

A Parents' and Caregivers' Guide to Supporting Youth with Eating Disorders

An online version of this resource can be found at nedic.ca

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National Eating Disorder Information Centre

www.nedic.ca

TABLE OF CONTENTS

- 1 Eating Disorders: An Overview
- 2 You May Have Noticed Numerous Changes in Your Child
- 2 Starting the Conversation
- 3 Stages of Change
- 4 Understanding the Levels of Care
- 6 Children's Rights, Caregivers' Responsibilities
- 7 Tips for Specific Situations
- 8 Support for Caregivers
- 9 Resources

Acknowledgements

The National Eating Disorder Information Centre (NEDIC) extends its gratitude to the parents/caregivers who provided their time and input for the development of this resource. We know that the advice and insights drawn from their lived experiences will be invaluable to families supporting a youth with an eating disorder, from detection to full recovery.

Disclaimer

The information in this resource addresses behaviours and warning signs associated with eating disorders and should not replace evaluation and treatment by a qualified professional. For additional support, please refer to our contact information, as well as other recommended resources, listed on the back of this booklet.



EATING DISORDERS: AN OVERVIEW

Eating disorders are serious mental illnesses characterized by persistent disturbances in eating and eating-related behaviours that result in harm to one's physical health, mental health, and/or psychosocial functioning.

There is no singular cause of an eating disorder. The development of an eating disorder cannot be attributed to a specific person, event, or gene. Eating disorders are complex illnesses that are best understood as the outcome of the interaction of multiple biological, psychological, and sociocultural factors. Risk factors include genetic vulnerability/family history, body dissatisfaction, low self-esteem, perfectionism, predisposition to experiencing negative emotions, dieting, and being stigmatized due to one's weight.

BASIC DEFINITIONS

- **Anorexia nervosa:** characterized by persistent behaviours (e.g., restrictive eating, over-exercising, diet pill misuse, and/or vomiting) driven by an intense fear of gaining weight or being fat that interfere with maintaining one's biologically-appropriate body weight
- **Bulimia nervosa:** characterized by recurring episodes of binge-eating followed by behaviours (which may include self-induced vomiting, laxative use, and/or exercise) intended to purge the body of the food consumed or compensate for food eaten and prevent weight gain; self-evaluation is connected excessively to one's weight and shape
- **Binge eating disorder:** characterized by recurring episodes of binge-eating that cause a great deal of distress; however, binge-eating is not routinely followed by compensatory behaviours
- **Avoidant/restrictive food intake disorder (ARFID):** characterized by inadequate food intake that interferes with growth and development, results in nutritional deficiencies, and/or negatively impacts psychosocial functioning; an individual with ARFID may be averse to certain characteristics (e.g., flavours, textures, or colours), be fearful of eating after having a distressing experience involving food (e.g., becoming physically ill after eating), or lack interest in eating; food avoidance is not related to overvaluation of body weight or shape or disturbances in the way body weight or shape are perceived
- **Other specified feeding and eating disorders (OSFED):** characterized by behavioural patterns that do not fit the criteria for the diagnoses listed above, but still compromise health and functioning

You May Have Noticed Numerous Changes in Your Child

BEHAVIOURS

- Increasingly restrictive eating pattern (e.g., adopting a new diet, progressively cutting out foods or food groups from their diet)
- Eating more than normal in frequency and quantity, even when not hungry
- Eating to the point of discomfort
- Avoiding foods based on their colour or texture
- Eating abnormally small spoonfuls at a time
- Disappearing to the bathroom after meals
- Eating alone or in secret, fear of eating with others
- When upset, food is one of the only things that comforts them
- Increased irritability/emotional dysregulation
- New or increased interest in grocery shopping, cooking for others, cooking or weight loss shows, diet books, etc.
- Highly intense and ritualistic exercise routines
- Opting for clothing that is either more concealing or revealing of their body shape or size
- Loss of interest in life, hobbies, friends, old favourite foods, etc.

PHYSICAL CHANGES

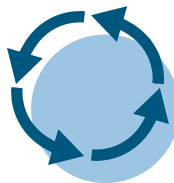
- Abnormal weight gain or loss
- Lack of growth in height
- Feeling cold all the time
- Frequent stomach aches or gastrointestinal issues
- Frequently fatigued
- Changes in sleep patterns (e.g. sleeping a lot more or less)
- Dizzy spells
- Brittle nails
- Constant dry mouth or bad breath
- Menstrual irregularities (e.g., loss of periods or absence of expected periods)



Starting the Conversation

UNDERSTANDING WHAT'S GOING ON FOR YOUR CHILD

- **Fear:** your child may be fearful of eating because they are afraid that it will lead to weight gain, or that eating certain foods will result in becoming ill, choking, or vomiting. They may be scared of losing control over what they eat, or being judged by you or their peers. They may not want to disclose that they are struggling because they may be afraid of burdening or upsetting you.
- **Anxiety:** it is common for people with eating disorders to experience high levels of anxiety, not just around food, but in general. Depending on their eating disorder, they may find that restricting, exercising, and/or purging reduces their anxiety, or that eating is soothing.
- **Shame:** your child may not welcome your concern when you first approach them, and may even react with anger or denial. Shame and ambivalence about the eating disorder and about recovery are common. Eating disorders are often stigmatized, which can influence your child's behaviours.
- **Beliefs:** your child may believe that their body is flawed, that this is connected to other problems in their life, and that controlling their body size or losing weight will solve those problems. They may have internalized societal messages that promote the belief that only certain types of bodies are beautiful and worthy. They may have misconceptions about food and different kinds of foods (e.g., fats/carbohydrates/sugars are bad) or about certain eating practices (e.g., that it is sensible to "trick" their body into sensing it has gotten enough food when it hasn't.)



Stages of Change

In any decision to change, there are phases a person goes through to process their thoughts before they take action. It is important to realize that your child could be in any one of these stages, and the process is not linear. These stages and the appropriate actions on your part will vary based on the age and current mindset of your child.

- **Precontemplation:** no intention of seeking help for their problematic eating behaviours/thoughts, often because they are unaware that their behaviour/thoughts are problematic or unaware of the potential consequences.
- **Contemplation:** recognition that there is a problem but ambivalence about the need to change. They begin to gain more awareness of the pros and cons of their current situation and of changing.
- **Determination and Preparation:** they believe that change will be beneficial are preparing to take action in the foreseeable future. They are planning some specific steps (e.g., calling a helpline for information about eating disorder treatment).
- **Action:** they have recently taken action and have the intention to maintain their behaviour changes (e.g., enrolment in a treatment program). They are working towards recovery.
- **Lapses and Relapses:** neither lapses nor relapses signal a return all the way back to the precontemplation stage. Lapses, single episodes of eating disorder symptoms, are part of the recovery process, but it is important to take them seriously and to bring back more support for whatever time is needed. Relapses – the return of disordered patterns – are also common experiences. Both lapses and relapses can play a part in a person learning about what works and doesn't work for them.
 - It is important to check in with them after major emotional events (e.g., going to a new school, parental conflict or divorce, losing a friend or breaking up with a romantic partner, being bullied or assaulted, doing poorly on exams, getting or losing a job, new living environment, etc.) to make sure they are coping in a healthy way.
 - If you notice the re-emergence of eating disorder signs or symptoms, act quickly. Early intervention promotes recovery.
- **Maintenance:** change has been sustained and the intention to maintain these positive behaviours is present.
 - Recovery will be a lifelong and evolving process.
 - Give your child an age-appropriate amount of autonomy. Depending on the nature of your child's eating disorder, periodic weight checks may be appropriate. Continue with emotional check-ins.

OPENING THE DOOR FOR CONVERSATION

Demonstrate empathy

- “I understand how upsetting this experience is for you.”
- “I can appreciate that you don't want to talk about your difficulties, but I care about you too much to drop the subject. How can I make it easier for you to talk about what's going on?”

Seek to understand

- “How would you describe what you're going through?”

Assure your commitment

- “Recovery can be a long and tough process but I'm here for you every step of the way.”

Be clear and explicit

- “I've noticed you seem to be avoiding a lot of foods lately – even your favourite foods – and I'm concerned that you may not be eating enough for your body to work well and grow as it should. I would like for us to see a doctor together.”
- “You seem to be having trouble with knowing how much food is enough for you. I've noticed you sometimes eat hardly anything and other times you eat more than usual. You seem unhappy. I think we need some guidance – I'd like for us to see a specialist this week.”

WHAT ARE MY OPTIONS FOR TREATMENT IF MY CHILD THINKS NOTHING IS WRONG?

This resistance will typically be in the precontemplation stage. It is important to note that none of these options are meant to come across as threatening or punitive, nor do any of these options have guaranteed outcomes.

- Minimize negotiation about how serious their condition is to avoid circular arguments.
 - Depending on their stage of change, they will not have the same perspective on their risk as you do, and discussion on the degree of their illness will likely turn into an endless debate.
- Enlist a health professional (e.g., a doctor or therapist) to evaluate them and provide them with psychoeducation.
 - Malnutrition can impair the brain's self-perception, so a person with an eating disorder may not be able to recognize that they have an illness.
- If your child is a mature teen, leverage and the revocation of some autonomy can be used in a non-threatening way.
 - “Can I drive you to treatment today or would you like to go yourself?”
- With young teens and children, it is a caregiver's responsibility to bring their loved one to appointments, and the appointments should not seem optional.



Understanding the Levels of Care

Outpatient Care

- Children who are medically stable may be treated on an outpatient basis (e.g., attending weekly therapy appointments). Most families, with professional help, are able to restore their children's health at this level of care. The recommended first-line treatment for youth with eating disorders is an outpatient approach known as Maudsley/Family-Based Therapy (see Types of Therapy).

Inpatient Care

- Children who are experiencing or at high risk of medical complications need to be hospitalized so they can receive 24-hour care. They may be placed in a general hospital setting for medical stabilization or, where available, in a specialized eating disorder unit.
- Inpatient eating disorder treatment includes medical monitoring, re-feeding/nutrition restoration, and/or symptom interruption. A typical week's schedule will consist of staff-supervised meals and snacks. In addition, an inpatient program may offer academic programming; increasingly, family-based meal support is being integrated into inpatient programs.

- Inpatient eating disorder units are staffed by multidisciplinary teams that generally include psychiatrists, nurse practitioners/nurses, psychologists, dietitians, social workers, child/youth counsellors, and educators.

Day Treatment

- Adolescents who are medically stable but for whom outpatient treatment is insufficient to reduce their eating disorder symptoms may require a day program. This typically involves attending a clinic 5 days per week from breakfast through dinner time.
- Day programs are staffed by multidisciplinary teams that generally include psychiatrists, nurse practitioners/nurses, psychologists, dietitians, social workers, child/youth counsellors, and educators.

Residential Treatment

- For adolescents who are medically stable but for whom outpatient or day treatment has been unsuccessful, residential treatment may be indicated. 24-hour care is provided, with aspects of inpatient care incorporated into some sites.

TYPES OF SUPPORT AND THERAPY

Family-Based Therapy (FBT)

- In FBT, parents are empowered to help manage their child's eating disorder symptoms and restore their child's health. There are three phases.
 - Phase one: parents are charged with establishing normal eating patterns, deciding what their child will eat for meals/snacks, ensuring adequate nourishment, and stopping problematic behaviours.
 - Phase two: age-appropriate control over eating is handed over to the child.
 - Phase three: treatment focuses helping the child establish a healthy identity.
- FBT includes child and parents (and siblings or other important family members) together in the sessions most of the time. Everyone hears what the others say, so confidentiality is not an issue. When a child or parent is seen individually, as happens sometimes, the therapist discusses what will be shared with the family with the person affected.
- Current evidence points to FBT as the best available therapy for a child or adolescent who has been ill for less than three years.

Cognitive Behavioural Therapy (CBT)

- CBT is based on the assumption that thoughts, emotions, and behaviours are interconnected and can be restructured to support new, healthier thoughts and actions.

Dialectical Behaviour Therapy (DBT)

- DBT is based on the assumption that self-destructive behaviours are caused by the inability to manage and regulate intense emotion.
- DBT combines cognitive behavioural techniques with mindfulness and acceptance strategies.

Emotion-Focused Therapy (EFT)

- In EFT, individuals learn how to manage their maladaptive emotions, as opposed to controlling what they eat as an outlet for the emotions

Peer Support Group

- Group members are all going through similar struggles and come together to support and empower each other.

QUESTIONS TO ASK YOUR DOCTOR

Because there is very little training about eating disorders in the medical curriculum, your family doctor or pediatrician may or may not have expertise in eating disorders. Parents are usually the first to notice changes in their children, so take confidence in your own knowledge of your child. Ask for an appointment that will give you adequate time to discuss your concerns. Be specific with the doctor about the changes you have noticed and ask to speak with them alone and together with your child (the doctor may also want to speak with your child alone). Tell the doctor why you think an eating disorder may be developing and that you understand that early identification is critical to recovery. If the doctor is familiar with eating disorders, they will take your concerns seriously and will check your child's weight and height, and blood pressure and heart rate (lying and then standing). They might compare the current weight with earlier weights on a standard growth curve chart to see if your child is growing appropriately. They *might* ask your child about other issues like sleeping disturbances, stomach aches, friends, bullying, school work, self-harm, and so on. If your doctor does none of these things, you can respectfully ask:

- “I’ve done some research and obtained some eating disorder assessment guidelines. Would you be willing to take a look at them?”
- “It may seem to you that I’m over-reacting, but I won’t be able to rest until I know that we’ve checked this out thoroughly. I believe there is some medical work to be done. When can we do this?”
- “We need a referral to a specialist with eating disorder experience. Who do you recommend?”
- “We need a referral to an eating disorders treatment program. I have the papers here and would like you to fill them out.” (*Forms are usually available online or from the program’s intake office*)



Children’s Rights, Caregivers’ Responsibilities

Eating disorders are serious mental illnesses with potentially grave consequences. Children and teens will not accurately estimate the risk that an eating disorder poses to their health. As such, it is up to parents to see that their child is supported to recovery. The treatment approach most strongly supported by research evidence is family-based treatment, in which parents take responsibility for managing the eating disorder symptoms. If you have a 16-year-old who has been up most of the night studying for an exam, and then later in the day, their older sibling offers to take them for a driving lesson, you have a responsibility to assess whether your 16-year-old can be allowed to accept. Technically, they have the right to make their own decisions at that age but in this situation, if they accepted the offer, you would likely overrule their decision in order to protect them from the potential danger of driving while inadequately rested. Similarly, you could overrule your child’s decision to forgo seeking professional help if their health is at risk.

Family-based therapy includes child and parents (and siblings at times) together in the sessions most of the time. Everyone hears what the others say, so confidentiality is not an issue. When a child or parent is seen individually, as happens sometimes, the therapist discusses with the client what will be shared with the family.

At later stages of eating disorder treatment, when symptoms are well managed, individual therapy may be recommended for your child. These therapy sessions are confidential and parents are not informed of the content unless there are specific reasons for doing so, e.g., suicidal impulses or re-occurrence of eating symptoms. Again the need to talk over something with parents would be discussed first with the young person.



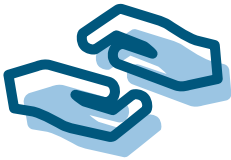
Tips for Specific Situations

Handling Holidays, Vacations, etc

- With extended family, set boundaries around topics that should not be talked about:
 - How much weight any family member has gained/lost, calorie counting, appearance-related comments, school stress, etc.
 - You can also proactively ask for scales to be put away, diet products to be hidden, etc.
- If you discern that your child is not ready to handle the eating in unfamiliar environments, it may be prudent to delay plans to travel or go on vacation.
- If you discern that your child is ready to handle a vacation with unfamiliar foods, give them information the food options available in advance and help them plan what they will eat.
 - While sticking to a regular schedule of meals and snacks, it can be helpful to challenge the child with a variety of foods.
- There is still a lot of stigma and misunderstanding around eating disorders and mental health issues in general. If you are confronted with a stigmatizing or ill-informed comment from another person, and you wish to respond, try to educate them without shaming them.

What are my Options for Treatment if my Child is Over 18?

- Once your child turns 18 or shortly before that, they will not be eligible for treatment in publicly funded child and adolescent programs and will have to seek support in adult settings. Currently most of these programs do not provide a gradual transition to typical adult treatment and your 18-year-old will be expected to adapt to the requirements of adult programs. This is changing as programs for “transition age youth” (generally people aged 18-24) are being developed. In these programs, parents are recognized as having a valuable role in supporting their child, although that role is determined collaboratively with the youth. Some transition age youth may initially choose not to involve their parents in their treatment.
- If your 18-year-old is living with you and has suicidal intentions or impulses, or they have not eaten for too long, you can take them to the emergency department of a hospital where they will be assessed for safety or medical stability and may be admitted.



Support for Caregivers

- **Educate yourself:** Seek credible information about eating disorders and learn as much as you can, like you're doing right now. The more you know, the better you can support your child.
- **Take care of yourself:** There is a long and challenging road to reach recovery. Just as your child may need help, you may need support during the journey. Don't hesitate to seek professional help and/or peer support for yourself and the entire family, if needed. Take time to practice regular self-care. Recognize that you cannot make your child get better – you can only help with the recovery process. Don't take on the role of a therapist.
- **Separate the issue from the person:** Most families find it helpful to see the eating disorder as separate from the person they know their child to be. It is like an intruder has taken over and is making your child behave in unfamiliar and sometimes very mean or nasty ways. Remind yourself that this is the eating disorder, not your child. Usually this happens around interactions related to food, and is a sign you are doing something right because the eating disorder is feeling threatened. Most likely, if your child yells at you, tells you they hate you, or otherwise lashes out at you, they will regret it later and feel ashamed for having done it. Try to maintain calmness in your voice and behaviours. When the episode has passed, find a way to re-connect with your child.

Maintaining Positive Relationships

- Refrain from making the entire relationship with your loved one about the eating disorder or food, continue to go on with your life. Allowing the issue to consume your life will only cause shame, guilt, and reinforce eating disorder behaviours.
- Allowing your child to contribute to the family routine encourages a sense of efficacy, autonomy, independence and personal responsibility, which all contribute to increased self-esteem.
- Engage in healthy social outings and hobbies that build their sense of worth and accomplishment that isn't associated with weight/appearance
- When conflicts arise: the person is never the problem in any conflict – the problem is the problem
 - Use “I feel” statements to avoid accusations and blame talk



Resources

NEDIC Helpline

Toll free: 1-866-633-4220 (1-866-NEDIC-20)
Toronto area: 416-340-4156
Online chat: www.nedic.ca
Helpline hours: 9:00am – 9:00pm EST (Mon–Thu),
9:00 – 5:00pm EST (Fri)

Families Empowered and Supporting Treatment of Eating Disorders (FEAST)

Around the Dinner Table is FEAST's online support forum for carers: www.aroundthedinnertable.org

Understanding Eating Disorders in Adolescence

An online educational resource for parents/caregivers of a youth with an eating disorder: www.canped.ca

BC Children's Kelty Mental Health Resource Centre – Eating Disorders

A website with many resources including the Parents Survive to Thrive Guide and video guide to providing meal support: www.keltyeatingdisorders.ca

ABOUT NEDIC

The National Eating Disorder Information Centre (NEDIC) has been helping Canadians living with and affected by eating disorders since 1985. Through our programs and services, we provide information, education, resources, support, and referrals to individuals experiencing eating disorders and related concerns, as well as the families, friends, and professionals who care for them. We are committed to ensuring people have access to trustworthy, up-to-date information to enable individuals to make informed choices.