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My child's
bone marrow
transplant:

**Getting
prepared**



Getting prepared

We know preparing for Bone Marrow Transplant can be overwhelming. Our experienced transplant doctors and support staff will be with you every step of the way to help you and your child understand the process.

What is bone marrow transplant (BMT)?

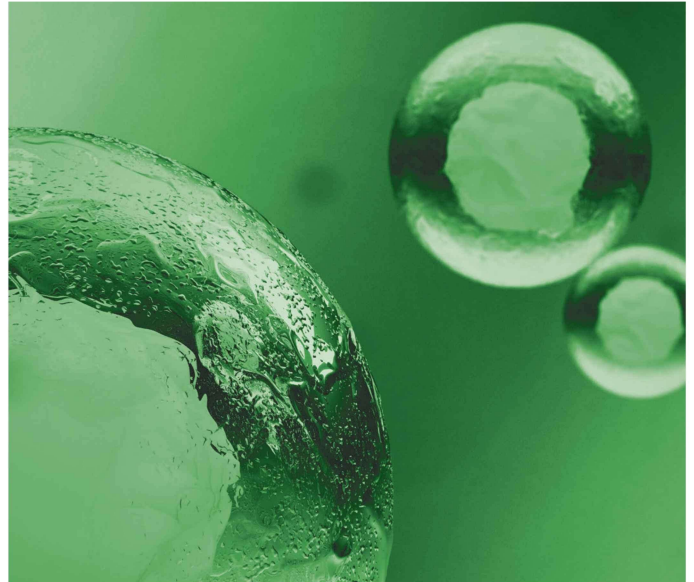
- Your child's immune system does not work properly and BMT is one way to fix this problem.
- The doctor will give your child strong doses of medicine (including chemotherapy and immune therapy) and sometimes radiation. This medicine will destroy the current immune system and make space for a new immune system to grow.
- To grow a new, healthy immune system, your child will get an infusion of his/her own stem cells or stem cells from a donor.
- The process of BMT, from the beginning to full recovery can take 1-2 years.

Where do stem cells come from?

- Some patients can donate stem cells to themselves. These cells will be frozen until we are ready to infuse them.
- Siblings can donate stem cells.
- Unrelated, volunteer donors can donate stem cells.
- Stem cells can also come from cord blood. Cord blood is collected from a mother after a baby is born. Cord blood is frozen until it is needed.
- We will choose a stem cell donor that is matched to your child. This matching will help make sure your child and the donor's cells do not reject each other after BMT.

What happens before transplant?

- When your child is ready to start BMT, both your child and the donor will go through testing. This testing is usually done outpatient and can take about two weeks.



What does the patient testing include?

- Meeting with the BMT doctor to go over the BMT consent form. During this meeting you will discuss what to expect with BMT.
- Multiple medical tests and lab tests.
 - This will help us look for any infections in the body that could cause problems during BMT.
 - This will also help us make sure your child's organs are strong enough for BMT (heart, lungs, kidney, liver, digestive system, etc.)
- Planning for a special type of IV catheter to use during BMT.
- Meeting with our fertility team to talk about ways to protect your child's ability to have children in the future, no matter how old they are during BMT.
- Meeting with our psychology team to see how we can help you and your family through this stressful and uncertain time in your life.
- Touring our hospital and the BMT unit.
- Meeting with members of our research team to go over any studies you could participate in during BMT. Our research studies help us improve BMT and the health of children. Participating in a study is up to you and your child, and if you choose not to participate, it will not affect your child's care.

What does the donor testing include?

- Seeing a doctor outside of our BMT program to make sure it is safe for them to donate stem cells.
- Meeting with our donor advocate (if the donor is a young sibling) to make sure they do not feel pressured to donate and that they understand what they are being asked to do.
- Setting a date for when they will be able to donate their stem cells.
- Checking labs to make sure they will be a good donor for your child.
- Meeting with a doctor to review the donor consent form.
- Getting shots of medicine a few days prior to donating stem cells, if needed. This medicine will help them make extra stem cells for your child.



The donor's stem cells will either be collected in surgery from the donor's hip bones or in a clinic by drawing out blood from the donor's arms and filtering it through a special machine.

The donor's stem cells will then be given to your child through an IV. This can be done up to two days after stem cells are collected (unless there is a plan to freeze the stem cells for later).

What to Expect with BMT?

- Your child will be admitted to the hospital when it is time to start BMT. They will stay in the hospital at least 1–2 months for BMT.
- After leaving the hospital, we'll need to see your child in our clinic frequently to make sure they are doing OK.
- The whole BMT recovery process can take 1–2 years.

Below are some things you may see while your child is recovering from BMT:

What you may notice:	What we can do:
Low white blood cells (WBC)	Protect your child from germs with special medicines. Keep them isolated in their room. Remind them to wash their hands and wear their mask.
Low hemoglobin (Hgb) or platelets	Give your child blood and platelet transfusions.
Upset stomach or vomiting	Give them medicines to help. Also give them things to try to distract their mind away from the upset stomach.
Mouth sores	Give them pain medicines.
Diarrhea	Give your child medicines to help. Make sure they stay hydrated.
Not wanting to eat or drink	Give your child nutrition through an IV or through a feeding tube that empties into their stomach.
Feeling tired	Help your child with activities for their mind and their muscles.
Hair loss and changes to skin or nails	Make sure your child wears sun protection to go outside for a couple months while their hair, skin and nails repair themselves.
Damage to other organs in your child's body (heart, lungs, kidneys, liver, blood vessels, etc.)	Our team will ask for help from the doctors who specialize in the organ that was damaged. If your child is very sick, we may have to move them to our Intensive Care Unit (PICU).
Low numbers of donor cells growing in your child's body	We will adjust your child's medicines. We may even need to give your child extra stem cells from their donor.
Graft versus host disease (GVHD) — is most often seen in the liver, skin, or digestive system but can affect any part of your child's body. This is where the donor cells fight your child's body. GVHD can vary from mild to life-threatening.	We will adjust your child's medications or start new treatments.

How do I pay for BMT?

- We know there are a lot of costs with BMT, including hospital stays, doctor visits, prescription medicines, home care, travel, meals, and lodging.
- We will work closely with your insurance company to get approval for your child's BMT.
- We suggest talking with your social worker or one of our financial advocates (513-636-0201) to find out how we can help you with your financial needs.

Numbers to remember:

CBDI Clinic (and doctor on-call): 513-517- CBDI (2234)

My child's:

Nurse Care Manager (always your best point of contact):

Name: _____

Phone: _____ Pager: _____

Email: _____

BMT Doctor: _____

Nurse Practitioner: _____

Social Worker: _____

Outpatient Pharmacy: 513-636-8808

Other resources:

Watch our videos about BMT at www.cincinnatichildrens.org/service/b/bone-marrow/videos

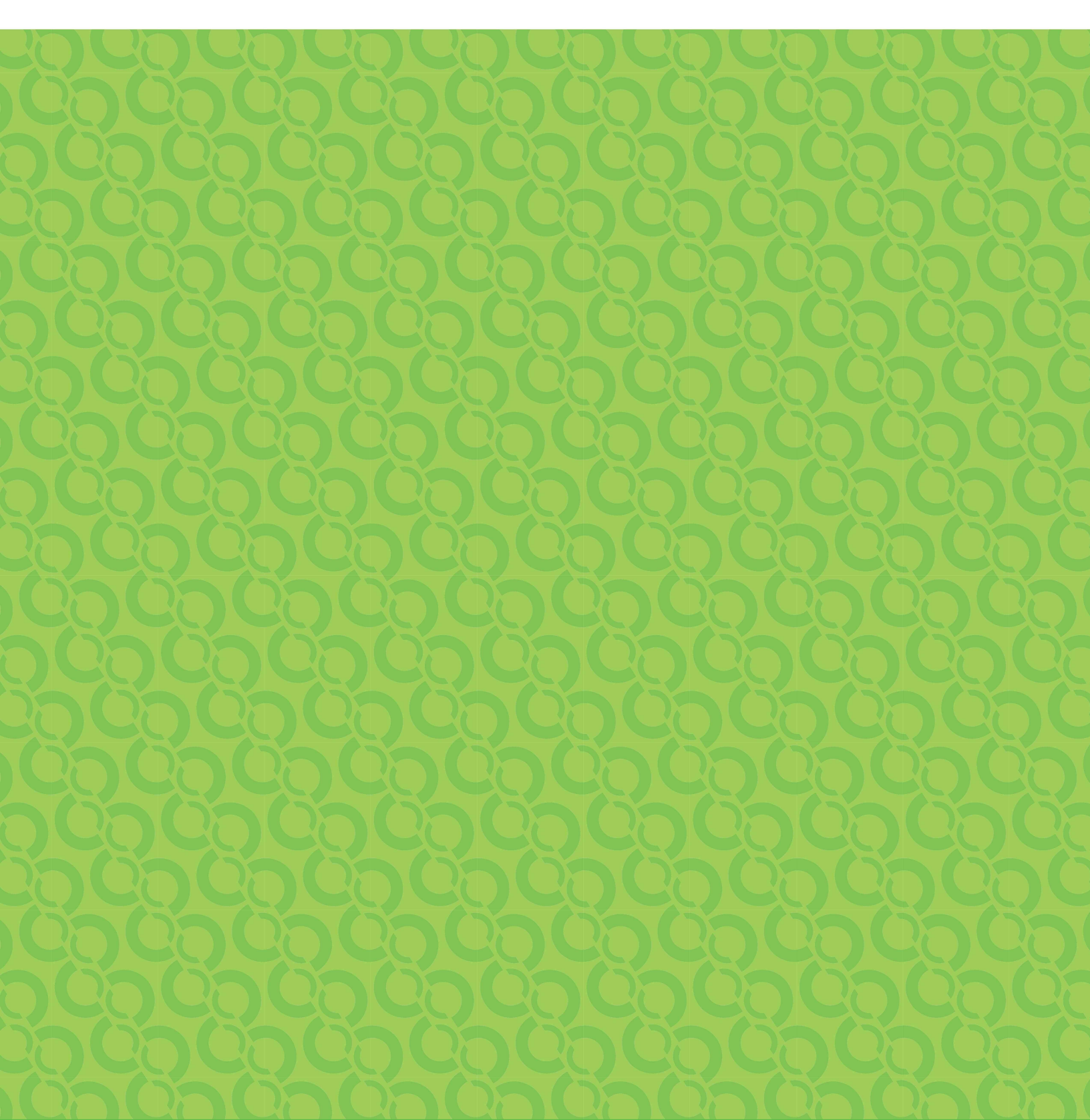


Concierge Services:

Can assist you with non-clinical resources before and during your stay, call 513-636-5009, or toll-free 1-888-894-1374 or concierge@cchmc.org.

Caren App:

Your personal mobile guide to visiting our institution. Available for both iPhone and Android; search for "Cincinnati Children's Caren" or visit cincinnatichildrens.org/caren.

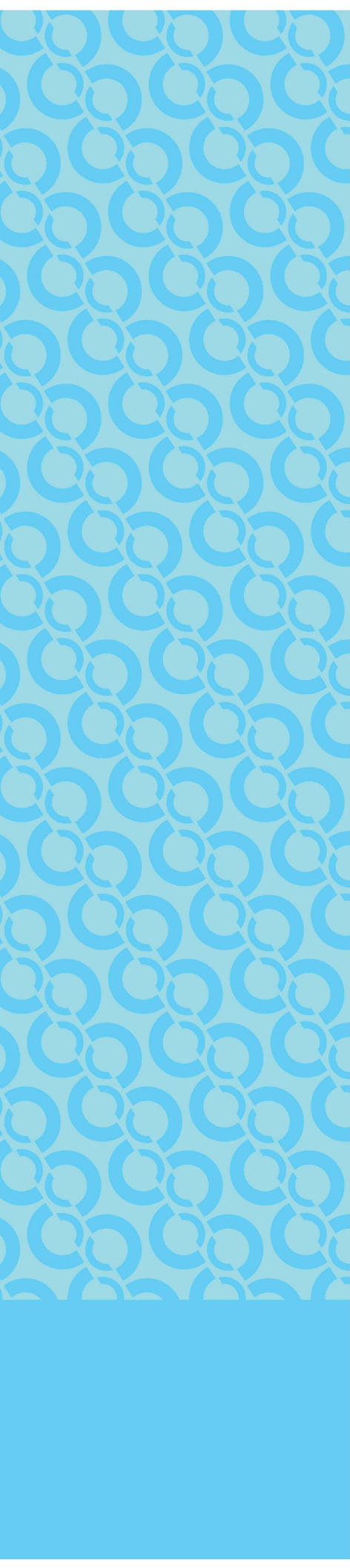




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My child's
bone marrow
transplant:

**At the
hospital**



At the hospital

Preparing for a hospital stay is never easy. If you are traveling from outside the Greater Cincinnati area, we will work with you to provide housing options for you and your family.

Here's more information to make your stay more comfortable:

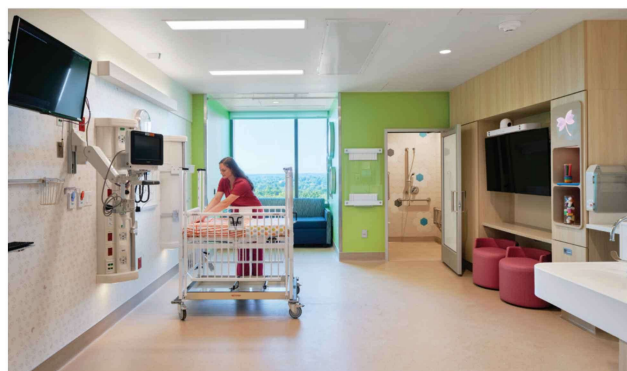
- Our Concierge Services staff can assist you with many non-clinical resources before and during your stay. Resources include:
 - Discounted lodging at area hotels
 - Complimentary airport and weekly shopping shuttles
 - Tickets to area attractions
 - Area amenities, including restaurants, parks, and shopping
 - Call 513-636-5009, or toll-free 1-888-894-1374 or email concierge@cchmc.org for more information.
- Our Caren Mobile App is your personal guide to make visiting Cincinnati Children's as easy as possible. Caren provides directions, a digital parking pass and spot reminder, cafeteria information, real-time updates of your child's surgery status, and more.
App: Available for both iPhone and Android; search for "Cincinnati Children's Caren"
Web: cincinnatichildrens.org/caren
- The Ronald McDonald House has lodging available to our patients who live far away (greater than 40 miles from the hospital). You can contact them at 513-636-7642 or by visiting www.rmhcincinnati.org. We encourage you to take a tour.
- There are many organizations connected with BMT who can offer patients and families financial assistance or support during BMT. Ask your social worker for a list of these organizations.
- Your child's nurse care manager can help with any FMLA (Family & Medical Leave Act) paperwork you may need filled out to be away from work during BMT.
- Visit the Family Resource Center (Location A1) for a place to relax and access many non-clinical resources, including:
 - A fully-equipped computer lab with printing, copying, faxing, and scanning capabilities
 - A charging station for your phone or tablet
 - Television and comfortable furniture
 - Complimentary coffee, tea, hot chocolate, and water
 - A kitchenette with microwave and refrigerator
 - An outdoor patio.

Our BMT unit:

- When your child is admitted to the hospital for BMT, they will be on our BMT unit, at Location G on the 5th floor (G5). The unit phone number is 513-636-4071.
- The nurse care manager can give you a tour of the unit.

Things you will see on the BMT unit:

- Locked doors where you enter and exit the unit.
- Private rooms with a bathroom, storage space, a sleeper chair, desk area, television with DVD player, and a phone.
- HEPA filtered air flow.
- Free Wi-Fi.
- Washing machine and dryer.
- Exercise room for caregivers.
- Bathroom with shower for caregivers.
- Lounge areas for caregivers with eating areas, couch, cabinet space, chargers for electronic devices, televisions, refrigerators, and microwaves (this area is not for siblings or other visitors).
- Teachers to help with school work.
- Chaplains for spiritual needs.
- Physical, occupational, speech, music, and holistic health therapists to help the body and mind stay strong through BMT.
- Patient access to the playroom and teenage/young adult activity room.
- Caregiver support groups and occasional donated meals.
- Patient access to toys, activities, and videos from our Child Life team.
- A doctor is present on the BMT unit 24 hours a day.
- Access to our Intensive Care Unit (PICU) for those who get very sick during BMT. The PICU has different rules from the BMT unit.
- Access to other specialty doctors (for the lungs, kidneys, digestive system, nutrition, heart, pain control, mental health, etc.).



Information for Parents/Caregivers:

- Each child will need a main caregiver (or a small group of caregivers) to help them through BMT.
- Your child's caregiver will also need to set aside time to take care of themselves. Caregivers should make sure they are getting enough rest, eating, taking breaks, and accepting help from others.
- We have multiple support groups available for you at the hospital. If you are interested in these, please contact the social worker assigned to your child.

Things you can do for your child:

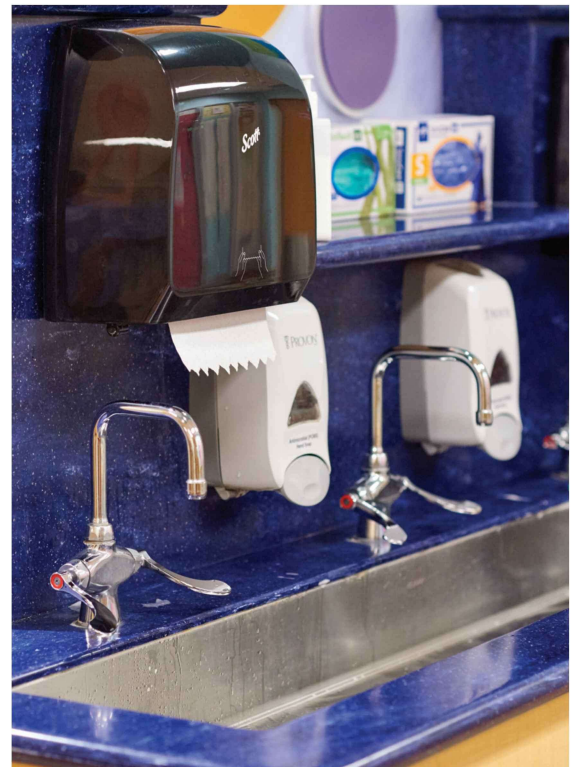
- Be with them in the hospital, at home, and at doctor appointments.
- Help make sure they take all of their medications.
- Make their meals.
- Watch and report any symptoms of illness or concerns about their health to the BMT team.
- Help them with personal care (bathing, going to the bathroom, dressing themselves, eating, etc.).
- Help with medical care (IV care, giving IV medicines, feeding your child through a tube that empties into their stomach, etc.).
- Ask other family members or friends to help care for your house and any siblings while you are away.

What should I pack for the hospital?

Things you can bring:	What not to bring:
Comfortable clothes and shoes	No live plants or flowers
A favorite blanket, toy, or stuffed animal	No toys that cannot be wiped clean or washed
Electronic devices	No toys that can retain water
Video game system	No decorative/holiday lighting
Photos of family, friends, or pets	No humidifier or fan.
Laundry detergent and dryer sheets	No coffee pot, crockpot, hot plates, or refrigerator
Books, crafts, or writing journal	No diffusers or incense
A limited amount of food to store in the parent lounge	Limit what you bring to the hospital to avoid clutter in your room
Personal items for caregivers	

Visitors on the BMT unit:

- Main caregivers will be given 24-hour access to the BMT unit. One caregiver is encouraged to stay overnight with the child.
- Your child should have a very limited number of visitors during BMT to avoid getting sick.
- All visitors must wash their hands before entering the BMT unit and when you enter or exit your child's room.
- Visitors should not come if they are sick (fever, runny nose, cough, vomiting, diarrhea, eye infection, rash or skin infection).
- Children (younger than 14 years old) cannot visit.
- Visitors can only be in the patient's room (not in the hallways or common areas).
- Caregivers or other visitors cannot use the bathroom in the patient's room.
- Only primary caregivers are allowed to eat meals in the patient's room. Food cannot be stored in the patient's room and meals must be disposed of within one hour of eating.
- All visitors will be given a health screening before visiting that day.



Keeping things clean on the BMT unit:

- It is important for your child, caregivers, and hospital staff to wash their hands multiple times throughout the day.
- If your child has an infection that could spread to others, they will have to stay in their room (“isolation”). The hospital staff will wear special clothing in the room, so they do not spread the germs to other BMT patients. Caregivers will not have to wear the special clothing but will be asked to stay out of the common areas as much as possible.
- Other patients and caregivers are not allowed to come into your child’s room.
- The door to your child’s room has to stay closed at all times.
- Your child must wear a N-95 mask (green mask) when they are out of their room.
- You should not sleep in bed with your child.
- Patients are expected to bathe daily and clean their mouths multiple times a day during BMT.
- A floor mat will be brought to their room for playing on the floor.
- Rooms are cleaned daily. Please put your child’s belongings away during this time so the room can be cleaned.
- Your child will change rooms every month to allow for a deep cleaning of the room.
- Use a cleaning wipe to clean items that are touched often (cell phones, television remote, electronic devices, etc.).
- Patients cannot go in common areas like the parent lounge.
- Clean up after yourself in the parent lounge. The refrigerator is cleaned out weekly.

Numbers to remember:

CBDI Clinic (and doctor on-call): 513-517- CBDI (2234)

My child’s:

Nurse Care Manager (always your best point of contact):

Name: _____

Phone: _____ Pager: _____

Email: _____

BMT Doctor: _____

Nurse Practitioner: _____

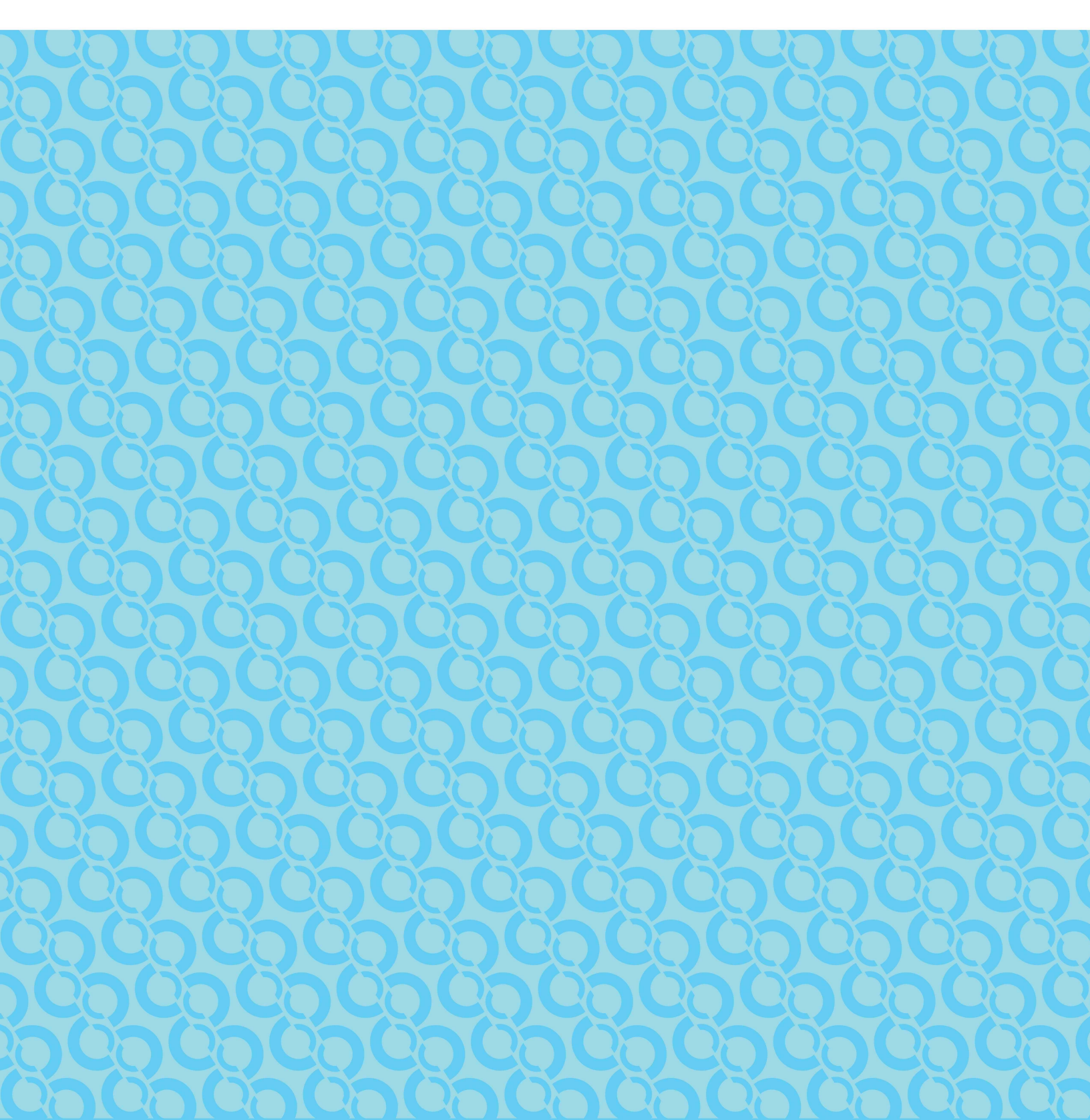
Social Worker: _____

Outpatient Pharmacy: 513-636-8808

Other resources:

Concierge Services: Can assist you with non-clinical resources before and during your stay, call 513-636-5009, or toll-free 1-888-894-1374 or concierge@cchmc.org.

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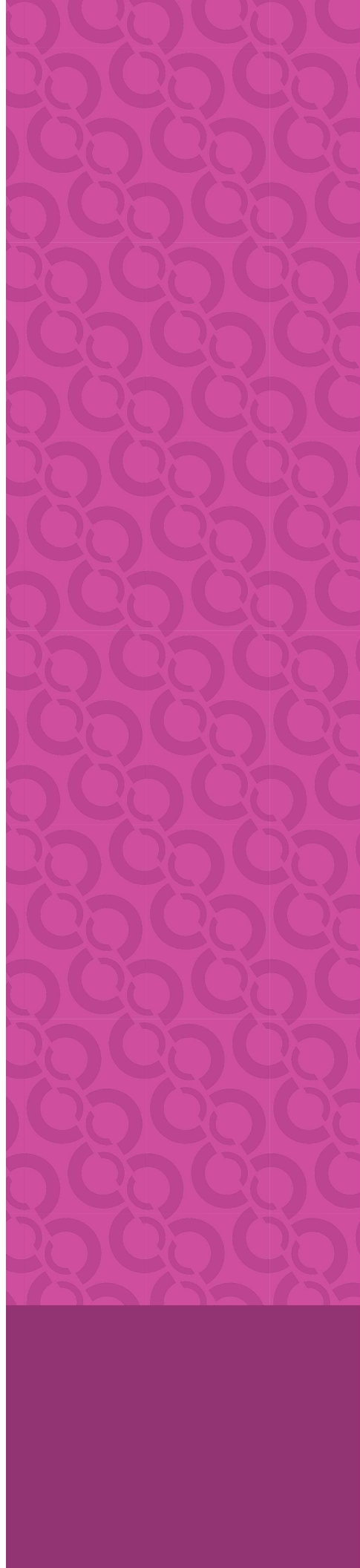
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My child's
bone marrow
transplant:

**Preparing
to go home**



Preparing to go home

Your doctor will work closely with you to decide when your child is well enough to be safely discharged from the hospital after BMT. Education is a large part of the discharge process.

Before your child can go home from the hospital, you will meet with a:

1. Home Care nurse, who will:

- a. Show you how to care for your child's IV at home.
- b. Show you how to give feedings or medications at home using special equipment.
- c. Schedule home care visits and supply deliveries.

2. Pharmacist, who will:

- a. Make sure you understand all of your child's medicines.
- b. Help you set up a medication schedule.

3. Nurse care manager, who will:

- a. Go over how to get your child's home ready before they leave the hospital and what to do while your child is at home.
- b. Go over symptoms of illness to watch for and reasons to call the doctor.
- c. Give you a copy of your child's appointment schedule.

4. Social worker, who can:

- a. Help you with money or transportation needs.
- b. Help with housing options if you do not live within 30 minutes of the hospital.

5. Physical Therapist, Occupational Therapist, and Speech Therapist, who will:

- a. Help your child keep their strength up and continue to do all their regular daily activities while at home.

Follow-up appointments at Cincinnati Children's:

- Please be on time for appointments.
- Your child will have appointments 2–5 times a week and these can last 2–8 hours each time.
- Bring any medicines or feeding supplies with you that your child will need to take while they are sitting at the appointment.
- You do not need to bring IV medicines.
- It is common for BMT patients to go back in the hospital for a few days if they get sick at home.

How to keep your child safe at home:

- Your child and everyone in the home should wash their hands often. This is one of the best ways to keep your child healthy.
- Limit the number of visitors you have in your home.
- Do not let people visit if they are sick (fever, runny nose, cough, throwing up, diarrhea, eye infection, rash, or skin infection).
- Your child should not go in public places like stores, restaurants, school, or church. The safest place for them is at home.
- Your child should wear their N-95 (green mask) when they are not at home, in the clinic, or in the car.

While at home:

- Apply sunscreen on your child every time they go outside.
- Do not smoke or use electronic cigarettes near your child. Do not allow others to smoke in your home.
- Avoid construction sites or home renovation projects.
- Avoid wood burning fires.
- Remove house plants.
- Your child should not work in the yard (cut grass, garden, rake leaves, etc.), or go outside while others are working in the yard.
- Your child should do school work at home until their doctor says they are ready to go back to school.
- Your child should not go swimming unless the doctor says this is OK.

Pets:

- Routine pet care is important (veterinary visits, bathing, etc.).
- Your child should not help with pet care.
- Your child should wash their hands after contact with pets.
- Pets should not sleep with your child.
- Animals to avoid: reptiles (turtles, snakes, lizards), birds, ducks, chickens, and other farm animals.

Cleaning your home:

- Your child should not help with cleaning the home.
- Toys should be cleaned frequently in a washing machine or with a cleansing wipe.
- Use cleansing wipes to clean items that are touched frequently (cell phones, remote controls, electronic devices, etc.).
- Your child should bathe and change their clothes at least once a day.
- Bedding and towels should be washed at least once a week and should not be shared with other family members.
- If your child is sharing a bathroom with others, the bathroom should be wiped clean before your child uses the bathroom.
- Dust the home with a wet cloth.
- Your child should be in a different room when others are vacuuming. They can return to the room 1 hour after the vacuuming.
- Change the furnace filters monthly.

Vaccines:

- Talk to your child's doctor before any people you live with get a vaccination.
- All caregivers and family members should get a flu shot each year.
- Your child's doctor will let you know when it is time to start your child's vaccines after BMT.

Teenage and adult patients:

- Do not return to work until your doctor says it is OK.
- Do not use tobacco, alcohol, and illegal drugs during or after BMT.
- Avoid having sex when you have low platelets or if one of you are sick.
- Use birth control when sexually active.
- Males should wear condoms to avoid infections.
- Females should not use tampons or douche.
- You may have decreased sex drive, vaginal dryness, pain, or problems keeping an erection.
- Please talk to your doctor about any symptoms or sexual concerns you have.

If your child gets sick at home:

When to call the doctor:	
Fever of 100.4° F (38° C) or greater - this is an emergency	Redness, swelling, or pain around your child's IV line
Chills or shaking	Skin rash
Coughing, sneezing, or runny nose	If they've been around someone who is sick
Not wanting to eat or drink	New or worse diarrhea, upset stomach, or throwing up
Not able to take medicines	Mood changes or sleeping more than normal
Coughing or throwing up blood	Pain or trouble peeing
Nosebleeds or bruising	Blood in your child's pee or poop

Medicines your child will take at home

Once your child has fully recovered from BMT, they will only need to stay on a few medicines or no medicines at all.

Type of Medicine:	How the Medicine Helps Your Child's BMT?	Other Things to Know:
Medicine to prevent infections	Helps protect your child from getting an infection while their immune system is weak	Your child will stop these medicines when their new immune system can fight infections on its own
Medicine to help keep your child comfortable	Helps control the side effects of BMT while your child recovers (upset stomach, throwing up, diarrhea, mouth pain, high blood pressure, high blood sugar, etc.)	These medicines can stop once your child starts to feel better after BMT
Liquid Nutrition	Given to your child during BMT when they can't eat or drink enough on their own. This will make sure they are getting the nutrition they need to recover.	This can go through your child's IV or a feeding tube that empties into your child's stomach. Some patients go home on this nutrition until their appetite comes back.
Anti-rejection medicines	Helps to make sure your child and their donor's cells do not reject each other	These medicines are very important! These medicines are only used if your child receives stem cells from a donor.
Medicines to prevent bleeding	Helps prevent female patients from having their periods while their platelets are low	Only used with female patients who have gone through puberty

Guidelines for eating after your child's BMT:

Before leaving the hospital, watch the video on "What to Eat" cincinnatichildrens.org/service/b/bone-marrow/videos/

Shopping for food:

- Avoid fruits or vegetables with bruises or cuts.
- Make sure food is not expired.
- Avoid buying cans with dents or rust.
- Avoid buying food that is torn or leaking.
- Do not buy food from open bins (candy, nuts, salad bar, sides at the deli counter, etc.).
- Avoid any sliced meats or cheeses (packaged meats/cheeses are OK)

Cooking food:

- Thaw frozen foods in the refrigerator, the microwave, or in cold water.
- Cook refrigerated, uncooked meat within 2 days of purchase.
- Cook frozen, uncooked meat within 4 months of purchase.
- Cook all raw meats to 165° F or greater.
- Your child should eat their meal within 2 hours of making it
- Avoid eating leftovers.
- Patients cannot touch or eat uncooked cake, cookie dough, or yeast.

What not to eat:

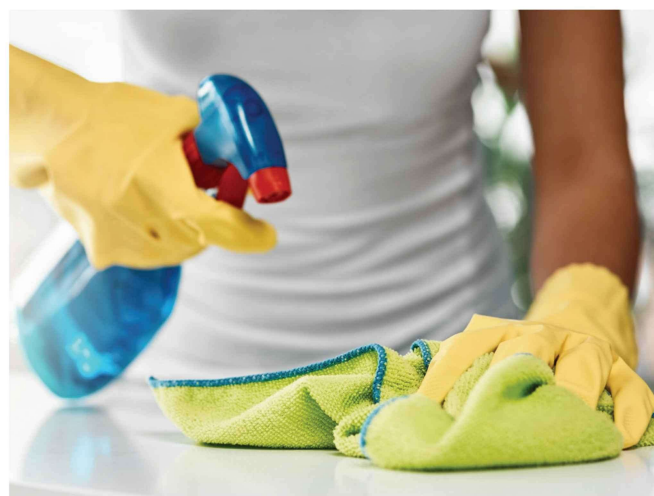
- Eggs that are not fully cooked (poached, sunny side up, egg nog, some salad dressings, etc.)
- Meats that are not fully cooked (smoked meats, raw fish, etc.)
- Cheese from unpasteurized milk (brie, feta, etc.)
- Raw sprouts
- Unpasteurized milk products and juices
- Honey

When eating at a restaurant, your child should:

- Avoid lettuce, tomato, or onion on sandwiches.
- Avoid lemon in your water glass.
- Use single serving ketchup, mustard, and mayonnaise.
- Avoid salad bars or buffet-style restaurants.
- Avoid restaurant salads.
- Avoid slushies, soft serve ice cream, or frozen yogurt.

Keeping your kitchen clean:

- Clean out the refrigerator often.
- Use hot water to clean the dishes.
- Change washcloths out each day.
- Wipe your kitchen surfaces often.
- Wash your hands before making food.
- Wash your hands after touching meat that has not been cooked.
- Do not let uncooked meat touch other foods.
- Clean lids of canned foods before opening them.



When to call 911:

- Trouble breathing
- Not responding
- Having a seizure
- Bleeding that will not stop

We want you to call us with anything that concerns you.

How to call the doctor:

- Dial 513-517-CBDI (2234), press option #2 and ask for the BMT doctor on-call

When your child has a fever at home:

- A fever of 100.4° F (38° C) or higher is an emergency for your child because of their weak immune system.
- Your child needs an IV antibiotic medicine started within 60 minutes of the first sign of fever.

How you can help:

- Always call 513-517-CBDI (2234) before coming to the CBDI clinic or the emergency room with a fever. This way we can be ready to help your child by the time you get to the hospital.
- Let the hospital staff know if your child sometimes has trouble with their IV.
- If needed, apply numbing cream before leaving the house.
- Have your child wear their N-95 (green mask) to the CBDI clinic or emergency room.
- Know what medicines your child is on.

Watch the video on How to take a temperature and how to call about a fever:

www.cincinnatichildrens.org/service/b/bone-marrow/videos

Numbers to remember:

CBDI Clinic (and doctor on-call): 513-517- CBDI (2234)

My child's:

Nurse Care Manager (always your best point of contact):

Name: _____

Phone: _____ Pager: _____

Email: _____

Doctor: _____

Nurse Practitioner: _____

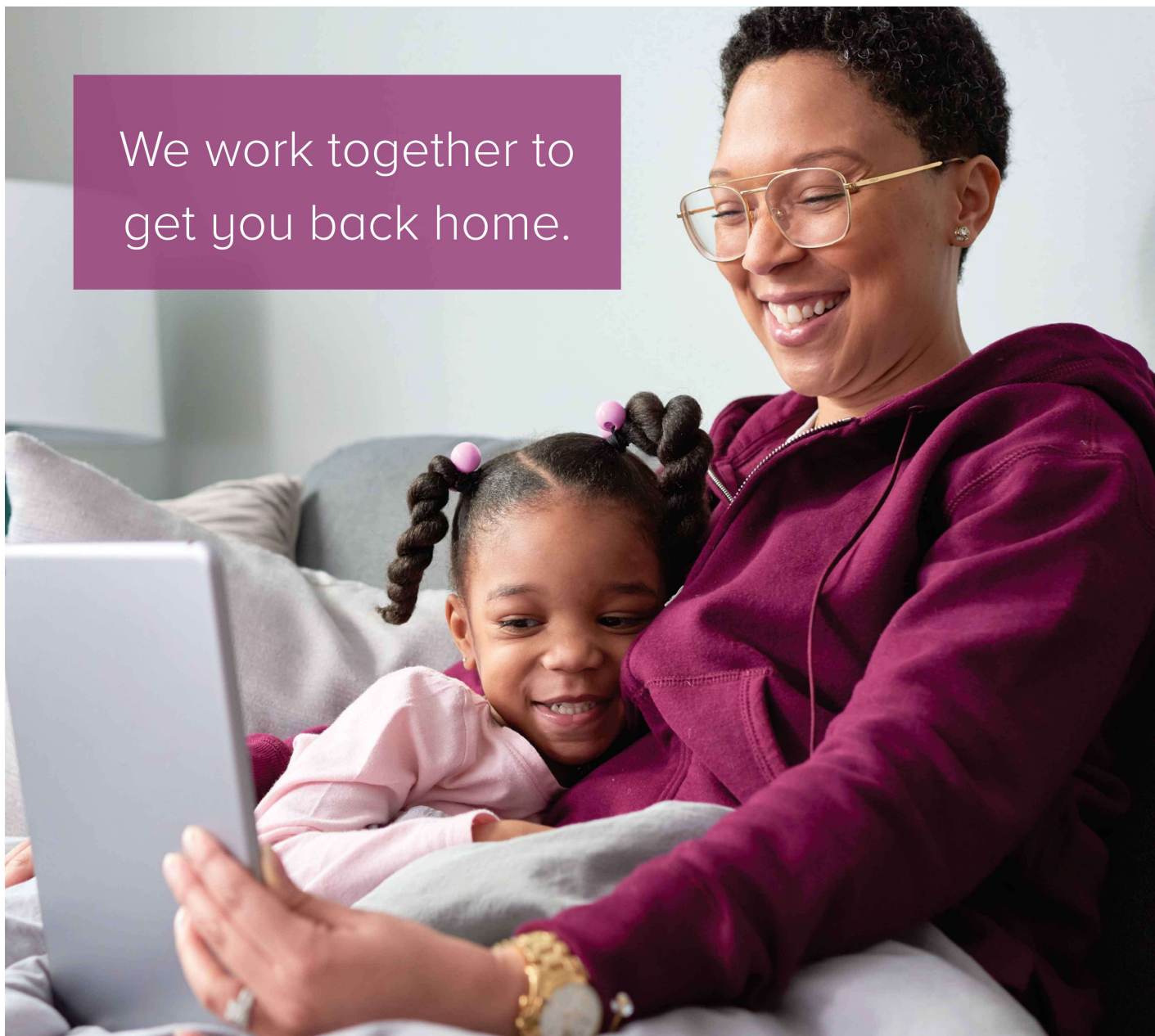
Social Worker: _____

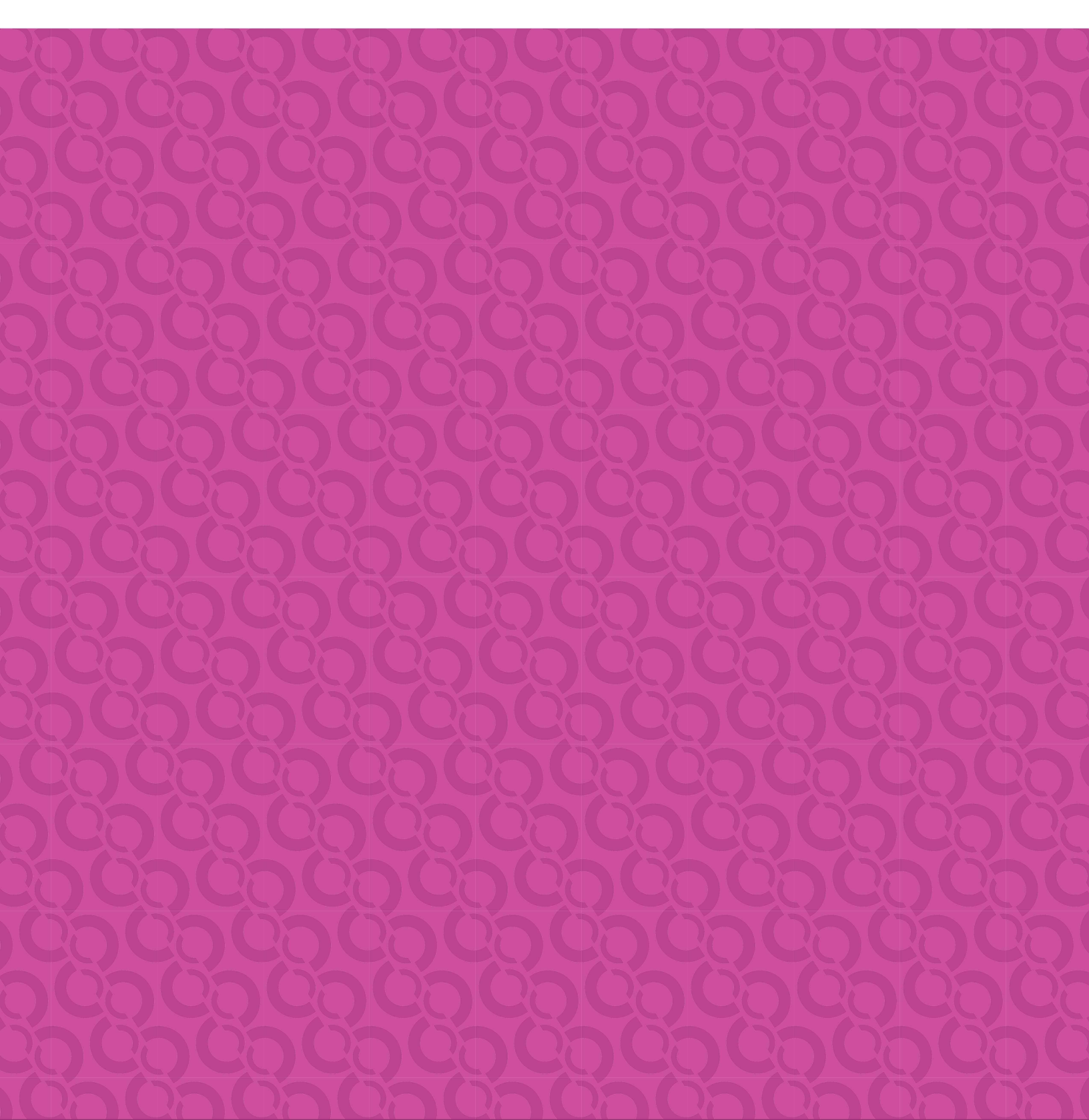
Dietician: _____

Outpatient Pharmacy: 513-636-8808

Home Care: 513-636-4663

We work together to
get you back home.







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My child's
bone marrow
transplant:

Recovery

Recovery

Now that your child is feeling better, many families tell us that learning to adjust to life outside the hospital can be difficult. You won't see your medical team as often, your child will reunite with family and can return to school or work. We know this may be both exciting and scary, and we will help you through this adjustment as much as possible.

Visits to the doctor:

- Your child will go to their BMT doctor less often (about 1 to 4 times a year).
- There is less worry about infection, so your child's BMT doctor will focus more on watching for possible late effects of BMT.
- Your child will get all of their childhood vaccines again. These can be done at your local doctor's office.

What are BMT late effects?

- At certain times after BMT your child will be scheduled for special testing.
- This testing will help the BMT team watch for possible problems that can happen after recovery from BMT.

Below is a chart of some of the special testing your child may see:

Tests:	Visits:	Labs (blood test):
Echo (a heart test)	BMT doctor	Vitamin levels
6-Minute Walk Test	Endocrine doctors - to check your child's growth and development	Amount of donor cells in your child's body (donor engraftment)
Pulmonary Function Test (a lung test)	Ophthalmology - to check your child's eyes	Immune system testing
Hearing Test	Heart, lung, liver, and kidney doctors - to check your child's organs	Labs to check your child's growth and hormone levels
Vision Test	Fertility or gynecology doctors	Heart, kidney and liver testing
Testing specific to your child's disease	Dentist	Fertility labs
DEXA scan of your child's bones	Behavioral Medicine	Research labs, if you and your child agreed

Meeting your child's donor:

- You are welcome to send anonymous letters, drawings, or small gifts to your child's donor at any time.
- If the donor was from the United States, you can ask to exchange contact information with your child's donor 1 year after your BMT. You will have to wait 2 years if the donor was from another country.
- Some donors and some patients will wish to remain anonymous after BMT and that's OK.

Insurance coverage:

- After your child's initial BMT recovery you may notice a change in the way your insurance covers your child's care.
- You may have co-pays for visits and medications again.
- Your insurance company may also deny certain medications or tests. We will work with your insurance provider to get the necessary approvals or, if needed, come up with a different plan.
- Your child's nurse care manager or our BMT financial team can help you with your insurance needs.
- When signing up for new insurance, make sure the new insurance will cover visits to Cincinnati Children's.

My medical team outside of Cincinnati Children's:

Local Doctor: _____

Home Care Company: _____

PT/OT/Speech: _____

Other: _____

What if I still need my child's BMT team?

You and your local team can always call us if there are questions or if your child is sick and you're not sure what to do.

CBDI Clinic (and doctor on-call): 513-517-CBDI (2234)

My child's Nurse Care Manager (always your best point of contact):

Name: _____

Phone: _____ Pager: _____

Email: _____



