

## Blood or Marrow Transplant (BMT): Post-Transplant Care

► **My outpatient clinic** \_\_\_\_\_

Telephone \_\_\_\_\_

► **My outpatient day hospital** \_\_\_\_\_

Telephone \_\_\_\_\_

► **After hours I call** \_\_\_\_\_

Telephone: \_\_\_\_\_

### What happens before I am discharged from the hospital?

Your medical team will give you detailed information about your medications, nutritional needs, how to care for yourself at home, how to contact your medical team for symptoms or questions, and when and where you will receive follow-up care. If you have a central catheter and will need to care for it, your nurse will make sure you understand what to do.

### Where will I receive outpatient BMT care?

You will be required to come for outpatient clinic visits at least 1 to 2 times each week after your BMT. These visits will take place in the outpatient clinics and day hospitals. Your medical team will let you know where and when to report.

#### My clinic visits:

(Days) \_\_\_\_\_

(Time) \_\_\_\_\_

The adult and pediatric outpatient clinics and day hospitals provide routine follow-up with the medical team, nurses, social workers, and dietitians. The outpatient day hospitals provide nursing care including outpatient intravenous

medication infusions, nursing assessments and care, and symptom management.

For safety reasons, children under age 12 are not allowed in the adult day hospital on 3SE-S. 3SE-S has a waiting room available behind the unit. A playroom is available behind the Admissions desk on the first floor.

### What happens during each outpatient clinic visit?

During each outpatient clinic visit, your blood will be drawn to check your blood counts.

Some specific blood tests may include:

► *Tacrolimus, sirolimus, or cyclosporine drug levels*

If you take one of these medications, you will have a blood test done on each outpatient visit. This blood test makes sure the amount of medication you are taking is the correct dose for you. Because this test is accurate only if your blood is drawn before you take your morning dose of tacrolimus, sirolimus, or cyclosporine, bring this medication with you and take it after your blood is drawn.

► *Cytomegalovirus (CMV)*

You will have a blood test for CMV (a virus) once a week. This blood test must be in the lab by 9 a.m. Please read the NIH handout on cytomegalovirus for more information.

Your outpatient clinic visit will include a visit from a member of your medical team. If you need more tests or treatment during your visit, your medical provider will let you know. Bring your medications for the whole day in case you need to stay longer than expected for testing or other care.

If you are coming to the Clinical Center for an outpatient clinic visit and have a runny nose, nasal congestion, sneezing, body aches, or fever, please call the clinic or day hospital before you arrive to let them know you have these symptoms. Wear a mask when you are in the Clinical Center and report directly to your clinic or day hospital.

### Can I still get infections after my white blood cell counts return to normal?

Yes. It will take time for your new immune system, the blood cells that help prevent and fight infection, to return to normal. Medications such as tacrolimus, sirolimus, cyclosporine, mycophenolate mofetil, and prednisone make it harder for your immune system to work properly.

Your medical team needs your help to know how you feel each day. You may have symptoms that help them identify an infection or side effect they can treat.

*If you have any of the following or any changes in your health, please report them to your medical team immediately:*

- ▶ Redness, pain, drainage at your I.V. catheter site
- ▶ Cough or difficulty breathing
- ▶ Runny nose/nasal drainage
- ▶ Feeling cold with or without a fever
- ▶ Sores on your lips, in your mouth, or on your skin
- ▶ Unable to eat or take your medications
- ▶ Nausea that will not go away or vomiting
- ▶ Burning or urgency with urination
- ▶ Unusual vaginal discharge

- ▶ Bleeding
- ▶ Diarrhea
- ▶ Skin rash or skin changes
- ▶ Pain
- ▶ Temperature of 100.4 degrees F (38 degrees C) or higher
- ▶ Not feeling well
- ▶ Increasing tiredness

### Are there other complications after transplant?

Yes. Your medical team will watch for signs of graft-versus-host disease (GVHD), cytomegalovirus (CMV), and infections. Please refer to the NIH handouts, “Graft-Versus- Host Disease: A guide for patients and families after stem cell transplant” and “Cytomegalovirus Infection: A guide for patients and families after stem cell transplant,” for more information.

### How do I contact my medical team?

Your medical team will give you the phone numbers for your outpatient clinic, day hospital, and inpatient unit before you leave.

**During business hours:** Call your day hospital or clinic for assistance.

**After hours:** Call the inpatient unit where you received your BMT.

A nurse will take your call and request your name, phone number, and questions or concerns. A member of your medical team will be notified immediately, and you should receive a return phone call. If you do not receive a return phone call within 30 minutes, please call back.

*NIH does not have an Emergency Department.* If you have a life-threatening emergency such as chest pain, difficulty breathing, seizure, or someone can't wake you up, please call 911. An ambulance will take you to the local Emergency Room where you will receive immediate care. This will not affect your participation in your research study.

If you require a blood transfusion at another hospital or clinic, inform the medical professional that blood products must be "irradiated and leuko-reduced" because you had a blood or marrow transplant.

### How can I prevent infections?

The transplant process and the immunosuppressive medications you receive after BMT raise your risk of infection. You are at risk as long as you take medications such as tacrolimus, sirolimus, cyclosporine, mycophenolate mofetil, and prednisone.

These activities will lower your risk for infection:

- ▶ Wash your hands often, before and after you eat and use the bathroom.
- ▶ Ask all visitors and family members to wash their hands.
- ▶ Ask family and friends not to visit if they are sick.
- ▶ Avoid gardening, lawn work, contact with stagnant water, and working with household plants.
- ▶ Avoid public transportation during busy times.
- ▶ Avoid crowds.
- ▶ Have a mask with you at all times and wear it anytime you cannot avoid crowds or people who are sick.

- ▶ Avoid pet and animal care.
- ▶ Keep air filters clean and change water in free-standing humidifiers daily.
- ▶ If you develop new symptoms, tell your medical team immediately.
- ▶ Avoid construction sites
- ▶ Avoid heavy household cleaning, such as handling garbage, dusting, vacuuming, and cleaning bathrooms.

### Will I go home with my central I.V. catheter?

Most patients go home with a central I.V. catheter to use for outpatient blood draws and medication administration. Your nurse will arrange for you and your caregivers to receive education on your catheter care.

### What activities can I do after BMT?

Walk! Walking daily helps raise your energy levels after BMT. Walking also helps you fill your lungs with more air, which lowers your risk for lung problems. It may take some time for your energy levels to improve after BMT, so take each day one at a time. Take a daily nap if needed.

Going with family members to the grocery store and shopping are good ways to slowly increase your activity. Choose times when it is less likely to be crowded, carry your mask with you if you cannot avoid crowds, and wash your hands often. Be aware of your energy levels so that you do not become too tired.

### Can I drive?

Some of the immunosuppressive medications used after transplant can make you feel shaky. They can also interfere with driving and carry a risk of seizures. Ask your medical team about driving after

transplant, as it depends on your health and medications.

### What can I eat after my BMT?

During and after treatment, you must be well nourished to maintain your strength and health. To make sure that your unique nutritional needs are met, a registered dietitian will work with you throughout your transplant. This team member will help you learn how to choose foods that will be not only safe for you to eat, but also easy to digest.

You can eat most foods. But because you are more likely to get sick from food that has gone bad, you will learn which foods to avoid, and how to prepare and store foods to keep them safe. Please refer to the NIH handout, “Don’t Let Your Food Make You Sick,” for more information.

At times, because your appetite may be less than usual, or because of possible side effects such as nausea, the foods recommended for you might differ from your usual foods. For example, your dietitian may recommend soups and fruit shakes instead of heavy meals. Foods with less fat, fiber or sugar might be suggested, depending on your symptoms. Your dietitian will try, as much as possible, to choose foods and beverages for your comfort.

### What is the role of my caregiver after BMT?

All BMT patients must have a caregiver with them for a period of time after discharge. Your caregiver is being asked to help you during your BMT by reminding you to do the daily activities described in this information, learning about your care and medications, driving you to and from appointments

at NIH, and supporting you through the process.

We know that you and your family and friends are going through the BMT process together. Encourage your caregiver to get plenty of rest, eat well, get regular activity, take personal time, and ask for help when needed.

### More NIH Information

Your nurse can get these documents for you:

- ▶ Don’t Let Your Food Make You Sick!
- ▶ Graft-Versus-Host Disease
- ▶ Cytomegalovirus Infection
- ▶ Welcome to 1NW (pediatrics)
- ▶ Welcome to 3SE-S (adult outpatient unit)

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National Institutes of Health Clinical Center  
Bethesda, MD 20892

Questions about the Clinical Center?  
<http://www.cc.nih.gov/comments.shtml>

4/10

