

### Point of Care Reference

Applicable to: Health Professionals

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This tool provides nutrition-related strategies and approaches to support health professionals include parents/caregivers in the treatment of eating disorders (EDs). The information is intended:

- To be used when providing care for children and adolescents with EDs who are medically stable, and in an outpatient setting.
- As a general resource only to help guide practice and is not meant to replace training in the assessment and treatment of EDs. It is also not intended to replace the medical counsel of a physician or individual consultation with a registered dietitian or a psychologist. Tailor care to the individual needs of the patient and their family/caregivers.

### Considerations: Scope of Practice, Competencies, and Roles

- It is the responsibility of health professionals to evaluate the situation of each patient in their care, ensure that they have the required competencies to provide ED care, and apply this tool appropriately.
- Consider the professional scope of practice, as well as program-specific roles and decisions to determine who is best suited to provide ED care to patients and families.
- Whenever possible, refer patients and caregivers to the appropriate health professional to receive specialized care tailored to their needs. Individuals:
  - with a possible ED should be medically monitored by a physician, and referred to a health professional who has training and experience in the assessment, diagnosis, and treatment of EDs. Patients can call the AHS Mental Health Help Line for support with finding a mental health provider (1-877-303-2642 or 811).
  - who are at high risk of malnutrition or who have a medical condition that is impacted by nutrition should be referred to an RD for nutrition care. For more information on referral to an RD and RD services available in Alberta Health Services (AHS), see [Nutrition Guideline: Referral to a Registered Dietitian](#) and visit [Referring Patients for Nutrition Services](#).
- For more information and resources to support practice, refer to [Point of Care Reference: Addressing a Possible Eating Disorder](#) and [AHS Addictions and Mental Health Information for Health Professionals](#).



# Including Parents/Caregivers in the Treatment of Eating Disorders

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### Including Parents/Caregivers in the Treatment of Eating Disorders (Topic Summary)

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### Treatment of Children and Adolescents with Eating Disorders

Parents/caregivers are an integral part of the treatment of their child's eating disorder.<sup>1</sup> Providing intervention in an outpatient setting gives patients and their families opportunities to engage in treatment and recovery, while still maintaining their daily routines. The following are key messages and recommendations<sup>2</sup> for strengthening parents'/caregivers' confidence in treating their child at home and can be incorporated into the approach of the multidisciplinary team to support the care of patients with eating disorders and their families.

Key Messages and Recommendations <sup>2</sup>	Sample Dialogue
<b>Parents/caregivers are essential members of their child's treatment team</b> <ul style="list-style-type: none"><li>Families are viewed as a critical resource for their child's recovery.</li><li>The family is guided and supported by the healthcare team, however, parents/caregivers know their child best and can provide quality interventions for EDs at home.</li></ul>	<ul style="list-style-type: none"><li>"Nobody knows [insert child's name] as well as you do. In order to best support them in recovering, we will need to work together to develop a plan."</li><li>"My role is to provide you with support if you have any questions about EDs and [insert health professionals role (e.g., nutrition, nursing, mental health etc.)]"</li><li>"We are here to help you get your child through this."</li></ul>
<b>Parents/caregivers are encouraged to take an active role in their child's recovery</b> <ul style="list-style-type: none"><li>Parents/caregivers are empowered that they are capable and equipped to help their child recover from their illness.</li></ul>	<ul style="list-style-type: none"><li>"You, as parents/caregivers, are the greatest asset your child has to recover from this illness."</li><li>"You know your child and you recognized that they needed help."</li></ul>
<b>Eating disorders may develop for a variety of reasons</b> <ul style="list-style-type: none"><li>No assumptions are made about what may have caused the ED to develop. This can help to remove blame for symptoms and behaviours from the patient and their caregiver.</li></ul>	<ul style="list-style-type: none"><li>"Eating Disorders are complicated medical illnesses. We do not know exactly what causes them. Parents or the child are not to be blamed, just like it would not be your fault if your child was diagnosed with diabetes or cancer."</li></ul>

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Key Messages and Recommendations <sup>2</sup>	Sample Dialogue
<p><b>Early intervention is an important part of recovery</b></p> <ul style="list-style-type: none"><li>• Delaying treatment for EDs can lead to a poor prognosis for recovery. It is crucial that the family focuses on symptom relief and intervening in ED behaviours as quickly as possible.<sup>1</sup></li></ul>	<ul style="list-style-type: none"><li>• “It’s difficult to see your child feeling anxious and scared. It is important to continue with the refeeding process to support their physical and mental recovery.”</li><li>• “Our goal is to start treatment early. Once [insert child’s name] physical health has improved, they will be better prepared to address their emotional and mental health concerns.”</li></ul>

### Considerations: When Higher Levels of Care Are Indicated

Some patients and families may require a higher level of intervention when:

- A patient requires immediate medical attention:
  - Symptoms of medical instability (e.g., unusually low blood pressure, cardiac arrhythmias, chest pain, severe and sudden onset of abdominal pain, seizures due to low blood sugar or potassium levels, severe dehydration, acute malnutrition, uncontrolled vomiting, refeeding complications)
  - Psychiatric emergencies such as suicide risk or severe concurrent psychiatric conditions
  - The patient has a medical emergency while in your office
- Parents/caregivers are unable to provide the level of support required for treatment at home. Examples may include:
  - Unable to take time from work to attend appointments or supervise meals due to schedules
  - Family is experiencing other stressors such as divorce, dealing with other illnesses or loss of work
  - Addictions or other mental illnesses in the family

### Role of the Treatment Team in Eating Disorder Care

The American Psychiatric Association<sup>3</sup> and the Canadian Mental Health Association<sup>4</sup> support a multidisciplinary approach to ED care. A brief description of dietitians’, parents’/caregivers’, mental health providers’, and physicians’ roles are provided on the following page. The roles of team members may overlap depending on program-specific responsibilities. Additional health professionals may be necessary, depending on the patient’s needs.

Establishing a therapeutic alliance and building trust with the patient and their parents/caregivers is a crucial aspect of care for all health professionals on the treatment team.<sup>5,6</sup> It is common for patients to feel nervous and overwhelmed during appointments. They may have a lot of anxiety regarding the topics that will be discussed and what the treatment recommendations will be. Take time to establish rapport and make the patient and family feel comfortable. To prevent overwhelming patients and their parents/caregivers during the first appointment, it may be necessary to gather and provide information over multiple sessions.

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Role of the Dietitian	Role of the Parent/Caregiver
<ul style="list-style-type: none"> <li>• Conduct a nutrition assessment</li> <li>• Assess parent's/caregiver's understanding of food and nutrition and develop a meal plan, if required, to meet nutritional needs and increase variety</li> <li>• Provide nutrition education and counselling as needed to:               <ul style="list-style-type: none"> <li>◦ Support parents/caregivers and their child during the recovery process</li> <li>◦ Increase parent's/caregiver's self-efficacy with feeding their child</li> <li>◦ Integrate food exposures as appropriate</li> <li>◦ Prioritize strategies to support weight restoration (if required)</li> </ul> </li> <li>• Set target weight ranges that support recovery<sup>7</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Take control of food in the initial stages by:               <ul style="list-style-type: none"> <li>◦ Planning and shopping for meals</li> <li>◦ Preparing and plating meals for their child according to their meal plan</li> </ul> </li> <li>• Provide meal supervision and eat with their child</li> <li>• Provide post-meal supervision and watch for compensatory behaviours (i.e., vomiting, over-exercising, abusing laxatives)</li> <li>• Model for their child how to tolerate the uncomfortable feelings that accompany it</li> </ul>
Role of the Mental Health Therapist/Psychologist	Role of the Physician
<ul style="list-style-type: none"> <li>• Help the family understand the serious nature of the illness and stay focused on treatment</li> <li>• Strengthen parent's/caregiver's confidence to take an active role in their child's treatment</li> <li>• Assess and monitor the child's mental health status, including the risk of self-harm</li> <li>• Address the family dynamics and emotional reactions to the illness</li> <li>• Monitor/treat for co-occurring psychological symptoms and conditions</li> <li>• Assess and treat the ED and any comorbid illnesses</li> </ul>	<ul style="list-style-type: none"> <li>• Physical assessment and medical monitoring</li> <li>• Provide an official diagnosis</li> <li>• Determine the appropriate level of care (i.e., outpatient or inpatient) and make referrals to specialty programs if required</li> <li>• Laboratory and other investigations</li> <li>• Medication management</li> </ul>

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### Parent/Caregiver Interventions in the Treatment of Eating Disorders

Depending on the severity of symptoms, stage of recovery, and adolescent development, parents/caregivers may need to provide supervision during and after mealtimes.<sup>1</sup> Younger children, or patients in the early stages of recovery, may need more intensive interventions, whereas others may be ready to take more of an active role in their own treatment. Collaboration with the parents/caregiver to determine the most appropriate level of care is recommended, however, health professionals and parents/caregivers need to remember that recovering from an ED is not a linear process. It is common for patients to move back and forth between stages of recovery.

The following strategies are based on evidence-based treatments, including Family-Based Treatment (FBT).<sup>1,8-10</sup>

Recommendations and Strategies <sup>1,8-10</sup>	Sample Dialogue and Supports
<b>Parents in Charge Approach</b> Parents/caregivers are encouraged to take charge of meals for their child. The focus is on interrupting harmful ED behaviours and facilitating weight restoration (if required)	
<ul style="list-style-type: none"> <li>• Early intervention and weight restoration for children and adolescents can help to reverse the effects of malnutrition.</li> <li>• Initial weight gain, within the first four weeks of treatment, is one of the best predictive measures of prognosis.</li> <li>• It is generally agreed that a rate of weight gain of 0.5 to 1.0 kg per week is appropriate in the outpatient setting.<sup>3</sup></li> </ul>	<ul style="list-style-type: none"> <li>• “Gaining weight is the most important intervention your child needs right now.”</li> <li>• “It is vital that [insert child’s name] begin the treatment process as soon as possible, in order to give them the best chance of recovery.”</li> </ul>
<ul style="list-style-type: none"> <li>• Provide education for parents/caregivers as required to help them understand the seriousness of the illness.</li> </ul>	<ul style="list-style-type: none"> <li>• “EDs are complex illnesses that affect both the body and the mind at the same time. Every system in the body is affected by malnutrition. It is unlikely that [insert child’s name] will get better unless we intervene”</li> </ul>
<ul style="list-style-type: none"> <li>• Provide nutrition interventions to support weight restoration prior to the patient beginning any psychological intervention.</li> </ul>	<ul style="list-style-type: none"> <li>• “It is important that your child works through their thoughts and feelings about what is happening to them, but right now, their brain does not have the nourishment it needs to think clearly and process information.”</li> <li>• “We need to give the brain the fuel it needs to function properly first, before we can ask it to take on the work of psychological therapy”</li> </ul>
<ul style="list-style-type: none"> <li>• Support parents/caregivers to take charge of their child’s food intake, including grocery shopping, cooking, and plating of food.</li> </ul>	<ul style="list-style-type: none"> <li>• “The symptoms of your child’s illness may be too strong right now to allow them to make rational choices. They need your support to make the best decision possible for them.”</li> </ul>
<ul style="list-style-type: none"> <li>• Parents/caregivers are responsible for preparing and plating meals for their child according to their meal plan.</li> </ul>	<ul style="list-style-type: none"> <li>• “I know you do not want to add a grain choice to breakfast. It is a part of the meal plan, so we need to include it. Would you like toast or oatmeal?”</li> </ul>

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Recommendations and Strategies <sup>1,8-10</sup>	Sample Dialogue and Supports
<ul style="list-style-type: none"> <li>Low-calorie foods and/or sugar substitutes are not recommended as they can be counterproductive and exacerbate ED behaviours.</li> </ul>	<ul style="list-style-type: none"> <li>"In the meal plan, we will not include low-calorie foods."</li> <li>"I understand that feeding your child their safe foods may make them feel less anxious but doing so may send confusing messages about their treatment plan."</li> <li>"Continue to prepare family meals in the same manner that you did before."</li> </ul>
<ul style="list-style-type: none"> <li>Parents/caregivers need to monitor for compensatory behaviours such as vomiting and excessive exercise</li> </ul>	<ul style="list-style-type: none"> <li>"I understand how tough it is to believe that your child is engaging in ED behaviours, but the illness can be deceiving. We need to be aware of the signs and symptoms."</li> <li>"It is important that your child remains with you for an hour after eating to make sure they do not have the opportunity to purge. If they need to use the washroom during that time, stand outside the door and have them talk/sing to you while inside."</li> <li>"If you are concerned with your child exercising or engaging in other compensatory behaviours at night, they may need to be supervised."</li> </ul>
<ul style="list-style-type: none"> <li>Depending on the age of the child and their maturity, clinicians may spend most of the visit with the child's parents/caregivers.</li> </ul>	<ul style="list-style-type: none"> <li>"What topics do you think [insert child's name] would benefit from learning about? Is there anything specific you think we should discuss today?"</li> </ul>
<ul style="list-style-type: none"> <li>Sibling relationships are maintained by assigning siblings a supportive role in treatment while leaving all supervisory responsibilities to the parents/caregivers.</li> </ul>	<ul style="list-style-type: none"> <li>"It's the parent's job to manage the food and eating. We do not want to put the responsibility of [insert child's name] recovery on their siblings."</li> </ul>
<p><b>A Gradual Return of Control to the Patient</b></p> <p>Patients may gradually require less supervision once consistent weight restoration is established, ED-related behaviours are reduced, and they are eating a greater variety of foods with less difficulty. At this stage, the child and family may feel more confident with their treatment plan. Some food fears may persist in this phase. This transition may gradually take place over several weeks and still includes some parental/caregiver supervision as appropriate.</p>	
<ul style="list-style-type: none"> <li>Parents/caregivers may allow their child to choose and plate their own snacks and/or be more involved in meal preparation.</li> <li>If this goes well, they may transition to one meal per day, such as unsupervised lunches at school, then two meals per day and so on.</li> </ul>	<ul style="list-style-type: none"> <li>"Do you feel [insert child's name] is ready to eat lunches on their own?"</li> <li>"What would you put together for a snack if we were not there?"</li> <li>"Do you feel ready to eat your snack on your own?"</li> </ul>
<ul style="list-style-type: none"> <li>The parents/caregivers continue to work on skill development such as:             <ul style="list-style-type: none"> <li>Challenging remaining food fears.</li> <li>Selecting foods that meet their nutritional goals.</li> <li>Resuming normal levels of physical activity.</li> <li>Normalizing eating behaviours.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>"Are there any foods we have not tried yet that are still scary for you?"</li> <li>"Do you know what you are having for supper tonight? Can you describe to me the portion you need for your meal plan?"</li> <li>"It's important that you include a snack after soccer. What kinds of foods could you have?"</li> </ul>

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Recommendations and Strategies <sup>1,8-10</sup>	Sample Dialogue and Supports
<ul style="list-style-type: none"> <li>Parents/caregivers continue to monitor for signs of ED behaviour such as excessive exercise, ditching of foods, vomiting, laxative abuse etc.</li> </ul>	<ul style="list-style-type: none"> <li>“It’s important to remember that ED recovery is not linear. Your child might be doing really well, and then have a setback. Not only is this common but it is expected! It is not something that you have done wrong, but a part of the recovery process. That is why it is important that we continue to watch for signs of behaviours.”</li> </ul>
<ul style="list-style-type: none"> <li>If weight gain begins to stall (less than 0.5 kg/week), parents/caregivers may need to return to an increased level of supervision to ensure the child is continuing to follow their appropriate growth curve.</li> </ul>	<ul style="list-style-type: none"> <li>“Until we see your child’s weight moving in the right direction again, we may need to provide more meal supervision”.</li> </ul>
<ul style="list-style-type: none"> <li>Encourage parents/caregivers to adjust how much control their child has over their eating based on their progress.</li> <li>For example, if they allow more independence and they realize their child is not ready, they can resume providing more meal supervision.</li> </ul>	<ul style="list-style-type: none"> <li>“You are learning as you go through this, and it can be difficult to know when the right time is to begin to give control back to [insert child’s name]. If they are not ready, we can adjust and try again later.”</li> </ul>
<ul style="list-style-type: none"> <li>Some children may benefit from individual therapy and/or nutrition education and counselling at this stage.</li> </ul>	<ul style="list-style-type: none"> <li>“Is there anything about nutrition you’ve read online or heard at school that you have questions about?”</li> </ul>
<p><b>Establishing A Healthy Independence</b></p> <p>Once the weight restoration phase is complete, patients and parents/caregivers learn to cope with upcoming challenges without using ED behaviours to manage stress. The focus of treatment transitions to assisting the patient in creating a positive identity and catching up on other developmental concerns.</p>	
<ul style="list-style-type: none"> <li>Explore upcoming challenges that the child may experience so that parents/caregivers can be aware and feel prepared. For example:             <ul style="list-style-type: none"> <li>Some patients report that maintaining a normal weight is more emotionally difficult than gaining weight. They may experience an increase in anxiety and sadness.</li> <li>ED beliefs can continue to be strong for months after weight restoration is complete.</li> <li>Patients may see an increase in some food fears, out of fear of “going over” their goal weight.</li> <li>The child may assume “they aren’t sick anymore” and worry that the increased attention they have been receiving from their parents/caregivers and treatment team will end.</li> <li>An increase in body image disturbances may occur at this stage.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>“The body heals first, but the brain can take time to catch up.”</li> <li>“Sometimes people assume that because your child “looks better” than they did before, their thinking is “better” too. This is usually not the case. In fact, it can be more difficult for patients to eat and challenge their food fears as their weight increases. We need to continue to be compassionate and validate their fears and emotions”.</li> <li>“Some of my patients feel happy when they reach their goal weight, but that isn’t the case for everyone. I am wondering how you are feeling right now?”</li> <li>“It’s common for patients to feel uncomfortable in their bodies at a higher weight. Sometimes the ED voice gets louder at this stage than it was before. Just because the body has healed, doesn’t mean the thoughts go away. Many children need extra support from their parents at this stage, not less.”</li> <li>“It’s important for [insert child’s name] to know we are aware of how they feel, and we are here to listen.”</li> </ul>



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Recommendations and Strategies <sup>1,8-10</sup>	Sample Dialogue and Supports
<ul style="list-style-type: none"> <li>Continue to assess the patient's progress and appropriate level of parental/caregiver supervision.</li> </ul>	<ul style="list-style-type: none"> <li>"Have you tried any new foods this week?"</li> <li>"Tell me about mealtimes. How is it going plating your own food?"</li> <li>"Have there been any new challenges lately?"</li> </ul>
<ul style="list-style-type: none"> <li>Monitor as required. There is no recommended protocol for ending services. Every family is different, and some may need more frequent follow-ups to ensure they are progressing.</li> </ul>	<ul style="list-style-type: none"> <li>"Things seem to be going well, so we can try spreading out our appointments, but if anything changes or you have concerns, let me know and I can check my schedule for an earlier appointment."</li> </ul>

## Exploring the Family's Relationship with Food

Providing client-centred care for patients with EDs involves the consideration of multiple factors,<sup>11</sup> however, for children and adolescents, the family's relationship with food may be given additional consideration. Care should be tailored to the individual needs of each patient and family. RDs can refer to Nutrition Service's NPG Eating Disorder Care for more information on conducting a nutrition assessment for patients with EDs.

Considerations when Exploring the Family's Relationship with Food	Sample Dialogue and Supports
<b>Family Schedules and Eating Patterns</b>	
<ul style="list-style-type: none"> <li>Does the family eat meals together?</li> <li>Explore family dynamics in connection to eating at home.</li> <li>Work schedules of parents/caregivers may limit their availability to supervise all meals.</li> </ul>	<ul style="list-style-type: none"> <li>"Will there be someone home in the mornings to eat breakfast with [insert child's name]?"</li> </ul>
<ul style="list-style-type: none"> <li>Some patients will have significant anxiety eating in front of others. Sitting down with a large group of people, even those in their immediate family, may make mealtimes more difficult. It may be best to have one parent/caregiver sit and eat with the child.</li> <li>Other patients might benefit from the family's support during mealtime. It is essential that the clinician explores with each family the eating environment that will work best for their child.</li> </ul>	<ul style="list-style-type: none"> <li>"Can you tell me a little bit about what meals look like in your home now? What about before your child got sick?"</li> <li>"Meals should be as calm and relaxed for your child as possible. [Insert child's name] may feel more comfortable eating with the whole family or just one parent. Either option is ok. Do what works best for your child ."</li> </ul>
<ul style="list-style-type: none"> <li>Activities of siblings or other family members may impact the scheduling of meals.</li> </ul>	<ul style="list-style-type: none"> <li>"Are there any family activities that occur over mealtimes?"</li> </ul>
<ul style="list-style-type: none"> <li>It may be necessary to have a parent/caregiver or responsible adult supervise lunches while the child is at school.</li> </ul>	<ul style="list-style-type: none"> <li>"It's important that all meals are supervised, at least in the beginning. Is it possible for a parent/family member to drive to the school on their lunch hour and have your child eat with you?"</li> </ul>



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Considerations when Exploring the Family's Relationship with Food	Sample Dialogue and Supports
<ul style="list-style-type: none"> <li>• Patients are often focused on the food that they are eating, and also the intake of their parents/caregivers and siblings.</li> <li>• It may be necessary to have the child eat with one parent/caregiver temporarily, to avoid comparisons with other family members.</li> <li>• It is not unusual for patients to feel self-conscious about the amount of food they are eating. Patients may be upset that they are eating more than their parents/caregivers and siblings. They may encourage other family members to eat more to help alleviate this guilt.</li> </ul>	<ul style="list-style-type: none"> <li>• “Right now, it probably feels as though you are eating a lot more than others. Your body needs more right now, because your metabolism is high, and your body is healing.”</li> <li>• “I know that it is hard right now to eat more than your [parents, siblings, caregivers]. That must be really difficult.”</li> </ul>
<b>Meal Preparation</b>	
<ul style="list-style-type: none"> <li>• Explore the roles that each family member plays in meal preparation and planning.</li> <li>• How are tasks distributed among family members? (i.e., grocery shopping, meal planning, meal preparation).</li> <li>• A child that is accustomed to more independence in preparing their own meals may struggle with parents/caregivers taking control of their food.</li> <li>• Parents/caregivers that are not used to planning meals and cooking for the family, may need additional guidance.</li> </ul>	<ul style="list-style-type: none"> <li>• “Can you tell me a little about who does the grocery shopping at home?”</li> <li>• “Who does the majority of the cooking at home?”</li> <li>• “It sounds like [insert child's name] is used to making their own meals. It may be a bit of a transition for them to allow you to prepare their food for them. We can reassure them that this is temporary and soon we will have them doing more cooking again.”</li> </ul>
<ul style="list-style-type: none"> <li>• Does the family cook/prepare most of the meals at home?</li> <li>• How often does the family eat out/order in?</li> </ul>	<ul style="list-style-type: none"> <li>• “Does your family have any favourite restaurants? How often do you eat there?”</li> </ul>
<ul style="list-style-type: none"> <li>• The child might want to be involved with meal preparation to ensure the parent/caregiver won't include ingredients they feel uncomfortable with (e.g., oils, butter, cream).</li> <li>• Although this behaviour may temporarily reduce anxiety, it significantly increases the ED's drive to control food intake, therefore, it should be avoided.</li> </ul>	<ul style="list-style-type: none"> <li>• “I feel confident that your parents understand the meal plan. They do not need to add in anything extra. What we have discussed is what you need.”</li> <li>• “Your parents know how much food you need. I know it is difficult, but you need to trust that what they cook is correct.”</li> <li>• “It may be best to watch a show in another room while your parents are making dinner.”</li> </ul>
<ul style="list-style-type: none"> <li>• Patients with EDs will often show signs of food obsession such as cooking or baking for others, but not eating the food they prepare.<sup>12</sup></li> </ul>	<ul style="list-style-type: none"> <li>• “If we are going to allow cooking or baking, we can not use low calorie/sugar-free substitutions.”</li> <li>• “If you want to make cookies, then you need to eat one. Your parents can share one with you. Don't worry, we can incorporate it into your meal plan”</li> </ul>
<ul style="list-style-type: none"> <li>• Grocery shopping can be overwhelming for patients that struggle with making decisions about what to eat.</li> <li>• Parents/caregivers may find grocery shopping with their child to be a very unsettling experience since some patients may feel compelled to examine food labels in an obsessive way.</li> </ul>	<ul style="list-style-type: none"> <li>• “For the time being, it may be best for your parents to do the grocery shopping. I am confident that they understand what kinds of food you need. When your thoughts improve and your anxiety is better, we can talk about this again.”</li> </ul>

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### Possible Education Topics for Parents/Caregivers

Interventions for children and adolescents undergoing treatment for an eating disorder are individualized. Although parents/caregivers take a primary role in meal planning and are key participants, it is still important to establish a relationship and build trust with the patient. Provide patients with age-appropriate information about nutrition and EDs to support their recovery. Patients and families can benefit from education on a wide range of topics during their child's treatment.<sup>11</sup> Use your professional judgement to adapt education to each patient's and family's needs. Some examples of frequently discussed education topics in eating disorder treatment are provided below.

Education Topics for Patients and Families	Sample Dialogue and Supports
<b>Nutritional Needs for Restoration and Growth</b>	
<b>Caloric Requirements in Refeeding</b> <ul style="list-style-type: none"><li>• Caloric needs for weight restoration are often perceived as counterintuitive. Parents/caregivers may voice concerns that they feel their child “is eating too much” or eating too much “unhealthy food”.</li><li>• Parents/caregivers may require ongoing education regarding adequate food intake to meet caloric requirements for adolescent development and weight restoration at multiple appointments.<sup>11</sup></li></ul>	<ul style="list-style-type: none"><li>• “I know the meal plan feels like a lot of food right now – and it is! Your child needs all of it to help heal and repair their bodies and get them back on their growth curve. Once the body has healed, we will lower the amount of food slowly to what feels more manageable.”</li></ul>
<b>Metabolism and Hypermetabolism</b> <ul style="list-style-type: none"><li>• Prior to the start of refeeding, resting metabolic energy rates (REE) may be as low as 50–70% of normal.<sup>12</sup> Patients may be fearful that because their weight is maintaining on such a low level of energy, increasing calories will result in dramatic weight gains.</li><li>• Once refeeding commences, there is a rapid increase in REE,<sup>13</sup> which appears to increase according to caloric intake. Because of this, calories should be regularly increased to support the body's rising energy needs.</li><li>• Children can remain hypermetabolic for up to two years, so it is important not to prematurely reduce caloric intake when target weights have been reached. The development of muscle mass requires the continuation of high-calorie levels.<sup>14</sup></li></ul>	<ul style="list-style-type: none"><li>• “When the body is not getting enough nutrition, it slows the metabolism down as a means to preserve itself. Once we start to introduce food again, the metabolism will increase and sometimes go higher than normal as the body tries to heal and repair itself.”</li><li>• “In order to keep up with your body's needs right now, we will need to keep adjusting your meal plan to include more food. I know that can feel scary, but we will not give you more than what your body needs”.</li></ul>

# Including Parents/Caregivers in the Treatment of Eating Disorders

## Point of Care Reference

Education Topics for Patients and Families	Sample Dialogue and Supports
<p><b>Growth Charts and Target Weights</b></p> <ul style="list-style-type: none"> <li>• Returning patients to their premorbid growth curve and continuing to follow it, is essential for reducing the risk of relapse.</li> <li>• A pre-existing growth chart may not be available for every patient, but if one is, it can be helpful in estimating the patient's target weight.</li> <li>• Parents/caregivers may be concerned that the goal weight suggested by the treatment team is higher than the patient's weight prior to becoming ill. Growth charts can be a useful resource for explaining the importance of returning the patient to their pediatric growth curve rather than a specific number.<sup>11</sup></li> </ul>	<ul style="list-style-type: none"> <li>• “Weight goals can be “a moving target” for children and adolescents and will increase appropriately over time to account for growth and development.”</li> <li>• “I understand that [insert child’s name] has never weighed [X amount of weight] before, however, our weight target is higher now than when they first became ill with their ED because they are a year older now. Our goal is the weight they would have been at this age, had they never been sick.”</li> </ul>
<p><b>Components of Weight Restoration</b></p> <ul style="list-style-type: none"> <li>• When patients hear adults say “You need to gain weight” most immediately interpret that they need to gain body fat. Education as to how the body restores weight may help reduce anxiety in the weight restoration phase.<sup>11</sup></li> <li>• Weight gain comes from multiple sources including rehydration, replenished glycogen stores, increased muscle/organ mass and increased bone density.</li> <li>• For patients that menstruate, a return of menses that often accompanies weight gain can be distressing. Many patients may view this as physical confirmation that they are no longer underweight.</li> <li>• Patients with EDs are often preoccupied with numbers (i.e., calories, weight, grams of macronutrients, and minutes of exercise) as a result of their illness.</li> <li>• Keep the discussion about numbers to a minimum.</li> <li>• If a weight check is necessary during the appointment, weigh patients backwards to avoid seeing the number on the scale</li> </ul>	<ul style="list-style-type: none"> <li>• The analogy of a cup can be helpful for patients to visualize this concept:</li> <li>• “An empty cup weighs less than a cup that is full of water, yet it remains the same size and shape. As the body rehydrates and gains back lean body tissues such as muscle, organs, and bones, it will become heavier but will not dramatically change in size/shape.”</li> <li>• “Many patients have mixed emotions when their menses return. I am wondering how you are feeling right now. Would it be helpful to learn about why your treatment team feels this is an important step for your recovery?”</li> <li>• “The average amount of calories teenagers need to provide energy and fuel their body depends on a lot of different factors (metabolism, genetics, gender, activity etc.)”</li> <li>• “I need to check your weight today, to help me understand your nutritional status, but I’m going to ask you to turn around and face away from the scale, so you can not see the number.”</li> <li>• “I know your ED wants to know the number. What is more important is whether or not your body is getting the nourishment it needs to heal”.</li> </ul>

# Including Parents/Caregivers in the Treatment of Eating Disorders

## Point of Care Reference

Education Topics for Patients and Families	Sample Dialogue and Supports
<b>Eating Disorder Symptoms</b>	
<p><b>Compensatory Behaviours</b></p> <ul style="list-style-type: none"> <li>• Avoid asking explicit questions regarding compensatory behaviours unless the patient and/or parents/caregivers provide this information.</li> <li>• Not all children may be aware of compensatory behaviours (vomiting, abusing laxatives or diet pills, excessive exercise, misusing insulin etc.) and discussing them in depth may lead to the unintentional consequence of providing information on hazardous weight loss techniques.</li> <li>• Use professional judgement and consider asking parents/caregivers if they suspect their child may be engaging in ED behaviours, without the patient in the room.</li> </ul>	<ul style="list-style-type: none"> <li>• “I wanted to ask you without [insert child’s name] in the room if you suspect they may be intentionally vomiting or using laxatives [or other behaviour] after meals? If so, would it be ok if we explored ways to keep them safe after eating?”</li> <li>• “Some patients with ED engage in these behaviours in secret. Even if you do not suspect your child is struggling with these behaviours, it is important to understand the warning signs so that you can recognize them should they occur.”</li> </ul>
<b>EDs are Mental Illnesses</b>	
<p><b>Eating Disorders are illnesses, not lifestyle choices</b></p> <ul style="list-style-type: none"> <li>• EDs are not a choice that the child has made. They are not about vanity or “being stubborn”.</li> <li>• EDs are brain-based illnesses, which impair thought processes regarding food and eating.<sup>15</sup></li> </ul>	<ul style="list-style-type: none"> <li>• “Foods that [insert child’s name] used to enjoy may be scary for them now due to how their brain is misinterpreting the messages it is receiving. This is why they cannot “just eat”.</li> </ul>
<p><b>Eating Disorders can be very scary for the patient</b></p> <ul style="list-style-type: none"> <li>• Children often lack the emotional maturity and life experience to understand what is happening to them.</li> <li>• The level of insight may vary from one patient to the next</li> <li>• A common response from patients when asked an open-ended question is “I don’t know.” This can be discouraging for parents/caregivers, as it shuts down communication.</li> </ul>	<ul style="list-style-type: none"> <li>• “Your child may not understand the emotions they are feeling or why they are in engaging in a behaviour. Answering “I don’t know” to a question may be their way of communicating to us that they feel overwhelmed and confused.”</li> </ul>
<b>Dealing With Emotions During Refeeding</b>	
<ul style="list-style-type: none"> <li>• Heightened levels of anxiety for the child can be difficult for parents/caregivers to manage.</li> <li>• Patients in the refeeding and weight restoration phases often experience heightened levels of anxiety.<sup>15</sup> Parents/caregivers can interpret this as their child “getting worse” or moving backwards in recovery.</li> <li>• Well-meaning parents/caregivers may allow their child to stall on weight gain and compensate on their meal plan in order to reduce the negative emotions they are experiencing.</li> </ul>	<ul style="list-style-type: none"> <li>• “I know it is difficult to see your child upset, and our instinct as parents is to try to make your child feel better, but it’s important to continue to teach [insert child’s name] how to manage their anxiety without using ED behaviours.”</li> <li>• “If we allow [insert child’s name] to restrict their intake when they are experiencing anxiety or anger, we are sending the message that it is ok to not eat when they are feeling upset.”</li> </ul>

# Including Parents/Caregivers in the Treatment of Eating Disorders

## Point of Care Reference

Education Topics for Patients and Families	Sample Dialogue and Supports
<ul style="list-style-type: none"> <li>Parents/caregivers may experience moments of anger or frustration directed toward their child.</li> <li>Caregiver burden may result in critical comments, hostility, and emotional over-involvement with the child, thus negatively affecting treatment outcomes.</li> <li>Parental warmth is associated with positive treatment outcomes.<sup>10</sup></li> </ul>	<ul style="list-style-type: none"> <li>“We all lose our tempers sometimes. There is no rule book for what you are doing, and I know you are doing the best you can.”</li> <li>“If we want [insert child’s name] to express their emotions in a calm manner, then we need to model to them how that is done.”</li> </ul>
<ul style="list-style-type: none"> <li>Parents/caregivers may experience burnout with the high levels of intervention that eating disorder treatment requires.</li> <li>Caregivers of children/adolescents with ED experience high levels of burden and psychological distress.<sup>10</sup> Recovery can be an intense and all-consuming task, requiring sacrifices from family members.</li> <li>Emotional and social supports for caregivers are imperative. Each member of the treatment team is an important source of support.</li> <li>Encourage parents/caregivers to seek support (e.g., family, close friends) or consider their own mental health counselling if required.</li> </ul>	<ul style="list-style-type: none"> <li>“I appreciate this is a stressful time for you and your family. How are you feeling?”</li> <li>“It’s important that you take the time you need to care for your needs. Is there anyone you feel comfortable with that you can talk to about how you are feeling?”</li> <li>“I have a list of therapists and supports in the community that may be able to help if you feel you need it.”</li> </ul>
<b>Use of Neutral Language to Describe Food</b>	
<ul style="list-style-type: none"> <li>An “All Foods Fit” approach is beneficial to help patients challenge their food fears and meet their high energy requirements.<sup>11</sup></li> <li>Be mindful of the language used to describe food.</li> <li>Use neutral terms to describe food. Food labels such as “good or bad”, “healthy or unhealthy”, “clean”, “junk”, etc. are not recommended.</li> </ul>	<ul style="list-style-type: none"> <li>“Many patients think of foods /food groups as “healthy or unhealthy”. Do you think of any foods in this way?”</li> <li>“How we think about food affects our emotions when we eat them. If we view food as “good or bad”, then we feel “good or bad” about ourselves when we eat them.”</li> <li>“There are no healthy or unhealthy foods, only patterns of eating.”</li> </ul>
<b>Meal Planning Strategies</b>	
<ul style="list-style-type: none"> <li>There is no one specific meal plan to use in eating disorder treatment.<sup>11</sup> Each patient and their family’s situation are different.</li> <li>Some families may have an intuitive sense of the amount of food their child needs, while others may benefit from more support from their health professional.</li> <li>Assess the parent’s/caregiver’s knowledge of food and nutrition, to determine if a meal plan is appropriate.</li> <li>If a meal plan is required, use one that is easy for the family to understand and follow.</li> </ul>	<ul style="list-style-type: none"> <li>“You are the expert on your own child, and we need to trust your instincts on how to feed them.”</li> <li>“Can you tell me a bit about your understanding of how your child should be eating?”</li> <li>“Recovery from an eating disorder usually requires more food and energy than what your child typically consumes. If you like, I can offer you some ideas on how we can add more food or develop a meal plan for [insert child’s name] to follow.”</li> </ul>

## Including Parents/Caregivers in the Treatment of Eating Disorders

### Point of Care Reference

Education Topics for Patients and Families	Sample Dialogue and Supports
<ul style="list-style-type: none"> <li>• Meal plans that provide structure can be reassuring to patients.</li> <li>• Eating at approximately the same time every day, following the portion sizes/exchanges agreed upon with the clinician, and having a parent/caregiver eat with the child can help establish trust.</li> <li>• Limit sudden changes or “surprises” in the routine.</li> <li>• RDs can refer to Nutrition Service’s NPG Eating Disorder Care for more information on types of meal planning tools and approaches.</li> </ul>	<ul style="list-style-type: none"> <li>• “Stability and routine are very important to helping your child feel safe around mealtimes. I know life can be unpredictable and changes to your schedules may come up, but the more we can make mealtimes a priority and follow the meal plan, the more we can help [insert child’s name] through their recovery.</li> </ul>

### Common Practice Questions for Health Professionals

Examples of common questions health professionals have when working with families to provide eating disorder treatment are provided below. Refer to [POC Reference: Common Practice Questions in Eating Disorders Care](#) for additional support.

Questions	Sample Dialogue
<p><b>A lot of the language suggested for parents/caregivers and patients seem to be authoritative. How can I take a firm, non-negotiable stance while still practicing patient-centred care?</b></p> <ul style="list-style-type: none"> <li>• Be a partner for families with EDs, by using a patient-centred approach to care.</li> <li>• Include parents/caregivers (and in appropriate circumstances, the child) in all decisions relating to treatment.</li> <li>• Empower parents/caregivers and model how to be firm with the ED itself – not the child.</li> <li>• By externalizing the ED and separating it from the child's identity, parents/caregivers and health professionals can prioritize treatment goals while still giving the patient compassionate care.</li> </ul>	<ul style="list-style-type: none"> <li>• “The treatment team is here to help support [insert child’s name] and you as parents through every stage of recovery. We will make all the decisions together in the best interests of [insert child’s name].”</li> <li>• “As adults, we need to show [insert child’s name] how to stand up to the ED, so they can learn to do it for themselves.”</li> </ul>

# Including Parents/Caregivers in the Treatment of Eating Disorders

## Point of Care Reference

Questions	Sample Dialogue
<b>“How do I address parents/caregivers that may have their own disordered eating beliefs/behaviours?”</b>	
<ul style="list-style-type: none"> <li>• Clinicians often feel that part of their role is to “correct” patients/parents/caregivers on their disordered eating beliefs/behaviours. While accurate nutrition education is important, challenging parents/caregivers may damage rapport with the family.</li> <li>• A more helpful approach may be to find a common goal with the parents/caregivers (i.e., “I want my child to build muscle”) and focus on ways to achieve that (i.e., increasing intake, eating regularly, eating a wide variety of foods)</li> <li>• As rapport grows, parents/caregivers may be more open to nutrition education topics.</li> <li>• Ask permission to share information with parents/caregivers.</li> <li>• Providing written resources for parents/caregivers that support recommendations may be more helpful than engaging in confrontational conversations.</li> </ul>	<ul style="list-style-type: none"> <li>• “I’m curious about what the term “healthy eating” means to you and your family. Can you describe that for me? Tell me more about why you feel that way.”</li> <li>• “You indicated that [insert child’s name] doesn’t seem to have as much strength as they used to and that they have lost muscle mass. Can you elaborate a little bit on that? Would you be interested in learning about the role that nutrition can play in that?”</li> </ul>
<b>“How do I address parents/caregivers that disagree with their child’s goal weight?”</b>	
<ul style="list-style-type: none"> <li>• Well-meaning parents/caregivers may feel that because their child was dissatisfied with their body image prior to the onset of their illness, returning them to that weight will trigger a relapse of ED behaviours.</li> <li>• Provide education to parents/caregivers that the best chance of recovery is dependent on the body returning to the patients’ pediatric growth curve.</li> <li>• It is common for patients’ weight to be higher than prior to their illness because they are older and have more growth and development to restore.</li> </ul>	<ul style="list-style-type: none"> <li>• “I can understand your concerns about [insert child’s name] gaining weight because they were unhappy before at a higher weight. In order to give them the best chance of recovery, we need to allow the body to fully heal and restore weight to where it’s genetically meant to be.”</li> </ul>



# Including Parents/Caregivers in the Treatment of Eating Disorders

## Point of Care Reference

### Common Parent/Caregiver Questions During Eating Disorder Treatment

Examples of common questions that parents/caregivers may have are provided below.

Questions	Sample Dialogue
<b>“What do I do/say if my child refuses to eat?”</b>	
<ul style="list-style-type: none"><li>• Be strong and be consistent. Provide a loving, but firm approach to eating and meals. Taking control of eating away from your child, may help reduce their guilt and anxiety about making decisions around food.</li><li>• Eat all your meals and snacks with your child. Stay calm and encourage them to eat. Being present with them, helps your child understand that eating is a priority.</li><li>• Avoid rationalizing with your child that they need to eat. Reassure your child that you are there with them emotionally, but you are going to make the choices about food for their health and well being</li></ul>	<ul style="list-style-type: none"><li>• “I know this is difficult for you. I am right here with you. We are going to get through this together.”</li><li>• “Everything is ok. You are safe. The food is not going to hurt you. Take another bite”.</li></ul>
<b>“What do I do if my child does not want treatment?”</b>	
<ul style="list-style-type: none"><li>• It is very common for adolescents to be resistant to treatment.</li><li>• Intensive and early intervention in children and adolescents with EDs offers the best prognosis for a full recovery.</li></ul>	<ul style="list-style-type: none"><li>• “Eating Disorders are not a phase or something your child will outgrow without your help. If left untreated, they can be lifelong mental illnesses.”</li><li>• “Remember it is the eating disorder that does not want the recovery process – not your child.”</li><li>• “As a parent/caregiver, you make the decisions regarding your child’s health and well-being until they are well enough to do so for themselves.”</li></ul>
<b>“How can I help my child develop a positive body image?”</b>	
<ul style="list-style-type: none"><li>• Set a good example for your child. Use positive language when talking about yourself and others. Avoid making comments on your body or the bodies of others.</li><li>• Focus on qualities apart from appearance. For example, compliment your child on their intelligence, humour and talents.</li><li>• Remove potential triggers from the home such as scales, mirrors and magazines that promote unrealistic body images.</li><li>• Monitor your child’s online usage and social media for diet and weight loss messaging.</li></ul>	<ul style="list-style-type: none"><li>• “I see the sparkle in your eye coming back! I love the way you laugh. It lights up the room.”</li><li>• “We do not need the scale in the house anymore. We are focusing on nourishing our bodies and giving them the nourishment, they need.”</li></ul>

# Including Parents/Caregivers in the Treatment of Eating Disorders

## Point of Care Reference

Questions	Sample Dialogue
<b>“How can I keep my child from bingeing and purging?”</b>	
<ul style="list-style-type: none"><li>• Follow a regular meal plan with three meals per day and snacks. Try to prevent your child from becoming overly hungry, as this will often lead to bingeing.</li><li>• Stay with your child after meals and do not allow them to use the washroom or isolate themselves in their room.</li><li>• It may be necessary to have a rule that bedroom/bathroom doors always remain open. In some cases, they may need to be removed from the hinges.</li><li>• Encourage collaboration with the child to find helpful distraction techniques after meals such as playing games, going for a walk, watching movies or listening to music.</li></ul>	<ul style="list-style-type: none"><li>• “Why don’t you do your homework here in the kitchen, while I do the dishes. Maybe later we can watch that show you like or play a game.”</li><li>• “I know your ED can feel overwhelming sometimes, that’s why we are going to supervise you after meals. We only want to keep you safe.”</li></ul>

# Including Parents/Caregivers in the Treatment of Eating Disorders

## Point of Care Reference

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