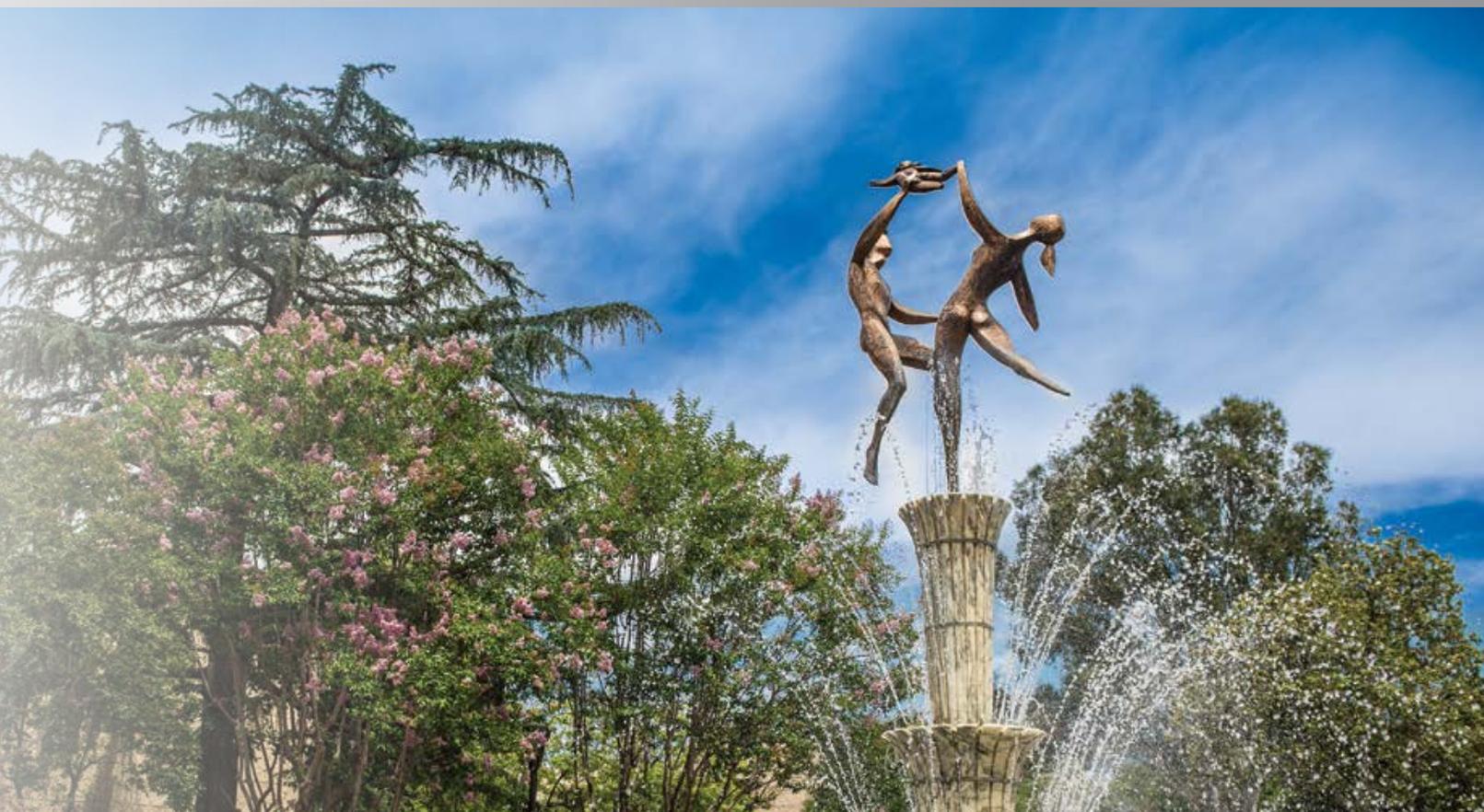


*“This is a great self-care manual
for life after your transplant!”*

— BMT Survivor

CHAPTER 11



Self-care After Discharge

Rehabilitation

Hygiene

Chapter 11

Self-Care After Discharge

The following are general guidelines only. In addition, **there are some differences between discharge instruction for autologous and allogeneic transplant patients.** Please refer to your specific discharge instructions.

When the case manager has received notification of your upcoming discharge, he or she will come to speak with you to confirm pharmacy information, caregiver arrangements, housing arrangements and have you sign the **Important Notice from Medicare and/or the Freedom of Choice** form. The case manager will fax a copy of your newly ordered medications to the pharmacy you have requested and attempt to find out your cost after meeting deductibles.

The day you are discharged from the hospital can be both exciting and frightening. You may feel glad to be leaving the hospital behind you, but frightened as you are losing the “safety net” of hospital staff that have been available to support your medical need. During this period of recovery, we will be there to help you take the first steps out of the hospital and start you back on the road to recovery.

After discharge from the hospital, you will be seen as an outpatient in the clinic, usually twice a week. Special instructions will be given to you upon discharge. You will need to stay in the Los Angeles area for approximately 100 days after transplant for close follow-up.

When you are discharged from the hospital, you will receive more detailed verbal and written discharge instructions. If you do not understand your instructions or have questions about them, we strongly urge you to speak to your nurse, doctor or pharmacist before you are discharged. The following are general guidelines:

Rehabilitation

When you go home, you will probably continue to feel fatigue and weakness for quite some time following your transplant. It will be very important to continue with the plan you established with your rehabilitation team while you were in the hospital. Exercise and activity, done at appropriate levels, are vital to regain your energy and strength.

We encourage you to exercise daily, whether it's taking a walk, spending a few minutes on a stationary bike, working out with your favorite exercise DVD or gentle yoga stretches. Exercise with a friend or make it a family affair. Everyone will benefit and you will develop a healthy routine. Before you know it, you will begin to feel stronger and more energized.

We also recommend that you participate in an activity that engages your mind every day. Just like your body, your brain needs to be challenged to recover from the “chemo fog” you may have experienced. Activities that challenge you, such as logic and math puzzles, memory and concentration games, and problem solving games are tasks that will give your brain a good workout.

Don't forget to have fun! When you get home, it's time to get back to some of your leisure pursuits. Perhaps you learned some new leisure skills when you were in the hospital that you'd like to pursue? Perhaps you made some new friends you'd like to stay in touch with? Perhaps there are people you'd like to catch up with? All of this is important and will help with your recovery.

If you are having difficulty at home, there may be resources available to help you such as home health physical and occupational therapy or outpatient physical and occupational therapy. Please ask your physician for a referral.

Top 10 Things Rehabilitation Services Wants You to Know

1. **Exercise/Activity** are *crucial* parts of the treatment plan and will help you *recover faster*. You will be expected to participate with therapists and *on your own* as instructed.
2. **Activity Check-off List** will be posted on/near the whiteboard in your room to help you and the staff track your progress.
3. **Fatigue** is an expected result of your treatment and *is not* a good reason to refuse/cancel rehab. Exercise/activity has been shown to reduce cancer-related fatigue —even when you don't feel like participating.
4. **Nausea** — If mild, you should attempt therapy prior to, or along with taking anti-nausea medication. Exercise has been shown to reduce side effects of chemotherapy such as nausea.
5. **Sleep** — The therapists will attempt to wake you up for therapy. This has been approved by your physician. Therapy may help regulate your sleep patterns that are often disrupted in the hospital.
6. **Lab values** — If not at critical levels, coordination of transfusion schedule with therapy schedule is important to ensure patients benefit from both.
7. **Shower** — You should attempt to shower daily to maintain your activity level, good personal hygiene and to maintain as much of your normal daily routine as possible.
8. **Clothing** — You should bring clothing (comfortable shoes such as T-shirts, sweats, etc.), make-up, etc., to dress daily to maintain personal routines and to maintain your activity level. Patients should bring shoes appropriate for exercise.
9. **Leisure activity** — You should bring leisure items from home to help cope with unstructured time (games, puzzles, books, tablets, computers, music, crocheting, etc.)
10. **Blood transfusions** — You can receive rehabilitation during blood transfusions if the transfusion has been running for at least 15 minutes.

HCT Weekly Rehabilitation Schedule

HCT PATIENT WEEKLY REHABILITATION SCHEDULE

	Sun.	Mon.	Tues.	Wed.	Thurs.	Fri.	Sat.
Occupational Therapy Plan: <ul style="list-style-type: none"> • Sit up for all meals • Dress in your own clothes: Daily • Shower every day • Engage in 1 activity that challenges short term memory or attention: Daily • Upper Body Exercise: Daily 							
Physical Therapy Plan: <ul style="list-style-type: none"> • Sit up in chair 3x : Daily • Walk 1x around the unit: Daily (if able) • Walk in room ___x (if not able to walk in unit) • Move from sit to stand 10xs: Daily • Lower Body Exercise: Daily 							
Recreation Therapy Plan: <ul style="list-style-type: none"> • Participate in 1 leisure activity: Daily • Socialize with 1 peer or family member: Daily • Attend group ___x per week 							
How many steps have you walked?							

You can walk in the hallways with WBC above 1.0 and ANC above 0.5. Ask your RN for clarification.

No exercise with platelets below 15K.

Self-care and Hygiene

Mouth Care

- You may use tap water to perform your mouth care. Do not use water from a well or spring.
- Brush your teeth after each meal and at bedtime.
- Do not use a regular toothbrush if platelet counts are less than 50,000.
- Use a soft toothbrush if tolerated, otherwise continue with toothettes.
- Any kind of toothpaste is acceptable.
- Avoid mouthwashes, since most contain alcohol and can irritate your mouth.
- Your doctor may want you to continue using antibacterial and antifungal solutions.
- Inform the doctor of any change in your mouth (increased dryness, bleeding or sores).

Bathing

- You may shower. Cover your VAD dressing before showering.
- Remember to change your VAD dressing immediately after showering or if it becomes wet, loose or soiled.
- Use mild soaps and shampoos.
- Avoid medicated or heavily perfumed products.
- Use make-up, aftershave or perfumes in small amounts. If you have a skin reaction, stop using these products.

Skin Care

- Your skin will be sensitive for a while, so apply soaps, cosmetics and perfumes lightly.
- Stay out of direct sun for at least one year. Use a sun protection factor (SPF) greater than 30 daily.
- Wear a hat and long sleeve shirt when outside.
- You may use a gentle skin moisturizer without perfume. Note any rash or blisters and report this to your doctor.
- Note if any skin change occurs after applying a product or eating some food.

Protecting Your Immune System

- **Autologous transplant** patients do not need to wear a mask unless instructed by your doctor.
- **Allogeneic transplant patients** will need to wear a mask for the first 100 days after transplant.
- When you wear a mask it should be a special mask called **N-95**. Wear the mask when you come to the clinic, are around any construction, are driving with two or more persons in the car or are in a crowd.
- Avoid crowds and stay away from anyone who may be sick.
- Your home should be well cleaned before you arrive.
- Do not do house cleaning yourself. Leave the room when cleaning is being done.
- Change air conditioner filters as recommended by the manufacturer.

Pets

Pets can carry disease and your doctor may recommend they be removed from the house for the first three months after stem cell transplant. If you have questions, please speak with your doctor.

- If your pets must stay with you, you should not sleep with the animal and they should not sleep in the same room with you.
- Keep your pets as clean as possible. You may want to have them tested for parasites or toxoplasmosis if there are any concerns.
- Do not clean the cat litter box, bird cage or fish bowl. Have someone else do it.
- Avoid contact with reptiles (e.g., snakes, lizards, turtles or iguanas).
- Always wash your hands after touching your pet.

Immunizations

Approximately one year after transplant your body will be able to develop antibodies to inactivated vaccines. At your one year follow-up evaluation, your doctor may order several vaccines to protect you against dangerous bacteria.

- If children in your family require polio vaccination, they should receive the inactivated Salk parenteral vaccine (given by injection), instead of the live Sabin oral type.
- Avoid contact with people who have been vaccinated with the Sabin oral polio vaccine or yellow fever vaccine for one month.
- Do not receive any live vaccines.
- Always check with your doctor before receiving any vaccines.

Signs and symptoms to report

Please report any of the following signs and symptoms in addition to any other concerns you may have:

- Temperature greater than 100. 5°F. It is important to take your temperature once in the morning and once in the evening and keep a written record. Bring your records to all outpatient visits.
- Persistent cough (Note any sputum production and color.)
- Shortness of breath and/or excessive fatigue.
- Blood in urine, stool or sputum, or bleeding from gums or nose
- Feeling dizzy or light-headed
- Nausea or vomiting not relieved by anti-nausea medications
- Difficulty emptying bladder, burning on urination, constipation or diarrhea

Contact your health care team for any questions or concerns:

Monday through Friday, from 8 a.m. to 4:30 p.m., call (626) 256-HOPE (4673)
After hours and on weekends, call the Nurse Triage Center at (626) 471-7133.

Sexual Activity

Quick Tips:

- Your sexual desire may be decreased following transplant. This is temporary, and normal desire will return.
- Your platelet count may be low, so be gentle.
- Practice cleanliness and “safe” sex. Remember — sex is a function of both the mind and the body. It takes time for both to heal. They do heal!

Men

Due to chemotherapy and/or radiation therapy, your semen occasionally may appear brown or dark orange. This is temporary. You may find it more comfortable to wear a condom. Report any continued brown discharge, pain or any other abnormal finding to your doctor.

Women

Due to chemotherapy and/or radiation therapy, your vagina may not become well lubricated. To prevent trauma to the temporarily dry tissue, we recommend using a water-soluble lubricating jelly. Have your partner wear a condom. Report any pain during intercourse or unusual problems to your doctor.

For more information

The following booklets from the American Cancer Society are available in the Sheri & Les Biller Patient and Family Resource Center:

- *Sexuality for the Woman With Cancer*
- *Sexuality for the Man With Cancer*

For more in-depth information, contact the American Cancer Society at (800) 227-2345. For questions about fertility, such as freezing eggs or sperm before chemo, ask for *Fertility and Women With Cancer* or *Fertility and Men With Cancer*. You can also find information on their website, www.cancer.org.

Mental Health

Everyone experiences some emotional reaction to their illness and transplantation, although every individual experiences them at different times and in different ways. Undergoing blood and marrow stem cell transplantation can have an impact on your thoughts, feelings and relationships.

Many individuals experience feelings of sadness, hopelessness, frustration, anger, anxiety, uncertainty and fear. These feelings may occur in addition to feelings of courage, hope and humor. As a result of this you may at times feel like you are on “an emotional rollercoaster” and feel overwhelmed. Many patients report that the prolonged course of transplant treatment and its unpredictable nature can be emotionally exhausting.

It is important to remember that your body and your mind are not separate — each affects the other. Being aware of and managing your emotions can assist your body in being as healthy as possible.

Social workers, psychologists, dietitians, pharmacists, nurses and doctors all work together on your transplant team to provide you the best care possible.

Suggestions for Patients

- Ask questions as frequently as needed.
- Write down questions and information during your transplant — sometimes your memory can be short and unpredictable.
- Be flexible with the potential ups and down of transplantation.
- Try to focus on what you can do, not on what you cannot do.
- Do the best you can to make each day count.
- Take one day at a time.
- Become familiar with the supportive services available at City of Hope. Your social worker is a good resource and can help connect you with other services such as psychology, psychiatry and Spiritual Care services. To speak with your social worker, call the Department of Clinical Social Work at ext. 62282.
- The Sheri & Les Biller Patient and Family Resource Center is also a good place to go for additional information, education classes, support groups and a variety of other programs. The center is located in the Main Medical building and is available for patients and their families and caregivers.

Taking Your Meds When Back Home

You will be required to take medications following your blood or marrow stem cell transplant. Before you are discharged, your doctor, pharmacist and nurse will answer questions you may have about your medications. However, it may help you to refer to the following guidelines:

- Know the name and dosage of your medications and carefully read the label on all medication containers. If you can't remember all the names, write the name and dosage on a piece of paper and carry it with you in your purse or wallet.
- Know the purpose of your medications, their benefits and the reason for their use.
- Know the possible side effects of your medications. When you are prescribed medications, your doctor or nurse will explain the possible side effects to you and what to do should they occur. It may help to use the "Notes" section in the back of this notebook to document this information for easy future reference.
- Understand the directions. Ask your doctor, pharmacist or nurse to explain directions on the label if you do not understand them.
- Always check with your doctor before you stop taking a prescribed medication or if you miss a dose.
- Do not use aspirin or aspirin-containing products without first checking with your doctor.
- Store your medications properly; avoid areas that are very warm, moist or in direct sunlight.
- Let your doctor know when you are getting low on any medications so refills can be ordered before you run out.
- During your clinic visits, your doctor will review your medications and make any changes in dosages that are necessary.