



What to Know Before Stem Cell Transplant (SCT)

A Guide for Patients & Caregivers







Before Stem Cell Transplant (SCT): What to Know

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Your Child's Care Team

The care teams at the Dana-Farber Jimmy Fund Clinic (JFC) and Boston Children's Hospital (BCH) will work together to coordinate your care. There are other members of your care team who are not listed below. Staff can connect you to them as needed.

Clinic Day:	-
Attending Physician:	-
Fellow:	_
Nurse Practitioner/ Physician's Assistant:	
Nurse Director/ Nurse Manager (JFC):	
ONN/ Oncology Nurse Navigator (JFC):	_
Psychosocial Clinician (BCH):	
Psychosocial Clinician (JFC):	
Resource Specialist:	_
Genetic Counselor:	
Who to Call for Patient Care • Weekdays 8 a.m. to 5 p.m.: Jimmy Fund Clinic (617) 632-3270	

- After 5 p.m. or anytime on weekends and holidays:
 - <u>Solid tumor, neuro oncology, hematologic malignancy patients</u>: Call (617) 632-3352 and ask for the pediatric oncology provider on call.
 - <u>Stem cell transplant patients</u>: Call (617) 632-3352 and ask for the pediatric stem cell transplant provider on call.
 - Bone marrow failure clinic patients: Call (617) 355-6363 and ask for the hematology provider on call.
- For life threatening emergencies call 911.





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Admission for Stem Cell Transplant (SCT)

Your child will complete screening tests before being admitted for stem cell transplant (SCT). After your care team reviews the results of the tests, they will let you know when the transplant will occur and what to expect for your child's SCT admission.

Conditioning Therapy

Before getting their stem cell transplant, your child will get conditioning therapy to:

- Destroy diseased cells.
- Remove normal cells in the marrow spaces of the bones so new stem cells will have room to grow.
- Suppress the immune system so that the body will accept new cells (if they are receiving cells from another person).

Conditioning may include chemotherapy, immunotherapy, and radiation.

The number of days of conditioning can vary. These days are counted using negative numbers (Day -7, Day -6, Day -5) leading up to the infusion day.

Day 0 is the day when the stem cells are given by IV (infusion). After Day 0, the days are referred to as Day +1, Day +2, Day +3.

Common Side Effects

- Nausea
- Vomiting
- Diarrhea
- Mouth sores (mucositis)
- Low blood counts (white blood count, red blood count, platelets)

Please note these are not all the possible side effects. Your care team will explain other side effects if they occur.

Engraftment

When the stem cell or bone marrow graft is making enough cells, this is called *engraftment*. White cell engraftment is usually 2-4 weeks after a stem cell transplant. It is when:

- The patient's ANC (absolute neutrophil count) is 500 or higher for 3 days following infusion of the stem cells <u>AND</u>
- The neutrophil count has gone up from its lowest number.

Patients may continue to receive red blood cell and platelet transfusions for weeks and sometimes months after the transplant.

Discharge

Before you leave the hospital, the care team will prepare you to take care of your child at home. You may need to come to the Jimmy Fund Clinic for follow-up visits. Your stem cell transplant team will tell you how often these visits are needed.

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Appointments Before Stem Cell Transplant (SCT)

Your child will have many tests and appointments before they are admitted to the hospital for stem cell transplant (SCT). The SCT team will help you schedule the appointments. An intake nurse will teach you and your child what to expect both before and during transplant.

Tests are needed before SCT to check that your child's organs are working and to look for any infection. The results will also be used to see if there are changes during or after transplant. Tests may include:

- Lumbar puncture, bone marrow aspirate, bone marrow biopsy, X-rays, CT scan, MRI, MIBG
- Heart tests (such as echocardiogram and EKG)
- Lung tests (such as pulmonary function tests PFTs)
- Eye exam
- Dental exam
 - Your child may need to take antibiotics before the exam.
 - If your child needs any dental care (such as filling a cavity or pulling a tooth), the dentist should first talk with the transplant provider.
- Hearing test
- Gynecologic and/or reproduction evaluations
- Kidney test
- Blood tests

Before being admitted for transplant, you will meet with the SCT team to talk about:

- Your child's disease status.
- The SCT process.
- Side effects of transplant and possible toxicities.
- Risk of infection.
- What to expect after discharge.

Your SCT Intake nurse will tell you what to expect when your child is admitted for SCT at Boston Children's Hospital. When possible, you will be given a tour of the unit. They will tell you about the daily routines for SCT patients there and answer any questions you may have.

If your child's treatment will include apheresis or peripheral blood stem cell collection, you will meet with the apheresis nurses. If the treatment plan includes radiation, you will meet with the radiation oncologists to discuss radiation planning.

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Preventing Infection for Stem Cell Transplant (SCT) Patients

It is very important to prevent infection in SCT patients. For this reason, when admitted to the hospital, SCT patients:

- Only leave the unit if there is a medical need to leave.
- May do throat and stool tests every week to look for infection. Your child must stay in their room while they wait for the test results (usually 3 days).
 - If the test is positive, they may need to isolate in their room.
 - If the test is negative, they can then leave their room to walk in the hallway or go to the activity room.
- Get a daily bath with medicated (chlorhexidine) wipes.
- Should brush teeth 2 times a day with a regular toothpaste (no whitening, charcoal, or other types).

Patient Rooms

- Rooms are cleaned each day by hospital staff.
 - Bed sheets and towels are changed daily and more often if needed.
- All rooms have bathrooms with a toilet, sink, and shower. <u>Only patients and adult</u> <u>caregivers may use these bathrooms</u>. There are bathrooms and showers for siblings and other visitors at both ends of the unit.
- Plants and flowers are not allowed on the unit.

Activity Room

When open, the activity room is only for a limited number of SCT patients and their caregivers.

The activity room is <u>not</u> to be used by:

- Siblings and other children who are not SCT patients.
- Patients and visitors of patients who are in isolation or on precautions.
- Non-SCT patients (including oncology), families, and their visitors.

Because infections can be spread on surfaces, patients should not share toys, games, or crafts. After toys are used in the activity room, they go in a bin for dirty toys to be cleaned. The bin is outside the activity room.

Visitor Rules

Caregivers, family, and friends who will be with your child should take steps to help them avoid any infection.

- Do not come to the hospital with any sign of infection (cough, fever, rash, vomiting, diarrhea).
- Visitors must be over 2 years old.
- All visitors must have had chicken pox or the chicken pox vaccine.
- No more than 3 visitors may be in the patient room at the same time.

At the hospital, wash hands or use hand sanitizer when you:

- Enter the inpatient unit.
- Enter a patient's room.
- Leave a patient's room.
- Pick something up from the floor (the object should be cleaned as well).
- Use the bathroom or help your child in the bathroom.

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What to Bring from Home for a Stem Cell Transplant (SCT)

All items you choose to bring from home must be clean and able to be washed or wiped down. Do not bring too much as there is not a lot of space to store things in the hospital room.

Toys, Games, Books

- Your child may bring their own gaming system, DVDs, or handheld devices.
- It is ok to bring a few favorite toys, books, and 1 or 2 stuffed animals.
 - Toys and stuffed animals that can be machine-washed and dried should be cleaned at home and brought to the hospital in a closed bag (such as a suitcase or plastic bag).
 - New toys can be brought into the room after taking off the wrapping.

Computers and Electronic Devices

Each patient room has an entertainment system and internet access.

- Laptop and tablet computers may be brought from home. If you don't have a tablet, you may use one from Boston Children's Hospital (BCH).
- All electronics brought from home will be checked by hospital staff to make sure they are safe to use at BCH.

Clothes

- Wash clothes and put them in a closed suitcase or bag to bring to the hospital. We suggest:
 - \circ Comfortable clothing that can be machine-washed and dried in a dryer.
 - Nonskid slippers or shoes.
- There is a washer and dryer with laundry soap on the 6th floor for patients and caregivers to use.

Bed Sheets, Pillowcases, and Blankets

The hospital has bed sheets, pillowcases, and blankets for you to use. If you choose to bring your own:

- Machine wash and dry them at home and bring them to the hospital in a closed bag (such as a suitcase or plastic bag).
- Blankets from home must be washed twice a week or if soiled.
- Sheets and pillowcases from home must be washed each day or if soiled.

Pictures

• Pictures from home must be able to be cleaned (wiped down).

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