

## Long-Term Recovery

The long-term recovery phase may take a year or longer. This is the time to re-establish your life after transplant. What does re-establishing your life entail? It means getting back to your life patterns such as returning to work or school or life at home and making the needed adjustments in relationships with your family and friends. It also may mean learning to adjust to the therapy needed for chronic or long-term complications. Former patients identified that the interruption in life plans, the adjustment in relationships with spouse, family and friends, the inability to have children and preparing to re-enter work and family life can be difficult adjustments to make. Some patients experience a sense of loss and discouragement. It is during this challenging time that patients often become involved again in the quest for meaning in their lives.

Re-establishing life varies from difficult and rough to easy going and smooth. Some patients express a positive view in that during their recovery, they have achieved a redirected life, greater compassion for others, and improved family relations. And the great majority of survivors report that the quality of their lives is now the same or better than before transplant. Despite the intensity of the transplant experience, most patients make effective adjustments in their life and maintain an optimistic outlook for the future.

This section along with the information you will receive from doctors, nurses and dietitians will help you manage your care when you leave the center. You may continue to be receive information about transplantation, please sign up for the quarterly newsletter that will be offered in your discharge packet.

Take pride in your journey through an intensive medical treatment, but remember that full strength and fitness will take several more months, and in some instances even years, to achieve. Don't be discouraged by persistent fatigue. Recovery is a slow process. Continue your programs of rest, exercise, and good nutrition.

### Immune System Recovery

Full recovery of immune function takes about 6-12 months after transplantation. Return of immune function may take longer if the patient has chronic GVHD and is taking medications that suppress the immune system. Patients are still vulnerable to infections. Symptoms such as fever, chills, cough, difficult breathing, severe diarrhea or vomiting should be reported to your doctor promptly.

## Preventing Infection

### CMV Monitoring

If you are CMV seropositive and on steroids or treated for CMV prior to day 100, or if you were seronegative, but were treated for CMV prior to day 100, you should be tested regularly for CMV by PCR during the first year. You will receive information at discharge to take to your local doctor.

### Exposures

Avoid crowds, especially during cold and flu season. Avoid people with a contagious infection. If not on Acyclovir medication, Varicella zoster immune globulin (VZIG) should be given to patients exposed to chickenpox or zoster (shingles) within the first year of transplant. VZIG is to be given within 48-96 hours after exposure and is effective for 3 weeks. If you are diagnosed with chickenpox or shingles in the first year, IV Acyclovir should be given.

### Handwashing

Continue to be as conscientious about handwashing as you have been throughout the transplant. Request family and friends wash their hands when they come into your home. Wear disposable gloves if you must change diaper-wearing children. Wash hands after disposing of gloves.

### Rash

Notify your doctor promptly if any rash develops.

### Temperature

Take your temperature if you are feeling ill or suspect a fever. Note time and circumstances.

### Animals and Plants

Avoid contact with body excretions of all animals as well as sleeping with pets. It is not recommended to bring new pets into the home during the first year, or thereafter, if on immunosuppression. 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. Normal cleanliness should be observed. If dryness is a problem, a lubricant is helpful. Drugs used for impotence should be avoided while on immunosuppression and not used without a cardiac evaluation.

### Swimming

Swimming may expose the immunocompromised person to microorganisms capable of causing infections. The immunocompromised person 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. The face should not be submerged under the water. Never swim with a central line in place. Hot tubs should be avoided.

## Nutrition Guidelines for Discharge Home

When you return home after your transplant, your immune system is still functioning below normal. You may also have increased nutrient needs due to medications or loss of muscle mass. Calories, protein, fluid, vitamins, and minerals are necessary for you to regain your immunity, maintain or achieve your weight goal, strengthen your muscles, and feel better!

### Food Safety

- *Allogeneic* patients should continue the “Immunosuppressed Diet” (Chapter 5) until off all immunosuppressive therapy (such as prednisone, FK506<sup>®</sup>, cyclosporine).
- When you discontinue the Immunosuppressed Diet continue to use care when purchasing foods, preparing meals and dining out. Situations where you cannot control the cleanliness of the food put you at greater risk for acquiring a food-borne illness. Examples include salad bars, smorgasbords, delicatessens, bulk food bins, free food samples offered in stores. Review the Food Safety Guidelines in the Patient/Caregiver Manual.
- Continue to avoid herbal and other preparations, since they may contain harmful ingredients or infectious organisms. Herbs are not regulated for purity or for effect on health.
- If you rely on well water at home, it should be tested for coliforms and *Cryptosporidium* immediately prior to your return home after treatment. Future testing must be performed at least once every year and preferably more frequently. To ensure safety, boil the water for one minute prior to drinking or using in recipes. Boiled water may be stored up to three days in the refrigerator. After three days it must be thrown away. (See “Water Safety”, Chapter 5.)

### Calories and Body Weight

- Your goal is to maintain or achieve an appropriate weight for your body size.
- It is important to consume a nutritious diet including a variety of foods to promote recovery of your immune system.
- If you are underweight, *weight gain* may be slow after transplant. Set small goals (2-4 pounds or 1-2 kg per month). Eat 3 meals daily, plus snacks. Drink beverages with calories and protein. Use medical nutrition supplements, such as Instant Breakfast<sup>®</sup>, Ensure<sup>®</sup>, Boost<sup>®</sup>, Scandi-Shake<sup>®</sup>, Polydose<sup>®</sup>. Exercise to promote muscle gain.
- If you are *overweight* and medically stable (as determined by your physician and dietitian), you may lose weight gradually - 1 pound/week. You must continue to consume a nutritious diet, following any special nutrition needs your dietitian has advised. Exercise is important to prevent muscle loss.
- Calorie needs increase with fever, infection, and physical activity. Some people with Graft-versus-Host Disease (GVHD) may require more calories to maintain or gain weight.

### Magnesium

- Cyclosporine and FK-506 increase magnesium loss from your body. Some people also lose magnesium due to other medications or after surgery or illness. Supplementation (pill or intravenous infusion) is usually necessary. Your physician may need to adjust your magnesium dose based on your serum magnesium level.
- Magnesium-rich foods include nuts, bran cereals, brown rice and whole grain breads.

### Fluid

- A high fluid intake helps flush your kidneys when you take medications that can impair kidney function, including Cyclosporine, FK-506, and some antibiotics. Ask your dietitian for your fluid goal.
- Serum (blood) Creatinine is a measure of kidney function. An above normal serum creatinine means that your kidneys are working below normal.

### Vitamin & Mineral Supplements

Take a multiple vitamin/mineral supplement for one year following your transplant to ensure you get the vitamins and minerals you need while your body and immune system are recovering. A generic brand is fine. If you are considering taking any supplement (including antioxidants and herbal preparations) in addition to the vitamin/mineral supplement that has been recommended, discuss its' safety with your dietitian.

When selecting a supplement, it should:

- Contain NO iron.
- Not be greater than 200% of the Recommended Dietary Allowance (RDA).
- Contain NO herbs or other plant materials.

- Recommended Supplements For Adults  
Mature Balance®, One-a-Day 50 Plus®, Centrum Silver®.

## Protein

Your protein needs were higher than normal early after transplant to allow repair of cell damage caused by chemotherapy and radiation. Protein continues to be an important part of your diet to promote recovery of your immune system. Your protein requirement returns to normal two to three months after transplant, unless you have lost a large amount of muscle or are taking prednisone.

Below are some protein-rich foods. Your dietitian will tell you your daily requirement. For calorie and protein information, please ask your outpatient nutritionist for the booklet, "A Guide to Good Nutrition.")

Protein Content of Selected Foods

Food Item	Serving Size	Grams Protein
Beans: baked	½ cup	7
lima	½ cup	6
refried	½ cup	8
Cheese	1 oz. or 1" cube	7
Cheese pizza (12")	¼	15
Chicken: breast	½	27
thigh or drumstick	1	14
wing	1	8
Cocoa, instant – mixed with water	1 cup	3
Cooked beef, fish, lamb, pork: size of a deck of cards	3 oz.	21
Cottage cheese	¼ cup	7
Cream soup (made with milk)	1 cup	6
Custard	½ cup	7
Egg	1	6
Hotdog (10 per pound) or luncheon meat	1 or 1 oz.	5
Ice cream or ice milk	1 cup	5
Lentils	½ cup	9
Macaroni and cheese: homemade or frozen	1 cup	12
packaged or canned	1 cup	7
Milk (nonfat, 2%, whole, buttermilk)	1 cup	8
Homemade Milkshake	10 oz.	9
Peanuts and other nuts	¼ cup	9
Peanut butter	2 Tbs.	8
Pudding	½ cup	4
Tofu	½ cup	10
Tuna	¼ cup	12
Yogurt: plain, coffee, vanilla	1 cup	12
fruit	1 cup	9
Ensure®	1 cup	9
Ensure Plus®	1 cup	13
Instant Breakfast (made with milk)	1 serving	15
Boost®	1 cup	15
Boost Plus®	1 cup	14



Nutrition Guidelines During Prednisone Treatment

- Protein: A protein-rich diet and exercise can help prevent muscle loss. Include a protein-rich food in every meal and consume 2 to 3 protein-rich beverages or snacks daily. Exercise can include walking, bicycling, low-impact aerobics.
- Calcium: Consume a calcium-rich diet and exercise daily to minimize bone loss. If your calcium intake is low, take a supplement of calcium carbonate (such as Tums® or Viactiv®) or calcium citrate (such as Citracal®).
- Vitamin D: This vitamin helps your body absorb and utilize calcium. Children on prednisone require 400 I.U. vitamin D daily. Adolescents and adults on prednisone require 400-800 I.U. daily. Vitamin D is obtained from your multiple vitamin, fortified milk and vitamin D-containing calcium supplements.
- Sugar (Glucose): If your fasting blood glucose level is above normal, ask your dietitian for diet guidelines. Avoid concentrated sweets, especially sugar-containing beverages and juices. Examples of concentrated sweets are:

cake	donuts	pie	soda pop
cookies	candy	fruit juice	sweet rolls
fruit-ades	coffee cake	ice cream	sugar, honey, syrup

- Potassium: You may need more potassium in your diet while taking Prednisone. The following are good sources of potassium:

salt substitute	bananas	melons
oranges	orange juice	potatoes
tomatoes	tomato juice	cream of tartar

- Salt: A high salt intake can worsen fluid retention caused by prednisone. Avoid salt, and salty foods such as canned, instant, and frozen soups and entrees, soy sauce, cured meats, and packaged sauces and seasonings. In general, processed foods contain too much salt.

Your dietitian can give you a more complete list.

Discuss With Your Doctor If:

- Your weight drops more than 2 pounds (1 kg) in 7 days
- You develop nausea, vomiting, diarrhea, stomach or intestinal cramps
- Your mouth becomes drier, sensitive, or develops sores
- You have swallowing difficulties

Resources

If you have nutrition questions after returning home, contact a SCCA dietitian.

## Medications

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

- Bactrim. This is a broad spectrum antibiotic specific to prevent pneumocystis pneumonia. Take if prescribed.
  - ⇒ If on tapering doses of Cyclosporine, take Bactrim until off Cyclosporine or at least until day 180 after transplant.
  - ⇒ If on Prednisone or other steroids, take Bactrim until 2 weeks after the last dose or at least until day 180 after transplant.
  - ⇒ If on treatment for chronic GVHD, take Bactrim as specified by your chronic GVHD protocol.
- 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.
- 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 immunosuppressive medications (Prednisone, Cyclosporine, MMF, Prograf).

## Immunizations

After the first year, patients receive killed-virus immunizations such as:

- Tetanus
- Diphtheria
- Inactivated polio
- Influenza
- Pneumonia
- Haemophilus Influenza type B
- Hepatitis B
- Hepatitis A – in patients with abnormal liver function tests or a history of liver disease.

If you do not return for your 1-year follow up, ask your doctor to contact the Long-Term Follow-Up Department about immunizations.

NOTE: Patients may receive tetanus shots safely within the first year after transplant, however, you may not respond because of your immature immune system.

If polio vaccine needs to be given to household members within the first year after transplantation, the inactivated vaccine is strongly recommended. Close contact between those receiving oral live vaccine and the transplanted patient should be avoided for approximately 2 months after vaccination, since live virus shedding can occur in the feces. If a household

member receives Varicella (chickenpox) vaccine, and then develops lesions (or pox), the patient needs to be isolated while the lesions are present. Isolation does not need to be used for family members given MMR (measles, mumps, and rubella) vaccination.

## Guidelines for Daily Living for the First Year



### Doctor's Visits

These should be regular for physical exams, blood counts, kidney and liver function tests. Usual recommendations are:

- Go weekly for the 1st month. Every other week for the next 2 months. Then every 3-4 weeks, depending on how you are doing. Your doctor will help decide.
- A one-year follow-up evaluation to assess disease status and late complications is necessary.

There is an increased risk of secondary malignancies following transplantation. Skin and mouth are the most common sites. A cancer screening evaluation is recommended including oral exams at 6 month intervals, complete physical exam (prostate/gynecological exam, etc.), occult blood in stool, retosigmoidoscopy/colonoscopy (according to age and history) and other disease staging as it applies to your disease. Patients transplanted for CML, a blood test for molecular studies (BCR/ABL) is recommended at six-month intervals through the 2<sup>nd</sup> year after transplant and yearly thereafter.

A bone marrow may be indicated if the BCR/ABL test is positive.

### Skin Care

Note changes in skin and report changes to your doctor:

- Color changes
- Presence of rash
- Scaly Skin
- Texture changes
- Stiff or tight joints

It is important to protect yourself from sunburn to eliminate the possibility of sun activation of chronic GVHD of the skin, and also to protect against skin cancer.

- Use sunblocking cream, SPF 15 or greater is recommended for all patients.
- Avoid long (over 1 hour) exposure to sun.
- Cloudy days still result in exposure to ultraviolet radiation.

If your skin is dry:

- ➔ Use oil in bath water.
- ➔ Use lanolin based lotion or Aloe Vera.
- ➔ Try natural soap for sensitive skin.

If dry skin is a problem, it is not necessary to bathe daily.

### Eye Care

See your ophthalmologist for any of the following changes:

- “Gritty” feeling
- Discharge
- Changes in vision
- Continual redness

Of the patients who receive irradiation, 20% develop cataracts. They form 1 to 5 years after transplantation. Cataracts are also more common in patients who receive long-term steroids. They can be removed surgically and lenses replaced.

### Mouth Care

Daily Care. Careful and thorough flossing and brushing are very important. 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. Use  $\frac{3}{4}$  teaspoon table salt with 1 quart of warm water.



Dental Visits. 5-6 months after you have returned home, see your dentist for examination. X-rays may be taken if appropriate. Routine dental cleaning and dental work should be postponed for at least 9-12 months after transplant.

Dry Mouth. See dentist for extreme problems with decay, but 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 change such as ulcers, stinging, burning, dryness, pain, difficulty eating, or loose teeth.

## Graft Versus Host Disease (GVHD)

Another form of GVHD, which may occur around day 80 or later, is called chronic graft-versus-host disease. This skin can become 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. Occasionally the esophagus, gastrointestinal tract and liver are affected. Weight loss from poor absorption of food can occur. Bacterial infections are common. Treatment protocols have been developed for this condition. The long-term follow-up team is available to you and your physician 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.

Treatment of chronic GVHD with immunosuppressive agents may last from a year to 4 years or more. But eventually the graft will develop tolerance to its new environment.

Report any of the following changes to your physician. Make sure your physician is watching for possible increases in your liver and kidney function tests.

- Skin: rash, discoloration, tightness, texture changes.
- Hair: thinning.
- Nails: texture changes, brittleness, ridges.
- Eyes: dryness, grittiness, irritation, blurring.
- Mouth: dryness, pain, sensitivity to foods or toothpaste.
- Vagina: dryness, irritation, tightening.
- Penis:** Irritation
- Digestive System: nausea, vomiting, diarrhea, loss of appetite, unexplained weight loss.
- Lungs: chronic cough, wheezing, shortness of breath.
- Liver: jaundice and elevated liver tests.
- Joints: unable to fully extend fingers, wrists, elbows, ankles or knees.
- Energy Level: unusual fatigue.
- Temperature: chronic low-grade fever.

#### Treatment of GVHD

The drugs used most commonly to treat GVHD are prednisone, cyclosporine, prograf, MMF (Cellcept), and Rapamycin.

All immunosuppressive drugs have some side effects. The more common ones are listed below.

Prednisone: osteoporosis, deterioration of joints, increased risk of infections, diabetes, and emotional ups and downs.

Cyclosporine (Neoral): kidney function issues, wasting of magnesium, tremors, headaches, seizures, nausea, increased blood pressure.

Tacrolimus (Prograf or FK-506): similar to cyclosporine.

Mycophenolate (MMF or Cellcept): nausea and vomiting, diarrhea, or decreasing white count or hematocrit.

Rapamycin (Sirolimus): decreased white cells or platelets, increased triglyceride level.

## Reconnecting with Life

Most patients feel vulnerable the first month or two 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."

### Return to Work or School

It is suggested that you wait at least 6-9 months, and perhaps 12 months, after transplant, 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 one year and possibly longer in some situations.

### Relationships

It may be difficult to resume old relationships as before 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, which could affect relationships. It might take some time to sort things out.

### Young Adults

The road to independence and maturity is more difficult for young adults who have been ill. Patient's feelings may fluctuate, sometimes viewing their parents as being overly concerned/involved; other times feeling insecure and seeking more parental dependence.

### Sexuality

Patients may have a low energy level or feel unlovable due to the changes that their bodies have undergone. Partners often hesitate to make sexual advances out of concern for the patient's health. Women can have vaginal changes and men may have some impotency problems. Medications can be the cause of some of these changes, which may disappear after stopping the drugs, and with time. It's important for both partners to talk about their feelings honestly, and to be patient with one another.

### Survivor Syndrome

Some patients have guilt feelings because they are alive when others did not survive. Frequently, discussion with a minister, priest, or rabbi can help put this in perspective.

### Looking Ahead

Some patients, especially those who had a stormy transplant course, find it hard to plan for the future. Give yourself time, but try not to be afraid to re-evaluate what you want to do for the rest of your life.

### Helpful Hints To Remember

- 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. You will feel well again.
- Try to take just one day at a time, particularly after you first return home.
- Don't be afraid to ask for professional guidance. You deserve it! Almost everyone receives some kind of help.
- Remember that the Center suggests most patients return one year following their transplant for re-evaluation.

# Common Questions Asked By HSCT & LTFU Patients

Questions Often Asked	Time after Transplant			
<b>*The general guidelines below may not apply to your case. You must discuss with your physician to assess if these rules apply to you.</b>	All Patients  Less than 6 months	<b>Not</b> Receiving Immuno-supression 6 months to 1 year	Receiving Immuno-supression  6 months to 1 year	Receiving Immuno-supression  More than 1 year
School	No	No	No	Ok
Hot tubs (1)	No	OK (1)	No	No
Swimming (1) (avoid head submersion & diving, use sun screen;	No	OK (1)	No	Ok
Gardening (digging in soil); mowing the lawn; raking leaves	No	No	No	No
Having plants in the home (not handling)	Ok	Ok	Ok	Ok
Making/kneading yeast breads	Ok	Ok	Ok	Ok
Carpenter work	No	No	No	No
Occasional woodworking (sawdust)	No	Ok	Ok	Ok
Animals, Birds, Reptiles, Fish, Other (not handling feces, litter boxes, cleaning utensils, or cages/tanks, etc.)				
➤ New pets in patient's household	No	No	No	No
➤ Cats/dogs (not sleeping with pets)	Ok	Ok	Ok	Ok
➤ Domestic birds (parakeets, parrots, etc) (not with respiratory problems)	No	Ok	Ok	Ok
➤ Poultry & wild birds (pigeons, chickens, ducks, geese, other wild birds, etc)	No	No	No	No
➤ Small cage rodents (gerbils, rabbits, hamsters, guinea pigs, hedge hogs, prairie dogs, etc) (Do not handle)	No	Ok	Ok	Ok
➤ Reptiles (snakes, turtles, lizards, iguanas, etc); ferrets	No	No	No	No
➤ Farm animals (pigs, horses, cows, llamas, etc) (Do not handle; stay out of barns full of hay)	No	Ok	Ok	Ok
➤ Wild & game animals (deer, elk, squirrels, bear, etc); exotic animals (monkeys, etc) (Do not handle)	No	No	No	No
➤ Zoos & petting zoos	No	No	No	No
➤ Public aquariums (do not touch marine life in handling tanks) (3)	No (3)	Ok (3)	Ok (3)	Ok (3)
➤ Animal trophy mounts in the house	Ok	Ok	Ok	Ok
➤ Fishing (fresh & salt water) (OK to handle fish if wearing gloves; do not bait hooks)	Ok	Ok	Ok	Ok

LONG - TERM RECOVERY

Golfing (sun protection required; without venous catheter device)	No	Ok	Ok	Ok
Spectator events and crowds (3) (church, movies, games, etc.) (No hand shaking)	No (3)	Ok (3)	Ok (3)	Ok (3)
Sexual activity	Ok	Ok	Ok	Ok
Working with mechanical equipment (oil changes, working on cars & engines, etc)	Ok	Ok	Ok	Ok
Camping and hiking	Ok	Ok	Ok	Ok
Down Comforters (with cover)	Ok	Ok	Ok	Ok
➤ Hunting (wild game and birds) and sport shooting (2) (Wear latex gloves when handling game; do not clean game)	No	Ok (2)	Ok(2)	Ok(2)
Horseback riding (Stay out of barns full of hay)	No	Ok	Ok	Ok

(1) No swimming in pools with no diapered or undiapered babies. No swimming if venous access device still in place (i.e., catheter). No patient history of sinusitis. Chlorinated and well-maintained pools preferable over uncertain water conditions of lakes, rivers and sea for swimming. Water aerobics OK.

(2) Shooting of rifles and shotguns not recommended if venous access device 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.

**Other Reminders:**

- Minimize: **exposure to dirt and aerosolized material.**
- Minimize: **sun exposure and use of sunscreen (SPF >15%).**
- Use: **hat, long sleeve shirts** and **pants** if outside for long period of time.
- Avoid contact with people with **respiratory illness** or other **transmissible diseases**
- Autologous and teenage patients should be discussed separately.

**Discuss with your physician** when restrictions may apply to your child's care after one year post transplant.

## Resources

### The Long-Term Follow-Up Department

Please contact your local physician for medical needs or emergencies. For transplant related questions that your physician 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 name and spelling of the patient, and the question. We will attempt to return your call in 24 to 48 hours.