Indian Academy of Pediatrics (IAP)

GUIDELINES FOR PARENTS

Post Bone Marrow Transplant/ Stem Cell Transplant Care

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10 FAQs on POST BONE MARROW TRANSPLANT/STEM CELL TRANSPLANT CARE

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2. What should I do when my child develops fever?
3. I have heard there is mouth pain and mucositis post-transplant, what can I do to manage it? How should I handle nausea, vomiting, and diarrhea during and after BMT?
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Post Bone Marrow Transplant/ Stem Cell Transplant Care

Q1

What is bone marrow transplant and who needs it? What are the success rates?

Bone marrow transplant (BMT) is a treatment modality for various cancerous conditions (such as blood cancer, lymphomas, brain tumors, neuroblastoma, etc.) as well as noncancerous conditions (such as thalassemia, sickle cell disease, aplastic anemia, immunodeficiency disorders, etc.) wherein healthy stem cells (usually from a donor) are placed in the patient's bloodstream. If the stem cells are taken from the patient themselves and given back after high dose of chemotherapy, it is called "autologous transplant". However, if stem cells are given from a healthy donor (related or unrelated), it is called allogeneic BMT. Following transplant, these healthy stem cells start regenerating more stem cells.

"Bone marrow transplant" and "stem cell transplant" are often used interchangeably, although a more appropriate scientific terminology, is hematopoietic stem cell transplant. All transplants used to treat cancers of the blood or bone marrow involve stem cells. Stem cells can come from:

- Bone marrow (your own or a donor's)
- Peripheral blood (your own or a donor's)
- Umbilical cord blood

Process for Bone Marrow Donation

Screening of a suitable bone marrow donor involves taking a simple cheek swab from the donor to analyze the deoxyribonucleic acid (DNA), and see if the same matches with that of the recipient. A bone marrow sample is not needed at this stage.

How long my child must stay in hospital after BMT?

Following a BMT, your child will have low total blood counts and it may take some time for the bone marrow to regenerate. Hence, your child will need to stay in hospital for nearly a month. However, even after discharge a strict follow-up is required for a few months.

Success Rates of Bone Marrow Transplant

Success rates of BMT depend on various factors such as disease for which BMT is required, condition of the patient before BMT, type of transplant, etc. The success rates, hence, can range from 60 to 90% based on above factors. You can have a more meaningful discussion on this specific to your child with the treating physician.

How should I prepare my home to receive my child after his/her BMT?

After bone marrow transplant, there is a period of low immunity which lasts for few months. During this phase, we need to protect these children from acquiring infections from the outside environment. After going home, we need to make sure that the surroundings are clean, hygienic, and dust free. You also must avoid visitors, especially if they are having any signs of infections such as cold, cough, vomiting, diarrhea, etc. Child's and the primary caretaker's personal hygiene is also important.

Q2

What should I do when my child develops fever?

Why my child develops fever?

Process of BMT involves administration of high dose of chemotherapy which results in low blood counts and neutropenia (decrease in white blood cell count). Neutropenia predisposes to infections which can lead to fever.

What to do?

Inform your healthcare team of any fever of >99°F as intravenous antibiotics can be given as early as possible.

Do's

- Reach out to hospital as early as possible (within 30 minutes of onset of fever).
- Make him wear loose clothes as per season.
- Keep the child well hydrated **(Fig. 1)**.
- Keep him/her in a cool airy environment.
- Medication (paracetamol) can be used in doses as recommended by your doctor.
- Tepid sponging with water at 23–30°C can be done.

Fig. 1: Keep the child well-hydrated.

Don'ts

- *Do not* over clothe the child.
- Use of ice-cold water for sponging is not recommended in fever.
- Do not self-medicate for fever.

Preventing Infections Post Bone Marrow Transplant

During period of low immunity post-transplant (which lasts for months post-transplant), avoid crowded area and contact of sick people that may expose the patient to infection. Patient should wear a surgical mask, whenever he needs to visit hospital for any reason which can be availed from any medical shop. Avoid all fresh fruits, vegetables, or any uncooked food as they can increase the risk of bacterial and fungal infection. Strict hand hygiene is the single most important step to prevent infection. Small children are most often at risk of transmitting viral infection, hence avoid contact with them as far as possible.

Q3

I have heard there is mouth pain and mucositis post-transplant, what can I do to manage it? How should I handle nausea, vomiting, and diarrhea during and after BMT?

Some chemotherapy drugs as well as radiation therapy cause mucositis which leads to redness, soreness, and ulcers in mouth which can be very painful. Proper oral care and mouth rinses with solutions as advised by your healthcare team will combat pain and prevent infection. You should encourage your child to carry out focused and effective oral hygiene (brushing, flossing, etc. carefully). Inform your doctor when your child first experiences a sore throat, mouth pain, or difficulty in swallowing so that pain medication can be started as early as possible. Severe pain in some patients may cause inability to swallow any liquids or medication. During this period, intravenous fluids, pain medications (like mucaine gel) and total parenteral nutrition are often required to alleviate pain, keep hydrated, and provide energy. Pain medication are meant for controlling pain, not to cure mucositis. Mucositis is temporary and typically resolves when patient's neutropenia improves.

Nausea and Vomiting

Post high dose of chemotherapy, most of the children feel nauseous and may vomit. Some antiemetic drugs are usually prescribed by your doctor to decrease the severity of nausea and vomiting. It may be preferable to avoid intake of milk products and large meal at a time which may aggravate the condition. You may give your child clear fluids and light and bland diets, which are easy to digest (such as rice, clear soups, dals, or eggs).

Diarrhea

Post chemotherapy, diarrhea is a quite common symptom. It is crucial to keep your child well hydrated by offering rehydrating fluids (such as ORS, *nimbu pani*) frequently. *Drinks to be avoided:* Milk products and fruit juices should be avoided as they may further worsen loose stool due to lactose and fructose intolerance. Keep your doctor informed about your child's condition.

Q4

How to take care of any bleeding, skin, and respiratory problems post-transplant?

Bleeding is often the result of low platelet count (thrombocytopenia), which is common following high dose of chemotherapy. Platelets may be transfused, if your child has very low platelet count or has incessant bleeding. It is better to use soft toothbrush and gentle brushing to prevent gum bleeding. Do not use medicines such as aspirin, ibuprofen, or naproxen, which can increase the risk of bleeding. Inform your doctor, if you observe any bleeding in the stool, or urine or if your child develops sudden onset of a severe and intolerable headache.

Skin Care

It is important that your child takes bath everyday with daily change of clothing. Avoid over-the-counter creams or lotions because it may sometimes exacerbate skin rashes and use only those that have been prescribed by your doctor. Regular washing of hands to be done especially after the following: Using bathroom, touching any ulcers or body secretions on your kids' body, and after giving oral care. Any skin rash seen in the post-transplant period can be due to medications or any viral or fungal infections. Any new skin rash should be evaluated by your doctor so that appropriate treatment can be given immediately.

Respiratory Problems

If your child develops cough and breathing difficulty following BMT, it could be related to postchemotherapy complications such as fluid overload and infection. Keep updated your healthcare team about above-mentioned symptoms for timely treatment to be given.

Q5

What is meant by rejection of graft and graft versus host disease (GVHD)?

The body's immune system can attack the donor stem cells and this is called rejection. The transplanted cells can attack the recipients' body cells and this is called graft-versus-host disease. Graft versus host disease is a manifestation that is seen post-transplant in individuals receiving allogenic transplant.

Features of Graft versus Host Disease

Acute GVHD typically occurs in the first 100 days after transplant. Chronic GVHD typically occurs after day 100 post-transplant. The most important manifestation of GVHD includes:

- *Skin rash*: Reddish, often itchy involving from <25% to >75% of the body surface areas. Blisters can also form in rare cases.
- Sudden onset of large volume loose watery stools, often greenish colored, occasionally associated with blood in stools and abdominal cramps.
- Severe nausea and vomiting associated with poor food intake that is unresponsive to typical antinausea medications
- Graft versus host disease of the liver manifests with elevated bilirubin and liver enzymes which clinically present with jaundice (yellowish discoloration of skin and eyes), itching, fluid in abdomen, and right abdominal pain and tenderness.

What to do?

If your patient develops any of these symptoms, inform your healthcare team so that treatment can be started off quickly. Delay in diagnosis and initiation of treatment can exacerbate the GVHD and its symptoms, making it more tough to control.

Q6

My child often feels low. How can I cheer up my child?

Although rest is the most vital part in tackling fatigue immediately post-transplant, it is also crucial for the child to remain out of bed as much as possible. Engage your child in light activities such as indoor games, puzzles, soothing music, and other hobbies such as painting to keep him/her busy and lessen boredom. Apt sleeping and healthy eating habits add to overall well-being of the kid and decreases the severity of fatigue. Engage your child in light exercise and increase the level as the child tolerates. Do not get disheartened if your kids energy level does not improve rapidly as it can take up to 4–6 months to fully to get better. Each recovers at his/her own pace. Hence, give time for recovery.

Q7

How do I handle the poor appetite of my child post-BMT? What should I feed my child?

Chemotherapy given during transplant causes nausea and poor oral intake in a lot of children. Offer your child small frequent feeds throughout the day. High protein diet is recommended.

General Food Guidelines after Transplant

- To rebuild your child's strength and muscle mass following transplant, well-balanced diet plays a principal role.
- To begin with follow "strict low bacteria" diet known as modified microbial diet or a neutropenic diet.
- Dietary checklist to be followed includes **(Figs. 2 to 7)**:
  - Avoid expired/perishable food.
  - To look for mold or insect contamination.
  - Not to consume leftover food of >2 days.
  - Foods should be held at proper temperature.

- Maintaining proper temperature for food items such as storing milk and dairy products in refrigerator and consuming freshly cooked food as early as possible, and not let it cool in room temperature.
- Food once taken out of the refrigerator should not be placed back again, dividing the food into individual servings and storing in containers separately will serve this purpose.
- Frozen food to be thawed either in refrigerator or defrosted in microwave rather than letting it to thaw in room temperature.
- Avoid prepackaged food-like meat or cheese.
- Filtered or boiled water should be used for drinking.
- Wash fruits and vegetables in clean water before use.
- Avoid fresh strawberries and raspberries, raw broccoli, cauliflower or sprouts.
- Avoid any vegetable or fruits that cannot be peeled before consuming.
- It is recommended not to share utensil for eating or drinking purpose.
- Avoid unpasteurized dairy products, juices (except homemade or canned), and honey.
- Supplement your child with daily minerals/multivitamins until his or her appetite improves.
- Inform your healthcare provider, if your child is facing any difficulties in eating, swallowing, or tolerating food.
- Avoid probiotics (live yogurts, probiotic supplements, or drinks).

Fig. 2: Avoid junk food, raw uncooked food, and large meals.

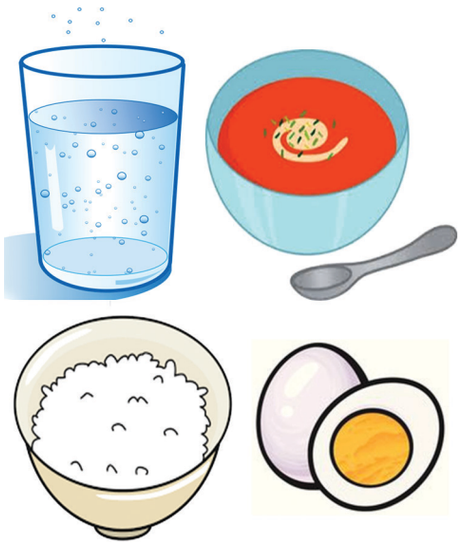
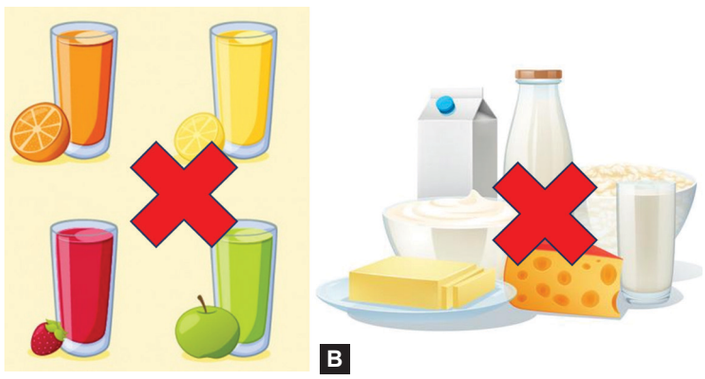


Fig. 3: Clear liquids and bland diet such as home-made soups, rice, and eggs.

Fig. 4: Oral rehydration solution (ORS) to prevent dehydration during loose stools.



Figs. 5A and B: Avoid fruit juices and dairy during diarrhea.

Fig. 6: Small frequent meals.

Fig. 7: High-protein diet.

Q8

Will there be any psychological issues with parents or my child during the whole bone marrow transplant (BMT) process?

You are likely to go through huge amount of psychological stress during this period. Get help from your medical team, social worker, psychologist or mental healthcare professional if yourself or your kid has issues in cope up of stress level that arises during the transplant process. It may be helpful to discuss with other parents who may share their experience and help you cope by sharing useful tips during this difficult period.

Q9

When can my child return to school? Can we keep pets and animals with my child? How to go about vaccination?

Your kids' return to school/work shall depend on type of transplant, your child has received and on speed of recovery. Your child shall not return to school or work for at least first 100 days after the transplantation. Those patients who have received allogeneic transplantation should not return to work or school for up to 1 year. Your child may need to do schoolwork at home during recovery. Talk with the teacher about how your child can keep up with schoolwork and stay connected with classmates.

Pets

Domestic animals are allowed at home excluding reptiles and birds. Keep away from reptiles and birds as their excreta can be source of many infections. Do not give a peck or cuddle your pet and avoid sleeping with them. Avoid any contact with farm or outdoor animals.

Vaccination

It is imperative that your child is kept away from children receiving live vaccines (like polio or chickenpox vaccine). This does not apply to inactivated vaccines which can be given to children living in same household. Transplant causes profound immunosuppression that the child will no longer have any immune memory to the infections for which he or she had been vaccinated in the past, and hence revaccination is done starting 1–2 years after transplantation. A detailed discussion regarding the revaccination for your child and the schedule for the same will commence as soon as 1 year of transplantation is completed. Even though your child cannot have a flu vaccine for at least 6 months post-transplantation, but you and your family members and other caregivers if any, must be vaccinated for the same.

Q10

What are the long-term side effects of bone marrow transplant (BMT)?

Some of the complications associated with BMT are not manifested until several months, or even years after treatment. Most of them resolve with time, but others may be permanent and need attention for long-term. These include:

- Infertility (inability to have a biological child, meaning you cannot become pregnant or make a woman pregnant when you want to)
- Cataract, an eye condition, that causes cloudy vision
- Endocrine problems such as thyroid problems, early menopause, osteoporosis
- *Other organ damage:* Lung, liver, heart, or bone damage
- Chronic GVHD
- Peripheral neuropathy
- Another cancer
- Psychological problems
- Learning problems

IMPORTANT POINTS TO REMEMBER

- Patient guardianship post-transplant is an essential caregiver task.
- Handwashing is an indispensable step to avoid infection.
- Even if inconsequential, any unusual symptom or change experienced by the patient should be notified to the healthcare provider.
- Early notification helps in quicker and prompt response, often saves the patient from precarious situations.
- You and your child might feel the need for certain amount of psychological assistance for few weeks after transplantation even after discharge and having returned home.
- Profound fatigue often lingers for many weeks after transplantation and might remain for up to 5–6 months post-transplantation.
- Pertinent nutritional intake and regular exercise is essential in optimizing your child's recovery once he/she has returned home.
- Exercise to be increased gradually and according to patient's tolerance.
- After discharge, the patient will be planned for follow-up visits with the bone marrow transplantation team.
- It is necessary that the patient keeps these appointments and is accompanied by the caregiver for any assistance for specified tests or when recovering from procedures (bone marrow biopsy, central line removal, etc.)
- Post-transplant adversity may sometimes occur after the patient has been discharged. Therefore, it is essential that the patient notifies his local physician and his bone marrow transplant unit or team immediately, in case of any problem.