

Helping your child return to health



Information for parents from the Pediatric Eating Disorders Program

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Inside this book

	Page
Part 1 – Your special role	
Introduction	1
Find the strength to help your child	2
Your child needs <u>your</u> help	4
Where to start	5
Learn as much as you can	6
Part 2 – The general approach to treatment	·
Take the eating disorder seriously	8
Separate the eating disorder from your child	9
Work together as a family	10
How parents can help	11
How other children can help	13
Understand how your child thinks	14
Learn to manage conflict	17
Part 3 – Specific ways to help your child	
Help your child eat normally	19
Take the focus off weight	23
Help your child return to healthy activity	24
Looking ahead	26
A summary for parents	27
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Part 1: Your special role

Introduction

Welcome to the Pediatric Eating Disorders Clinic. Our team of health professionals wrote this booklet to help parents learn about the approach we use to treating eating disorders. Applying this approach can dramatically improve your ability to take control of the eating disorder and return your child to health.

Use the information in this book as a general guide. A trained therapist will create a specific plan for your child's therapy, based on your child's needs and your family's situation. The therapist and other members of the health care team will help with any difficulties you have along the way.

For this approach to be successful, you need to take an active part in your child's therapy. It will help to learn as much as you can about your child's illness and treatment.

Find the strength to help your child

We know that this is a stressful time for you, your child and your family. As a parent of a child with an eating disorder, it is normal for you to have mixed emotions.

You may feel:

- anxious or afraid for your child's health
- overwhelmed with information
- confused by conflicting advice from books and other health care providers
- angry about the impact this illness is having on your family
- helpless or defeated if you don't know what to do
- guilty if you think you might have caused this to happen

All of these feelings are normal.

When your child is diagnosed with an eating disorder your first reaction is usually fear. You never expected this would happen and you want answers:

- Why did this happen?
- Is my child going to be all right?
- What can I do?

It turns out we can do a great deal. It isn't easy and it isn't quick, but eating disorders are treatable. We believe that all young people have the ability to achieve full recovery from an eating disorder. Parents and loved ones have an important and powerful role to play in recovery. It takes a lot of hard work. But you are not alone. We will work together to stop letting the illness overpower your child and your family.

Along the way you will learn about eating disorders and develop skills to help your child. You will also gain confidence and trust in your abilities as a parent. As you become more hopeful and confident, your child will believe that you have the strength to help break the hold of the eating disorder.

Our aim is to empower you so that you can take an active role in your child's treatment. Your involvement will improve your child's chances of a full and complete recovery.



Your child needs your strength. You are the key to your child's return to health.

Your child needs your help

Eating disorders usually occur during the teenage years. During this period of development, children naturally become more interested in their appearance and strive for more privacy and independence. It can be hard for parents to know what behaviours are normal for teen development and what are signs of a serious health problem.

Eating disorders can be confusing for parents.

- You may feel that you are prying when asking your child about personal habits related to food and exercise.
- You may have heard that taking control away from your teen will make the problem worse.
- You want your child to have enough freedom to develop independence, but you know she/he still needs your love and guidance.
- You may wonder if the stormy relationship with your child is to be expected because she/he is a teenager.

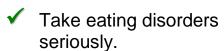
An eating disorder is a serious illness. Just like with any other illness, parents need to be involved in their child's treatment and recovery. Even though your child may insist that she/he is fine and want to make her/his own decisions, **your child does need your help** to regain a healthy weight and normal eating habits.

The eating disorder causes your child a lot of anxiety related to food and weight. This anxiety may lessen briefly when she/he feels in control of these issues. However, the anxiety returns quickly and may be even stronger than before. This leads your child to greater food restrictions and weight loss. This starts a cycle of weight loss and worry. Your child's sense of control is just an illusion. The eating disorder has control and you need to help your child take it back.

Treating an eating disorder requires a team approach. You know your child and family best. This makes you an expert and a valuable part of the health care team.

Where to start

Parents often say they don't know where to start to help their child. Here is a checklist to guide you through the first steps.



- Educate yourself. Learn as much as you can about eating disorders and the approach to treatment.
- Make sure both parents read "Help your teenager beat an eating disorder".
- Come to your child's appointments. Take an active role in your child's therapy.
- Talk to your doctor and therapist about your concerns.
- Learn where to get more information and support.

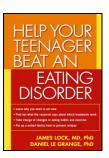
The rest of this booklet will give you more information about each of these points.

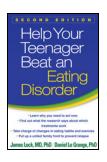
Please write down any questions you have so we can discuss them at your next visit.

Learn as much as you can

At your clinic visits, the health care team will help you better understand eating disorders and learn how to help your child recover. Please feel free to ask questions at any time. As well as talking with professionals, there are many ways to educate yourself.

Recommended reading





2005

2015

We recommend that both parents read our handouts and the resource book:

Help your teenager beat an eating disorder

by J. Lock and D. LeGrange (2005 or 2015 edition).

You may borrow a copy from us or buy it online.

Information on the internet

You can find more information by visiting these websites. If you don't have a computer at home, use one at the Public Library.

www.feast-ed.org

- Families Empowered and Supporting Treatment of Eating Disorders.
- Information and support for parents and caregivers helping loves ones recover from eating disorders.



www.maudsleyparents.org/

 A non-profit, volunteer organization of parents who have used a family-based treatment called the "Maudsley approach" to help their children heal from eating disorders.

www.eatingwithyouranorexic.com/

 A website for parents and caregivers of children with anorexia nervosa.

www.aedweb.org

 The Academy for Eating Disorders is a professional organization that provides information about eating disorders to the public.

www.nedic.ca

 The National Eating Disorders Information Centre is a Canadian non-profit organization that provides resources on eating disorders.

Part 2: The general approach to treatment

Take the eating disorder seriously

Your child is not choosing to be defiant.
This is not a teenage "phase" that she will outgrow.

Eating disorders are serious conditions that can affect every aspect of your child's life. At first, they may start out mild and your child may tell you that she/he is fine. However, research shows that if eating disorders are not treated they can lead to severe health problems, such as those listed in the chart below. Some young people may die if their illness is not treated.

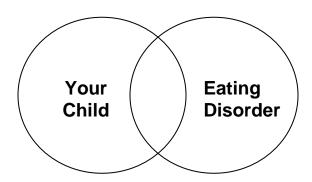
Complications of eating disorders			
Medical	 low temperature and blood pressure weakness and fatigue loss of periods and fertility heart problems brittle bones (osteoporosis) 		
Psychological	chronic depressionsubstance abuseanxietythoughts of suicide or self-harm		
Social	 poor relationships with peers poor school performance limited social skills family and other complications 		

Taking action now can prevent serious health problems from developing. With early and intense treatment, your child has a greater chance of a full recovery.

Separate the eating disorder from your child

It is helpful to see the eating disorder as something separate from your child. This is called "externalizing" the eating disorder. Doing so makes it much easier to fight the illness while continuing to love and care for your child.

This picture shows your child and the eating disorder as two circles.



Over time, the eating disorder circle can cover more of the circle that represents your child.

Remember that your child, the way she/he was before the eating disorder, is still there.

Your child needs your help to prevent the eating disorder from taking over more and more of her/his thoughts and behaviours.

It is important to know that your child may not want to return to being the young person she/he was before the eating disorder took hold. Before the eating disorder, it is likely that your child was struggling with many issues relating to her/his mood, self-concept and worries about the future. With support and treatment, young people with eating disorders often make many changes in how they communicate and the life choices they make. This can be a major period of adjustment for the whole family.

Work together as a family

Our approach to treating eating disorders is family-centred. We believe that families are the best resource for recovery.

When a child has an eating disorder, each person in the family is affected. And each of them will be able to help the child recover, in his or her own way.

Getting your family involved in treatment can accelerate your child's recovery.

Family therapy does not mean there is something "wrong" with the family or that "family problems" are the cause of the eating disorder. Family therapy simply means that all family members work together, with the help of a team of trained health professionals to help the child recover.

The health professionals can help family members:

- cope with the impact of the eating disorder on their lives
- improve communication and support one another

Your family's top priority needs to be returning your child to health. This can be difficult, as many things compete for attention such as work, school and the needs of other family members. Many parents find that they need to dramatically slow life down and take time to decide what is really important and necessary for the family.

How parents can help

Parents often spend a lot of time wondering why their child has an eating disorder. They may think that it is somehow their fault. Although it is natural to want an explanation, it may not be possible to find the exact cause.

We know that genetics play a major role in the development of an eating disorder; not family problems and not choice. Genetic relatives of people with eating disorders have a 7 to 12 times greater risk of also having an eating disorder. Knowing that there is a genetic factor can help you understand the eating disorder as a serious medical illness, not something to regard with any shame or guilt.

Eating disorders are most likely caused by the interaction of many factors. We do know that parents do not cause eating disorders to happen. We also know that while parents are searching for a cause, the eating disorder deepens its hold on their child.

Don't waste time and energy wondering "Why?" Your child needs your help right now.

You can start helping your child right away. The first thing to do is to give your child lots of emotional support while helping her/him to change eating behaviours. Your child needs enough nutrition to overcome the physical and psychological effects of starvation. Spending time restoring your child to a healthy weight greatly increases the chance of a complete recovery.

We ask parents to be directly responsible for changing eating behaviours at home. We will help you learn how to do this. Children and teens with eating disorders come from all types of families; those with two parents or a single parent, parents who are separated or divorced, blended families and families with same-sex parents. No matter what type of family you have, we encourage the adults in a child's life to work together. It is best for your child if you are consistent; using the same approach and giving the same messages. As issues come up, talk things over and make decisions together. If this becomes a challenge for you, talk with your child's therapist.

Each of you has parenting ideas and skills that have been successful in the past. Draw on these experiences and use each other's strengths.

A strong alliance between parents is the best defense against an eating disorder.

Parents may deal with stress in different ways and have different ideas about what is best for their child. Some disagreements and frustrations can be expected. It is best to discuss and resolve issues privately, away from your child. Continuing to disagree or argue in front of your child can be a major barrier to effective treatment. Your child needs to see you as a team, united against the eating disorder.



More information is available!

Read the information sheet "Working together" for more tips on how to do this.

How other children can help

Whether they seem to show it or not, your other children are affected by the eating disorder. They can see how the eating disorder affects you and their sibling. They may feel worried, frustrated or angry with their sister or brother for "causing all these problems" for the family. At the same time, they may feel a duty to protect and help their sibling. These mixed feelings can be confusing.

It is important to include them. This may involve bringing them to clinic to take part in family therapy.

Children can provide support to their sister or brother. However, they should not be responsible for watching their sister or brother and reporting back whether she or he is eating or not.

Siblings are helpful by distracting your teen, often by making her/him laugh. Distracting your teen from worries about food can lower stress especially at meals.



More information is available!

Read the information sheet "Helping your child manage mealtime stress" for more tips on how to do this.

Understand how your child thinks

No doubt you have tried many times to reason with your child. You may have repeatedly explained why she/he needs to eat or why a particular food is not harmful. But all attempts to reason with your child fail. Your child's behaviour doesn't change. Both of you become frustrated and she/he says, "You don't understand me. No one understands!"

This feeling is very real for your child. And in a way it's true; you don't understand. Your child's behaviour related to food, eating, weight and exercise doesn't make sense to you. It simply is not logical.

Your child behaves this way because the eating disorder has distorted her/his thinking. It prevents your child from thinking clearly about food and body image. It allows a set of unhelpful beliefs and expectations to develop in her/his mind. Your child may have irrational ideas about the consequences of eating or exercising. For example, she/he may believe that eating one muffin will cause her/him to gain weight.

Distorted thinking also prevents your child from seeing things as they really are. Your child may minimize positive things and magnify negative things. For example, your child's success at school, sports or extracurricular activities may no longer give her/him a sense of accomplishment. Instead she/he may dwell on things that she/he sees as "failures", like a mark of A- when she/he expects to get A+. Your child may set unrealistic goals for her/himself and feel worthless, a failure or a bad person when they aren't achieved. Your child responds by restricting food even more.

The medical term for these illogical thoughts is 'cognitive distortions'. We also call them 'thinking traps'. They are often a side effect of starvation.

Thinking traps are firmly planted in your child's mind. To your child, her/his beliefs and actions do make sense.

Logic or debate will not budge these beliefs. You cannot argue your child out of an eating disorder.

Starvation makes your child become preoccupied with thoughts about food. Your child may think of little else but how to avoid the next meal. Not eating may give her/him a temporary sense of accomplishment, strength and power. She/he may have organized her/his entire life around restricting food. Your child may see eating anything at all as a personal failure and a sign of weakness. Even eating a small amount of food can lead to intense feelings of guilt and anxiety.

Your child's behaviour shows that she/he is out of control, but your child sees it as a way to stay in charge and show her/his independence. For your child, the disordered eating behaviours are a way to manage problems, look and feel better or improve performance. She/he may be proud of what she/he has achieved and deny it is causing serious health problems.

Your child may not want your help. She/he may insist, "I can take care of this myself". Even though you are afraid of what might happen to her/him, you may want to believe that she/he can get better by herself. This is unlikely to happen because of the physical and psychological effects of starvation. Your child's efforts are no match for a powerful eating disorder.

To help your child, you must first accept that she/he cannot grasp reality and think logically. Then, try to understand the way she/he thinks and views things. Once you have identified the thinking traps she has fallen into, you will know how to respond effectively.

An effective response is to help your child learn to use coping statements.

Coping statements are positive thoughts that can replace anxious thoughts. For example, if your child thinks, "I am never going to get better" she can learn to deliberately replace this thought with "I've made changes before, I can do it again". To work well and lower anxiety, coping statements need to be personalized. Your child has to identify coping statements that will work for the thoughts and situations that make her/him anxious.

Learning about 'thinking traps' and 'coping statements' can help you understand and support your child. However, your child's therapist is responsible to work with your child on this aspect of improving her/his mental health.



More information is available!

Read the information sheet "Using coping statements to avoid common thinking traps" for more tips on how to do this.

Learn to manage conflict

As you begin to challenge the eating disorder and insist that your child eat for recovery, she/he may become more anxious and distressed. Your child may express these emotions through challenging behaviour. This can be very upsetting.

It is hard to hear your child say thinks like, "Can't you see how unhappy you are making me", "I don't want to eat that; you're killing me" or "I hate you". You may start to question whether you should be insisting that she eat normally. But if you back away from this goal, the eating disorder will continue.

The best thing to do is to see the illness as something separate from your child. For example, if your child refuses to eat, it is not because she/he is choosing to be defiant. This is an effect of the eating disorder on your child. By separating the two, you can fight the eating disorder while continuing to love and care for your child.

It is the illness that distorts your child's thinking and causes the disordered eating behaviours. It is not your child's fault. Blaming your child or making her/him feel guilty will only make things worse. Negotiating or arguing with your child will not work. Instead, firmly explain to your child that the illness does not allow her/him to make appropriate decisions related to food and exercise at this time. Even though the eating disorder causes you and your child great distress, don't let it make you become enemies.



More information is available!

Read the information sheet "10 tips to managing meltdowns" for more tips on how to do this.

Take care of yourself

Making changes in your life to help your child can be difficult. At times you may feel angry, overwhelmed or feel like giving up. It can help to talk with your spouse, someone close to you or a member of the treatment team. We are here to help you.

Take care of yourself. Try not to neglect your own interests and relationships. Keeping the balance in your life can help you stay strong and healthy so that you can help your child.

Part 3: Specific ways to help your child

Help your child eat normally

Be available

Changing your child's eating behaviours requires a lot of time and effort. You and your spouse will need to be available for all meals and all snacks for at least the first several weeks and often for many months. Being there gives your child structure, emotional support and encouragement to eat. As a parent you can't make your child eat, but you can create an environment where this is more likely to happen.

Find a way to adjust your schedules so that you can be present for as many meals as possible. You may decide to use vacation or sick time, or take a leave of absence. If it would be helpful, the pediatrician can write a letter to support your time away from work.

Some parents consider removing their child from school or beginning home schooling. This is not something we recommend. Your child's pediatrician and therapist have many ideas about how to make sure that your child nutrition is supported while she/he is at school. Please talk with your child's treatment team before making any major changes.

Think of food as medicine

Recovery can only come about when your child eats enough healthy foods to allow her/his body and mind to work normally again.

Even if your child protests, "there's too much food" or "I can't possibly eat all this" it is still necessary for her/him to have the set amounts of nutrition.

Your child may say," I'm full" or "my stomach hurts", even after eating only a small amount of food. This is because she/he is eating more than usual and it takes longer to digest food after a period of starvation.

You can be empathetic to your child's feelings, but you must insist on full nutrition. Negotiating with the eating disorder by allowing your child to reduce her/his nutrition will make it harder for you to hold the line in the future. It will also cause the eating disorder to need to try and negotiate foods and amounts in the future. This adds to your distress and your child's anxiety. Be firm and consistent.

To relieve stomach upset, follow a meal with a soothing activity such as watching a movie or listening to music. Using a heating pad or hot water bottle is not recommended as prolonged use could cause a rash or burn.

Set natural consequences

An important way to fight an eating disorder is establishing natural consequences for not eating. These consequences can motivate your child to eat and gives you another way to respond other than getting angry, bribing or using threats.

Natural consequences are a way of protecting your child. They should not be viewed as punishment.

Eating disorder behaviour	Natural consequence
Not eating breakfast	Not going somewhere (school, social event, work, library) until the food is eaten.
Refusal to complete full nutrition	Removal from activities that require 'extra energy' eg. soccer.
Not eating school lunch	You go to school and eat with her/him or she/he comes home at lunchtime and eats with you.
Food refusal	Stays in her/his room on bed rest. Only reading or homework is allowed, no other distractions.

You need to be clear about what you expect and what will happen if your expectations are not met.

Sticking to the plan can be stressful. You may wish the plan was easier, shorter or could be done by someone else. But carrying out the plan must be done and is best done by the parents.

Plan successful meals

The treatment team will help you learn how to:

- plan and prepare your child's meals
- supervise your child during meals and snacks
- discourage disordered eating behaviours during meals
- return to normal nutrition and eating patterns

Eating disorder treatment begins with a period of intense meal support that may last for months. During this time, parents need to supervise their child during meals and snacks.

It is helpful to have both parents present for dinner. Before a meal, decide which parent will supervise your child. Taking turns can give each of you a break and shows your child that both of you can and will support her/his eating. When supervising your child, being supportive and empathetic can help keep things relaxed. However, you may need to firmly guide your child through the meal so that the food is eaten in a reasonable amount of time.

Having to eat can make your child more anxious. She/he may try to bargain with you about the food. It may be tempting to give in, but you need to be firm. Do not negotiate with your child. Instead, you may say something like this: "I know you feel strongly about this and I know you are distressed. I'm not going to discuss this with you again. It only makes you more upset. I'm not going to be flexible with the amount of nutrition you that has been prescribed for you. I won't negotiate with the eating disorder."

Try to have the family eat together. Keep the conversation away from food, weight or other issues related to the eating disorder. Talk about other topics that interest your family.

Over time, setting these limits will bring your child a sense of safety and control over the power of the eating disorder. Once your child has regained and maintained her/his weight, you will not need to supervise meals so strictly. Work with your child's treatment team to decide together when you can begin to offer your child more control and less supervision.

Many children and teens find the supervision parents provide reassuring. They tell us that it lessens their guilt and anxiety. Removing it too soon can cause unexpected set backs and unnecessary distress.



More information is available!

Read the information sheet "Helping your child manage mealtime stress" for more tips on how to do this.

Take the focus off weight

Your child may focus obsessively on her/his weight and weigh her/himself many times a day. This constant checking is done for reassurance.

Weight has become a way to judge whether she/he:

- feels good or bad
- is a success or a failure
- is likable or unlikable

Clothing, food, activity and even the time of day can make weight vary. Frequent weighing is not going to be accurate. We recommend that you remove your household scales. This also sends an important message to your child about how important body weight is to other family members.

During treatment, your child will only be weighed once a week. This is all that is needed to tell how things are going. Using the clinic scales lessens disputes about which number is 'accurate'. All treatment decisions are made based on the weight as measured by the clinic scale.

Helping your child return to healthy activity

Your child is currently not eating enough calories to maintain her/his weight and support exercise. Her/his body is under extreme stress and requires adequate nutrition and time to heal.

If your child does not eat enough calories (food energy) to balance the energy 'burned' during physical activity:

- Your child's body will start breaking down muscles to use for the calories missing in her/his diet.
- Muscle in the heart can be used for calories. Over time, this can result in a slow heart rate (bradycardia) or a heart attack.
- A girl's periods (menstruation) may stop. This is called amenorrhea. Turning off the reproductive system is her body's way of saving energy. This in turn may cause your daughter's bones to weaken. Weak bones can break more easily during exercise and result in stress fractures and chronic pain.

Physical activity requires additional food intake. For many patients and their families, regular adequate nutrition is already a struggle without having to take in more food to allow for activity.

Exercising before your child is eating normally may keep her/him from getting better. We need time without exercise to sort out what is healthy activity for your child and what is part of her/his eating disorder behaviour.

How you can help

Your child may be anxious about the disruption in her/his level of activity. It will help to talk about this. Reassure your child that she/he can resume activity once her/his physical and emotional health improves.

At the clinic, your child will learn about how to include healthy, balanced activity:

- Healthy exercise needs a healthy body, which requires good nutrition.
- Exercise is for health, enjoyment, socialization and preparation for sport.

When your child can resume exercise

To start exercising again, you child must:

- be willing to eat according to her/his treatment plan
- be at an appropriate weight for her/his height and age
- be growing normally
- have normal hormone levels

Please talk with the pediatrician or your child's therapist about developing a plan for your child's return to health activity.

Looking ahead

Once your child is eating normally with your help and is close to her/his normal weight, the focus of treatment changes. You can gradually begin to back off and let your child resume more control of eating. Start with one small step, such as letting your child have snacks without supervision. As your child begins to eat well without supervision, you can give her/him more control. This process can take several months.

The final goal is to help your child continue through the normal stages of teenage development. Your child will still need your love and support even as she/he becomes more independent.

The members of your child's treatment team are always available to help you.

If you have any questions or concerns, ask us at your next visit or call 905-521-2100, ext 73497

Helping your child return to health

A summary for parents

- ✓ Separate the eating disorder from your child. Fight the illness. Continue to respect, love and care for your child.
- ✓ Don't blame yourself or your child for the problems you're having. Blame the illness.
- ✓ Attend appointments with your child. Meet regularly with your child's treatment team. Keep the lines of communication open.
- ✓ Work with the health professionals to come up with a treatment plan that is realistic for your family. Have clear expectations for yourself and your child.
- ✓ All family members work together. Resolve disagreements privately.
- ✓ Be patient. Changing behaviours takes time.
- ✓ Don't give up. It is important to be persistent with your efforts.
- ✓ Don't try to argue or negotiate with your child. Your child's illness prevents her/him from thinking clearly.
- ✓ Encourage your child. Try not to criticize or punish her/him.
- ✓ Help your child find ways to manage stress. Make sure she/he
 is well-rested.
- ✓ Take care of yourself. Try to reduce or manage your stress.

 Find support from family, friends and health professionals.

