

# 08

## What to Expect From Discharge and Throughout Your Recovery

It takes about six months to a year before the new bone marrow is fully working and able to make the white blood cells, red blood cells, and platelets your body needs. Remember you now have a new immune system! As time progresses, you will be hitting important milestones in your recovery. It is important you and your caregiver understand what these different milestones mean, and the kind of follow-up care you can start preparing for. Your health care team is on this journey with you. Talk to your health care team about your concerns and questions.

These instructions will be given to you and your caregiver at the time of your transplant. It is important you and your caregiver understand all aspects of your healing and recovery- physical, mental, emotional and spiritual. Your health care team will give you different instructions and education during your hospital stay to prepare you to go home and to know how to continue to follow all instructions for your healing and safety when you are home.

### **My Follow-up Appointments**

Immediately after transplant, you will be seen in the clinic, usually twice a week. You will need to stay within an hour away in traveling time from City of Hope Duarte campus for about 100 days after transplant for close follow-up. There will also be recommended tests and evaluations for six-months and yearly (12+month) appointments. The frequency of your follow-up appointments will depend on your progress through your first-year post-transplant.

During this time, your doctor will be checking for:

- Infections
- Bleeding
- Any sign of graft-versus-host disease
- Your ability to take your medications as prescribed
- Your overall well-being

## PREPARING TO GO HOME CHECKLIST

This is a sample of a general checklist that can be used to help you get started in preparing to go home.

<p><b><u>Preparing your home</u></b></p> <p><b>Cleaning your home:</b></p> <ul style="list-style-type: none"><li><input type="checkbox"/> Carefully vacuum all carpets, furniture and drapes. Shampoo if soiled.</li><li><input type="checkbox"/> Change all air filters and turn off humidifiers.</li><li><input type="checkbox"/> Buy new cleaning supplies (gloves, sponges, wipes) to keep your bathrooms, kitchen clean at all times.</li></ul> <p><b>Pets:</b></p> <ul style="list-style-type: none"><li><input type="checkbox"/> Talk to your doctor about any pets you have at home.</li></ul> <p><b>Visitors:</b></p> <ul style="list-style-type: none"><li><input type="checkbox"/> Remind your visitors to wash their hands and not to visit if they are sick.</li><li><input type="checkbox"/> If you have children: ensure they are clean (showered, clean clothing) before any contact.</li></ul> <p><b>Shopping:</b></p> <ul style="list-style-type: none"><li><input type="checkbox"/> Talk to your case manager, social worker, and nurse about how to prepare your home before your patient comes home. Begin your shopping list:</li></ul> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>	<p><b><u>Grocery shopping list</u></b></p> <p><b>Preparing meals:</b></p> <ul style="list-style-type: none"><li><input type="checkbox"/> Make sure you have antibacterial soap to wash hands before preparing meals.</li><li><input type="checkbox"/> Clean all cutting boards and counter tops.</li><li><input type="checkbox"/> Wash all pots, dishes, utensils with very hot soapy water, rinse very good, and let them air dry.</li><li><input type="checkbox"/> Wash all fresh fruits and vegetables.</li></ul> <p><b>Food safety:</b></p> <ul style="list-style-type: none"><li><input type="checkbox"/> Cook all meats and white meats to safe internal temperatures.</li><li><input type="checkbox"/> Buy only pasteurized cheeses.</li><li><input type="checkbox"/> Buy only pasteurized egg products.</li></ul> <p><b>Shopping:</b></p> <ul style="list-style-type: none"><li><input type="checkbox"/> Talk to your dietician about meal planning. Begin your shopping list:</li></ul> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>	<p><b><u>Daily Precautions and Self-Care</u></b></p> <p><b>Taking your medicines:</b></p> <ul style="list-style-type: none"><li><input type="checkbox"/> Keep track of the names and instructions for each medication. <i>Use a phone application or a medicine diary to keep track.</i></li><li><input type="checkbox"/> Always check with your doctor before you stop taking any medicines.</li><li><input type="checkbox"/> Store all medicines properly, avoid very warm, moist areas.</li></ul> <p><b>Other needs:</b></p> <ul style="list-style-type: none"><li><input type="checkbox"/> _____</li><li><input type="checkbox"/> _____</li><li><input type="checkbox"/> _____</li><li><input type="checkbox"/> _____</li><li><input type="checkbox"/> _____</li><li><input type="checkbox"/> _____</li></ul>
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# Self-Care At Home

## VISITORS

When you return home, many of your friends and family may want to visit you. While their visits are meant to cheer you up, they may also put you at risk for infections. To protect yourself you will need to be very clear with your visitors about how they can keep you safe. Remind them about universal precautions — frequent hand washing, not visiting if they have been sick or exposed to someone who has been sick. Your caregiver can also help by screening guests and making sure that you received guests only when you are feeling well enough to have company.

## PROTECTING YOUR IMMUNE SYSTEM

- Autologous transplant patients will need to wear a mask after transplant as instructed by your doctor.
- Your home should be well cleaned before you arrive.
- Do not do house cleaning yourself. Leave the room when cleaning is being done.
- Avoid crowds and stay away from anyone who may be sick. (malls, parks, retail stores, churches, etc.). Wear masks if you need to go.
- Change air conditioner filters as recommended by the manufacturer.
- You can wear contact lenses but make sure to clean them thoroughly when you put them in. Do not reuse cleaning solution.

## IMMUNIZATIONS - Protecting your Immune System

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 or viruses.

- Do not receive any live vaccines.
- Always check with your doctor before receiving any vaccines.
- If children in your family require polio vaccination, they should receive the inactivated Salk parenteral vaccine (given by shot), instead of the live Sabin given by mouth type.
- Avoid contact with people who have been vaccinated with a “live virus” vaccine, such as MMR, Varicella or FluMist for six weeks (including children living in your house).

## SEXUAL ACTIVITY

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 an act of both the mind and the body. It takes time for both to heal. You are

encouraged to follow these important steps when you resume sexual activities. Talk to your doctor about any concerns or questions you may have about the following information.

- Sexual activities should be avoided until platelet counts are above 50 without transfusions and until absolute neutrophil counts are above 500. If you are not sure, please speak with your doctor before resuming sexual activities.
- Remember you and partner must maintain good mouth hygiene. You should not kiss if you have any mouth sores or bloody gums.
- Shower or wash your hands and genitals before and after sexual activity.
- Use a condom/barrier protection each time you have vaginal, oral or anal sex.
- Use water-soluble lubricant to decrease irritation during sexual activity.
- If possible, urinate before and after intercourse.
- Ask your nurse about helpful online resources and support about sexuality and intimacy after treatment.

## MEDICATIONS

- It is very important that you take your medications as prescribed. Please make sure you understand all instructions.
- Most patients obtain a pill box with several slots for each day to help organize their medications.
- Bring a list of medications and all of your medications with you to all your follow-up appointments. We will review them and make any changes if needed.



# Self-Care and Hygiene

## MOUTH CARE

- You may use tap water to do your mouth care. Do not use water from a well or spring.
- Brush your teeth after each meal and at bedtime.
- Use a soft toothbrush if tolerated, if not continue with toothettes.
- If you wear dentures, keep them clean to prevent infections. Soak them daily in any type of denture cleaner, and following cleaning directions. Your dentures may need refitting after transplant.
- Any kind of toothpaste is acceptable.
- Avoid mouthwashes since most have alcohol and can irritate your mouth. Use a bland rinse.
- 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. Before showering, cover your VAD dressing with an impermeable cover.
- Remember to change your VAD dressing right away after showering or if it becomes wet, loose, or soiled.
- Use mild soaps and shampoos.
- Use make-up, aftershave or perfumes in small amounts. If you have a skin reaction, stop using these products.

## SKIN AND NAIL 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 sunscreen greater than 30 SPF 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.
- You can wear makeup, but buy all new products after your transplant.
- Do not get a manicure or pedicure in a nail salon while your immune system is still recovering. Do your nail care at home with your own tools.

## BLEEDING

**If you have any injury that causes bleeding, stay calm and follow these steps:**

- If you cut yourself, put a clean, dry gauze pad, towel, or cloth over the cut. Press firmly. Keep pressing to apply pressure until the bleeding stops. If the bleeding does not stop, elevate the wound, apply ice and call your doctor.
- If you have a nosebleed, sit up and lean forward slightly. Don't tilt your head back. Squeeze the bridge of your nose firmly between your thumb and forefinger for at least 10 minutes without letting go. If bleeding does not stop, keep squeezing, apply ice, and call your doctor.
- In case of a serious injury, it is important you wear medical alert jewelry at all times. This will help the treating doctor know your condition. If you are admitted to another hospital, ask the doctor to call City of Hope right away for guidelines on the blood products that are best for you.

## ACTIVITIES

- If you are at risk of bleeding, avoid contact sports, weight lifting, moving furniture, bicycling, or skiing. Mild exercise such as walking or use of a stationary bike is encouraged.
- Do not get body piercings or tattoos after your transplant. These activities increase your risk of hepatitis and other infections.
- Do not swim in oceans, lakes, or public pools for one year after your transplant or as long as you have a VAD (vascular access device).

## HOME ENVIRONMENT

- Because your immune system will be very weak during your recovery and up to a year after your transplant, it is important to have a clean home to return to after transplant. You may wish to arrange ahead of time to have your house cleaned. You should not be the one cleaning the house.
- Keep all toilets, showers, counters, sinks and tubs very clean. Use a disinfectant regularly. Bleach or ammonia is recommended. Never mix bleach and ammonia together, this could create a toxic gas.
- Avoid sharing towels, wash cloths, or bed linens with other family members.
- Carpets and rugs should be carefully vacuumed. Carpets with visible soiling need to be shampooed.
- Drapes, blinds and furniture should be cleaned.
- Change filters in air conditioners and furnaces as recommended by the manufacturer.
- Turn off humidifiers.

- Do not remodel your home or do major repairs such as opening any walls or pull up old carpet at this time. This activity can cause mold spores to be released into the air.
- Remove fresh or dried flowers from your home. You may have to remove house plants. Please speak with your doctor.
- Until approved by your doctor or nurse practitioner, avoid working in the yard or garden or being in the area when someone else is doing yard work.

## PETS

- Pets can carry disease. They may put you at greater risk for infection while your immune system is recovering. 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 fishbowl. Have someone else do it.
- Avoid contact with reptiles (e.g., snakes, lizards, turtles or iguanas).
- Always wash your hands after touching your pet.
- Remember it is highly important to always report changes in signs and symptoms.
- Do not go to any petting zoos.

# Where and When to Call for Help

## NURSING TRIAGE CALL CENTER

A registered nurse is available 24 hours a day at the Nursing Triage Call Center to answer City of Hope patients' questions about health problems or self-care issues that may arise. This service is for non-life-threatening situations only. For concerns, call the **Nursing Triage Call Center, 24 hours at (626) 471-7133.**

For questions about a medication refill or renewal, please call the City of Hope pharmacy at **(626) 301-8304** or call the pharmacy where your medication was filled if other than City of Hope.

### When Should I Call the Nursing Triage Call Center?

You should call for urgent but not life-threatening health problems, such as:

- High fever (100.5 F or higher)
- Nausea, vomiting or diarrhea that is not controlled by your medicines
- Uncontrolled pain
- Problems with your central venous access device (e.g., VAD or PICC line)
- Any other health problem where you were told to call City of Hope

You should also call the Nursing Triage Call Center if you have other non-urgent health problems and are not sure what to do or have questions about self-care procedures.

Based on the information you provide; your nurse can answer your questions and make recommendations. If needed, the nurse can call your doctor, instruct you to come to City of Hope or tell you to go to the nearest emergency room. If you wish to speak with your doctor about your concerns or the nurse's recommendations, the nurse will arrange that for you. When calling the Nursing Triage Call Center, please have your medical record number available.

### When Should I Call 911 Instead of the Nursing Triage Call Center?

**DO NOT** call the triage nurse if you have a life-threatening emergency. **Call 911 right away if you have a life-threatening emergency:**

- Severe chest pain
- Difficulty breathing
- Uncontrollable bleeding
- Signs of shock (rapid weak pulse, cold pale clammy skin, confusion, rapid breathing)
- Unconsciousness
- Poisoning
- Serious injuries or burns

If you go to an emergency room, identify yourself as a City of Hope patient.





## Rehabilitation

When you go home, you will likely continue to feel fatigue and weakness for quite some time after 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 right levels, are vital to get back 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 videos or gentle yoga stretches. Exercise with a friend or make it a family affair. Everyone will benefit and you will develop a healthy routine. 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 heal 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 is 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 doctor 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. Work with your OT to establish a routine that allows you to alternate activity and rest.
- 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. Work with your occupational therapist (OT) to establish a routine that allows you to alternate activity and rest.
- 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 are expected to shower daily to maintain your activity level, prevent infections, and maintain as much of your normal daily routine as possible.
- 8. Clothing** — You should bring clothing (such as comfortable shoes 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 PATIENT WEEKLY REHABILITATION ROUTINE

Name:

S	M	T	W	TH	F	S
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Occupational Therapy Plan	Relaxation activity that reduces stress								
	Cognitive activity that stimulates your brain								
	Upper body and breathing exercises								
	Sit up for all meals								
	Shower every day								

Physical Therapy Plan	Sit up in chair three times								
	Walk 1 mile around the unit if able								
	Walk in the room (if not able to walk in halls)								
	Stand up 10 times								
	Lower body exercises								

Activity Plan	Participate in one leisure activity								
	Socialize with one peer or family member								

Laps Walked									
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You can walk in the unit hallways throughout your hospitalization.  
 Ask your OT/PT for clarification on exercises when platelets are below 15.

## Caregiver Support

Throughout your recovery, your caregiver is an important part of your transplant team. Your caregiver will be responsible for helping you to safely recover by monitoring and reporting symptoms to your health care team, managing medications and your daily activities. Your caregiver may also be partnering with you to handle communications with other family and friends to share about your health updates. Throughout this experience, your caregiver will often need support too.

Your caregiver can find education, resources and support at the Sheri & Les Biller Patient and Family Resource Center to help care for their physical, emotional, and spiritual health.

Visit the Biller Patient and Family Resource Center at the Duarte campus or [CityofHope.org/Caregivers](https://www.cityofhope.org/caregivers) to navigate and connect with all the resources available to you.

Available in the center are:

- City of Hope caregiver education, support and resources
- Caregivers Connect, is a support group where caregivers can take time to relax, get support and get to know other caregivers
- A Caregivers Guide: Tips and Tools for Reducing Caregiver Stress
- Disability and Paid Family Leave Resource Hub

You can also visit City of Hope's [HOPEFUL.org](https://www.cityofhope.org/hopeful) to access discussion groups, advice, wellness articles and healthy recipes, as well as to connect with other caregivers.

## Diet and Nutrition After Transplant

Eating the right foods and drinking enough liquids make an important difference in your recovery. Food safety is also especially important for transplant recipients to reduce the risk of foodborne illness. You and your caregiver may ask to meet with a clinical dietitian from City of Hope. The dietitian will instruct you and your caregiver on a diet plan and food safety guidelines. The dietitian also will provide you with information on shopping for food, food preparation and food storage.

### RESPONSIBILITY FOR MEALS

It is the duty of the patient or the patient's caregiver to buy foods and make meals that follow the food safety guidelines. Groceries may be purchased from local markets. Restaurant meals and take-out foods are not recommended.



## PREPARING AND SERVING FOOD

Please refer to these steps:

- Wash your hands before handling any food.
- Clean areas that you will be using to make food, such as cutting boards and countertops. These areas should be cleaned with hot soapy water. As an added precaution, clean cutting boards and counter tops may be cleaned with a weak bleach solution. Use 1 tablespoon unscented liquid chlorine bleach per gallon of water. Allow areas to air dry. Rubber or plastic cutting boards may be run through the dishwasher.
- Wash dishes, pots and utensils with very hot soapy water. Rinse with running hot water. Allow them to air dry. Do not use dish towels to dry them. Can openers can be cleaned in the same way.
- When cooking in a microwave, cover food, stir and rotate for even cooking. Rotate by hand or use a microwave with a turntable during cooking.
- A barbecue grill may be used but must be thoroughly cleaned before use.
- Cook foods to safe temperature. Use a food thermometer to measure the inside temperatures of cooked foods.

## FOOD STORAGE

Cooked foods should not be eaten by the patient if left at room temperature for more than two hours. All leftover foods should be placed in the refrigerator. No leftovers should be consumed if stored longer than two days in the refrigerator or one week in the freezer. Before serving, leftovers should be heated thoroughly.

## FOOD SAFETY

It is important to be mindful of the way you prepare, cook, and store your foods. Below is a list of important tips to keep everyone safe from foodborne illness.

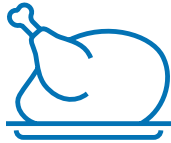
## Essential Food Safety Guidelines



Wash hands, utensils and cutting boards before and after contact with raw food.



Use a thermometer and refer to the temperature chart (below).



Keep raw meat and poultry apart from foods that won't be cooked.



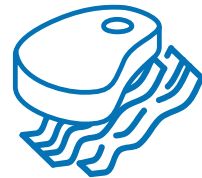
Chill leftovers and takeout foods within two hours and keep the fridge at 40 F or below.

## USDA recommended safe minimum internal temperatures\*

**145 F**

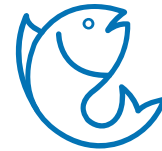
With a three minute rest time

BEEF, PORK, VEAL,  
LAMB, STEAK, ROASTS  
AND CHOPS



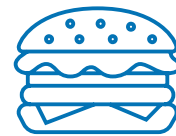
**145 F**

FISH



**160 F**

GROUND BEEF, PORK,  
VEAL AND LAMB



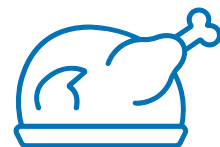
**160 F**

EGG DISHES



**165 F**

TURKEY, CHICKEN AND  
DUCK; WHOLE PIECES  
AND GROUND



\*IsitDoneYet.gov

Type of Food	Foods Allowed	Foods to Avoid
<b>Meat, deli and poultry</b>	<ul style="list-style-type: none"> <li>Meat or poultry cooked to safe minimum internal temperatures</li> <li>Hot dogs, lunch meats or deli meats reheated to steaming hot or 165 F</li> </ul>	<ul style="list-style-type: none"> <li>Raw or undercooked meat or poultry</li> <li>Hot dogs, deli meats or luncheon meats that have not been reheated</li> </ul>
<b>Fish and seafood</b>	<ul style="list-style-type: none"> <li>Previously cooked seafood heated to 165 F</li> <li>Canned fish and seafood</li> <li>Fish cooked to safe minimum internal temperatures</li> </ul>	<ul style="list-style-type: none"> <li>Any raw or undercooked fish, shellfish or food containing raw or undercooked seafood, e.g. sashimi (found in sushi, ceviche, etc.)</li> <li>Refridgerated smoked fish</li> <li>Partially cooked seafood, e.g. shrimp and crab</li> </ul>
<b>Milk</b>	<ul style="list-style-type: none"> <li>Pasteurized milk</li> </ul>	<ul style="list-style-type: none"> <li>Unpasteurized (raw) milk</li> </ul>
<b>Cheese</b>	<ul style="list-style-type: none"> <li>Cheese that is labeled "made from pasteurized milk" such as hard cheeses, processed cheeses, cream cheese, mozzarella and soft cheeses</li> </ul>	<ul style="list-style-type: none"> <li>Soft cheeses made from unpasteurized (raw) milk, such as feta, brie, camembert, blue, queso fresco (Mexican cheese type).</li> </ul>
<b>Eggs</b>	<ul style="list-style-type: none"> <li>At home: use pasteurized eggs/egg products when preparing recipes that call for raw or undercooked eggs</li> <li>All other pasteurized eggs need to be fully cooked</li> <li>When eating out, ask if pasteurized eggs were used</li> </ul>	<ul style="list-style-type: none"> <li>Foods that contain raw or undercooked eggs such as homemade Ceaser salad dressing, raw cookie dough, and egg nog</li> </ul>
<b>Fruits and vegetables</b>	<ul style="list-style-type: none"> <li>Washed fresh fruits and vegetables</li> <li>Cooked sprouts</li> <li>Cooked frozen or canned fruits and vegetables</li> </ul>	<ul style="list-style-type: none"> <li>Raw sprouts (alfalfa, bean or any other sprouts)</li> <li>Unwashed fruits and vegetables</li> <li>Fruits or vegetables that have visible bruising, mold or soft spots</li> </ul>
<b>Pâtés</b>	<ul style="list-style-type: none"> <li>Canned or shelf-stable pâtés or meat spreads</li> </ul>	<ul style="list-style-type: none"> <li>Unpasteurized, refridgerated pâtés or meat spreads</li> </ul>
<b>Honey</b>	<ul style="list-style-type: none"> <li>Honey labeled as "pasteurized"</li> <li>Baked goods, cereals, snacks and other foods containing honey that have been pasteurized</li> <li>Cooked, nonpasteurized honey</li> </ul>	<ul style="list-style-type: none"> <li>Nonpasteurized honey</li> </ul>

## What to Do About Problems Caused by Cancer Treatment

These are some of the problems that may happen because of your cancer treatment. Remember that each person is different. Not everyone will have the same problems and not all these suggestions will work for everyone.

Problems	Suggestions
Bloating (over-full feeling after just a few bites)	<ol style="list-style-type: none"><li>1. Eat small meals often (every two to three hours).</li><li>2. Avoid fatty, fried and greasy foods.</li><li>3. Avoid gas-forming foods (cabbage family and beans).</li><li>4. Avoid carbonated drinks and any foods you usually do not tolerate.</li></ol>
Constipation	<ol style="list-style-type: none"><li>1. Eat high-fiber foods including fruit and vegetables, nuts and seeds, whole grain breads, cereal and bran.</li><li>2. Add bran to your diet slowly.</li><li>3. Drink plenty of fluids (at least eight glasses a day).</li><li>4. A glass of prune juice or hot lemon water taken in the morning may help regularity.</li></ol>
Dehydration	<ol style="list-style-type: none"><li>1. Drink plenty of fluids, including popsicles, broth, juices, etc.</li><li>2. Sports drinks such as Gatorade and Propel can also be helpful.</li></ol>
Diarrhea	<ol style="list-style-type: none"><li>1. Start with broth or a popsicle and slowly add foods low in roughage (steamed rice, applesauce, dry toast or bananas, plain or vanilla yogurt).</li><li>2. Let carbonated beverages lose their fizz before drinking.</li><li>3. Drink plenty of fluids to replace fluids lost.</li><li>4. Avoid fatty, greasy and spicy foods, raw vegetables and fruits, and nuts.</li></ol>
Dry Mouth	<ol style="list-style-type: none"><li>1. Add gravy, sauce or mayonnaise to make solid foods easier to swallow.</li><li>2. A liquid diet may be helpful.</li><li>3. Sucking on hard candy (especially lemon drops) and popsicles, or chewing gum may help to create more saliva.</li></ol>



Problems	Suggestions
Heartburn	<ol style="list-style-type: none"> <li>1. Avoid hot and spicy foods.</li> <li>2. Limit acidic foods such as tomato products and citrus fruits.</li> <li>3. Limit use of garlic and onions.</li> <li>4. Do not lie down for at least one hour after eating.</li> </ol>
Indigestion	<ol style="list-style-type: none"> <li>1. Eat small meals often.</li> <li>2. Avoid eating too much at one time.</li> <li>3. Avoid foods that are greasy or spicy.</li> </ol>
Loss of appetite	<ol style="list-style-type: none"> <li>1. Eat small meals often and snack between meals.</li> <li>2. Choose high-protein, high-calorie foods and try to get one-third of your daily needs at breakfast.</li> <li>3. Increase activity before meals.</li> <li>4. Make mealtimes pleasant, relaxed and unhurried.</li> <li>5. Set an attractive table and use a small plate.</li> <li>6. Choose foods that smell good to you (fresh baked bread, cookies and soup).</li> <li>7. Be creative with desserts and load them with calories (whipped topping, chocolate).</li> <li>8. Choose what you like to eat.</li> <li>9. Try different kinds of food.</li> </ol>
Milk intolerance (drinking milk may cause cramping, bloating and diarrhea)	<ol style="list-style-type: none"> <li>1. Avoid milk and dairy products.</li> <li>2. Use Mocha Mix, Lactaid Milk, soymilk products and other lactose-free products.</li> </ol>
Sore throat	<ol style="list-style-type: none"> <li>1. Eat small meals often, served cold or at room temperature.</li> <li>2. Try bland, soft or liquid foods.</li> <li>3. Avoid citrus, tomatoes, spicy foods, alcohol and vinegar.</li> <li>4. Foods usually well-tolerated are applesauce, cold liquids, cooked cereal, Gatorade, diluted juice, broth, plain pasta and scrambled eggs.</li> </ol>

Problems	Suggestions
Nausea and vomiting	<ol style="list-style-type: none"> <li>1. Eat small meals often.</li> <li>2. If you vomit after the treatment, do not eat until several hours after treatment.</li> <li>3. Eat and drink slowly. Do not force foods if they make you full or sick.</li> <li>4. Rest after eating, but don't lie down for at least one hour.</li> <li>5. Salty foods, soda, crackers, toast, baked potatoes and rice are often well-tolerated.</li> <li>6. Avoid overly sweet, greasy, hot or spicy foods, or foods with strong odors.</li> <li>7. Cold foods have fewer odors and may be more appealing.</li> </ol>
Difficulty swallowing	<ol style="list-style-type: none"> <li>1. Eat small meals often.</li> <li>2. Foods should be soft or cooked until tender.</li> <li>3. Foods and beverages that are thicker usually are easier to swallow than thin liquids.</li> <li>4. Cut foods bite-sized and add gravy or sauces.</li> <li>5. Use high-protein supplements (Ensure, Boost).</li> <li>6. Avoid hard and dry foods (nuts, crackers, popcorn and potato chips).</li> </ol>
Strange taste to your foods	<ol style="list-style-type: none"> <li>1. Try different seasonings and sauces.</li> <li>2. Prepare foods that look and smell good to you.</li> <li>3. Rinse your mouth often.</li> </ol>
Water retention	<ol style="list-style-type: none"> <li>1. Avoid salty foods (potato chips, pickles, soups, ham).</li> <li>2. Do not add salt to your food at the table.</li> </ol>
Weight loss	<ol style="list-style-type: none"> <li>1. Eat small meals often.</li> <li>2. Choose high-protein, high-calorie foods.</li> <li>3. Add extra butter to noodles, rice or vegetables.</li> </ol>

# Mental Health After Treatment

City of Hope supportive care professionals who can help:

- Spiritual counselors (chaplains)
- Psychologist/Psychiatrist
- Clinical social workers
- Grief counselors
- Support groups

## EMOTIONAL CONCERNS AFTER TREATMENT

It is normal to have many different feelings after treatment ends. Just as you need to take care of your body after treatment, you need to take care of your emotions. For many cancer survivors, it is a stressful time filled with new routines to learn, as well as mixed feelings about what they have just gone through. Many people find themselves unsure of how to move forward, wondering, "Now what?" It is common for many cancer survivors to have a complex and often conflicting feelings about their diagnosis, treatment and recovery.

It is normal to feel relieved that treatment is over, yet angry or sad about having gone through such a serious illness. You may also feel anxious and fearful about the cancer coming back or worried that the treatment did not work.

Realizing that life after diagnosis and treatment never really goes back to what it was before cancer. Many survivors find they are not able to return to their old "normal" life but must adapt to a "new normal." It is normal, too, to feel confused about what you have been through and to be concerned about the future. Sometimes these emotions can be overwhelming, interfering with your day-to-day activities and even your health.

**Some common psychological concerns after cancer treatment include the following:**

- Worrying about your health
- Feeling stress
- Depression
- Anger
- Feeling alone
- Guilt

## FEELINGS AFTER TREATMENT

Emotions (stress, anxiety, sadness, frustration) may not always feel pleasant. When directed they can always be helpful. The first step for, all of us, is to understand how we can regulate and direct our emotions. Once you learn to manage your emotions, you will begin to feel less overwhelmed (stressed).

## **SOCIAL CONCERNS AFTER TREATMENT**

Having cancer can change relationships with the people in your life. It is normal to notice changes in the way you relate to family, friends and other people that you are around every day — and the way they relate to you. When treatment ends, families are often not prepared for the fact that recovery takes time. Families also may not realize that their relationships and communications may have changed permanently as a result of cancer. You and your family may need help to deal with the changes and keep the “new” family strong.

Some survivors say they would not have been able to cope without their family members and the help they offered. In addition, even though treatment has ended, they still receive a lot of support. Even though treatment has ended, you may face problems with your family. Problems that were present before the cancer may still exist, or new ones may develop. You may still need to depend on others during this time, even though you want to get back to the role you had in your family before. At the same time, your family may still be adjusting.

## **SPIRITUAL CONCERNS AFTER TREATMENT**

Survivors often express the need to understand what having had cancer means to their lives now. In fact, many find that cancer causes them to look at life in new ways. They may reflect on spirituality, the purpose of life and what they value most. Cancer survivors often report that they look at their faith or spirituality in a new way. For some, their faith may get stronger or seem more vital. Others may question their faith and wonder about the meaning of life or their purpose in it. Many say they have a new focus on the present and try to live each day to the fullest.

Many survivors have found that their faith, religion or sense of spirituality is a source of strength. They say that through their faith they have been able to find meaning in their lives and make sense of their cancer experience. Faith or religion can also be a way for survivors to connect with others in their community who may share similar experiences or outlooks or who can provide support. Studies have also shown that for some religion can be an important part of both coping with and recovering from cancer. It is common to question your beliefs after cancer. These questions can be difficult, but for some, seeking answers and searching for personal meaning in spirituality helps them cope.

Some common spiritual concerns after cancer treatment include the following:

- Finding comfort and meaning
- Finding purpose in life
- Uncertainty
- Positive changes

## TAKING ACTION

### Recognize the signs of emotional distress.

Being exhausted much of the time, not sleeping enough or feeling impatient, irritable or forgetful.

### Take care of your body, mind and spirit.

Some people develop or increase unhealthy habits, such as smoking, drinking too much alcohol or using prescription medicine improperly. If you notice that you are doing these types of things, seek professional help. Meet with an expert such as a psychiatrist, psychologist or clinical social worker. They will listen to your concerns. They can even help you create a plan for how to share your concerns with your partner.

## COPING TIPS

Understanding what your new normal is can take time. Here are some tips that may help:

- Reflect on what you have been through. It is healthy to take time for yourself and to reflect about what matters most in your life.
- Identify changes you might want to make in your life.
- Take time to understand what is your new normal.
- Recognize what you have learned and what is changed about yourself.
- Pray or meditate to help you gain perspective.
- Seek spiritual support.
- Keep an active, healthy lifestyle.
- Join a support group. Talk with others who have had similar experiences.
- Keep a journal and write about your experience and where you want to go in life now.
- Consider medications for anxiety and depression.
- Consider volunteering as a “peer” for cancer patients who are still receiving treatments. Ask your doctor or nurse about programs that you can volunteer for or connect with.







"As a survivor, your attitude helps you adapt and adjust to a new life after transplant."

— BMT Survivor

# Survivorship

- Adapting to the Changes Affecting Your Life After Transplant
- How to Talk About Staying Healthy After Transplant
- Self-Care After Transplant Can Be Different for Everyone



# 09

## Survivorship

The term “cancer survivor” includes anyone who has been diagnosed with cancer, from the time of diagnosis through the rest of his or her life. Family members, friends and caregivers are also part of the survivorship experience. The word “survivor” helps many people think about embracing their lives beyond their illness.

The end of cancer treatment is often a milestone. You are probably relieved to be finished with the demands of treatment and are ready to put the experience behind you. Yet, at the same time, you may feel sad and worried. It is common to be concerned about whether the cancer will come back and what you should do after treatment. When treatment ends, you may expect life to return to the way it was before you were diagnosed with cancer. However, it can take time to recover. You may have permanent scars on your body or you may not be able to do some things you once did easily. Or you may even have emotional scars from going through so much. You may find that others think of you differently now — or you may view yourself in a different way.

While cancer is a major event for all who are diagnosed, it also brings with it the chance for growth. As hard as treatment can be, many cancer survivors have told us that the experience led them to make important changes in their lives. Many say they now take time to appreciate each new day. They also have learned how to take better care of themselves and value how others care for them. Others draw from their experience to become advocates to improve cancer research, treatment and care.

Those who have gone through cancer treatment describe the first few months as a time of change. It is not so much “getting back to normal” as it is finding out what is normal for you now. People often say that life has new meaning or that they look at things differently now. You can also expect things to keep changing as you begin your recovery. Your new “normal” may include making changes in the way you eat, the things you do and your sources of support.

Many cancer survivors have told us that while they felt they had lots of information and support during their illness, once treatment stopped they entered a whole new world — one filled with new questions. Many survivors of cancer and their family members have questions about what to expect. You may have some of the same questions. In this section, we will discuss key concerns that may affect your life after BMT, how to talk about the concerns with your doctor/nurse practitioner, and coping tips that can help you through this time of transition.



At City of Hope, we have many services that are provided to help patients with survivorship concerns. The Sheri & Les Biller Patient and Family Resource Center offers a number of support services, including patient navigators, pain doctors, psychiatrists, psychologists, social workers, chaplains, physical therapists, healing arts workshops, peer support groups, health information, complementary medicine, nutrition education and much more.

## Adapting to the changes affecting your life after transplant

### KEY THINGS TO KNOW

- Once treatment is over, what can you do to stay healthy.
- Understanding and recognizing the challenges that transplant survivors face is an important start to living a healthy life after transplant.
- There is important information and advice about nutrition, physical activity, and dietary supplements that you will need to learn about to help improve your quality of life and survival.
- Cancer rehabilitation helps a person with cancer obtain the best physical, social, psychological and work-related functioning after cancer treatment.
- The goal of rehabilitation is to help a person regain control over many aspects of their lives and remain as independent and productive as possible.
- Rehabilitation can be valuable to those recovering from cancer treatment.

## How to Talk About Staying Healthy After Treatment

As part of your follow-up care, ask your doctor/nurse practitioner about developing a wellness plan that includes ways you can take care of your physical, emotional, social and spiritual needs.

Ask your doctor/nurse practitioner to suggest other members of the health care team for you to talk with such as a social worker, dietitian or physical therapist.

Call your doctor/nurse practitioner if you have any ongoing symptoms, such as pain, fatigue, cough, etc.

## Self-care After Transplant Can Be Different for Everyone

### SUPPORTIVE CARE PROFESSIONALS WHO CAN HELP INCLUDE:

- Physical/Occupational therapist
- Dietitian
- Social worker
- Psychologist

Be aware of what is recommended for your follow-up care after treatment, including your wellness plan.

### STAY AS ACTIVE AS POSSIBLE.

- Maintain a healthy weight.
- Work at your own pace.
- Consult a physical therapist about what types of exercises are best for you.
- Check with your doctor before starting any exercise program.

### MAINTAIN A HEALTHY DIET.

- Try to get all of your nutrients from foods instead of from supplements.
- Check with your doctor regarding any food or diet restrictions.
- Ask your dietitian to help you create a nutritious, balanced eating plan.
- Choose a variety of foods from all the food groups. Try to eat at least five to seven servings a day of fruits and vegetables, including citrus fruits and dark-green and deep-yellow vegetables.

## SLEEP

- Try to practice a regular sleep schedule and keep it up.
- It is important to listen to your body. If you are tired, stop and rest.
- Getting enough sleep will help give you the energy you need for recovery.

Seek counseling from psychologist/psychiatrist, chaplain or social worker if needed. Reduce stress by exercising, meditating and relaxing.

## FINANCIAL AND WORK CONCERNS

Many cancer survivors are able to continue working through and beyond their treatment. Others may have to stop working during treatment and return later. Whether returning to their old jobs or beginning new ones, some survivors are treated unfairly when they return to the workplace. Employers and employees may have doubts about cancer survivors' ability to work. Employers may regard making any special arrangements as a hardship on the business. Research shows that cancer survivors who continue to work are as productive on the job as other workers.

Supportive care professionals who can help include:

- Social workers
- Hospital financial counselors

### Coping Tips:

- Learn about your company's rules and policies related to sick time. It is important to know that there are laws that protect you in the workplace.
- Develop a plan to cope with changing financial needs or daily expenses (e.g., medicines, housing, rent/mortgage, transportation, insurance, groceries).
- Organize a financial record-keeping system.
- Join a support group. Talk with others who have had similar experiences.

## IF YOU HAVE QUESTIONS, PLEASE CONTACT ONE OF THE RESOURCES BELOW.

- City of Hope **(800)826-HOPE (4673)**
- Sheri & Les Biller Patient and Family Resource Center **626-218-CARE (2273)**
- Clinical Social Work **(626)218-2282**
- Spiritual Care Services **(800)826-HOPE (4673)**



“ This guide helped me think about other resources I can access at City of Hope such as visiting the Sheri & Les Biller Patient and Family Resource Center.”

— BMT Survivor

# Resources, Glossary and Terms

- Tips for Finding Information on the Internet
- Internet Resources for Cancer Information
- Glossary and Terms