

Welcome to Stem Cell Transplant



Riley Hospital for Children
Indiana University Health

Welcome to Stem Cell Transplant!

The nurses, doctors, and staff on the Stem Cell Transplant Unit at Riley Hospital for Children are here to support you before, during and beyond your hospital stay. This packet is meant to help you and your family *before* your admission into the hospital. Our hope is that it will help you get ready for your stay with us and will also give you an idea of what to expect while you are in the hospital. If you have any questions before admission that we have not addressed in this packet, please contact your Stem Cell Transplant Coordinator, Cathleen Kelley (317-948-0619) or Linda Simison (317-948-0639).

We look forward to seeing you soon and getting to know you and your family!

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What to Bring to the Hospital

We want to make your admission and stay as comfortable and easy as possible. Because stem cell transplant patients are in the hospital for a few weeks, below are some items that we recommend that you bring with you on the day of your admission to the hospital:

- **Stem Cell Education Binder (a must have)**
- Favorite food and snacks
 - Shelves, a small cabinet, and a small refrigerator are provided for you in your room for storage
- Comfortable clothing
 - Favorite pajamas, loose-fitting clothes
 - Underwear
 - Socks
- Favorite blankets, pillows (no down pillows, please)
- Favorite toys, games (just remember that stuffed toys must be new or freshly washed)
- Favorite DVDs/movies
- Video games (there is a Wii and a Playstation 2 in the room)
- Favorite electronics
- Reading books
- Activity/coloring books
- Decorations for the room (be creative and have fun with it!)
- CAREGIVERS (Mom, Dad, Grandparents, etc.)– you also need to bring items such as those listed above for yourself! You need to take good care of yourself so you can take good care of your loved one!

Please note that Child Life is available throughout your hospital stay to provide fun activities and crafts as often as you need them. Movies, Play Station and Wii games are available at the secretary's desk. The hospital also has a Family Library with a great selection of movies and video games.

Daily Routines

Vital Signs

Vital signs (often referred to as “vitals”) include heart rate, respiratory (breathing) rate, blood pressure, oxygen saturation (often referred to as “sats”), temperature, and pain. Throughout the hospital stay, vitals will be taken every four hours, even throughout the night. This is required by our doctors to ensure your child’s safety. Some medications, blood products, or procedures will require vital signs to be obtained more frequently.

Monitors

When chemotherapy begins, 3 stickers (EKG leads) will be placed on your child’s chest and a “band-aid” like piece of tape with a red light on it (pulse oximeter sticker) will be placed on a finger or toe. These will give a continual read-out of your child’s heart rate, respiratory rate, and amount of oxygen in the blood. This is a safety measure that allows staff to closely watch your child both in the patient’s room and in the nurse’s station. EKG leads and pulse oximeter stickers should be changed at least every 8 hours to keep your child’s skin from becoming irritated or blistered from the stickers. Staff often will do this during vitals signs or after a bath. It is ok for you to remind staff that it is time to change the stickers.

Daily Weights

Every morning between 6 AM and 7:45 AM staff will need to weigh your child. We know this is early, but weight is *vital* information in planning daily care for a patient during stem cell transplant. The doctors need this information early in the day. It enables them to know if your child has too much or too little fluid in his or her system, to safely determine the right amount of medication for the day, and to assess for any possible side effects and treat them before they become a problem.

Rounds

Every day the medical team (which may include doctors, nurse practitioners, physician assistants, nurses, pharmacist, dietician, social worker, and case manager) will come to your room to discuss the current medical plan. Family is encouraged to be a part of this discussion. Rounds will keep you informed and

updated on your child's condition and care. This is also a great time to bring up any concerns or questions that you may have.

IV Pumps

All IV medication will run through an IV pump. The pump will sound a beeping alarm for various alerts that the nurse must answer. If the IV pump alarms when the nurse is not in the room, please put on the nurse call light for assistance. Many people are reluctant to push their nurse call light for silencing of the IV pump. Be assured that your nurse WANTS to know if the IV pump is beeping. In many places on the floor, staff cannot hear the beeping and very much appreciate you notifying them that there is a need. As a safety precaution, do not silence or turn off the pump.

Hygiene

In order to decrease the risk of infection, your child must take at least one bath per day and have the bed linens changed. Warmed bath packs containing an ingredient that kills bacteria on the skin will be provided for the daily bath. Aquaphor, a thick lotion, will be provided on admission, and it should be applied at least twice a day to help keep the skin protected and healthy throughout the hospital stay. Peridex, a mouthwash, will also be provided to keep your child's mouth clean and healthy. Regular mouth care also may help reduce mouth soreness as well as decrease the risk for many bacterial infections. Nail clippers are not to be used at any time during your stay because your child is at high risk of bleeding or getting an infection in any area where the skin is open. Filing of the nails is allowed and encouraged. Certain medicines and radiation treatments may require more baths or not allow the use of lotions for a certain period of time. Staff will teach you about these things *if* they apply to you at the time of your admission.

Labs

Around 4-5 am every morning, a nurse will come in to draw labs from your child's central line, PICC, or port. These labs include a complete blood count (CBC) and any other labs that the doctor wants to check on your child. Our clinical nurse educator will provide you with teaching that will help you understand the CBC lab results. The doctors discuss the results of these labs during rounds and decide if your child needs blood, platelets, or other treatments. Labs may be drawn at additional times during the day if they are needed.

Blood Cultures

If your child has a temperature of 38 C (or 100.4 F), your child is considered to have a fever. Although bacterial, viral, and fungal infections cause fevers, low white blood cell count can also cause fever. It is almost certain that your child will have a fever at some point in their hospitalization. A fever does not always indicate illness, but because of your child's risk for infection, the first fever is treated as a medical emergency, and antibiotics are ordered immediately. Before antibiotics are given, blood cultures are drawn from your child's central line, PICC, and/or port as well as from a vein on an arm, hand, or foot (referred to as peripheral blood cultures). Peripheral blood cultures involving a "stick" are only drawn with the **first** fever to help the doctors to determine a possible source of infection. Of course, any "stick" is unpleasant, but in this case it is extremely important. It helps to maintain patient safety by giving the doctors information to direct the plan of care. If your child continues to have fevers, blood cultures are only drawn from the central line, PICC, and/or port every 24 hours.

Medicine

The medicine at the hospital may look different than the medicine from home because the hospital may use a different brand. This can change the color and shape of a pill. If medicine looks different, or if you have any concerns about the medicine, ask the nurse. Do not give any medication from home unless otherwise approved. Because nurses scan medications that match the patient ID band, **your child *must wear* his/her patient ID band and allergy band at all times. The ID band can be work on the wrist or the ankle. This is a very important safety measure and is not optional.**

Restroom

Whenever your child uses the bathroom or has his/her diaper changed, staff should be notified so that it can be measured and disposed of safely. Staff records **all** patient output, and the doctors review this information during rounds.

Phones

To make a local call from the phone in the patient room, dial 9, then the number you want to reach. Phone cards are available in the gift shop for long distance phone calls. You may also use your cell phone.

Meals

After you are admitted, you will be given an age appropriate menu from Classic Cuisine. At this time your child will be on a regular diet. On Day -1 (one day before transplant) or when your child's ANC (a measure of your child's immune function) is below 500, your child's diet may be modified to reduce risk of eating foods that could cause an infection. You will be given a menu that reflects those modifications at that time if it is necessary. You can make an order by dialing *33 from the room phone from 6:30 AM until 7:30 PM.

A small nutrition room is available on the unit and includes a refrigerator/freezer, microwave, toaster, and coffee maker. It is also stocked with basic snacks such as crackers, milk, etc. Any patient food that is placed in the unit refrigerator or freezer must have a label on it. Please do not eat food that has another patient label on it. In addition, each patient room has a mini refrigerator in it available for your personal use. Food from home must follow the diet guidelines provided to you by the dietician. If your child has a specific dietary craving, the unit dietician can make special orders to have that food available for your child. Families are also allowed to prepare food at the Ronald McDonald House on the first floor of the hospital.

Isolation

Because of your child's risk for infection, your child must remain on the unit at all times after admission. Live plants are not allowed on the unit because they may carry insects or germs. Any ill visitors, children under the age of one year, and children or adults who are not up to date on their immunizations will be not allowed on the unit. This is to protect all patients. In addition it is important that you do not share clothes, bibs, blankets, or toys with other patients, and do not touch other patients or their belongings.

Hand washing or use of the foam hand sanitizers outside the rooms is **REQUIRED** for **EVERYONE** who enters the patient's room. This applies to **ALL** family and visitors and hospital staff. Everyone should wash their hands or use hand sanitizers when entering into your child's room, before touching your child, and when leaving the room. In addition to keeping hands clean it is also important to keep surfaces that are frequently touched very clean. Staff members regularly clean certain surfaces in the room that are common for your child or staff to touch.

Family members are encouraged to help staff keep your child's room as clean as possible to protect him/her from infection.

General Stem Cell Transplant Unit Isolation Guidelines

- ALL visitors need to check in at the front desk upon arrival on the unit. They will be asked screening questions by staff to make sure they are not at risk for transmitting any illness to the patients.
- Siblings will be allowed to visit patients in their room after they have undergone screening at the SCT unit desk. Siblings may also visit in the playroom with the patient/sib as long as no other patients are in the room and the sibling has been screened by staff.
- More than one patient may be in the play room at one time as long as the patients are not considered to have a potentially transmittable infectious disease.
- Patients are NOT allowed to go to the hem/onc unit or burn unit to visit other patients. The only appropriate reason to leave the unit would be for physical therapy or when going to the school room.
- Patients will need to wear N95 masks whenever they leave the SCT unit.
- For parents of patients not potty trained, parents are allowed to use the toilet in the patient room. However, for parents of patients who are potty trained, you are requested to use the bathroom directly outside of the Stem Cell Transplant Unit. This is in keeping with hospital policy and addresses the safety of our patients.
- Indiana University Health isolation policies will be followed for patients with, or suspected to have, communicable diseases

Visitation

Parents can stay with their child at all times, but we encourage only one parent sleep overnight in the patient's room. Recliners are in every room, and cots are available for parents to sleep on as well. It may be possible for social work to arrange for a room at Ronald McDonald House for those family members who also want to spend the night. For safety reasons, you are not allowed to sleep in the bed with your child, and your child may not sleep in the cot with you.

Each unit at Riley is locked, and families receive a code to open the unit door and family lounge upon admission. Do not share this code with anyone, and do not let anyone follow you into the unit that you do not recognize as another patient's family member. This is to ensure maximum patient safety. ALL visitors must first stop at the information desk on the first floor to take a brief health survey. This is to prevent an ill person or child under one year of age from entering the unit. Friends and family who have had a cold, fever, or diarrhea in the last 24 hours, or who have been exposed to chicken pox, measles, or tuberculosis should

not visit to protect all stem cell transplant patients. When visitors arrive, they will need to ring the bell just outside the doors to the unit. The secretary will open the doors for them and will then ask you if you want to have visitors. If you agree to visitors, the secretary will lead them to your room. To help prevent infection, your nurse may limit the number of visitors in the room at one time.

Visiting hours are from 11 AM to 9 PM every day.

Social Media

Patients and families often develop friendships with staff members. However, in order to maintain patient privacy, staff have been told that they are not allowed to connect with patients and families on social media websites such as Facebook. After discharge, please feel free to visit and chat with staff anytime on the unit.

Health Care Team

Our Approach: Family-Centered Care

The staff on the Stem Cell Transplant Unit at Riley Hospital for Children understands how important family is to your child's well-being. Our team recognizes that family members are part of the health care team. Decision-making is shared among all members of the health care team, including the patient and the family. Each member of the team does their part to make certain that your child gets EXCELLENT care!

Doctor

Directs and oversees all of your child's care

Nurse Practitioner

Directs and oversees your child's care along with the doctor. Teaches you and your child about the treatment plan

Physician Assistant

Directs and oversees your child's care along with the doctor. Teaches you and your child about the treatment plan

Nurse (RN)

Gives direct care to your child. Gives medicine and treatments. Helps with procedures. Helps with communication between the family, patient, and health care team

Certified Patient Care Assistant (CPCA)

Helps the nurse with direct care. He/she may take vital signs, give baths, sit with and/or play with your child (time permitting) when you need to take a break

Patient Services Assistance (PSA)

Cleans your room and takes your child to tests throughout the hospital if necessary

Unit Secretary

Puts your child's medical orders into the computer and answers the phone at the nurse's station; screen visitors entering the unit, assist patients with DVDs, video games, and controllers

Case Manager

Follows your child's hospital stay and helps prepare the patient and family for discharge from the hospital

Stacey Corman, RN

317-944-0807 (Office)

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Joyce Crane, RN

317-944-0808 (Office)

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Day Shift Coordinator

Assists all staff and the manager, manages the daily "business" of the unit, teaches patients and families, answers questions and addresses the concerns of patients and families.

Dianna Kluttz, RN

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Darby Burns, RN

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Social Worker

Helps your family with special needs; helps coordinate care among the health care team; helps with discharge planning. **See resources for names and numbers.**

Child Life Specialist

Has activities, games, and toys for use during the hospital stay; **see resources for names and numbers.**

Resources

Social Work

Each of the Social Workers who work for the Pediatric Stem Cell Transplant program at Riley Hospital are Master's prepared and licensed in the state of Indiana. They also have special training in pediatric hematology/oncology.

Every family who has a child undergoing stem cell transplant has one of these social workers to provide the following services: emotional support and counseling, crisis intervention, child and family advocacy, patient and family support programs, financial assistance referrals, lodging (Ronald McDonald House/hotel) and transportation needs, school re-entry support, assistance with insurance and entitlement programs, and help with preparing the home after stem cell transplant. Please contact your Social Worker for help with any of these services.

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Child Life

Child life seeks to alleviate the stress of hospitalization for the patients and their family. Child life specialists help to reduce anxiety related to hospitalization by providing emotional support, opportunities for normal growth and development, and creating a physical environment that supports healing. Child life helps patients and families in a variety of ways that might include medical play, painful procedure distraction, creative expression, pain management, and socialization. Child life encourages mastery of emotional, coping, communication, and play skills. Child life can also provide massage therapy services to patients, with physician's orders, for pain management and relaxation.

Abigail Rainey, CCLS, CMT

Child Life Specialist

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Art Therapy

Art therapy is the therapeutic use of art making to achieve specific goals, such as expression of feelings, increased coping, reduced stress and improved physical, mental and emotional functioning. On the Stem Cell Transplant Unit, art therapy helps patients through various media including paint, clay, collage, knitting, building, and many other types of media. In some sessions, the art therapist provides directives developed on an individual basis to help a patient cope with hospitalization, while at other times the patient is in charge of directing the session. Art therapy can also be used to encourage patients to communicate with the medical team, therefore giving the patient a voice in his or her treatment plan.

Michelle Itczak, MA, ATR-BC, LMHC

Art Therapist

317-948-0897 (Office)

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Music Therapy

Music therapy involves the use of music to work towards a non-musical goal, such as expression of feelings, increased relaxation, or improved coping. On the Stem Cell Transplant Unit, music therapy is often used to help patients express their feelings by playing musical instruments or writing songs. Some patients prefer to simply listen to their favorite types of music with their music therapist, or to listen to music played by their music therapist to help them feel more comfortable and relaxed. Music therapy can also be used to encourage patients to play and have fun in their rooms, which could help them to cope better with the hospitalization.

Lauren Servos, MT-BC, CCLS

Music Therapist

317-944-1146 (Office)

lservos@iuhealth.org

School

School is offered during the regular school year, Monday through Friday, for patients in kindergarten – 12th grade. A volunteer tutor or Educational Liaison (school teacher) tutors the children in their rooms on the Stem Cell Transplant Unit. If patients are tutored, the school program will send an attendance card to the patient's teacher with the number of days they received school services in the hospital for his/her attendance record. Education Liaisons can help with any school questions or issues your child may be having. Some ways we help patients are by contacting your child's teacher to help, getting assignments while patients are in the hospital, arranging homebound instruction if needed, and assisting with IEP or 504 plan meetings if needed.

Stacy Willett, BS

Educational Liaison

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Additional Information

Food

Cafeteria: On the first floor of the Atrium (“old” hospital entrance). Their hours vary. Please check their schedule which is posted outside the cafeteria or ask your nurse.

Red Wagon Café: On the first floor of the Simon Family Tower in the main lobby. They are open daily from 6 AM to 2:30 AM.

The Patio: On the first floor of the Riley Outpatient Center (ROC). They are open Mon-Fri from 11 AM to 2 PM.

Nature’s Table: On the first floor of the Atrium (“old” hospital entrance), near the cafeteria. They are open Mon-Fri from 6 AM to 10 PM, Sat-Sun from 6 AM to 7 PM.

Coffee/Snacks: The Copper Moon is located across from Nature’s Table on the first floor of the Atrium. They are open Mon-Fri from 6 AM to 9 PM, Sat-Sun from 7 AM to 5 PM.

Family Library

The family library is in the Snyder Family Resource Center, which is located on the first floor behind the atrium. Hours are:

Monday – Friday: 9 AM – 5 PM
Weekends and evenings vary

Smoking

For the safety and health of patients, visitors, and staff, smoking is not allowed. Riley Hospital is a smoke-free campus. Smoking is not allowed in any IU Health building or on the property/grounds including walkways, parking garages, and tunnels.

Ronald McDonald House at Riley

The Ronald McDonald House at Riley offers a place for families of inpatients to relax. It is open from 9 AM – 9 PM and is located in the Snyder Family Resource Center on the first floor of the hospital behind the atrium.

Services include the following:

- Living room with a fireplace and TV
- Kitchen and eating area where you can make a meal or snack
- Pantry stocked with donated food items
- Laundry room
- Quiet room to read, meditate, or rest
- Showers available from 1 PM – 3:30 PM every day

For safety reasons, patients cannot come into the Ronald McDonald House at Riley.

Gift Shops

There are three gift shops at Riley. All offer candy, children's toys, clothing, balloons, cards, magazines, and other gifts.

The **Raggedy Man** gift shop is on the first floor near the Atrium lobby. It is open Monday-Sunday 9 AM – 8 PM

The **Over The Rainbow** gift shop is in the Riley Outpatient Center (ROC). It is open Monday-Friday 9 AM – 5 PM.

The **Cheerful Sunrise** gift shop is located in the Simon Family Tower main entrance lobby. It is open Monday-Friday 9 AM – 8 PM, Saturday and Sunday 12 noon – 5 PM

Safety Store

The Safety Store has about any and every item you could need to keep your child safe. All items are sold at cost and generally are about half of the price you would pay at a retail store. Store hours are Monday-Friday from 9 AM-4 PM.

Parking

You can park in the Simon Family Tower Garage or the Riley Outpatient Center (ROC) garage.

- Please contact your social worker for additional information regarding reduced charge for parking in the Riley Outpatient Center (ROC) garage for outpatient appointments or the Simon Family Tower garage parking passes for your SCT admission.

Handicapped parking is available in all garages. A monthly surface lot pass is available in Hospital Administration (Room 1960). Reduced rate coupon books for parking are available in the gift shops.

CaringBridge

CaringBridge is a place to set up your own free, personal website. It is a way to share information with your family and friends during the hospital stay. Staff in the library can help you set it up. Call them at 317-948-1645 for more information.

Patient Satisfaction

We are here to take care of your child. **You are important to us.** We want to meet all your needs. Please talk with the unit manager or the day shift coordinator if you are not completely satisfied. Your child's care, comfort, and recovery are our main concerns.

After discharge, you may get a survey in the mail. It will ask you about your child's hospital stay. Please share your feelings and complete the survey – your thoughts are important to us.

Discharge

Discharge planning and teaching begins before admission to the unit. As the time for discharge approaches, IV medications will be changed to those taken by mouth, IV or enteral nutrition will be running fewer hours or not at all and your child will be encouraged to begin eating and drinking more. If your child has been on pain medication, these will be slowly weaned. The nurses will teach you the skills you will need after discharge such as changing a central line dressing, sterile technique, and cap changes. You will also be taught about all of the medications your child will continue to take after discharge. In addition to these “medical” issues, please let us know if there is something you want to learn that you have not been taught. As you have heard, there are NO silly questions.

Discharge from the hospital comes with a variety of emotions ranging from relief to finally leave the hospital to anxiety about losing the “safety net” of the hospital environment. Our goal is that when you leave Riley Hospital for Children to care for your child either at home or at the Ronald McDonald House, you will have the skills and confidence necessary to carry on the excellent care you have received at the hospital.

Home Readiness Checklist

- Steam-clean upholstery, drapery and carpets (preferably by a professional)
 - Do not use dry-powder chemicals (such as Chem-dry)
- Clean all surfaces in your home
 - Use strong household cleaner (Lysol, Pine-sol, etc.) for most (non-wood) surfaces, following the instructions for “disinfection” on the product label
 - Pay special attention to: door handles, kitchen surfaces, inside of the refrigerator, bathroom, non-wood tables, mini-blinds, TV remote control, telephone headset, and toys that cannot be washed in the laundry
 - Wipe down walls with soap and water
 - Use wood surface cleaner (Pledge, Murphy’s Oil Soap, etc.) on wood
- Burn gas logs only (no wood-burning stoves or fires)
- Change furnace/air filters immediately before discharge and regularly thereafter according to filter product instructions
 - Utilize central air (if available)
 - Keep windows closed
- Clean vent ductwork (if applicable)
- Mop the floors
- Wash all bed linens in hot water
 - Continue to wash 1-2 times per week after discharged home
- Ensure that the patient has his/her own bed with his/her own pillow (foam – not down or feather)
 - Place a mattress protector around the upper mattress of the bunk bed if the patient sleeps on the bottom mattress of a bunk bed
- Wash all toys that can be laundered in hot water
- Avoid fresh plants, flowers, greenery, or live decorations (including live Christmas trees)
- Avoid sand, dirt, and clay
- Maintain pet health (vaccinations current, recent healthy check-up)
 - No new pets
 - Do not allow your child to sleep with the pet or allow the pet to lick the child on his/her face
 - Clean litter boxes daily (patient should not touch the litter box)
 - Prevent patient contact with animal feces, cages, reptiles, exotic pets, rodents, or birds
 - Practice hand hygiene after pet contact

- Prepare food according to the neutropenic/low-bacteria diet guidelines
 - Remember: avoid fast-food restaurants and leftovers
- Arrange transportation for the following:
 - Home
 - Clinic
 - Emergency