Chapter 7 - Long-Term Recovery

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“The actual BMT in the hospital was doable, the recovery is the hard part.” BMT survivor
How to Take Care of Yourself in the First Year

“The most important advice I could ever give to someone dealing with life after transplant is: waste no time wishing you could get back exactly to where you were before transplant. Your life will instantly become more fulfilling and enjoyable the moment you stop being, say 70%, of what you used to be and becoming 100% of what you are now!” -BMT Survivor

The long-term recovery phase may take a year or longer. This is the time to reestablish your life after transplant. What does reestablishing your life entail? It means gradually getting back to your life patterns at work, school or at home, and making adjustments in relationships with your family and friends. It may also mean learning to adjust to the therapy needed for chronic or long-term complications. Former patients have noted that the interruption of life plans, the adjustment in relationships and preparing to re-enter work and family life can be difficult adjustments to make. You may experience a sense of loss or discouragement. Some people become involved in the quest for deeper meaning in their lives. You may want to seek therapy to help you cope with chronic health issues and emotional responses to the challenges of treatment and recovery. You may find that you will benefit from counseling to gain tools for coping with issues of chronic illness or feelings of loss, anxiety, stress, worry and depression.

Reestablishing your life may vary from difficult and rough to easy and smooth. During their recovery some patients express a positive view caused by achieving a redirected life, greater compassion for others and improved family relations. The majority of survivors report that their quality of life is now the same or better than before transplant. On the other hand, some patients struggle and become discouraged as they cope with the various life changes. Despite the intensity of the transplant experience, most patients make effective adjustments in their life and maintain an optimistic outlook for the future.

In addition to the information in this manual, you will receive information from doctors and nurses, which will help you manage your care when you leave the clinic. If you wish to continue receiving transplant information, please sign up for the quarterly Long Term Follow Up newsletter that is included in your discharge packet. You can also access this newsletter online at www.fhcrc.org/science/clinical/ltfu, “related content”, “LTFU newsletter”.

Take pride in your journey through an intensive medical treatment, but remember that full strength and fitness will take several more months, or sometimes years, to achieve. Recovery is usually a gradual process. Continue your programs of rest, exercise and good nutrition.
**Transition to Home**

The Long-Term Follow-Up (LTFU) department offers telephone consultation services to you and your primary doctor when you return home. Call your local doctor for everyday concerns. Call your oncologists for treatment related issues. LTFU consultation is available at SCCA if you or your doctor is concerned about transplant-related side effects or complications. It is a real possibility that you may be readmitted to a hospital during your first year after transplant.

**Self-Care Steps**

You can play a proactive role in your own recovery by taking responsibility for the following self-care steps.

**Doctor’s Visits**

These include physical exams, as well as labs and tests (such as blood counts and kidney and liver function tests). Our standard recommendations are:

- Weekly visits for the first month and every other week for the next 2 months. Then go once every 3 to 4 weeks, depending on your progress. Your doctor will help you decide.
- A one year follow-up evaluation is necessary to assess disease status, late complications and to receive vaccinations. Call 206-667-4415 to make your one year follow-up appointment.

**Skin Care**

Note any of the following changes in skin, and report them to your doctor:

- Color changes
- Rash
- Lesions
- Scaly skin
- Texture changes and thickening
- Stiff or tight skin around joints

It is important to protect yourself from UVA (Ultraviolet and UVB Radiation) and UVB rays for two reasons: exposure can cause sun-activated, chronic graft-versus-host disease (GVHD) of the skin and also add to the increased risk of skin cancer. Take the following steps to protect yourself from harmful rays.

Protect your lips with SPF (Sun Protection Factor) 30 ChapStick®

- Use sunscreen: SPF 30 or greater is recommended for everyone, reapply every hour while outdoors
- Wear clothing with SPF protectant manufactured into the fabric such as Columbia®, Solumbra® and ExOfficio®
- Avoid long (over 1 hour) exposure to sun
- Apply sunblock or wear SPF clothing even on cloudy days, as they still result in exposure to ultraviolet radiation.

If dry skin is a problem, it is not necessary to bathe daily.
- Use oil in bath water
- Use lotion
- Try natural soap for sensitive skin

**Nail Care**

You should not have manicure and pedicures if your immune system is still recovering and on antibiotics. You should avoid fake nails, and cutting your cuticles.

Once your ANC (Absolute Neutrophil Count) is greater than 1500, without need for transfusions, and you are off high dose steroid (greater than 1mg/kg,) you can consider a manicure or pedicure. Make sure a single basin is used, and equipment is sterilized between each person. Please check your facility for licenses and state guidelines at: [http://www.dol.wa.gov/about/news/2011/201106NailSalons.html](http://www.dol.wa.gov/about/news/2011/201106NailSalons.html)

**Eye Care**

See your eye doctor (ophthalmologist) for any of the following changes:
- “Gritty” feeling
- Discharge
- Changes in vision
- Continual redness
- Continual dryness without relief from eye drops
- Pain or sensitivity to light
- Sensitivity to wind
- Burning
- Excessive tears

Of the patients who receive total body irradiation pre-transplant, 20% develop cataracts within 1 to 5 years after transplantation. Cataracts are also more common in patients who receive long-term steroids. Cataracts can be removed surgically and the lenses will be replaced. Many patients who develop chronic GVHD will experience eye problems which can be severe. Adequate management of GVHD of the eyes is necessary to avoid severe complications (see chronic GVHD section). Discuss with your eye doctor whether it is appropriate to change the prescription for your glasses. You may wait until you are receiving less medication such as prednisone that can affect eyesight.
Daily Mouth Care
Careful flossing and brushing are very important to maintain your dental health and prevent infections. Continued use of saline rinses can help if your mouth is dry, if you have excessive mucous or if you are being treated for oral fungus. Rinse mouth using ¾ teaspoon table salt in 1 quart of warm water.

Dental Visits
See your dentist 6 months after you return home for an exam to monitor for tooth decay and overall oral care. Routine dental cleaning and dental work should be postponed for at least 12 months after transplant, longer if you are still on an immunosuppressant. Your dentist should also monitor for oral cancer every 6 months. If dental work is necessary and you are still receiving immunosuppressant medication you will need an antibiotic based on recommendations from the American Heart Association. If urgent dental care is needed in the first year or while you are still on drugs that affect your immune system (those that help prevent or treat graft-versus-host disease), you should take oral antibiotics prescribed by your doctor, before dental work is done.

Dry Mouth
See a dentist if you have extreme problems with decay. However, fluoride and excellent oral hygiene can minimize or prevent this. Daily home use of fluoride brush-on gels or custom fluoride trays is recommended. Follow guidelines provided by the Oral Medicine department. Saline rinses or other non-prescription products, such as Biotene®, can help to relieve dryness.

Mouth Changes
Contact your physician for any changes such as ulcers, mucoceles (clear blisters on the soft area of the roof of your mouth or the inside of your lower lip), stinging, burning, dryness, pain, difficulty eating or swallowing, or loose teeth.
Common Symptoms

“The new normal is not a bad normal, just different. Perspective is everything.”
-BMT Survivor

Cognitive Changes
The issue of cognitive changes is receiving more research attention. Cancer causes biochemical changes that are now suspected of contributing to cognitive changes, even before any treatment. High-dose chemotherapy and radiation affect cognitive function. Studies show varying incidences of “chemo brain” among transplant patients. However, research indicates that the decrease in memory, multi-tasking ability and attention which characterize post-treatment cognitive changes resolve for a majority of people after about a year. People can return to their pre-transplant cognitive functioning anywhere from one to five years post-transplant. Some people will continue to have memory or fine motor difficulties. If you are still having difficulties with cognitive changes after one year, ask your doctor for a referral for neuropsychological testing so you know what your deficits are and what you can do about them. Review the symptom sheet in the manual. In the meantime, help your memory by keeping a notebook where you put all the things you want to remember. Make sticky notes about things you do not want to forget, like taking a medication before you go to bed. Put the sticky note by something you always remember, like brushing your teeth. Keep a basket by the door for the things you need to take with you like keys or glasses.

Sleep
Most people have difficulty with sleep at some point during and after transplant. It can be hard to get on a regular cycle of sleep and worry tends to increase as people lie in bed awake. Medication should be a short term solution, not a lifetime aid. Tips that help include keeping the bedroom dark and cool, and going to bed and getting up at the same time each day. Get out of bed and do a relaxing activity like reading if you do not sleep after 30 minutes of trying. Learn relaxation skills that help your body and mind to relax while you are lying in bed.

Depression and Other Feelings

“People are entitled to their feelings. And they’re entitled to them at every stage of treatment and survivorship. We know from the science of emotion that the most harmful way, the most damaging way, to manage emotions is to try to dictate them.”
-Dr. Karen Syrjala (in Surviving Survivor Stereotypes by Curtis Pesmen)
You may continue to experience significant distress following your transplant. Sometimes, this can lead to feelings of sadness or depression and associated symptoms such as worry, anger, and fatigue. Distress can also lead to changes in sleep and eating patterns. Even post-traumatic stress can happen. We recommend making time and saving energy to participate in activities that you enjoy, so life is not entirely about your health. Spend time with friends and family. If these symptoms continue for more than a couple of weeks, it is important to discuss them with your doctor or nurse. Some people find that talking to a therapist after transplant is very helpful. There is so much that most people have been through and have to cope with after treatment. Talking with a therapist can help you reclaim your life and make sense of what you have gone through.

Fatigue, Weight and Exercise

“Some problems such as fatigue can begin during therapy and may continue indefinitely, though the duration and severity differs greatly between individuals.”
- Rabiya Tuma, PhD, Treatment Aftershocks

Many people report increased fatigue after transplant. Exercise is an effective way to decrease this fatigue over time. We recommend a program of daily moderate exercise, such as walking. Increase the distance and pace as your strength and stamina increase. It is also important to rebuild muscle through a program of gradually increasing weight training. Couple this with stretching, yoga and/or gentle fitness classes. See if a YMCA near you has a low cost cancer survivorship program, or ask for a physical therapy referral to get an exercise plan from someone who has experience with exercise after cancer treatment. If you exercise at a moderate level and have rebuilt muscle, but your fatigue continues or if your fatigue increases, talk to your doctor about other possible causes of fatigue. The best exercise is the one that you do regularly! Follow the advice of the nutrition staff. Eat healthy foods.

Osteoporosis for Allogeneic Transplant Recipients

Osteoporosis or bone loss may happen in some patients. It is related to irradiation, use of steroids, inactivity and low hormone levels. Weight bearing exercise is recommended to help prevent or stabilize osteoporosis. You may need calcium and vitamin D supplements, or bone rebuilding medications. You can discuss this with your local physician.
Immune System Recovery

Adequate immune function takes approximately 1 year after transplantation to recover. Adequate immune function may take longer if you have chronic GVHD or are taking medications that suppress your immune system. During this time you are still vulnerable to infections. Symptoms such as fever, chills, coughing, difficulty breathing, severe diarrhea or vomiting should be promptly reported to your doctor.

Cytomegalovirus (CMV) Monitoring
You may need weekly CMV monitoring after treatment. At discharge you will receive specific recommendations to take to your local doctor.

Exposure to Others
Avoid crowds, especially during cold and flu season. Avoid people with a contagious infection. Please contact your healthcare provider if you are exposed to chicken pox or shingles.

Hand Washing
Continue to be as careful about hand washing as you have been throughout the transplant process. Perform hand hygiene frequently by washing your hands with soap and water or applying an alcohol-based hand sanitizer that contains 60-85% alcohol.

Ask family and friends to wash their hands or use hand sanitizer when they come into your home. Wear disposable gloves if you must change a diaper. Wash hands after disposing of gloves.

Temperature
Take your temperature if you are feeling ill, shaking chills or suspect that you have a fever. Note time and circumstances. Notify your doctor promptly if you have a temperature of 100.9° F or 38.3° C or more.

Rash
Notify your doctor promptly if any rash develops.

Animals and Plants
Avoid contact with body excretions of all animals and do not sleep with pets. Do not bring new pets into the home during the first year or thereafter, if you are taking immunosuppressant medications. Established household pets and plants may remain in the home. Gardening is not recommended while on drugs that suppress the immune system.
Sexual Activity
Limiting the number of sexual partners is advised. Use condoms for protection against Sexually Transmitted Infections (STI). Normal cleanliness should be observed. Use birth control as necessary to prevent pregnancy, as you may not be sterile. Discuss with your doctor and nurse. If dryness is a problem, a lubricant may be helpful. Drugs used for impotence should be avoided while you are on an immunosuppressant, and should not be used without a cardiac evaluation.

Swimming
Swimming may expose you to microorganisms capable of causing infections. You should measure the benefits of swimming against the potential risks of these infections. If swimming or water aerobics is the preferred or recommended method of exercise, it should be done in a well-maintained pool with adequate chlorination. Your face should not be submerged under the water. Never swim with a central line in place. Also, do not swim for the first 6 months after the transplant or if on drugs that treat GVHD within the first year. Hot tubs should not be used for the first 6 months after transplant or if you are on drugs that treat GVHD.

Travel
Take extra medications with you when you travel and consider where you could receive the treatment you need if you became ill. Move around during flight or transit time to prevent blood clots that could lead to a major lung problem.

Many patients travel home within the first 6 months after transplant. As with any activity involving risk, weigh the specifics of your situation. To minimize risks when traveling:
Take a copy of critical medical records with you.
- Seek medical care promptly for new symptoms.
- Control your environment by avoiding crowds and maintaining infection precautions.
- If you fly, ask to be moved if you are seated near someone with respiratory symptoms. Carry hand sanitizer and wipes.

Other Reminders
- Minimize exposure to dirt and aerosolized material
- Minimize sun exposure, use sunscreen (SPF greater than 30)
- Use hat, long-sleeve shirts and long pants if outside for long period of time
- Avoid construction sites
- Avoid contact with people that:
  - Have cold and flu symptoms like coughing and sneezing.
  - Display symptoms of other types of infections such as vomiting or skin rashes.
Immunizations

Patients generally receive post-transplant immunizations starting at one year. These killed-virus and killed-bacterial immunizations include:

- Tetanus
- Diphtheria
- Pertussis
- Meningococcal
- Inactivated polio
- Influenza
- Pneumonia
- Haemophilus influenza type B
- Hepatitis B
- Hepatitis A
- HPV (ages 9-26)

If you do not return for your 1-year follow up, ask your doctor to contact the Long-Term Follow-Up Department about immunizations. If a household member receives the Varicella (chickenpox) vaccine, you should be taking acyclovir. If a household member develops lesions (or pox), you need to be isolated while their lesions are present.
Graft-Versus-Host Disease (GVHD)

One form of GVHD which may occur around day 80 or later is called chronic graft-versus-host disease. Approximately 50% of patients who receive allogeneic transplants are diagnosed with chronic GVHD, with some variation in the incidence related to characteristics of the donor and the source of the stem cells. GVHD can affect any organ. Unfortunately, 15% of the patients develop a severe chronic GVHD that goes on for many years and may lead to disability. The range of medical issues caused by GVHD can be mild to severe.

You might notice your skin becoming dry, scaly and discolored with patches of thickened or hardened underlying tissue. The surface of the eyes and mouth can become dry. Mouth lesions may develop. Sometimes the esophagus, gastrointestinal tract or liver are affected. Weight loss due to poor absorption of food or GVHD increased catabolism (burning more calories despite adequate eating) can occur. Bacterial infections are common. Treatment protocols have been developed for GVHD and the Long-Term Follow-up team is available to you and your doctor if you develop symptoms after going home. Having GVHD may not be all bad. It has been found that patients with GVHD have a lower risk of the cancer returning after transplantation than patients who do not develop GVHD.

Report any of the following changes to your doctor. Make sure your doctor is watching for possible changes in your liver and kidney function test results as well.

- **Skin:** Rash, thickness, discoloration, tightness, texture changes, shining, itching
- **Hair:** Thinning or coarse
- **Nails:** Texture changes, brittleness, ridges
- **Eyes:** Dryness, grittiness, irritation, burning, blurring, discharge, tears, sensitivity to light or wind
- **Mouth:** Dryness, pain, sensitivity to hot/cold foods or toothpaste, ulcers, white lacy changes on gums and cheeks
- **Vagina:** Dryness, irritation, tightening
- **Penis:** Irritation
- **Digestive System:** Nausea, vomiting, diarrhea, loss of appetite, unexplained weight loss
- **Lungs:** Chronic dry cough, wheezing, shortness of breath
- **Liver:** Jaundice and elevated liver test numbers
- **Joints:** Unable to fully extend fingers, wrists, elbows, ankles or knees, joint pain, or stiffness
- **Energy Level:** Increased fatigue
- **Temperature sensitivity:** Cold intolerance, inability to sweat
Treatment of GVHD
The median duration for treatment of chronic GVHD with immunosuppressants (therapies that suppress the immune system such as prednisone, tacrolimus, cyclosporine, sirolimus, mycophenolate mofetil, etc. varies between 2 to 3 years after the initial diagnosis of this complication. Approximately 10% of patients require 7 years or more treatment for chronic GVHD. Eventually the graft will develop tolerance to the new body and the GVHD will resolve without the need of treatment.

Therapies most commonly used for chronic GVHD are prednisone, cyclosporine, tacrolimus, rapamycin, mycophenolate mofetil, and others. All immunosuppressive drugs have some side effects. The most common toxicities of drugs used for the treatment of GVHD are listed below.

- **Prednisone**: Osteoporosis, deterioration of joints that can require joint replacement, increased risk of infections, diabetes, cataracts and emotional variance, changes in body habitus (weight gain, moon face).
- **Cyclosporine (Neoral®)**: Kidney function issues, wasting of magnesium, tremors, headaches, seizures, nausea, increased blood pressure.
- **Tacrolimus (Prograf®)**: Similar to cyclosporine.
- **Mycophenolate mofetil (MMF or Cellcept®)**: Nausea, vomiting, diarrhea, bleeding, decreasing white blood cells count, anemia.
- **Rapamycin, Sirolimus (Rapamune®)**: Decreased white cells or platelets, increased triglyceride level, edema, and others.

Despite the side effects of medications used to treat chronic GVHD, adherence to the treatment schedules and doses is of the utmost importance in the long term. Damage from untreated or undertreated chronic GVHD to the eyes, lungs and skin cannot be reversed. It is worse than the side effects of the medications used to treat it.
Medications

Your medications are important to help you maintain your general health. Please take them as prescribed.

- **Bactrim® (sulfamethoxazole-trimethoprim):** This is a broad spectrum antibiotic specifically for the prevention of pneumocystis pneumonia and for prevention of certain types of bacterial infections (Streptococcus pneumonia and Haemophilus influenza).
  - Take this medication if prescribed for at least 6 months after transplant, or longer if continued on immunesuppression medications.
  - Always take Bactrim® (or an alternate drug) when taking immunesuppression medications.
  - If on tapering doses of immunesuppression medications, take Bactrim® until 6 months after treatment of chronic GVHD.

- **Acyclovir or Valacyclovir:** These drugs are antiviral agents used to prevent varicella zoster (shingles). If one of these is prescribed, it should be taken for the entire first year, and should be given concurrently while on immunesuppression and for six months after completion of taper.

- **Hormones:** Hormones may be prescribed for women in premature menopause due to the effects of conditioning therapy.

- **Immunosuppression:** Keep accurate records of dates when stopping or restarting imunosuppressive medications (prednisone, cyclosporine, MMF, tacrolimus, rapamycin). Imunosuppressive medications may require your blood levels to be checked.
Secondary Cancers

There is an increased risk of getting a different cancer in long term survivors after transplantation. The risk starts to increase at 5 years after transplantation. Skin, mouth, thyroid and breast are the most common sites of secondary cancers after transplant. Cancer screening evaluation is recommended and includes: complete skin examination, oral exams, breast examination and mammograms (woman), prostate examination (men), colonoscopy (according to age and history), and others as applicable. Original disease restaging is also recommended at periodic intervals depending on the diagnosis. For patients transplanted for CML or acute lymphocytic leukemia PH+, blood monitoring for the BCR/ABL by PCR test is recommended periodically.
Reconnecting with Life and Survivorship

“This has been five years that I wouldn’t wish on my worst enemy, but strangely enough, wouldn’t trade for the world.”

-BMT Survivor

It is normal to feel vulnerable after returning home. These feelings are valid, but don’t push the panic button every time someone sneezes! It’s important for you to see your friends and return to normal activities too. Just use common sense -- “when in doubt, don’t.” Some patients, especially those who had a stormy transplant course, find it hard to plan for the future. Make a specific detailed plan for something you want to do. This helps you to feel like you are moving toward something, not just marking time while you recover.

Helpful Hints to Remember

- It is healthy to find a “silver lining” in your situation. It doesn’t mean that you forget the clouds, it’s just that the clouds are not the whole story.
- You are your own best friend. Take care of yourself. Get enough rest, exercise and good nutrition. Be patient with yourself and others.
- Watch for changes in your body, hair, nails, eyes, skin, mouth and joints. Tell your doctor of any changes.
- Try to take one day at a time; focus on your goals for today, particularly after you first return home. Make sure you include something you enjoy in each day.
- It is normal to feel alone at times; it’s true that no one else has been down your road and really knows what it is like for you. Make it a goal to connect with people and do activities you enjoy so that you start to feel like part of your community, even if at first you don’t feel like it.
- Remember that your caregiver and family have also been through a major challenge. Check in with them weekly to let each person describe what they are experiencing. You don’t need to fix each other’s’ concerns; just use this as a time to listen and reflect upon what each person is feeling. Ask if there is anything that would make things better.
- Do not be afraid to ask for professional guidance; you deserve it! Almost everyone receives some kind of help.
- Check with your employer to see if you have access to an Employee Assistance Program (EAP).
- SCCA suggests that you return 1 year following your transplant for re-evaluation.
Relationships
It may be difficult to resume old relationships as they were before your BMT because your experience has changed your perspective on life. Your illness may have affected the feelings and perspectives of the people around you and it may have produced role changes that can affect relationships. People report that these changes can be very positive, but they also can take some time to sort out. Make sure each person in your family has a chance to describe their fears and concerns. Even if it is hard, try to give each person a chance to describe what is going on in their lives and in their thoughts. Caregiver partners may be accustomed to taking care of you and home tasks. Expect that these role changes can take some time to get back to normal. You can help them along by discussing a weekly plan for who will do what. As you are ready to take on more responsibilities, you can make this clear to your caregiver. With friends, it might help to discuss your views of what is different in your life and how much the person’s friendship still means to you. Sometimes you may have to reach out to friends rather than waiting for them to come to you.

Returning to Work or School
Returning to work and/or school is very complicated. You need to be ready both physically and emotionally. We suggest that you wait 6-12 months after transplant to return to work or school, but home tutoring or work in a home office can precede these dates. You may be eligible for social security benefits because of your inadequate immune system. This will be the case for at least 1 year and possibly longer if you are on immunosuppressive medication for GVHD. There are many organizations that assist cancer and transplant survivors with employment issues. For more information on your employment rights, see the Resources section at the end of this chapter.

The Department of Vocational Rehabilitation offers counseling to people who have an emotional or physical disability. Some people are even eligible for social security. See resources below for additional information:

- Department of Vocational Rehabilitation [www.dshs.wa.gov/dvr/](http://www.dshs.wa.gov/dvr/)
- Americans with Disability Act [www.ada.gov/](http://www.ada.gov/)
- Cancer and Careers [www.cancerandcareers.org](http://www.cancerandcareers.org)

Financial Concerns
Many people report insurance and financial concerns. We recommend that you look into social security and private disability insurance. Look online and at the Resources at the end of this chapter for more information on BMT financial concerns.

Young Adults
The road to independence and maturity is more difficult for young adults who have been ill. Feelings may fluctuate, sometimes viewing parents as being overly concerned and involved, and at other times feeling insecure and wanting more parental guidance and reassurance.
Many young adults report that starting to date and sexual activity can be times of uncertainty. An excellent resource for young adults experiencing this is [www.planet-cancer.org](http://www.planet-cancer.org).

**Sexuality**

“Nobody wants to talk about it. It becomes a self-propelling problem, in that, the longer time goes by, people then also become kind of less connected with that part of themselves.”

-Sharon Bober, PhD

Most men and women notice a drop in sexual desire during the first year. Make time for intimacy so that you begin to re-awaken those feelings. You may have a low energy level or feel unattractive due to the changes that your body has undergone. Partners often hesitate to make sexual advances out of concern for your health. Women can have vaginal changes and men may have erection problems. Medications can be the cause of some of these changes; problems may disappear over time or after stopping the drugs. Hormones can change for men and women after transplant. For men, it often takes a full year for testosterone levels to return to normal, affecting both erections and desire. It’s important for both partners to talk about their feelings and to be patient with one another. Begin to set aside “date” time to be romantic, include touching in your intimate time together. Start trying sexual activity even if your desire is not back to its previous level. If dryness or irritation is a problem, a silicone-based lubricant can be helpful. Water-based lubricants are also safe, but won’t last as long. If graft versus host disease or sensitivity is a problem, ask to see a sexuality-after-cancer specialist or look online at BMT websites on sexuality to learn more about what can be done for these problems. After cardiac evaluation, drugs used for erectile problems can be helpful for some men.

**Survivor Syndrome**

“Little studied, survivor guilt brings with it a host of issues that can cause depression, anger and self-blame that may even compromise health.” Kathy Latour, *Getting Through Survivor Guilt*

You may have feelings of guilt because you are alive when others did not survive. You may also have a strong sense of grief and loss. Even though you are glad to be alive, it is normal to feel that you have lost things that you will never again be able to regain. Discussion with a counselor, minister, priest or rabbi can help put this in perspective. If you aren’t sure what you want to do with yourself, or feel like you want a change, give yourself time to recover while you discover what you most want to do. Some people re-evaluate what they want to do for the rest of their life. Having survived this adventure, you might decide to try another new one!
Survivorship Clinic
Cancer and its treatment can result in some potentially long-lasting or late-onset effects. The SCCA Survivorship Clinic addresses various problems cancer survivors may face after therapy ends. These include pain, fatigue, and fear of recurrence, living with uncertainty, neuropathy, lymphedema, bone loss, sexual dysfunction, cardiovascular disease, memory issues, and future cancer risk.

At the survivorship clinic, our medical staff will talk with you about how to assess and manage late complications or issues you may be experiencing, and develop a plan to support your future health.

As part of your appointment in the Survivorship Clinic you will receive an individualized Treatment Summary and Survivorship Care Plan. This includes an evaluation and information on the prevention of the late effects of your cancer and cancer treatment, recommendations and resources for dealing with long-term effects, and suggestions for healthy lifestyle behaviors. Copies of the treatment summary, survivorship care plan, and any recommendations made during the appointment are shared with your health care team, including your oncologist and primary care provider. We will work in partnership with these providers to make sure your survivorship needs are being met. We do not provide testing for recurrence of your cancer; this care will continue to be provided by your oncologist.
To schedule an appointment in the SCCA Survivorship Clinic please call (206) 288-1024. Visit the Survivorship Clinic website at www.fhcrc.org/survivorship.

Transitional Transplant Clinic (TTC) is a clinic for patients with complex conditions such as GVHD that is not well controlled, serious infections, or other complex conditions that require extensive ongoing management. Talk with your nurse if this is right for you.
Sample Letter for Returning Home

To my family and friends:

I am recovering from a Blood or Marrow Transplant (BMT). I am able to return home, but my recovery from this procedure can take months. Here is a list of things you should know about my recovery:

My Risk for Infection Continues: It will take at least ____ months for my immune system to recover. It's possible that it could take even longer, depending on what medications I will need or what complications might arise. I am at a higher risk for infection and will need to pick activities that minimize my risk of infection.

Hand Washing Etiquette: Hand washing is the most effective way to prevent infection from spreading. I was taught to wash my hands frequently. My family, friends and visitors will be asked to do the same when in my company. Please don’t be offended if I remind you to wash your hands.

Time to Eat: I have to follow a special diet while my immune system recovers. If you wish to help by providing meals, I would be happy to give you a list of what I can and cannot eat.

Fatigue: I will have both good and bad days. I would like to see you; however, short visits will be better for me. Some days I might not be up for long conversations or involved activities. Exercise can help with fatigue. I might ask you to join me on a walk.

Memory and Concentration: The treatment and medications I take can affect my memory and ability to concentrate. Don’t be surprised if I forget something you tell me. I expect this to improve as I recover.

My Caregiver: _________ had a lot of responsibility while we were away from home. Now that we are home, _________ will still have caregiver responsibilities along with all the usual home and work routines. If you would like to help, here is a list of suggestions:

- Drive me to and from appointments.
- Run errands for my caregiver or visit with me so my caregiver can have a break.
- Take my children out for an activity.
- Help with household chores and/or yard work.
- Remember my caregiver with a phone call or offer to do something fun.
- Join me for a walk!
- Walk the dog.

Please remember, all of your help and phone calls are appreciated as I move forward with my post-transplant life! The support of family and friends is an integral part of this transition. Thank you so much for your support.

Sincerely,
Resources and Websites

Blood and Marrow Transplant Information Network
www.bmtinfonet.org/

Bone Marrow Transplant Forum, BMT-TALK
To subscribe to the mailing list, send an email to listserv@listserv.acor.org, write only “SUBSCRIBE BMT-TALK” in the message body along with your first and last name.

Center for International Blood & Marrow Transplant Research
Recommended Tests and Procedures

Emotional Support for Transplant Patients Cancer Survivors Network
http://csn.cancer.org/

Employment Rights Cancer and the Americans with Disabilities Act
www.eeoc.gov/facts/cancer.html

The Job Accommodation Network
http://askjan.org

Fair Employment for Cancer Patients and Survivors
http://csn.cancer.org/node/161348

Fertility
Resolve Support Group for infertile couples:
www.resolve.org

Help with Post-Transplant Medication Costs Patient Access Network Foundation
http://www.panfoundation.org/
Hospitals and Clinics

Seattle Cancer Care Alliance
www.seattlecca.org

Fred Hutchinson Cancer Research Center
www.fhcrc.org

University of Washington Medical Center
www.uwmedicine.org/patient-care/locations/uwmc/Pages/default.aspx

Seattle Children’s
www.seattlechilddrens.org

Insurance and Employment Rights
www.canceradvocacynow.org

National Bone Marrow Transport Link
www.nbmtlink.org/resources_support/support.htm

National Marrow Donor Program
http://marrow.org/Physicians/Post-Transplant_Care/Post-Transplant_Care.aspx
Search Post-Transplant Care

National Organizations

National Cancer Institute

National LGBT Cancer Network
www.cancer-network.org/

American Cancer Society
www.cancer.org

National Coalition for Cancer Survivorship
www.canceradvocacy.org
Men’s Health
www.menshealthnetwork.org

Pediatric

American Childhood Cancer Organization
www.acco.org

Children’s Oncology Group
www.survivorshipguidelines.org

Human Growth Foundation
hgfound.org

Skin Care

Skin Cancer
www.skincancer.org

Sun Safety
www.fda.gov, search “Sun Safety”

Sun Precautions Clothing
www.sunprecautions.com or Phone number 1-800-882-7860

Women’s Health
North American Menopause Society
www.menopause.org

National Women’s Health Network
http://nwhn.org/

Health Insurance Pamphlet ACS

Young Adult
http://myplanet.planetcancer.org/
The Long-Term Follow-Up Department
Please contact your local doctor for medical needs or emergencies. If you have transplant-related questions that your doctor is unable to answer, or to schedule your long-term follow-up appointment, leave a voice mail message and one of the long-term follow-up staff members will return your call. Please leave the spelling of your name in addition to your question. We will attempt to return your call within 24 to 48 hours during weekdays. Your call will be reviewed and an experienced transplant nurse will return your call within 24-48 hours.

Long-Term Follow-Up Physician Program Guidelines:
http://www.fhcrc.org/content/dam/public/Treatment-Support/Long-Term-Follow-Up/physician_guidelines.pdf

FHCRC Long Term Follow Up:
www.fhcrc.org/ltfu
Click on “Information for Patients” in the left hand navigation column.

Long-Term Follow-up Post-Transplant Screening and Preventive Practices:
http://asbmt.org/displaycommon.cfm?an=4

Contact Information for LTFU
Phone number: (206) 667-4415
Toll Free Fax: (206) 376-8197
Fax: (206) 667-5619
Email: LTFU@seattlecca.org
## Common Infection Control Questions

<table>
<thead>
<tr>
<th>Questions Often Asked</th>
<th>Time after Transplant</th>
</tr>
</thead>
<tbody>
<tr>
<td>The general guidelines below may not apply to your case. You must discuss with your physician to assess if these rules apply to you. Pediatric patients: Discuss with your physician when restrictions may continue to apply to your child’s care after one year post transplant.</td>
<td>All Patients</td>
</tr>
<tr>
<td>School</td>
<td>No</td>
</tr>
<tr>
<td>Hot tubs (avoid all public hot tubs) (6)</td>
<td>No</td>
</tr>
<tr>
<td>Swimming (1) (without venous catheter device, avoid head submersion &amp; diving, use sun screen)</td>
<td>No</td>
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<tr>
<td>Gardening (digging in soil); mowing the lawn; raking leaves</td>
<td>No</td>
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<tr>
<td>Having plants in the home (not handling) (4)</td>
<td>Ok</td>
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<tr>
<td>Making/kneading yeast breads (5)</td>
<td>No</td>
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<tr>
<td>Carpenter work</td>
<td>No</td>
</tr>
<tr>
<td>Occasional woodworking (sawdust)</td>
<td>No</td>
</tr>
<tr>
<td>Animals, Birds, Reptiles, Fish, Other</td>
<td>Ok</td>
</tr>
<tr>
<td>Cats/dogs (not sleeping with pets, no feeding pets, no bathing or grooming pets)</td>
<td>Ok</td>
</tr>
<tr>
<td>New pets in patient’s household</td>
<td>No</td>
</tr>
<tr>
<td>Cleaning feces, litter boxes, utensils, or cages/tanks, etc.</td>
<td>No</td>
</tr>
<tr>
<td>Domestic birds (parakeets, parrots, etc) (not with respiratory problems)</td>
<td>No</td>
</tr>
<tr>
<td>Poultry &amp; wild birds (pigeons, baby chicks, chickens, ducks, geese, other wild birds, etc)</td>
<td>No</td>
</tr>
</tbody>
</table>
The general guidelines below may not apply to your case. You must discuss with your physician to assess if these rules apply to you. Pediatric patients: Discuss with your physician when restrictions may continue to apply to your child’s care after one year post transplant.

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<thead>
<tr>
<th>Questions Often Asked</th>
<th>Time after Transplant</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>All Patients</td>
</tr>
<tr>
<td></td>
<td>Not Receiving Immuno-</td>
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<tr>
<td></td>
<td>suppression to 1 year</td>
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<tr>
<td></td>
<td>Receiving Immuno-</td>
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<tr>
<td></td>
<td>suppression to 1 year</td>
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<tr>
<td></td>
<td>Receiving Immuno-</td>
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<tr>
<td></td>
<td>suppression More than 1</td>
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<tr>
<td></td>
<td>year</td>
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<tr>
<td>Small cage rodents (gerbils, rabbits, hamsters, guinea pigs, hedge hogs, prairie dogs, etc) (Do not handle)</td>
<td>No</td>
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<tr>
<td></td>
<td>Ok</td>
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<tr>
<td></td>
<td>Ok</td>
</tr>
<tr>
<td></td>
<td>Ok</td>
</tr>
<tr>
<td>Reptiles and amphibians (snakes, turtles, frogs, lizards, iguanas, etc); ferrets</td>
<td>No</td>
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<td>No</td>
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<td></td>
<td>No</td>
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<td></td>
<td>No</td>
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<tr>
<td>Farm animals (pigs, horses, cows, llamas, etc) (Do not handle; stay out of barns full of hay)</td>
<td>No</td>
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<tr>
<td></td>
<td>Ok</td>
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<tr>
<td></td>
<td>Ok</td>
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<tr>
<td></td>
<td>Ok</td>
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<tr>
<td>Wild &amp; game animals (deer, elk, squirrels, bear, etc) (exotic animals, i.e., monkeys, etc) (Do not handle)</td>
<td>No</td>
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<td></td>
<td>No</td>
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<td></td>
<td>No</td>
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<td></td>
<td>No</td>
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<tr>
<td>Zoos &amp; petting zoos</td>
<td>No</td>
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<td></td>
<td>No</td>
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<td></td>
<td>No</td>
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<td></td>
<td>No</td>
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<tr>
<td>Public aquariums (3) (do not touch marine life in handling tanks)</td>
<td>No</td>
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<td></td>
<td>Ok (3)</td>
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<td></td>
<td>Ok (3)</td>
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<td>Ok (3)</td>
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<td>Animal trophy mounts in the house</td>
<td>Ok</td>
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<td></td>
<td>Ok</td>
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<td></td>
<td>Ok</td>
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<tr>
<td>Fishing (fresh &amp; salt water) (OK to handle fish if wearing gloves; do not bait hooks)</td>
<td>Ok</td>
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<td>Ok</td>
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<td></td>
<td>Ok</td>
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<tr>
<td>Hunting (wild game and birds) and sport shooting (2) (Wear latex gloves when handling game; do not clean game; without venous catheter device)</td>
<td>No</td>
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<td>Ok (2)</td>
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<td>Ok(2)</td>
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<td>Ok(2)</td>
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<tr>
<td>Horseback riding (Stay out of barns full of hay)</td>
<td>No</td>
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<td></td>
<td>Ok</td>
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<td></td>
<td>Ok</td>
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<td></td>
<td>Ok</td>
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<tr>
<td>Golfing (2) (sun protection required; without venous catheter device)</td>
<td>No</td>
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<tr>
<td></td>
<td>Ok</td>
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<td>Ok</td>
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<td></td>
<td>Ok</td>
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<tr>
<td>Spectator events and crowds (3) (No hand shaking)</td>
<td>No</td>
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<td></td>
<td>Ok (3)</td>
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<td></td>
<td>Ok (3)</td>
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<td></td>
<td>Ok (3)</td>
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<tr>
<td>Sexual activity</td>
<td>Ok</td>
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<td></td>
<td>Ok</td>
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<td></td>
<td>Ok</td>
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<tr>
<td>Working with mechanical equipment (oil changes, working on cars &amp; engines, etc)</td>
<td>Ok</td>
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<td>Ok</td>
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<td></td>
<td>Ok</td>
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<td></td>
<td>Ok</td>
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<tr>
<td>Camping and hiking</td>
<td>Ok</td>
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<td></td>
<td>Ok</td>
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<td></td>
<td>Ok</td>
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<td></td>
<td>Ok</td>
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<tr>
<td>Down comforters (with cover)</td>
<td>Ok</td>
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<td></td>
<td>Ok</td>
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<td></td>
<td>Ok</td>
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<td>Ok</td>
</tr>
</tbody>
</table>

1) **No** swimming if venous access device still in place (i.e. catheter). No patient history of sinusitis. Chlorinated and well-maintained pools. Uncertain water conditions of lakes, rivers and the ocean for swimming are Ok if water tested routinely for safety by local state and health departments; avoid small bodies of standing water (lakes and ponds).
Swimming in pools used by non-toilet trained babies and children not recommended. Water aerobics Ok.
(2) Shooting rifles/shotguns & golfing is not recommended if venous access devise still in place (i.e., catheter).
(3) Recommend caution and an understanding of the risk involved when participating in public events or going to locations with large crowds.
(4) Real Christmas trees: in the water reservoir of the tree stand, use water solution of 1 part chlorine solution (Chlorox®) in 10 parts water.
(5) Wash hands thoroughly with soap and water after kneading dough.
(6) Avoid all public hot tubs.