

## Long-Term Recovery

The long-term recovery phase may take a year or longer. This is the time to re-establish life after transplant. What does re-establishing life entail? It means getting back to life patterns such as returning to work or school or life at home and making the needed adjustments in relationships with family and friends. It also may mean learning to adjust to the therapy needed for chronic or long-term complications. Former patients and parents identified that the interruption in life plans, the adjustment in relationships with family and friends, the inability to have children and preparing to re-enter school, 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 and parents 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 and parents 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 care when you leave the Center.

Take pride in the journey you and your child have completed through an intensive medical treatment, but remember that your child's full strength and fitness will take several more months, and in some instances even years, to achieve. Don't be discouraged. Recovery is a slow process. Continue 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 the doctor promptly.

## Preventing Infection

### 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 your child is diagnosed with chickenpox or shingles in the first year, IV Acyclovir should be given.

### Handwashing

Continue to be as careful about handwashing as you have been throughout the transplant. Request family and friends to wash their hands when they come into your home.

### Rash

Notify the doctor promptly if any rash develops.

### Temperature

Take your child's temperature if he or she is 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 or playing in dirt/sandbox is not recommended while on drugs that suppress the immune system.

### 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 for You and Your Child

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

### Food Safety

- When your child discontinues 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 your child 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 Chapter 5 of 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, bring tap water to a rolling boil 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 child’s goal is to maintain or achieve an appropriate weight for his body size.
- It is important for your child to consume a nutritious diet including a variety of foods to promote recovery of his immune system.
- If your child is underweight, *weight gain* may be slow after transplant. Set small goals (1-2 pounds or 0.5 – 1.0 kg per month). Encourage your child to eat 3 meals daily, plus snacks. He should drink beverages with calories and protein. Use medical nutrition supplements, such as Instant Breakfast<sup>®</sup>, Boost<sup>®</sup>, Ensure<sup>®</sup>, Polycose<sup>®</sup>. Exercise is necessary to promote muscle gain.
- If your child is *overweight* and medically stable (as determined by the physician and dietitian), he or she may lose weight gradually – ½ to 1 pound/week. He must continue to consume a nutritious diet, following any special nutrition needs the dietitian has advised. Exercise is important to prevent muscle loss.
- Calorie needs increase with fever, infection, and physical activity. Some children with Graft-versus-Host Disease (GVHD) may require more calories to maintain or gain weight.

### Magnesium

- Some children lose magnesium due to medications or after surgery, illness or autologous transplant. Supplementation (pill or intravenous infusion) is usually necessary. The physician may need to adjust your child’s magnesium dose based on the serum magnesium level.
- Magnesium-rich foods include nuts, bran cereals, brown rice and whole grain breads.

### Fluid

- A high fluid intake helps flush the kidneys when your child takes medications, including some antibiotics. Ask your dietitian for your child’s fluid goal.
- Serum (blood) Creatinine is a measure of kidney function. An above normal serum creatinine means that your child’s kidneys are working below normal.

### Vitamin & Mineral Supplements

Have your child take a multiple vitamin/mineral supplement for one year following transplant to ensure he gets the vitamins and minerals he needs while his body and immune system are recovering. A generic brand is fine. If you are considering giving any supplement (including antioxidants and herbal preparations) in addition to the vitamin/mineral supplement that has been recommended, discuss its’ safety with your SCCA 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 Children  
Fruity Chews<sup>®</sup>, Sesame Street Vitamin Chewable Tablets<sup>®</sup>. (Follow the dose listed on the label for the age of your child.)
  
- Recommended Supplements For Teens And Adults  
Mature Balance<sup>®</sup>, One-a-Day 55 Plus<sup>®</sup>.

## Protein

Your child's 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 child's diet to promote recovery of his or her immune system. Your child's protein requirement returns to normal two to three months after transplant, unless he has lost a large amount of muscle or is taking prednisone.

Below are some protein-rich foods. Your dietitian will tell you your child's 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 High Protein®	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 encourage your child to 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 child’s calcium intake is low, give a supplement of calcium carbonate (such as Tums® or Viactiv®) or calcium citrate (such as Citracal®).
- **Vitamin D:** This vitamin helps your child’s 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 child’s multiple vitamin, fortified milk and vitamin D-containing calcium supplements.
- **Sugar (Glucose):** If your child’s fasting blood glucose level is above normal, ask your dietitian for diet guidelines. Your child should 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:** Your child may need more potassium in his 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
<i>(The dietitian can give you a more complete list.)</i>		

- **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.

Children Under 18 Years of Age

Height and weight should be measured at the doctor’s office *every month*. Record these values on the growth chart provided by the dietitian. When your child returns to the Center for long-term evaluation, bring the growth chart with you.

Discuss With Your Doctor If:

- Your child’s weight drops more than 1 to 2 pounds in 7 days.
- Your child develops nausea, vomiting, diarrhea, stomach or intestinal cramps.
- Your child’s mouth becomes drier, sensitive, or develops sores.
- Your child has swallowing difficulties.

## Resources

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

## Medications

Your child's medications are important to help you maintain your general health. Please give them as prescribed.

- Bactrim or Dapsone. This is a broad spectrum antibiotic specific to prevent pneumocystis pneumonia. Give if prescribed.
- Acyclovir or Valacyclovir. This medication is used to prevent or treat viral infections, such as varicella zoster (shingles). Some patients may be required to take this medication until day 365 post-transplant.
- Hormones. Hormones may be prescribed for females in premature menopause due to the effects of conditioning therapy.

## 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 your child does not return for a one-year follow up, ask the doctor to contact the Long-Term Follow-Up Department about immunizations.

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 nubella) vaccination.

Note: Patients may receive tetanus shots safely within the first year after transplant; however, they may not respond because of an immature immune system.

## 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 your child is doing. The 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 child's disease.

### Children

Height and weight needs to be measured every month. Growth and development may be impaired after transplant and hormonal supplements may be needed.

### Skin Care

Note changes in skin and report changes to the doctor:

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

It is important to protect your child from sunburn 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 child's 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 then it is not necessary to bathe daily.

## Eye Care

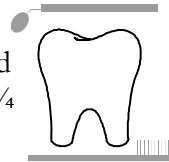
Take your child to an ophthalmologist for any of the following changes:

- Discharge
- Changes in vision
- Continual redness

Of the patients who receive irradiation, 20% develop cataracts. They form 1 to 5 years after transplantation. They are also more common in patients who receive steroids long term. 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 child's mouth is dry, if your child has excessive mucous, or if your child is 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 and your child have returned home, see the 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.

**Children.** Between age 1-12 years, children should be examined for progress in the development of permanent teeth. X-rays to confirm dental development should be taken prior to the routine extraction of any baby teeth.

**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 the physician for any change such as ulcers, stinging, burning, dryness, pain, difficulty eating, or loose teeth.

## Reconnecting with Life

Most patients and parents 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 your child to see his friends and return to normal activities, too. Just use common sense -- "when in doubt, don't."

### Return to School

Doctors suggest that your child wait 12 months after transplant before returning to school. This provides enough time for your child's immune system to be at full strength to resist some of the common ailments found in the school setting, like colds, chicken pox, or influenza. Individual times may vary, so check with your child's doctor. Home tutoring can precede these dates.

### Relationships

It may be difficult to resume old relationships as before because your child's experience has changed your perspective on life. His illness may have affected the feelings and perspectives of

the people around you, and it may have produced role changes, which could affect any 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.

#### Children and Siblings

Some children develop fears and have nightmares. Encourage them to talk, draw, or act out their feelings. Professional help may be needed. Siblings often resent the special attention the patient received and start demanding recognition. This can take the form of temper tantrums, lying, stealing, running away, etc. Bad behavior attracts attention. Try to be understanding and get professional help when needed. Many states have special programs for siblings of a child with special health needs. Check with your doctor.

#### Survivor Syndrome

Some patients have guilt feelings because they are alive when others didn't make it. Frequently, discussion with a minister, priest, or rabbi can help put this in perspective.

#### Looking Ahead

Some patients and parents, 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, your child and your family want to do for the rest of your life.

#### Helpful Hints To Remember For You And Your Child

- 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 child's 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

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 doctor for medical needs or emergencies. For transplant related questions that your doctor is unable to answer or to schedule your child’s 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.