorder/?v=6cc98ba2045f

> Government of South Australia – Department for Education Health care plans for individual care – information for health professionals

https://www.education.sa.gov.au/sites/default/files/hsp210-oral-eating-drinking.docx

Meal support and understanding eating disorders

> Medical complications of eating disorders (10+ mins)

https://www.youtube.com/watch?app=desktop&v=oHJLQTAa7nI

> Understanding eating disorders (2 mins)

https://www.youtube.com/watch?app=desktop&v=kellmifqfq4+

> Anorexia-parent to parent: What we wish we had understood (40min)

http://parents-to-parents.org/favicon.ico

> Parents and eating disorders treatment (4 mins)

https://www.youtube.com/watch?app=desktop&v=axso3aqdfvo+

> When your child refuses to eat (6 mins)

https://www.youtube.com/watch?app=desktop&v=of9dghuohnq+

> Lessons for parents: the recovery process (5 mins)

https://www.youtube.com/watch?app=desktop&v=w4iutppomzw+

> Supporting your child through recovery (3 mins)

https://www.youtube.com/watch?app=desktop&v=ihxephidlns+

> Eating Disorders Meal Support: Helpful Approaches for Families (35 mins)

https://www.youtube.com/watch?app=desktop&v=ppslduultwe+

> Maudsley Parents Organisation

http://maudsleyparents.org/welcome.html

> Eva Musby

https://www.youtube.com/watch?app=desktop&v=2o9nzawcklc&list=plvgyqbykqsbhubidllc7t3v7bn0lmlcve++

- Eating Disorders from the Inside Out – Laura Hill

https//www.youtube.com/watch?app+desktop&v+ueysoexcwre+

Facebook Support Groups

- ATDTfb - Eating Disorder Family and Carer Support (International)
- FEEDS – Facebook for parents and caregivers (local group in SA)
- EDFA – Facebook group for families and caregivers
- Strive carer support group for South Australia families through Eating Disorders Families Australia (EDFA) site

Online Resources

- http://maudsleyparents.org
- http://www.mirror-mirror.org
- http://evamusby.co.uk
- http://www.feast-ed.org
- http://www.maudsleyparents.org/images/printerfriendly_recipes.pdf
- https://www.refinery29.com/minnesota-starvation-experiment
- https://www.facebook.com/FEASTeatingdisorders
- https://www.aroundthedinnertable.org/?forum=136439#gsc.tab=0
- https://thebutterflyfoundation.org.au/
- https://www.nedc.com.au/
- https://www.edfa.org.au/

Books

- Help your teenager beat an eating disorder second edition – by James Lock and Daniel le Grange (the Guilford Press, 2015)
- Feeding your anorexic adolescent – by Claire Norton (2009)
- Anorexia and other eating disorders – How to help your child eat well and be well – by Eva Musby (ARICA, 2020)

For more information

Women's and Children's Hospital
Paediatric Eating Disorder Service
Telephone: 8161 6344
www.sahealth.sa.gov.au

Interpreter

Government of South Australia
SA Health

Notes: