



A guide to your stay on 3B1

***Information for
patients and
caregivers***

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, and staff. 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 unit on a weekly basis. You may be cared for by one or more pediatricians during your stay on the unit. These doctors work in the Eating Disorders Outpatient Program and understand the illness and your needs.

Child and Adolescent Psychiatrist

- Child and Adolescent Psychiatrists are experts 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 most of the children and teens who stay in the hospital. When it may be of help, the psychiatrist can discuss treatment options including medications with you and your family.

During your hospital stay, you may have many questions.

We welcome your questions at any time.

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 unit and are available to coach patients and parents through the process.
- Nurses will orient you to the unit and are available to answer your questions.
- Nurses are your communication bridge to the rest of the team.

Child and Youth Workers (CYW)

- Child and Youth Workers specialize in providing you with the skills to help manage distressing thoughts and emotions. They will work with you to come up with meaningful coping strategies that can be applied to not only your current challenges, but everyday life stressors.
- Child and Youth Workers can help meet your needs by providing you with resources such as distractions, skills based groups and activities, as well as a safe, non-judgmental space to explore your emotions, thoughts, and urges.

Registered Dietitian (RD)

- Dietitians specialize in nutrition and are available for consultation with you or your family during your hospital stay.
- A dietitian can provide you and your parents with nutrition education and support you in your ongoing treatment.

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.

Social Workers

- Social workers will support you and your family throughout your hospitalization. They will help to orient you and your family to the unit as well as to outpatient treatment. They will ensure you have a referral or appointment booked with an outpatient provider prior to discharge.
- A social worker will meet with you and your family to get to know you and your family better. The information gathered helps our team create a plan as to how to best support you and your family while in hospital as well as after discharge.
- Social workers will help facilitate the weekly family meeting which takes place on Monday mornings.
- Please feel free to ask the social workers if you have any questions about your inpatient or outpatient treatment plan or any other questions that come to mind.

Teachers

- Teachers are available to help you once you are well enough to do school work.
- The teacher will talk with your community teachers with your consent to make sure that you keep up in school and make a smooth transition back to school after discharge.

Medical and Allied Health Students/ Clinical Externs

- 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 Nurses and CYWs will provide you and your family with an overview of the routines and activities while in the hospital as well as the unit expectations for patients and families.

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.

From 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 may be able to re-engage with school as our teachers come around to meet with you. You will not be permitted to be physically active or exercise. The nurses and CYWs are available when you need extra support.

There may be times you will eat your meals and snacks with a member of our staff team. We will also encourage your parents to support, supervise and take part in meals, especially dinner and evening snack.

While on the unit, you can store your belongings in your bedside table and on the shelves in your room. For safety reasons, we ask that personal items i.e. suitcases, stuffed animals, etc. 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 unit.
- Please do not bring any jewelry or valuables including cellphones.
- Please see attached list for further details on permitted and not permitted items

Use of cell phones/electronics

The use of cells phone by patients is **not** allowed on the unit. We ask that cell phones and other communication devices such as iPads not be brought to the unit.

This policy is in place to:

1) Protect patient and family confidentiality and privacy so that patients do not access their cameras or social media and record video or audio of other patients or families without their consent.

2) Support patients in their recovery. Certain social media content can interfere in a patient's progress and seeing their own reflection can be triggering for patients.

Tablets and computers can only be used by a patient when they are supervised by a parent to allow patients to complete their school work. If these items are being used without supervision, parents will be asked to take the item home or the unit will have it securely stored until the patient leaves the hospital.

We understand that not being able to text friends during your stay may be difficult. You will have a unit phone which you can use to call your family. When your parents are not at the hospital, they are always welcome to call your room or your nurse.

Confidentiality

We respect the privacy of your personal health information.

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

Phone: (905)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 as well as the privacy of other patients and families.

Confidentiality means 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, audio and video recording is not permitted on the unit.

Skill Building

Taking part in our programming can help increase your chance 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 unit programming. We also expect that parents (both parents where possible) will participate in the assessment, treatment, and weekly family meetings with your treatment team.

The unit treatment programming has been designed to provide you and your family with additional tools to increase your chances of recovery.

The child & youth and social workers will help you work towards your goals through skill work.

Skills include:

Coping Skills

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

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 team 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 manage this experience.
- Tolerate and shift the experience of challenging emotions such as shame and guilt which can keep you stuck or distressed.

Mindfulness Skills

These skills 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

Caregiver Education and Support

There is a caregiver education group every **Monday at 1pm** on the unit that goes over:

- Treatment recommendations
- Family-based treatment (FBT) and eating disorders basics
- Skills that caregivers can use to support their child

There are options for parent support groups in the community:

- Danielle's Place offers a bi-monthly virtual drop in group for parents
- For more information or to register for this group please email daniellesplace@rockonline.ca.

Your nutrition and activity

You may be in the hospital to gain weight. Your weight needs to be restored to a safe level. Our goal is to help you gain weight daily with a goal of about 2 to 4 pounds per 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.

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 is medicine and essential to improve your health and restore your weight.

The care team will make the decisions around meals off unit.

Nutrition

- Your doctor and dietitian will decide on the total nutrition your body needs to repair and recover.
- Adjustments will be made to your nutrition based on your medical status and progress.
- Meal plans will be reviewed to meet your allergies, intolerances or religious/cultural practices
- A staff member 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 support and to supervise your meals, to prepare for when you go home. Staff are available to guide parents in how to do this.
- To allow us to make accurate decisions about your medical care, no outside food or drinks (including food or drinks from home) is permitted on the unit.
- Staff will work with you and your family to get ready for short passes off the unit for meals or snacks. At this point, parents can select nutrition to bring from home that they feel is appropriate for your continued health.

Activity

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

- While in the hospital, patients on our unit are not permitted to be physically active or exercise. If a patient is observed by parents or staff to be engaging in exercise, including prolonged standing or pacing, they may be provided with 50ml of Ensure to replace the energy that has been expended.
- 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 a staff member know. We can help you find some strategies that will help.

- When you are deemed to be stable enough to do so, you may be allowed off unit for a 20 minute wheelchair ride with family at the discretion of the medical team. Patients are required to remain fully seated in the wheelchair for the entire duration of the time off unit.

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.
- Challenge 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 eat food from the hospital cafeteria or a nearby restaurant and eat with the support of a family member.
- Actively encourage family meals – with a staff member. Then, in the hospital cafeteria or an outside seating area.

Meal guidelines

- Crackers, cookies, muffins and cereal bars are not to be crumbled.
- Hands are to be on the table or tray during meals.
- 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, weight, shape, appearance 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 excessive movements are not permitted.

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 may 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/caregivers

***You can do it.
We can help.***

Family is an essential part of recovery. As your child's parent or caregiver, you are a valuable part of the treatment team.

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

Your role in treatment will include taking part in:

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

- supervising your child's meals and snacks
- weekly family meetings – we strongly encourage both parents/caregivers to attend where possible
- parent support and education with a social worker
- developing tools and strategies to support your child

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.

Caregivers are welcome on the unit with their child at all times. The more present parents and caregivers are to learn skills in supporting their child the better. We encourage you to be present to eat meals with your child and to take your child off the unit for meals, when permitted, to prepare for treatment at home.

Many parents find that this is an ideal time to ask for extra support from the staff for meal support and to ask questions.

Getting ready to go home

From the beginning of your hospital stay the treatment team will be preparing patients and families for discharge. The treatment team will ensure that outpatient medical and therapeutic appointments have been set up for patients upon discharge.

Our team will help set you up for a successful discharge home.

The real treatment starts at home.

Planning for home

Discharge may be an exciting and worrisome milestone for patients and families.

Please feel free to discuss any concerns or questions regarding discharge with a member of the treatment team.

To plan for a successful discharge parents should consider:

- Having groceries or meals prepared at home
- A plan for school i.e. lunches/nutrition breaks and gym/health class
- A schedule for meal prep and supervision
- Distraction and support activities before, during and after meals
- Creating clear expectations for your child around nutrition and activity at home

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. Parking at the hospital can be included as a medical expense on your income tax return. If finances are a concern please speak with a social worker.

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 <https://www.rmhcscsco.ca/> to review the details and criteria for staying at Ronald McDonald House.

A social worker will review this option with you if you live more than 45 km from Hamilton.

When you leave the hospital

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

After leaving the hospital, patients will receive outpatient care for their eating disorder.

The social workers will connect you to an eating disorders program based on the region that you live in.

Most outpatient eating disorders programs have a multidisciplinary team that can include pediatricians or nurse practitioners, dietitians, therapists and psychiatrists.

The goals of outpatient care are to:

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

You will return to the care of your pediatrician or primary care practitioner who 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 Program 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.

You can give feedback confidentially to the Program Manager, Jen Hoppe, at 905-521-2100, ext. 73195.

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.

Questions?

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

Notes

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