Survivors' Guide for Bone Marrow/ Stem Cell Transplant

What to Expect and How to Get Through It

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Post-Transplant Guidelines

During the period immediately following hospitalization, you will be vulnerable to potential infections and will need to take extra precautions. The time of immuno-suppression varies from person to person and depends upon the type of transplant and the number of immuno-suppressants being taken.

People who have had autologous transplants tend to be least immunocompromised since they do not need to take immuno-suppressants to combat GVHD. As a result, they are less vulnerable to infections than recipients of transplants from donors. Because of this, autologous transplant recipients only must follow the guidelines for a few months' post-transplant. People who have undergone a transplant from a donor, however, should follow the guidelines more strictly and for a longer period. Since every patient's condition is different, the best way to determine how long to follow these guidelines is to consult directly with your physician. In general, the period will range from a few months to a year or more depending on the type of transplant and your condition. Coping with all the restrictions post-transplant requires a lot of energy and effort.

Conforming to the safety guidelines often entails changes in long-time habits and attitudes. Often, conforming to the guidelines is frustrating and takes a great deal of conscious effort and energy. The experiences of the two transplant patients here are typical: When I finally did go home, it was weird. So many restrictions and rules. I couldn't work (something I had done since I was 12 or 13 with paper routes), couldn't be around a lot of people ... especially kids, so shopping was pretty much out, as were visitors with colds.

I hated having to be so picky about everything - the food I ate, the people I had contact with, the things I touched. It was strange having to avoid things I normally wouldn't even notice such as a construction site or a baby in the supermarket. I also became hyper-aware of anyone who sneezed or coughed anywhere in my vicinity.

Although living with these recommended precautions can be challenging, maintaining good hygiene is a very important part of regaining your health and avoiding infection during the period of immuno-suppression. How strict you want to be about hygiene ultimately depends on you. Some transplant survivors who responded to the questionnaire adopted very strict hygiene standards and didn't eat out at restaurants

for several months post-transplant, always wore latex gloves in public rest rooms, washed their toothbrush with soap before using it, etc. Others adopted less strict standards. The extent to which you choose to restrict your activities and where you decide to draw the line is up to you and your doctor.

In the months following the transplant, it is helpful to remember that these restrictions are temporary. In the scheme of a lifetime, six months or a year of avoiding certain foods or certain places is a minor sacrifice. Keep in mind that you will have the rest of your life to pursue these activities.

Hand Washing

Following the transplant, you should wash your hands frequently during the day as hand contact is by far the most common way of contracting infections. Many bacteria and viruses are transmitted by touching telephones, doorknobs, or other objects and then touching one's mouth, nose, or eyes. Frequent hand washing is the best protection against infection and should be done regularly before eating meals, taking medications and after using the toilet or any public restroom. Ideally, everyone who encounters you should wash their hands frequently to minimize the transmission of micro-organisms that can cause infections. Here are some recommendations offered by patients:

- Institute a "hand washing policy" in the house.
- Purchase anti-bacterial soap for kids that is just for them to use to get them in the habit of using it.
- Always carry latex gloves and alcohol wipes so that you can always pull them out if you are in a public restroom or some other place that is not as clean as you would like.

Personal Hygiene

After the transplant, personal hygiene is of paramount importance. Make sure to bathe daily, using soap and shampoo. Often, your skin post-transplant will be dry and sensitive. If this is the case, frequent applications of body lotion can be helpful. Using milder soap can also reduce dryness and irritation. As part of general hygiene, towels and clothing should be changed daily.

Contact with People

To restrict potential exposure to bacteria and other infection-causing agents, it is generally recommended that you restrict touching or hugging to a few special people with whom you have frequent contact. It is also important to avoid settings in which you are likely to encounter sick people. This will mean avoiding crowded spaces such as movie theaters and restaurants during peak hours, crowded elevators, schools and auditoriums. Although this does not mean that you must avoid public places altogether, it is probably wise to limit your exposure to large numbers of people. You should avoid kindergarten and school settings since children are more likely to be sick than adults. Since the transplant can destroy previous immunity to disease, it is also important to avoid contact with babies or adults that have been vaccinated with live viruses such as polio within the last 30 days.

If someone living with you gets sick, check with your medical provider to determine how much risk the infectious person poses to you and what the best course of action is. It is likely that the sick individual will be advised to move temporarily until he or she is no longer infectious. If that is not possible, arrange to have the person stay away from you as much as possible.

If you choose to eat at restaurants, make sure to choose ones that have a reputation for cleanliness and serve fresh foods. In the period that you are immuno-compromised, don't hesitate to ask when the food was last prepared and to ask that food be prepared fresh especially for you. Many restaurants will accommodate you.

Hygiene in Your Home

Your living quarters post-transplant should be kept clean. Again, there are no hard and fast rules as to the degree of cleanliness you should maintain. The recommendations vary according to the type of transplant you have had and your degree of immuno-suppression. In any case, the amount of dust, mold and fungus in the house should be kept to an absolute minimum as these have the potential to transmit infection and disease. Depending on the amount of dust and soil in your house, the house should be cleaned once a week or every few days. The bathroom and eating area should be cleaned most often, and dirty sponges should be replaced weekly. You may also consider having the refrigerator cleaned prior to stocking so that it is free of mold

spores that can get into your food. Using a cleaner with antibacterial disinfectant properties such as Lysol or bleach is recommended. Using a damp cloth to clean dust is more effective than a feather duster as feather dusters stirs up dust and disperse it in the air. If you have the resources to do so, hiring a housekeeper to do housework and allocating tasks to family members can be extremely helpful.

Plants and Pets

As part of the general cleanliness and hygiene requirements, it is recommended that you avoid keeping fresh plants and flowers in your home as the organisms that grow in dirt, water and plants can cause infections. In general, you should avoid handling plants in the first few months following the transplant. For the same reason that you should not have plants in the home, you should avoid contact with soil, lawn waste or compost. Thus, refrain from gardening or sitting on grass, logs or dirt. This restriction should not prevent you, however, from enjoying the outdoors.

In general, it is recommended that you limit your contact with animals and household pets during the first 100 days of post-transplant. During this time, you should not clean up after your pets or touch any human or animal excrement. It is particularly important to avoid cat litter boxes and bird cages. You should check with your physician to determine the extent of contact you may have with your pets.

Construction Sites and Fireplaces

It is often recommended to avoid construction sites as they often have upturned earth, old wooden beams or other materials which may expose you to dust or fungus. If you are aware of a construction site in your neighborhood, consider walking upwind from it or going around the block to avoid it. If you are driving by, roll up your windows.
Also, stay away from wood burning fireplaces and from inhaling smoke from burning logs.

Exposure To the Sun

The effects of radiation, chemotherapy, as well as certain drugs may increase your skin's sensitivity to sunlight. During the first-year post-transplant, stay out of the sun as much as possible and apply sunscreen with a sun protection factor (SPF) of 25 or above when going outdoors, even on overcast days. On sunny days, wear protective coverings such as hats, sunglasses and long-sleeved shirts for at least a year post-transplant.

Swimming Pools

It is also recommended to avoid swimming in lakes or public pools until your immune system has reconstructed itself. Check with a member of your medical team before resuming swimming activities.

Food Safety

Until the time when your immune system will rebuild itself, you will be at a greater risk for developing food-related infections. Thus, in the period following the transplant, it is extremely important to follow food safety guidelines. Although the food guidelines may vary slightly from center to center, a good rule of thumb to follow is to eat only those foods that have been freshly prepared in a clean environment, and which have not been sitting out for any length of time. The following recommendations have been adapted from patient guidelines at the Fred Hutchinson Cancer Research Center. You will receive similar or additional recommendations from the dietician at your transplant center.

Grocery Shopping

- Check "sell by" and "use by" dates and do not buy items that are out of date.
- Do not buy or use any bulging, damaged or deeply dented cans.
- Make sure frozen foods feel solid and that refrigerated foods are cold.
- Do not buy cracked or unrefrigerated eggs.
- Store groceries promptly after shopping.
- Do not buy bulk food from self-service bins.

Food Preparation

- Prepare food on surfaces that have been thoroughly washed in hot soapy water. You can clean cutting boards in a solution of ten parts water mixed with one part household bleach.
- Use separate cutting boards for cooked foods and raw foods.
- Do not use raw, unpasteurized eggs in uncooked foods since raw eggs are the perfect medium for the growth of bacteria such as salmonella.
- Discard eggs, egg mixtures or prepared egg dishes left at room temperature for more than an hour.
- Wash the tops of cans and the can opener before use.
- All meats should be cooked until well-done and should have no remaining pink color.
- Foods should be cooled inside the refrigerator rather than outside. A good way to do this is to divide large amounts of hot food into small, shallow containers for quick cooling in the refrigerator.
- Do not eat perishable foods that have been left out of the refrigerator for more than two hours.
- Do not eat food that has been sitting in the refrigerator for more than three days. A helpful way to keep track of the number of days prepared foods and other perishable items have been sitting in the refrigerator is to put a date on them once they have been opened. It is also helpful to refrigerate only the amount of food that you will eat in two or three days and freeze the rest.
- Thaw meat and fish in the refrigerator.
- Throw away food that has any mold on it.
- Never taste foods that look or smell strange.
- Wash and rinse fruits and vegetables thoroughly before eating them.

The following section provides a list of foods that are more likely to carry infection-causing organisms. In addition to the foods listed here, there may be other foods that your transplant center recommends that you avoid. To get a full listing of foods to avoid, make sure to discuss food safety guidelines thoroughly with your dietitian or medical provider.

Foods to Avoid

- Free food samples
- Foods at potluck meals where you don't know how food was prepared or how long it was sitting out of the refrigerator
- Food from sidewalk vendors, delicatessens, smorgasbords, buffets and salad bars
- Soft serve ice cream, milk shakes and frozen yogurt from yogurt machines
- Sushi, raw fish, smoked fish
- Sodas from fountain machines
- Raw eggs, Caesar salads containing raw egg, mayonnaise-based foods, custards or other dishes that may contain raw eggs
- Well water (check with your transplant team for specifics)
- Unpasteurized honey, milk, cheese and yogurt
- Unrefrigerated cream
- Unroasted nuts or nuts in the shell
- Aged cheeses such as certain sharp cheeses
- Moldy cheeses such as brie and blue cheese

Non-traditional nutrition supplements such as herbal preparations should be avoided as they may contain toxic impurities or infection-causing fungi, yeast, molds or bacteria. These can be life-threatening for a person with a weakened immune system. Unsupervised high dose vitamin/mineral supplements should also be avoided, as they may interfere with various medications or may be harmful to major organs, especially the liver and kidneys.

Smoking/Alcohol/Drugs

Your risk for lung damage post-transplant will considerably increase. It is, therefore recommended that you avoid smoking before, during or after your transplant. You should also avoid secondhand smoke.

The damaging side effects of alcohol are also the greatest post-transplant. For this reason, you should avoid alcohol for the first six months post-transplant. If you are still taking medications for six months post-transplant, do not drink alcohol until you have discussed the matter with your physician.

Do not take any over-the-counter medications without consulting your BMT doctor or clinical nurse specialist.

Work/School

Avoid work and school for at least 3-6 months after an autologous BMT and longer after an allogeneic BMT. The time you take off depends on the kind of work you do, and the degree of fatigue caused by work. A computer consultant working at home, for example, may be able to return to work much earlier than an elementary school teacher. Give yourself time to take care of yourself and fully recover. You deserve it!

Sexual Activity

Generally sexual activity is considered safe as long as both you and your partner are healthy, keep good hygiene and have no sexually transmissible diseases. Before beginning sexual activity, however, please talk with a member of your transplant team to see if there are any restrictions that pertain to your case.

Some transplant centers recommend using a condom post-transplant whereas others maintain that a condom is not necessary if you are in a mutually monogamous relationship and neither of you is suspected of having a sexually transmissible disease. If one of you has a sexually transmissible disease, it is recommended that you refrain from sexual activity as a condom may not provide a sufficient barrier during the time of immuno-suppression. Some BMT centers recommend refraining from unprotected oral-genital sex during the time of immuno-suppression whereas others maintain that is safe if oral hygiene is good and there are no oral lesions, genital lesions or mucositis. Anal sex should be avoided until your physician feels it is safe for you.

The extent to which the transplant affects one's sexual life varies dramatically from individual to individual. Low libido is a very common problem after transplant. However, some people resume an active and satisfying sexual life shortly after transplant whereas others find that their sexual life is greatly disrupted.

Changes in body image or sexual desire post-transplant can disrupt old behavior patterns or lead to insecurities about starting new relationships. Often the physical toll of the transplant and the resulting side effects such as nausea and lower energy levels

may reduce the desire for sexual activity. In other cases, worry or depression or nervousness about one's ability to "perform" and to be sexually attractive post-transplant may also result in loss of desire. This can happen in the form of impotence for men, but you should check with your physician to rule out a medical cause.

In the period following the transplant, some patients find that they need to modify what they define as sexual pleasure. Here are the reflections of two people: In terms of sexuality, my husband and I had to redefine what that meant for us. Sometimes, simply being close to each other is how we were intimate post-transplant. Now almost a year later, I notice that my sexual drive has decreased, and it takes me more time to feel aroused.

> *After the transplant, my partner and I had to make a few modifications like using more lubricants. However, even though I had much less energy post transplant, we were still able to have an active and satisfying sex life.*

If your sexual drive post-transplant is reduced, it is important to explore other ways of intimacy such as touching, holding hands, hugging and kissing. At this time, communicating with your partner is key to modifying your sexual routine in a way that will meet your needs for love and intimacy. Recognizing that your feelings of concern about resuming an active sexual life may be shared by your partner is a good starting point for discussion. Once you begin sharing your feelings, you may find that your partner has been holding back because of apprehension about appearing to be over-eager, insensitive or of hurting you physically in some way.

One suggestion to reduce nervousness when you first resume intimate physical contact is to set certain limits on sexual activity. You and your partner, for example, may choose to devote an evening to all-over body touching where each partner takes a turn touching and being touched. If this feels comfortable, then you can try adding some genital touching during the next session. If lack of sexual desire persists, androgens, which are sometimes referred to as "male hormones", can also be taken by both men and women to increase sexual energy. For patients who are not in a relationship, finding a partner and resuming sexual activity post-transplant may provoke a great deal of anxiety. Although the sad reality is that some potential lovers may reject you because of infertility or because you have had cancer, try not to limit yourself by not dating at all.

After all, almost everyone with and without cancer can get rejected for a multitude of reasons. Although you may avoid rejection by not dating, you may also miss the opportunity to build a happy and rewarding relationship.

Women and Sexuality

Sexuality post-transplant can also be affected by the effects of early menopause which can result from chemotherapy and radiation treatment. The symptoms of early menopause include hot flashes, vaginal dryness and tightness, as well as mood shifts and irritability. Not all women become menopausal. In some rare cases, women have regained ovarian function post-transplant and in some very rare instances, women have also regained fertility and given birth to healthy babies.

For most women who do experience early menopause, hormone replacement therapy is effective in alleviating many of the symptoms. It is also useful in reducing some of the risks associated with early menopause, such as osteoporosis (weakening of the bones). The use of estrogen creams applied directly to the vagina can be effective in improving vaginal dryness without having systemic effects. Women who experience vaginal dryness post-transplant may also find the use of a water-soluble lubricating jelly helpful. Other women may also experience painful intercourse because of vaginal graft versus host disease. This should be discussed frankly with your health care team. There are several interventions available:

> *Because my secretions dried up with the chemo-induced menopause, I have a difficult time sexually. My husband and I haven't stopped, but we must use a lot of lubricants, and some positions are quite painful.*

Acknowledgements

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National Marrow donor Program (NMDP)
World Marrow Donor Association (WMDA)
European Bone Marrow Transplant (EBMT) textbook for nurses