



Paediatric Bone Marrow Transplant : Discharge Advice

A patient who had a BMT will have low body resistance to infection. The immune system will take at least 6 months to a year to recover.

Patient co-op shop: A place where a patient can buy different necessities, e.g. surgical masks and Transpore tape.

Medical Issues

Medication

Medication preventing PCP: Oral Septrin or Pentamidine inhalation is needed for a period of time. Take medication as instructed by the doctors or nurses. Do not change or alter dosage of recommended medication without medical advice.

Keep drug allergy card at all times if you have any allergies.

Please inform our doctors if you are taking other forms of medication or traditional Chinese medicine.

For follow up

Please remember your blood group is _____ and the BMT date is _____.

A post-BMT patient should attend their follow up clinic on the date and time stated on the appointment slips.

When they attend their follow up or are admitted to hospital, please bring all medication for checking.

If the patient is taking cyclosporine (CSP): Do not take CSP before the follow up, as blood will be taken to assess the CSP levels. Please bring the medication and take it after blood has been taken.

Seek medical advice

Measure the child's body temperature twice a day and observe any changes to the child's condition and skin integrity etc.

Inform healthcare professionals when there is:

- High Fever: an oral/tympanic temperature of more than 38.5°C or an axilla temperature of more than 38°C.
- Low fever: an oral/tympanic temperature of 38 – 38.5°C or an axilla temperature of 37.5 - 38°C for more than 1 hour.

- Running nose, cough, vomiting, bleeding, not able to pass urine, diarrhea, constipation, mouth

ulcers, abdominal pain, or pain from any location, abnormal conditions (e.g. rashes, blisters), problems concerning central lines, and/or emotional problems.

- Exposure to people with measles or chickenpox.
- Contact child who just has vaccination.
- Planning for medical check-up or vaccination in other medical institution.

For emergency, please dial 999 or attend a nearby A&E.

For enquiries, you can dial 2255-3445 (K8N ward)

In The Following Time	Bring A&E Letter
Between 9AM and 5PM, Monday to Friday	To K8N
Between 9AM and 12PM, Saturday, Sunday and public holidays.	To K8N
Other Times	To QMH A&E Dept

Prevent Infection

Avoid dusty environments and construction sites.

Avoid contacting pets, animals and plants, as they contain bugs.

Wear surgical mask when going out and change the mask every 4 hours or when it is wet.

Wash your hands thoroughly before meals, after toileting, and before and after central line care.

Avoid contacting people with cold, flu, chicken pox, measles and any viral infections.

Do not share towels or bar soaps for bathing. Use liquid soap instead.

Immunization

After a year post-BMT, you will be arranged a date to receive vaccinations during a consultation with health care professionals.

Graft Versus Host Disease, GVHD

Acute GVHD usually occurs 3 weeks after transplant. When the infused stem cells are growing, donor white blood cells may reject and damage recipient's body tissues. The patient's liver, oral cavity, gastro-intestinal tract and skin or may be affected. Symptoms may include rash, vomiting, diarrhoea, jaundice and abdominal cramps. The patient is prone to infection. Each patient will be taking some prophylactic medication for GVHD, e.g. Cyclosporine. If GVHD occurs, additional medication will be needed to control the condition.

Chronic GVHD usually occur 100 days post-BMT. It may not be related to acute GVHD. Different organs can be involved.

Please be aware of any changes to your child's condition.

Skin	Rash, dryness, hardness, darkening, blisters and peeling
Hair	Hair loss
Nails	Change in nail shape
Oral cavity	Ulcers, decreased saliva secretion and swallowing difficulties
Gastro-intestinal tract	Diarrhoea, poor appetite, abdominal cramps and vomiting
Liver	Jaundice, limb swelling (oedema), abdominal swelling (ascites), easy bruising and lethargy.
Lungs	Shortness of breath, cough, blue skin (cyanosis), and decrease exercise tolerance
Eyes	Dryness, eye redness
Bladder	Blood in urine, frothy urine, pain on passing urine.
Muscles and bones	Joint stiffness, contractures affecting daily activities
Kidneys and heart	Limb swelling (oedema), and increased body weight
Bone marrow	Abnormal blood counts

Home Care

Home environment

Please keep home clean at all times. Throw away old newspapers, books and shoes.

It would be preferable if a single room is prepared for the patient.

Clean your home with damp clean cloth daily.

Change bed sheets, pillow case weekly. Bed quilt, mattress should be put under the sun, to kill some of the bacteria.

Clean air-conditioner filters weekly.

Change curtains monthly.

Clean carpets once every 3 months.

Keep your home well-ventilated, in suitable humidity and enough amount of sunlight. Use of dehumidifier or humidifier is of personal discretion.

Avoid contact with substances such as gasoline, cleansing products, solvents, atomizing paint, fertilizers or pesticides for they are toxic to your bone marrow

For the first year post transplant,

- ◆ No pets
- ◆ No pot planting, fresh flowers in vase
- ◆ Always avoid high humidity, strong wind, dust accumulation
- ◆ Avoid dry dusting with the use of feather duster, floor sweeper or dry cloth

Central line care

Wrap the central line with a small plastic bag and secure over the chest into a 'U' shape before taking a bath.

Do not wet the central line dressing when bathing.

Perform hand hygiene before line care.

Have exit site dressing and line flushing twice a week. Keep the line well secured.

Observe the line exit site for pain, redness and discharge.

Make arrangements with nurse for line care after discharge.

Personal hygiene

Bath daily and use a clean towel each time. A used towel should be washed, dried, and ironed.

Change underwear and socks daily.

Keep shoes clean and dry, protect your feet with well-fitted shoes, avoid open toe shoes and avoid wearing other people's shoes

Skin care

Do not have excessive sun exposure for 6 months post-BMT, wear long sleeve clothing or bring an umbrella.

Apply sunscreen when going out to prevent graft-versus-host disease and skin infections.

Always apply skin lotion to dry skin.

Oral care

Use saline to rinse your mouth (oral cavity) before and after meals. Brush your teeth twice a day.

Rinse with 'Bactidol' and distilled water or saline twice daily if neutrophil count $< 1 \times 10^9 /L$.

Eye care

Wear a pair of sunglasses, use an umbrella when going out. If patient is experiencing dry eyes, please seek medical advice.

Hair care

Use mild hair care products (e.g. non-medicated or anti-dandruff products).

Apply moisturizers or olive oil for scalp dryness.

Protect head with hats or wigs. Please clean hat or wigs regularly.

Hair will take 3-4 months to grow (more time will be required for patients receiving total body irradiation).

Daily Activities

Exercise

You may feel tired easily. Have enough sleep and do deep breathing exercises regularly. You can increase exercise tolerance gradually by taking a walk, climbing stairs or cycling.

Travel

Half a year post discharge: You should avoid public transport, especially the train and MTR. You should take private car or taxi instead.

Avoid crowded areas, such as Chinese restaurants, cinemas and avoid places with heavy air pollution.

Consult our doctor if you plan to travel to other countries.

Emotional Support

Under the influence of medication or changes in appearance caused by illness, you may experience a degree of emotional upset. Please share your worries and feelings with your parents or friends. Consult a clinical psychologist if necessary.

Schooling or work

Discuss with a doctor regarding when you should go back to school. It usually takes 6-8 months for autologous transplant patients and a year for allogeneic transplant patients. The child may easily get chicken pox or other types of infection when attending school. Their caretaker should diligently monitor any changes to the child's condition.

Diet and Nutrition

Diet:

Consultation with a dietician will be arranged before discharge.

Maintain a balanced, nutritious diet, have a high protein and caloric intake and have small meals.

Have moderate fluid intake, approximately _____ ml.

Rinse eating utensils with boiled hot water before use.

After BMT, you may experience mouth dryness, change in taste and appetite. These may subside after a few months.

Avoid having take-away food.

Consult our doctors if there is any query.

◆ **Body Weight:** Should keep the body weight within healthy range (BMI = 18.5 to 23)

◆ For adult: Body Mass Index (BMI) = Body weight (kg) / Height (m)²

BMI	Classification
<18.5	Underweight
18.5-22.9	Normal
23-24.9	Overweight
>25	Obese

◆ **Daily Energy Requirement**

Underweight (BMI<18.5)	40 – 50 Kcal/kg x ideal weight (kg)
Normal (BMI 18.5-22.9)	30 – 35 Kcal/kg x ideal weight (kg)

◆ **Maintain adequate daily nutrient intake**

Fluid	◆ 2000ml or above (minimum 8 cups of fluid)
Protein (4 Kcal per gram)	◆ 15% of energy from protein ◆ Good sources of protein include meat, poultry, fish, eggs, milk, dairy and soy products.
Carbohydrates (4 Kcal per gram)	◆ 55% of energy from carbohydrates ◆ Good sources of carbohydrate include congee, noodles, rice, bread and biscuits
Fat (9 Kcal per gram)	◆ 30% of energy from fat ◆ Good sources of fat include cooking oil, such as peanut oil, corn oil and margarine
Minerals	◆ e.g. sodium, potassium, iron and magnesium
Vitamins	◆ e.g. vitamin A, B, C, D and E

◆ **Rich food sources of potassium / magnesium**

Food sources	Potassium	Magnesium
Vegetables	Green leafy vegetables, corn, potato, pumpkin, tomato, carrot, Jew's ear, lily flower, dried beans	Dark green leafy vegetables, beans, peas
Fruits	Banana, mango, honeydew, orange, longan, guava	Banana
Meat	-----	All kinds of meat
Others	Malted sugar, ketchup, milk, bovril	Nuts, wholemeal products

◆ **Food choices**

Food	Time			
	3 months +	6 months +	9 months + (home)	9 months + (dinning out)
1. Fruits	Yes	Yes	Yes	Yes

2. Preserved foods (e.g. preserved vegetables)	No	No	+/-	+/-
3. Dried foods (e.g. shark fin, abalone, fish maw, dried scallop, dried figs and dates, lotus seeds, birds nest, dried longan)	Yes	Yes	Yes	Yes
4. Fermented foods (e.g. salted fish, salted egg, shrimp paste, preserved bean curd)	No	No	+/-	+/-
5. Sauces (e.g. ketchup, soya sauce, oyster sauce, sugar, salt, XO sauce, sesame oil, chili sauce, seafood sauce, peanut butter, mustard)	Yes	Yes	Yes	Yes
6. Dairy products (e.g. Fresh milk)	Yes	Yes	Yes	Yes
7. Dairy products (e.g. ice cream, yogurt)	No	?	?	?

Key:

Yes = Suitable to Eat No = To Avoid + / - Eat less ? Caution is needed

◆ **Caution on food choices and preparation**

1. Fruits should be washed, skinned and seeds removed.
2. Dried foods should be soaked in water overnight, seeds to be removed, then washed thoroughly before cooking
3. Seasonings, spices and sauces must be added before cooking.
4. For dairy products: Dairy products should be individually packed, and cheese should be processed.

**The above information is for general guidance.
Please consult QMH K8 ward Tel 2255-3445 for any queries**