

A guide to your stay in the hospital

Information for patients and parents

The Pediatric Eating Disorders Program

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Welcome to McMaster Children's Hospital

You need the medical care and support that can only be provided in a hospital.

We strive to make our hospital a safe, caring and accepting place for you to begin recovery. You have been admitted to the hospital because you have serious health problems related to an eating disorder.

Young people are admitted for different health reasons. For some, it may be that their weight is dangerously low. For others, it may be a low heart rate or blood pressure, or abnormal blood tests.

The main reasons you are here are to:

- improve your health so that you become medically stable
- have your weight restored to a safer level
- begin eating normally again
- learn positive coping skills
- strengthen family communication and supports
- plan for how you can maintain your health at home
- gain confidence in being able to remain well and gain weight for growth and development

Most teenagers with eating disorders recover from their illness. However, we know that this takes a long time.

While you are in the hospital, your treatment team will begin to teach you and your family about your illness. Please feel free to ask questions about your illness and our approach to helping you.

Your health care team

All team members have experience helping young people with eating disorders.

We can help you learn about your illness and start you on the path to recovery.

During your hospital stay you will be cared for by a team of health care providers, staff and volunteers. You and your family are an important part of this team. Together, we can identify your health needs and develop a plan of care to meet those needs.

Here is a description of how each team member will work with you and your family.

Adolescent Medicine Pediatrician

- These pediatricians specialize in working with and understanding the needs of teenagers. They are experts in the diagnosis and treatment of eating disorders in children and teens.
- Adolescent Medicine Pediatricians rotate on the Eating Disorders ward on a monthly basis. You may be cared for by one or more pediatricians during your stay on the ward. These doctors work with the Eating Disorders Outpatient Program and understand your illness and your needs.

Child and Adolescent Psychiatrist

- The Child and Adolescent Psychiatrist is an expert in the diagnosis and treatment of eating disorders, and other mental health illnesses experienced by young people.
- The psychiatrist takes part in the assessment of children and teens who stay in the hospital and guides the eating disorders team. When it may be of help, the psychiatrist can discuss medication options with you and your family.

During your hospital stay, you may have many questions.

We welcome your questions at any time.

Registered Dietitian

- The dietitian specializes in nutrition and will meet with you and your family during your hospital stay.
- The dietitian can provide your parents with nutrition education and support, to guide your passes from the hospital and continued outpatient success.

Registered Nurses (RN)

- Nurses have a central role with the eating disorders team. As well as monitoring your health and providing bedside care, nurses provide meal support. They know that eating is a challenge for the young people on our ward and are available to coach patients and parents through the process.
- Nurses will orient you to the program and are always available to answer your questions.
- Nurses are your communication bridge to the rest of the team.

Nurse Practitioner (NP)

- The nurse practitioner is an advanced practice nurse.
- The NP works with the team to provide ongoing assessment and management of your care while on the ward.

Child Life Specialist

- The Child Life Specialist can help you adjust to being in the hospital. This specialist will work with you to provide distraction, by planning activities you can do by yourself and as part of a group, with other patients in our program.
- The Child Life Specialist will give you emotional support and help you find ways to manage your feelings.

Patients and families are an important part of our team.

For the best possible care, you and your family will work closely with our health care providers, staff and volunteers.

Therapists

- The therapist team includes psychologists and social workers. They work with the rest of the team to understand and treat eating disorders. Each therapist has extensive experience in the treatment of eating disorders and a unique set of skills.
- All therapists provide a combination of family and individual counseling. They also participate in the group programming available on the ward.
- Your therapist will take part in weekly family meetings during your hospital stay. The therapist will also provide the ongoing outpatient therapy your family will need.

Teachers

- Teachers are available to help you, once your pediatrician feels that you are well enough to do school work. When permitted, you will be able to go to the classroom each morning.
- The teacher will talk with your community teachers to make sure that you keep up in school and make a smooth transition back to school after discharge.

Volunteers

- Volunteers may provide activities. They can let you know about social activities on the ward that you may take part in or help you get supplies for crafts.
- We try to choose volunteers who have interesting skills to teach, such as knitting, jewelry making and origami. Let us know your interests.

Medical and allied health students

 McMaster Children's Hospital is a "teaching hospital". Students who are learning to become doctors, nurses and other professionals are part of the health care team. All students are closely supervised.

About your hospital stay

The Registered Nurses on the Pediatric Eating Disorder Team are here to support you and your family. The Eating Disorder Team Registered Nurse will provide you and your family with an overview of the routines and activities while in the hospital.

As you progress through the program, you will acquire more responsibilities and privileges. The nurse can answer your questions, give you emotional support and help with your recovery through nutritional supervision and coping strategies.

At the beginning of your stay, you will be asked to stay in bed, so that your body can recover. As your body's health begins to improve, you will be able to attend school and take part in more activities. You will not be permitted to exercise. The nurses and Child Life Specialist are always available when you need extra support.

At first, you will eat your meals and snacks with the nurses and the other teens on the ward. We will encourage your parents to support, supervise and take part in meals, especially dinner and the evening snack.

While on the ward, you can store your belongings in your beside table and on the shelves in your room. For safety reasons, we ask that personal items be limited as there is not a lot of storage space.

What to bring to the hospital:

- Bring a pair of slippers for walking around the ward.
- Please do not bring any jewelry or valuables.
- Leave your medications, supplements and razor at home. If you bring any of these items to the hospital, we will ask you to give them to the nurses when you arrive.

Use of cell phones

We ask that cell phones and other communication devices not be brought to the unit. You will have a house phone to communicate with your family.

We understand that not being able to text friends during the day may be difficult. However, in our experience, using a cell phone often causes our patients significant distress. Patients find it stressful to try to manage the demands of their friends and their social life, while they are adjusting to their hospital stay.

When your parents are not at the hospital, they are always welcome to call your room or your nurse.

Confidentiality

We will respect the privacy of your personal health information.

For more information about Patient Privacy, contact the Privacy Office:

Phone: 521-2100 ext. 75122

E-mail: privacy@hhsc.ca

Entering a treatment program is a personal experience for you and your family. It is essential that we protect your privacy and that of other patients and families.

Without your permission, we will not talk about you, your needs or treatment with anyone other than your parents and the members of your health care team.

We will not give you any information about other patients, their needs or treatment decisions.

You can help by not sharing information about patients and families in the program with other people.

To ensure the confidentiality of all of our families, picture taking is not permitted on the ward.

Group activities

Taking part in our group activities can help increase your chances of recovery.

Expectations

Your health care team will decide when you are able to be off bed rest, and when it is safe for you to take part in our treatment program. We expect all patients to participate in the group program. We also expect that parents (both parents where possible) will participate in our parent groups and weekly family meetings with your treatment team.

The groups have been designed to provide you and your family with additional tools to increase your chances of recovery.

The nursing staff can provide you with the current schedule and orient you to the groups offered.

Groups may include:

Distress Tolerance Skills

Experiencing emotions is a complex process, involving your feelings, your body's responses, and your outward expression of emotions through behaviour.

Each person's experience is unique.

Our groups can help you learn to:

- Tolerate and manage strong emotions more effectively.
- Learn to experience both positive and negative emotions.
- Understand how emotions can fluctuate and how to manage this experience.
- How to tolerate and shift the experience of challenging emotions such as shame and guilt, which can keep you stuck or distressed.

Coping Skills

The coping skills group can help you manage difficult eating disorder thoughts with delay and distraction. Group activities are designed to help you use coping skills effectively. Some activities will be new, others you may want to use more often.

Mindfulness-Based Stress Reduction (MBSR)

This group can help you:

- learn how to focus on the present, to reduce your anxiety about the future
- accept who you are and reduce negative thoughts about yourself

Body Image

Body image distress is a normal experience for patients on the ward. We offer a Cognitive Behavioural Therapy (CBT) group, which can help you to understand your thoughts, feelings and behaviours, and challenge you to make changes in your daily life.

Parent Education and Support Group

Group activities help parents build skills and confidence.

This group helps parents develop skills and confidence in managing day-to-day situations. One of the team therapists will provide a brief presentation of common challenges when parenting a child with an eating disorder. Parents also learn through informal discussions and problem solving in small groups.

Weekend Planning and Skills Teaching Group

Parents and their children review skills learned throughout the week, and discuss how they can be used during day and weekend passes from the hospital.

Your nutrition and activity

You are in the hospital to gain weight. Your weight needs to be restored to a safe level. Our goal is to help you gain at least 0.2 kg a day. This is about 2 or 3 pounds a week. Your nutrition and activity will be adjusted each day to ensure this weight gain.

We will weigh you every morning, after you have used the bathroom, wearing only your hospital gown and underwear. All jewelry (body piercing excepted) must be removed. The nurse may ask you to remove the 3 cardiac stickers before you are weighed.

Do not eat or drink before you are weighed.

Some patients are in the hospital to interrupt the symptoms of their eating disorder (bingeing and purging). For you, weight gain may not be a goal.

Nutrition

- Your doctor and dietitian will decide on the total nutrition you will need. This is not negotiable.
- At first, you may need a nutrition supplement (like a milkshake) instead of food. The amount of nutrition you need will be decided each day, based on your health and weight gain.
- You will get to make some choices about what you eat and drink. The dietitian or nurse will ask you what foods and drinks you prefer. As the hospital meals are planned ahead of time, it will not be possible to make same-day changes to your meals.

Nutrition is essential to improve your health and restore your weight to a safer level.

A Registered Nurse will supervise all of your meals and snacks.

- The nurses will organize your meals and stay with you while you eat your meals and snacks.
- Early in your hospital stay, your parents will start to supervise your meals, to prepare for when you go home. Nurses are available to guide parents in how to do this.
- To allow us to make accurate decisions about your medical care, no outside food (including food from home) is permitted.
- Staff will work with you and your family to get ready for short passes within the hospital and then, longer passes outside of the hospital. At this point, parents can select food choices they feel are appropriate for your continued health. Many families begin passes off the ward by bringing a meal or snack from home to the Ronald McDonald Room.

Activity

You are not allowed to exercise while you are in the hospital.

- While in the hospital, patients in our program are not permitted to exercise.
- We know that it can be very hard for patients with eating disorders to stop exercising. If you find it very hard to let your body rest and the urge to exercise is very strong – please let your nurse and doctor know. We can help you find some strategies that will help.
- Please take the elevators, not the stairs, when you leave the ward for a walk or a pass.

Guidelines for your meals

These meal guidelines are based on research and our experience.

Following the guidelines can help you learn to eat normally again.

One of the goals of your hospital stay is to learn to eat normally again.

To help you achieve this goal, we will:

- Organize and supervise your meals and snacks.
- Help you re-learn normal eating skills.
- Discourage eating-disordered behaviour during meals.
- Challenge you to eat foods outside your comfort zone.
- Reintroduce foods that you once enjoyed.
- Provide challenge opportunities where you can select your own food from the hospital cafeteria or a nearby restaurant and eat with the support of the team dietitian.
- Actively encourage family meals with a staff member. Then, at the Ronald McDonald Room, a local restaurant, or your home during a day or weekend pass.

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Meal guidelines

- Crackers, cookies, muffins and cereal bars are not to be crumbled.
- Napkins are to wipe hands, not food.
- Spreads (such as cream cheese, salad dressing, jam and peanut butter) are to be finished.
- Crusts on sandwiches and pizza must be finished.
- Coatings on food, such as breading, are not to be removed.
- Pulling food apart is not permitted. We encourage everyone to take normal sized bites.
- Food, body size and eating disorders are not discussed at the table.
- We encourage everyone to sit in a relaxed and comfortable manner. Leg shaking, standing up, and crunches are discouraged.
- The nurse will replace bruised fruit with another piece of fruit.

How your family can help

Family and friends may also need help to cope with the impact of the eating disorder on their lives and yours.

Your family can help you overcome an eating disorder. We will encourage your family members to be with you for as many meals as possible while you are in the hospital.

Several family meetings will take place during your hospital stay. At family meetings we get to know you and your family. This also helps with the plans for your discharge from the hospital.

Information for parents

You can do it. We can help.

Our goal is to ampower you to support your child

Family is an essential part of recovery. As your child's

Our goal is to empower you to support your child through the recovery process.

Your role in treatment will include taking part in:

- groups that provide support and build skills
- supervising your child's meals and snacks
- weekly medical update meetings we strongly encourage both parents to attend where possible
- parent support and education groups
- planning and supporting day and weekend passes
- family meals with your child's therapist
- family based therapy

We will help you by giving you advice, education and support along the way. Please feel free to share your concerns and questions with any member of the treatment team.

Check with your child and the nurse to review the daily and weekly schedule. This will help you know the best time for visits from family and friends.

We expect that you will be present during the weekend to eat meals with your child and to take your child off the ward for passes, when permitted.

There is no group programming on the weekends. Many parents find that this is an ideal time to ask for extra support from the nurses for meal support and to ask questions.

We encourage you to be available to supervise your child's meals and snacks in the hospital.

Getting ready to go home

When your health is medically stable, you may be offered an overnight or weekend pass. The goal of a pass is to let you practice eating in a normal environment and to help you to prepare for going home.

A pass gives you a chance to practice the skills needed to support your child's recovery.

Our team will help you learn how to have a successful pass.

Planning for day and weekends passes

Passes are an important part of planning for your child's discharge from hospital and transition to wellness.

They are a good way to practice new skills to supportively re-nourish your child, while still having the back-up and support of the health care team at the hospital.

During your child's stay, he or she will have the opportunity to have both day and overnight passes. The parent group therapist will walk you through how to have a successful pass. We also have worksheets to help you understand and approach common problems that most parents and teens experience while on a pass from the hospital.

To plan for a successful pass:

- Use the time set aside for the weekly team meeting to discuss your child's readiness to face this challenge.
- Take part in regular meals on the ward with your child. This will give you a really good sense of the amount of food your child needs to eat to gain weight off the ward.
- Be open and clear with your child about what the pass will look like: when you will leave and return, how you will spend the time out of the hospital, and whether friends or extended family will be involved.

- Speak with your spouse or partner about what activities will be planned or if a quiet day at home with family is more appropriate.
- Attend the parent skills-building and support group.
- Consider how you will provide diversion and distraction for your child without increasing his or her activity level.

Parking

Monthly parking passes are available at the Parking Office (in the red section of the hospital underground parking lot). All users pay the same rate.

We encourage parents to buy a monthly pass while their child is in day hospital, so that parking issues do not prevent them from taking part in parent groups, family meetings and treatment sessions. Parking at the hospital can be included as a medical expense on your income tax return.

For fast access or pick ups, parking on the ground floor of the hospital (not underground) is available free to patients for up to 15 minutes. Please be aware that there is no daily limit for these spaces.

Do not park outside the front door of the hospital. This area must be clear for ambulances and buses.

Ronald McDonald House

Ronald McDonald House is an excellent resource for out of town families whose child is receiving medical care at McMaster Children's Hospital. Located beside the hospital, it has a home-like setting for a nightly fee.

If you live outside of the Hamilton area, go to www.rmhhamilton.ca to review the details and criteria for staying at Ronald McDonald House.

A Social Worker from our program will review this option with you if you live more than 45 km from Hamilton and are waiting for an inpatient bed with our program.

When you leave the hospital

Throughout your recovery we will continue to give you information and support.

After leaving the hospital, most patients are offered outpatient care for their eating disorder.

If there is an eating disorders program closer to where you live, we will connect you with this program.

The goals of outpatient care are to:

- ✓ help you understand your illness
- ✓ help you slowly change food behaviours
- ✓ help you learn healthy ways of coping
- ✓ help you learn to maintain a healthy weight
- help your parents learn how to work together, to take charge of the eating disorder and return you to healthy functioning

The therapist who was part of your hospital care will continue to see you at the clinic, or connect you with a therapist in your home community program.

You will return to the care of the Eating Disorders Clinic Pediatrician who diagnosed your illness and knows you best.

Recovery can take a long time and a lot of hard work, but we believe it is possible for every young person. Setbacks are common and expected.

Providing feedback

We welcome your feedback.

This information helps us to improve our service.

The Eating Disorder Day Hospital Team welcomes your feedback as it helps us to understand the needs and experiences of patients and parents. We use your feedback to change and develop our program to better meet your needs.

We appreciate hearing directly from you. We invite you to share your comments, compliments and concerns by talking with a staff member during your stay.

We may also ask you to complete an exit survey at the end of your Day Hospital treatment.

You can give feedback confidentially to the Program Manager, Paul Agar, at 905-521-2100, ext. 77671.

If you feel that you or your family received excellent care, you can contact Public Relations at 521-2100, ext. 75387 to nominate a person, group or team who has gone above and beyond to enhance health care at Hamilton Health Sciences.

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Questions?

If you would like more information or you have questions or concerns, please speak with any member of the Eating Disorder Team.

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