Going Home After Allogeneic Bone Marrow Transplant
WHO TO CALL IF I NEED HELP

Monday to Friday, 9 a.m. to 5 p.m.

My Contact Nurse is: ____________________________

Phone number: 416-813-7512

Evenings after 5 p.m., weekends and holidays
416-813-7500, ask for the Haematology/Oncology Fellow on call

What to say when calling the hospital:
“My child is a bone marrow transplant patient,
their BMT was on: ________________.”
Include your child’s diagnosis and symptoms.

For information about your clinic appointments: 416-813-8608

Clinic location at SickKids:
Sears Cancer Clinic, 8th floor, Burton Wing

My Social Worker is: ____________________________

Phone Number: ____________________________

My CCAC Case Manager is: ____________________________

Phone Number: ____________________________

Call Emergency Services (911) immediately if your child:
• Is not breathing or having severe difficulty breathing.
• Has skin or lips that look blue.
• Is having a seizure and you have not been told these can be managed at home.
• Does not wake up after you’ve attempted to wake them (loss of consciousness).
WHAT TO BRING TO CLINIC

1. Your child’s health card.
2. Your medication calendar and all medications for the day.
3. If needed, your records of eating and drinking at home.
4. Blood pressure cuff and stethoscope if applicable.
5. Any questions you wish to discuss.
6. Snacks, toys and activities for the day.
7. An overnight bag, in case your child needs to be admitted unexpectedly.
THINGS I NEED FOR HOME

We recommend you have a digital oral thermometer to use at home.

- Tympanic thermometers (in the ear) are not recommended.
- Measure your child’s temperature under the tongue (preferable), or in the armpit.
- You can buy a thermometer at any drug store.

CCAC contact information

A community nurse may visit your home to care for your child’s central line and give any IV fluids or medications. Please contact your case manager with any questions or concerns.
APPOINTMENTS I HAVE TO GO TO

When to go to clinic
Before going home you will receive an appointment time for clinic.

Where to go
Sears Cancer Clinic, 8th Floor, Burton Wing or 8D day hospital.

What to expect in clinic
• Your child will have bloodwork drawn from their CVL.
• Your child will be checked by a nurse and a doctor.
• As needed, you will see
  • a pharmacist
  • dietitian
  • social worker
• Any other tests or procedures will be explained to you.
• Please expect to stay in clinic for several hours.
HOW MY CHILD MIGHT FEEL AND WHAT TO DO

Call right away for these symptoms:

1. Fever or signs of infection
   Measure your child’s temperature under the tongue or in the armpit. Whenever possible, take your child’s temperature by mouth.

   Your child has a fever if their:
   • temperature is 38.3°C or more by mouth one time or;
   • temperature is 38°C or more by mouth for one hour or more.

   If checking for fever under your child’s arm, your child has a fever if their:
   • temperature is 37.8°C or more under the arm one time or;
   • temperature is 37.5°C or more under the arm for one hour or more.

   Do not give your child Tylenol at home unless directed by a BMT team member.

2. Breathing problems, a cough or cold symptoms

3. Bleeding
   • Nose bleeds or bleeding from the gums
   • Bruising
   • Blood in urine or stool

4. Not eating or drinking
We do not recommend any home renovations around the time of transplant.

- We suggest you vacuum and dust your home weekly.
- Bed linens and bathroom towels should be washed weekly.
- Your child’s laundry may be washed with the family laundry.
- Do not use humidifiers unless you wash them daily.

**Skin care**

- Your child should continue to bathe or shower every 1-2 days.
- Keep skin clean and moisturized.
- When outside, cover skin as much as possible with light, loose clothing and a hat to prevent sunburn and bug bites.

**Sun protection:**

- Skin is more prone to sun burn after chemotherapy or radiation.
- Sunscreen with minimum SPF15 should be used year round.

**Preventing insect bites:**

- Use 10% DEET products formulated for children.
- Calamine lotion, polysporin, aloe vera or coolpacks help with pain and itch from bug bites.

**Immunizations**

- Vaccinations will be discussed with your team on an individual basis.
- We recommend that your child and all family members receive the yearly flu shot.
- We recommend that all family members’ vaccinations are up to date.
5. **Vomiting or diarrhea**
   Any signs of dehydration, dry skin, less or dark coloured urine, fewer wet diapers than usual.

6. **Leaking or broken central venous line (CVL)**

7. **Headaches or feeling more tired than usual**

8. **Skin changes**
   - Rash or blisters
   - Itchy skin
   - Changes in skin colour

9. **Pain**
   Pain anywhere in the body, such as the mouth, abdomen, chest, or joints.

10. **Exposure to infections**
    For example; chicken pox.

**Visiting the Emergency Room (ER)**
If your child’s central line breaks or your child has a fever or another emergency your healthcare provider will tell you to go the Emergency Room. When you arrive in the ER, tell the healthcare provider that your child just had a bone marrow transplant, is immunocompromised and needs to be isolated as soon as possible. Make sure that the ER team knows that your child cannot have an enema, suppository or rectal temperature.
**Nutrition**
- Please continue to follow the Low Bacteria Diet for 6 months.
- If you have lost your copy of the Low Bacteria Diet, it is available online through AboutKidsHealth www.aboutkidshealth.ca (search for “Low Bacteria Diet”).
- Your child will see a clinic dietitian as needed.

**Water**
If you live in a rural area, on a farm, or have a cottage, you may have questions on the safety of your drinking water. Please discuss any concerns with your BMT team.
- Your child should not drink from wells.
- Your child should not drink water from lakes or rivers.

**Swimming**
- We do not recommend swimming in public pools.
- Swimming in lakes and private pools is OK if the caps and dressing can be covered with plastic wrap or plastic bags and the dressing is changed immediately after, if it is moist or peeling off.

**Sand and Soil**
- Your child should not play in sandboxes or parks with sand surfaces to avoid contact with animal excrement.
- Your child should not participate with gardening or planting due to the presence of fungus in soil.

**Housekeeping**
No special cleaning of your home is required after transplant. There is no need to remove carpets or draperies, or indoor plants.
MEDICATIONS MY CHILD NEEDS TO TAKE

• A pharmacist will meet with you before you go home and provide you with a medication calendar if your child is going home on new medications.

• Please bring medications and your calendar from home to your clinic visits.

• Let us know right away when your medication supply is low.

• Remember to keep medications locked and out of reach of children and pets.
Exposure to illness
Please call right away if your child has been exposed to any person who has developed:

- chicken pox or shingles
- measles or mumps
- cold sores

Returning to school or daycare
To help prevent infections, your child should not return to school or daycare for approximately 6 months after transplant. Please discuss your plans with your transplant team.

Pets
We do not recommend getting a new pet around the time of transplant. If you have pets, we suggest having someone look after them for the first 6 months after transplant. We understand this is not possible for all families. If you have pets at home:

- Your child should avoid rough play with your pet.
- Do not allow the pet to sleep with your child.
- If you have a cat, do not allow your child to come in contact with the cat litter box. The litter box should be cleaned daily.
- If you have a bird or reptile, do not allow your child to come in contact with the animal or cage.
- Wash hands after any contact with your pet.
CHANGES TO MY ROUTINE

The following instructions should be followed for **6 months** after transplant.

**Hand washing**
The most important way to prevent infection is by washing your hands. All family members and visitors should wash their hands often.

**Isolation from crowds**
A crowd is any group of 3 or more people not well known to you. Avoid shopping malls, movie theatres, parties and crowded public places. This will help limit the risk of exposure to infections.

**Visitors**
Family and friends may visit unless they are sick. Carefully screen all visitors before visits.

Please ask all visitors:

*In the last 2 days have you had a fever, skin rash, sore throat, cough or cold symptoms, or any vomiting or diarrhea?*

If YES, it is not safe to visit.