

SURVIVORS' GUIDE FOR BONE MARROW/STEM CELL TRANSPLANT



What to Expect and How to Get Through It

by Keren Stronach



***nbmt*LINK**

National Bone Marrow Transplant Link

ATTITUDE

The longer I live, the more

I realize the impact of attitude on life.

Attitude, to me, is more important than facts.

*It is more important than the past, than education,
than money, than what other people think or say or do.*

It is more important than appearance, giftedness or skill.

It will make or break a company...a church...a home.

*The remarkable thing is we have a choice every day regarding the
Attitude we will embrace for that day. We cannot change our past.*

We cannot change the fact that people will act in a certain way.

We cannot change the inevitable.

*The only thing we can do is play on the one string we have,
and that is our Attitude. I am convinced that life is 10%
what happens to me and 90% how I react to it.*

And so it is with you...

We are in charge of our Attitudes.

– Charles R. Swindoll

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This guide is dedicated to Josh, my family and all the people whose love and support carried me through the transplant process.

– KEREN STRONACH

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The information in this guide should not be construed as medical advice. Please consult with your physician regarding your medical decisions and treatment. The listed resources are not intended to be endorsements.

For additional copies of this booklet, contact:

National Bone Marrow Transplant Link

20411 W. 12 Mile Rd., Suite 108

Southfield, Michigan 48076

800-LINK-BMT (800-546-5268) or 248-358-1886

www.nbmtlink.org

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FOREWORD

There is a large community of bone marrow/stem cell transplant survivors who are now living full and rich lives. These people had to face many of the same tough decisions that you are facing. The following section describes their experiences, their difficulties, recommendations and insights.

Since each person's way of coping with the transplant varies dramatically, I have tried to provide an inclusive and comprehensive picture so that different people can find recommendations that speak to their temperament and personality. As you read this, it may be useful to keep in mind that some of the suggestions may be inappropriate for you. Adopt those that seem appropriate and ignore the others. In the end, there is no "right way" to go through a transplant. Each person must find what is most appropriate for him or her.

As the primary writer, I have undergone two transplants from an unrelated donor at the Fred Hutchinson Cancer Research Center. In addition to recounting some of my own personal experiences, I have included the experiences of 25 former transplant patients, each of whom took the time to answer an extensive questionnaire. Amongst the respondents, nine had an autologous transplant, ten had a donor who was a sibling and six had an unrelated donor.

This guide begins with a brief introductory section explaining some of the nuts and bolts of a bone marrow/stem cell transplant and follows with the transplant journey as seen through the eyes of those who have traveled this path before you. I hope you will find the collective experience of other survivors helpful in guiding you through the transplant process. I wish you a successful journey.

OVERVIEW OF THE BONE MARROW/STEM CELL TRANSPLANT PROCESS

When I was first told that I would need a bone marrow/stem cell transplant (BMT), I mistakenly thought that I would have to undergo some kind of surgical procedure involving my bones. In fact, nothing of the sort happens. The transplant procedure itself is a simple procedure, similar to a blood transfusion, and does not involve any cutting or stitching. In a transplant, high dose chemotherapy and, in some cases, radiation, is used to destroy cancerous or diseased cells in the body. In accomplishing this goal, the treatment also destroys a person's bone marrow, the site where stem cells are produced. Stem cells are the cells that give rise to the rest of blood cells. In order to restore the ability to make blood cells, a person must be given healthy stem cells to replace the stem cells in the marrow that were destroyed.

The bone marrow/stem cell transplant procedure was originally developed in the late 60's to treat cancers and diseases of the bone marrow. The idea was to destroy the diseased bone marrow with chemotherapy and radiation and then to replace it with a donor's healthy marrow. Since then the procedure has been refined and has been expanded to treat many other conditions, including cancers and diseases that do not involve the bone marrow. In the last few years, for example, transplants have sometimes been used to treat testicular and other solid tumors. In these cases, when the stem cells in the bone marrow are healthy, a person does not need to receive stem cells from a donor, but can use his or her own stem cells for the procedure. The type of transplant you will have depends on whether you use your own stem cells or the cells of a donor to replace stem cells destroyed by chemotherapy and/or radiation. Before undergoing transplantation, it is also important to look into some of the new and promising treatments that are under investigation.

One new development is a procedure called *non-myeloblastic stem cell transplant*, also referred to as a mini-transplant. As a result patients undergoing this type of transplant have far fewer side effects and do not experience the typical hair loss, mouth sores and other symptoms that are characteristic of conventional transplants. If further study proves promising, this type of mini-transplant may become more widely available. The mini-transplant and the experiences of those undergoing mini-transplants are not discussed in this guide. However, more information about this procedure can be obtained by calling the National Bone Marrow Transplant Link, which is listed in the Resource Listing.

The development of new drugs such as STI 571, also known as Gleevec, may make it possible for individuals with Chronic Myelogenous Leukemia to avoid undergoing a transplant altogether. At the time of this writing, Gleevec is being tested to determine its effectiveness in treating a number of different diseases.

Before deciding to undergo a bone marrow/stem cell transplant, make sure to inform yourself about treatment options and alternatives, get a second opinion,

weigh the benefits and risks of each treatment and then, armed with information, make the choice that is going to be best for your situation.

Autologous Transplant

In an *autologous transplant*, one's own healthy stem cells are removed and stored until the time of the transplant. Chemotherapy and, in some cases, radiation is then administered to destroy the diseased cells in the body. This treatment also destroys the stem cells in the bone marrow. The stem cells that were removed and stored before the treatment are returned to the patient at the time of the transplant to replace the stem cells that were destroyed.

Usually autologous transplants are done when the bone marrow is healthy and the disease lies elsewhere in the body. In some instances, however, autologous transplants are done even when the bone marrow is diseased. When this is the case, the bone marrow that is removed may be treated or purged to clear out cancer cells. Currently BMT centers across the country use different methods to purge marrow. It will be up to you and your physician to decide how your marrow will be treated if it needs to be purged.

Allogeneic Transplant

When a person cannot be his or her own donor and the stem cells need to be taken from someone else, the transplant is called an *allogeneic transplant*. If the donor is a relative, the transplant is called a related allogeneic transplant. If it is from an unrelated donor, it is referred to as an unrelated allogeneic transplant. To find a donor, you will need to have your blood tested and tissue-typed (not the same as blood type) so that it can be compared and matched to blood samples of potential donors. This is done through a test called the human leukocyte antigens (HLA) test which examines certain antigens or proteins on the surface of your white blood cells. These antigens serve as a kind of "fingerprint" and play an important role in the body's ability to distinguish between "self" and "other". There are several pairs of antigens that are considered important in determining the degree of fit between you and your donor. If you match your donor on these important sites, there is a good chance that your new stem cells will recognize you as self and will function effectively in your body. If you do not match your donor on these sites, the donor's stem cells may recognize certain organs or tissues in your body as foreign and may attack them. This is called *graft versus host disease* (GVHD). The more closely matched you are to your donor, the less likely you are to get GVHD.

Syngeneic Transplant

In a *syngeneic transplant*, the donor is an identical twin and the stem cells will be genetically identical to the stem cells that will be destroyed by the chemotherapy and/or radiation. In these cases, as in an autologous transplant, the patient does not get GVHD because the new stem cells are identical to the marrow that is destroyed.

The length of time you will spend in the hospital will depend in part on the

type of transplant that you have and the hospital where you are receiving your care. Nowadays many autologous and some allogeneic transplants are done on an outpatient basis. In some cases, however, autologous transplants may require a two to three week hospital stay and allogeneic transplants may require a hospital stay of three to five weeks or longer, depending on your condition and the specific procedures followed at your transplant center.

What is Bone Marrow?

Bone marrow is the spongy center of your bones where blood is produced. It is also the home of your immune system. Bone marrow contains the parent cells, called *stem cells*, that later mature into white blood cells (infection fighting cells), red blood cells (oxygen carrying cells) and platelets which aid in blood clotting. The numbers of your blood cells will be closely monitored throughout the transplant process. As your transplanted stem cells begin to produce blood cells, your blood counts will begin to rise and you will begin to regain your immunity, strength and energy.

White blood cells or *leukocytes* are cells which fight infection and comprise an important part of your immune system. When your white count is low, you are at greatest risk for infection. During the transplant, your white count will be carefully monitored. *Neutrophils* are a common type of white cell which play an important role in fighting infection. During the transplant, your medical team will be closely monitoring your neutrophil count, which is also referred to as your ANC (Absolute Neutrophil Count).

Red blood cells or *erythrocytes* make up about 45% of the volume of the blood in a healthy individual. Their function is to carry oxygen from the lungs to the rest of the body. Red blood cells transport oxygen on a molecule called hemoglobin. During the transplant, your hemoglobin levels will be monitored in order to determine your red blood cell level. If your hemoglobin falls below a certain level, you will need a red blood cell transfusion.

Platelets are essential in the process of clotting, thus preventing excess bleeding and bruising. When your platelet count is low, your risk of bleeding is high. Your platelets will therefore also be monitored to assess your risk of bleeding and to determine when a platelet transfusion is needed.

Once the stem cells in the bone marrow are destroyed by the chemotherapy and/or radiation treatment, you will no longer be able to produce life-sustaining blood cells unless you receive new stem cells to replace those that were destroyed. The stem cells will be taken either from you or from your donor and will be given to you once the chemotherapy/radiation is completed.

Methods of Stem Cell Collection

Stem cells, which are produced in the bone marrow, can be collected in a variety of different methods. Traditionally stem cells were collected from a large bone such as the hip bone. In this procedure, known as a bone marrow harvest, a needle is inserted into the marrow space of a large bone and stem cells are

removed directly from the bone marrow. In the last few years, *peripheral blood stem cell* (PBSC) transplants have become more common. In this case, the patient or donor donates stem cells that are collected from the circulating blood stream instead of from the bone. The collection of stem cells from the blood is done through a process called *apheresis*. In some cases, stem cells are collected from the placenta and the umbilical cord of a newborn baby. This is known as an *umbilical cord blood transplant*. Interestingly, this type of cord blood transplant poses a lower risk of graft versus host disease (GVHD) than other forms of transplantation when the stem cells are collected from the bone marrow or the peripheral blood.

T-Lymphocyte Depletion

In some cases, the stem cells that are collected undergo a process known as *T-lymphocyte depletion*. In this process, T-lymphocytes, a type of white blood cell, are removed from the stem cells before they are given to the patient. This is done to reduce the incidence of graft versus host disease (GVHD), which is caused by the new immune system attacking healthy cells in the patient because it does not recognize the patient as “self”. Removing the T-cells makes it less likely that the new immune system will mount an attack against the patient.

However, T-lymphocytes are also beneficial as they help the donated stem cells take hold or engraft, and they also play a role in reducing the risk of relapse. Although T-lymphocytes pose a risk to the patient because they attack healthy cells (GVHD), they also attack residual cancer cells in a process known as graft versus leukemia effect, thus reducing the risk of relapse.

There is significant additional information about the medical aspects of the transplant process. Some excellent sources of information are listed in the Resource Listing at the end of the guide. Here, my intention has been to provide only a brief overview of the medical aspects of the transplant process and to focus on the experiences and recommendations of survivors as they progress through the transplant. My hope is that by hearing their voices, you will feel less isolated in your journey and be able to utilize some of the coping tools and recommendations of those who have taken this path before you.

PREPARING FOR THE TRANSPLANT

Once the decision to undergo a transplant has been made, there are several important steps that can be taken to prepare for the experience. On an emotional level, preparing for a transplant may entail spending time with friends and family or taking time out to be alone to experience one's feelings regarding the transplant. On a physical level, this may include eating a healthful diet, getting good dental care and maintaining an exercise routine. On a practical level, it may mean choosing a transplant center, organizing caregiving arrangements and obtaining items for the hospital stay.

Emotional Preparation

Facing the prospect of a transplant can be devastating, evoking feelings of dread, panic, and helplessness. Coming to grips with the idea that you may have a life-threatening disease while simultaneously dealing with a tremendous volume of information and new medical jargon can be mind-numbing. As you prepare for the transplant, it is common to feel overwhelmed by emotions. During this time, you are likely to experience feelings of anxiety, self pity and self blame. It is also normal to feel betrayed by your body and feel anger and jealousy towards others who do not have to face the same ordeals that you face. At times, you may find that your feelings undergo intense fluctuations, alternating between hope, anticipation and fear.

Another reaction you may have is that of denial. You may find yourself responding to the situation by becoming emotionally numb and very task oriented. As you go through various emotional responses, be understanding and gentle with yourself. After all, you are facing some of the most stressful situations you will ever face.

The transplant may also be seen as a new lease on life and, as such, a source of great solace and hope as well as a great challenge to overcome. Radical alterations in emotions and moods, as well as periods of relative calm, are all part of the common ways of coping to the idea of a transplant.

How you choose to cope with the prospective transplant depends on how you perceive it, your feelings, your personality and your own individual way of coping. You may wish to take a highly active stance in the process and research all medical and alternative options or to hand over control to others, or do some combination of the two. Do whatever works for you. In the following sections you will find suggestions and strategies that others have found useful.

Express Your Emotions

If you are experiencing great anxiety or fear, give yourself permission to express these emotions so that you can process them. Choose to express your emotions to people who are personally meaningful to you and who can be supportive. If certain people are not helpful, don't feel guilty about avoiding them and focusing on your own needs. Seeing a professional therapist, particularly one who has had experience counseling people with life-threatening diseases, can be very helpful. One woman writes:

I saw a therapist to deal with all my feelings. I was honest about my fear of death and what it would do to others.

Another patient found it useful to face the issue alone before she included others:

I dealt with the news that I needed a transplant by giving myself license to take a break from everything and just cry and cry. I spent three days in my room just crying. Although I spoke to a few close friends and family members, more than anything I needed to be able to vent my feelings out alone. Only after processing it alone, was I able to really include others and get support from them.

A common theme that was reiterated by almost every survivor was the importance of honest open communication. In the words of one respondent:

It's important to let your family and friends know what you are going through. Let your feelings be known and it will make things a whole lot better.

Contact a BMT Survivor or Join a Support Group

Contacting someone who has undergone a transplant can be very helpful and calming. Here are the experiences of two patients:

I was put in contact with someone who had a transplant at Hopkins about a year before I did. She was a wonderful emotional support. She answered all my questions, made herself available any time of day or night (by telephone as she lived in another state), and let me rant and cry as needed. I couldn't have made it through the months leading up to my transplant without her.

I tried to locate as many people as I could who had experienced a transplant and found out all the information I could about it. Talking to others who had been through it was really helpful.

Contacting a transplant survivor can be done through the National Bone Marrow Transplant Link (nbmtLink), where you can call or email requesting to speak to a transplant survivor who has been in a situation similar to your own. A peer volunteer who has undergone a transplant will usually contact you within a few days. Another possibility is to ask a member of your medical team or your social worker to put you in touch with someone who has undergone a transplant. If you have a computer and a modem, an effective way to get in touch with many transplant survivors is by signing on to a computer mailing list that specializes in bone marrow/stem cell transplants or certain kinds of cancer. Please check the Resource Listing to find out how to sign on and how to contact a survivor. Remember the information on these sites may not always be accurate or apply to you.

Joining a support group where you can meet and openly share your hopes and fears with other individuals living with cancer can also be helpful. Sometimes, in the presence of others with cancer, it is easier to talk about issues that cancer brings up than with friends and family who may feel a need to protect you or who may feel uncomfortable or afraid of bringing up “negative” feelings. A group led by a skilled facilitator can provide a safe haven in which to explore feelings about cancer, life and death. Although talking about death can be scary, it can also provide relief to have a place to air one's emotions about these difficult issues and hear others express theirs:

Getting cancer has made me realize that I am mortal and it has been really helpful to have a support group where I can discuss my fears about death and all the emotions surrounding my vulnerabilities.

Explore Books and Tapes

Books describing the experiences of others with cancer can be particularly helpful, as can many of the “self-help” books about coping and relaxation:

To handle the emotional side, I cried a lot at first, but then I got my hands on all the positive books I could find—Where the Buffaloes Roam, Bernie Siegel books, Norman Vincent Peale, Robert Schuller. I was going into this with a positive attitude—which is very important. Also I listened to a Health Journey tape “Guided Imagery and Affirmations” every day. It would help me relax and fall asleep.

Reading autobiographies of others with cancer made me feel less isolated, less sorry for myself. It was comforting to know that others had gone through similar experiences, sometimes more difficult than mine.

Some survivors found that certain self-help books made them feel responsible for causing their disease. In reading these books, remember that you are not in any way to blame for your condition. Cancer is caused by complex reasons having to do with the environment, genetic, social and individual factors. Cancer can strike anyone. If a book you are reading makes you feel upset, put it down. You are not obligated to read a book just because a well-meaning friend has recommended it.

Reduce Stress

During this time, it might be helpful to think of ways that you can reduce superfluous stress in your life. Although you may not be able to avoid some of the factors that are stress producing, such as your diagnosis of cancer, there may be ways to cope with your stress. Establishing a clear set of priorities and letting go of less important obligations can reduce the amount of pressure that you feel. Some people find it useful to make a list of the factors contributing to stress and examining ways to reduce the pressures. One suggestion is to allocate tasks to family and friends who want to help. Some friends may be willing, for example, to help you gather information about different transplant centers or to help you find books and tapes about visualization or some other topic of interest.

Often people around you will not know how to help and will be grateful to you for providing them with concrete suggestions. Many of those who feel close to you are likely to feel helpless in the face of your diagnosis and impending transplant. Thus, by giving them concrete suggestions of things they can do, you may not only be helping yourself, but may be helping them as well. Here are the recommendations of two patients:

When people ask “What can I do” have a list of things you need help with at your fingertips and let them know specifically what they can do . . . be direct about what you need.

When people asked me what they could do for me, I gave them tasks. For example, there were so many books I wanted to read so I asked people to read them for me then to give me a summary.

Going on a meditation retreat or cancer retreat can also reduce stress. One patient writes:

I went to a one day workshop with Bernie Siegel that was helpful and also

attended a two day meditation retreat which did a lot to calm and relax me.

Another patient writes:

Before the transplant my husband and I participated in a holistic health program through the Cancer Support and Education Center in Menlo Park. The ten week course helped me to gain emotional strength and to better understand my immune system.

A different patient who was frustrated by the endless questions of her friends and family solved the problem by doing the following:

I made copies of some of the information [about my condition] and I gave this out to friends and family so they'd understand it better and quit bugging me with endless questions!

Sometimes continuing with your normal routine is the most effective way of reducing stress. One patient wrote that for her “just keeping our life pretty normal helped us cope.”

Practice Relaxation Techniques

Practicing stress reduction techniques that feel nurturing such as muscle relaxation, meditation, hypnosis or imagery may be helpful to you. Some people find that meditation reduces their level of anxiety and is helpful in combating depression as well as lowering their level of discomfort and pain. Those of you interested in finding out more about stress reduction techniques can find a list of recommended books in the Resource Listing.

Get in Touch with Your Spirituality

Spirituality can also be an important source of comfort during this period. Many patients report that prayer and/or meditation can be a source of support and psychological well-being:

Prayer, as mundane as it may sound, proved to be the most sacred form of emotional support for me. I suppose it was because many times it was difficult for me to articulate my most intense fears to others, but in my quiet meditations, when I sat with my most intense fears, I felt a higher power comfort me, and I don't think one has to be religious to feel this presence.

The best way to cope with all these afflictions, is to thank God and the doctors for another day of precious life, and to keep in mind that it will get better.

Only my wife's support and prayer to God really helped.

Participate in Activities You Enjoy

Reducing stress in your life can also be accomplished by incorporating activities that you find most relaxing, healing and fun. Here are the accounts of two transplant survivors:

To cope emotionally, I stopped working three months before the transplant thanks to the generosity of my co-workers who donated sick leave to me; spent a lot of time with my family; pampered myself and was pampered by my husband, parents, sister, and brother, who was my donor; went to Maui

for ten days one month before the transplant.

My husband and I watched as many humorous shows as we could and kept a full social schedule so that our lives could remain as normal as possible.

Explore Creative Outlets

Finding creative outlets for one's feelings or creative ways to feed feelings of hope can also be an effective way of coping with emotions and reducing stress:

I responded to the news that I needed a transplant by venting my emotions in poetry and art. I also had an "art party" in which I invited my close friends to draw positive posters about the transplant. Everyone made beautiful "Transplants Cure People" posters which I hung up in my room and later in the hospital.

I kept a journal beforehand . . . expressing my feelings. I also wrote meaningful quotes for myself and wrote letters to loved ones.

In addition to writing a journal, you may wish to keep a notebook handy to record important information and phone numbers, particularly since during times of upheaval, it may be more difficult to keep everything in mind.

Put Your Legal and Financial Affairs in Order

Taking care of loose ends and putting one's affairs in order does not necessarily signify an anticipated negative outcome. Sometimes, by dealing with difficult issues that may come up in the event of one's death, it is possible to put these issues aside and focus on more positive things. One patient writes that to cope emotionally he did the following:

I made efforts to put my business affairs in order, made final arrangements with the Neptune Society in case I didn't make it, notified my clients that I intended to resume my service to them when I recovered after being out of circulation for a while. All of this was necessary before I could fully concentrate on the ordeal and recovery.

Another woman expressed this as follows:

To cope emotionally, I put all my financial affairs in order with an Estate Organizer I bought. I also dealt with some issues between my children . . . and myself about events that had occurred in their lives—divorce, etc.

Putting together a Living Will stating your desires in the event that your medical situation deteriorates is also important. Your social worker or physician may be a good resource to help you articulate your desires regarding critical care. Knowing that these issues are addressed beforehand can help you set your mind at ease and may also reduce pressure from family members who may feel uncomfortable about bringing these issues up for fear of distressing you or seeming to be overly negative.

You should also consider taking advantage of your benefits options such as Social Security Disability Benefits or the possibility of *viatication*—a process in which you can sell your life insurance as a way of helping you pay for medical

and other expenses. Also be aware that as someone with a cancer diagnosis, you might be able to cancel student loans or get financial aid from certain organizations to reduce financial pressures post-transplant. Information about these and other resources can be found in the Resource Listing.

Don't Take People's Reactions Personally

People who are close to you may be undergoing a lot of emotional turmoil themselves as a result of your diagnosis. They may feel helpless and panicked and may not know how to reach out and communicate. You may feel abandoned at times or feel very angry with loved ones for not comprehending your needs. These emotions are understandable and normal. However, it may be useful to remember that everyone involved may need some extra understanding and compassion during this difficult period. In some cases, friends or family members may withdraw, not because they don't care, but because they are too overwhelmed by their own feelings of fear, helplessness and uncertainty as to how to treat you. If you do get some unexpected reactions from loved ones, remember that their reactions probably have a lot to do with their own feelings. One patient advises:

Communicating with family members is very important, so keep the channels open. They need to know what you are doing and you need to know what they are doing. I guess that the art of compromise is heightened while everyone is getting used to having a person with a serious illness in their midst. We who are ill need to do some compromising too.

Seek Medical Information

Seeking medical information can sometimes reduce fear and help people regain a sense of control. This can be done through library and electronic research, by talking to doctors, former transplant patients, by visiting transplant centers, and by calling different cancer organizations that have knowledgeable people who can respond to your questions and concerns. For more information about such organizations, please consult the Resource Listing.

In seeking out information, remember that it is always appropriate to seek a second or even third opinion. Most doctors expect you to get a second opinion, and they will not feel hurt by your decision to do so. When, where and how you will be transplanted may prove to be the most important decision of your life, and you have every right to seek a number of medical opinions:

When I was diagnosed, my whole family and I went on an information-seeking mission. We called doctors all over the country, explored various medical options, and found out as much as we could about the different transplant centers.

When consulting a physician, don't hesitate to ask for information a second or third time. Having a close friend or family member attend doctor's meetings with you can be useful as it will allow you to review the information with someone else and to confirm that you understood the information correctly. Taping the medical sessions can also be helpful.

Take Time for Yourself

Often, in times of stress, people become forgetful or experience mood swings. In this difficult period, take time to extend understanding and compassion to yourself. Give yourself permission to change your mind, to take things one day at a time, to pamper yourself and to feel sad. By taking the time to re-evaluate and to make changes in your life, you may find that some of the best parts of your life may be expanding during the time when you are facing the worst trauma of your life. Allow yourself to think deeply about who you are and what matters to you so that you can prioritize your life and expand those areas that are most meaningful to you. Try as much as possible, not to give up hope. In the words of Michael Lerner, “Give yourself permission to hope, even in the face of all the statistics that physicians may present to you. Statistics are only statistics. They are not you. There is no such thing as false hope.”¹ A wonderful essay by Stephen Jay Gould titled “The Median is Not the Message” speaks to the way in which statistics can falsely rob us of hope, while at the same time explaining the importance of correctly interpreting statistics.² Keep in mind that being hopeful does not mean that you need to be positive all the time. You are still entitled to “bad” days.

Telling Your Children

Telling your children about the need for a transplant can be a difficult and delicate process. Depending on their age and temperament, children will react differently, responding with denial, fear, anger or acceptance. Generally it is not a good idea to keep the situation hidden from them as they will often be aware that something is wrong and may blame themselves. It is not uncommon, for example for young children to think that their actions somehow caused a parent or a sibling to get cancer. It is, therefore, very important to remove any blame. Assure them that nothing they or anyone else did caused the cancer. For a very young child saying something to the effect of “Dad is very sick and has to go to the hospital so that the doctors can help make him better” may be enough. For older children a more extensive explanation is better. One woman who had just been diagnosed with CML handled the situation as follows:

I discussed with my doctor ways in which I could tell my teenage daughters (12 and 16). She suggested while we were still in the initial stages of testing to say “there are a few things that this could be, an infection, a blood disorder and possibly leukemia.” This gave my daughters a few weeks to process this life changing information. It also provided an explanation for my anxious behavior.

When you explain the situation to them, try to the extent possible, to balance optimism and pessimism. Telling them that the person will be completely better after the treatment may make them confused and upset if that turns out not to be the case. However, it is important not to scare them with a lot of pessimistic

1 Michael Lerner, *Choices in Healing*, MIT Press, Cambridge, Massachusetts, 1994, p. 7.

2 Stephen Jay Gould, “The Median is Not the Message,” *DISCOVER/JUNE 1985*, also available on www.cancerguide.org

information. Try to present the information realistically but in the most hopeful light that you can. Reassure them that the family member needing the transplant will be getting the best care possible at a transplant center with state-of-the-art equipment and excellent physicians. Utilizing the help of professionals to answer their questions can also be helpful:

When the transplant was decided upon, we took our children to my doctor and she explained the process and answered all their questions. We also utilized a trusted family therapist to provide our children every outlet for their fears and concerns.

In your discussion, it is important not only to communicate information, but also to listen and acknowledge your children's reactions and feelings. Let them know that their feelings—anger, sadness, fear and confusion—are normal, and that you also share some of these feelings.

You may also want to make sure that they know that cancer is not contagious. Some children may fear that someone else in the family will “catch” it, and so it is important that they understand that this is not the case.

Explaining the treatment is important since the greatest fears often spring from the unknown. Let children know about the transplant process and prepare them for some of the possible side effects such as the loss of hair or other physical changes. Let them know that once the family member is well again these changes will generally reverse themselves. You might also consider taking them to see the transplant facility if possible.

Finally, answer the questions as honestly as you can. If the child asks questions you don't have answers for, do not be afraid to say “I don't know”. Generally the amount of information you give is less important than the manner in which you convey the information. To the extent possible, try to provide an environment where it is okay to talk about and ask questions regarding cancer and the transplant process.

Making Your Hospital Stay Easier for Your Child

Before heading to the hospital, you can do a few simple things that might make your absence easier on your children. Some suggestions include reading a favorite story into a tape recorder so that your children can listen to the story and hear your voice anytime they want. Giving your children a piece of your clothing to sleep in such as a T-shirt, can also provide them with a sense of comfort. Preparing some pre-addressed envelopes to take with you to the hospital with note cards to send home on a daily or weekly basis can make it easy to communicate with your children and remind them of your love. On days when you are feeling too tired, you can simply draw a heart and drop it off in the envelope to send home.

Physical Preparation

Exercise

Many people undertake some kind of regular exercise routine to improve their physical conditioning in preparation for the transplant. The extent and rigor of

the exercise you choose will depend in part on your general activity level and physical condition. Some people will be able to exercise vigorously whereas others may choose very moderate exercise routines involving just short walks or stretches in bed. One survivor writes:

Physically, I felt like I was in training for a marathon. I thought that the better physical condition I was in when I went in for my transplant, the better chance I had for survival. I walked several miles every day and in the summer I swam laps at the pool.

Another person writes:

I was determined to be in the best possible shape for the transplant. I exercised religiously, going on long hikes in nature. I undertook several long back packing trips as I love to be outside and wanted to get as much of the outdoors as I could before I was going to be enclosed in a hospital room.

Others said that exercise became important “even if it was just a walk or fifteen minutes on a treadmill.” Ideally, you should find some kind of exercise you enjoy. Joining a gym or finding friends who enjoy similar physical activities may be helpful. In addition to conferring physical benefits, exercise may be a helpful way to channel stress and promote general well-being.

If your medical condition does not allow you to undertake a rigorous exercise routine, be aware that many people enter the transplant in poor physical shape and do extremely well. To the extent that exercise is an option for you, consider doing some mode of exercise suited to your medical condition.

Nutrition

Eating a healthy diet and meeting your basic nutritional needs is important prior to transplant. Intuitively, we all know that a well-nourished body fights infection, aids healing and deals with the demands of very aggressive treatment protocols better than a poorly nourished one. It is beyond the scope of this guide to discuss in detail the different alternative nutritional therapies. The recommendations vary from that of the American Cancer Society which is described below, to the macrobiotic diet which entails eating primarily cooked foods, to diets using nutritional supplements, etc. When considering an alternative diet, do some research to ensure that it provides all the necessary nutrients and then discuss it with your physician. Unless you are severely obese, it is not advisable to undergo rapid weight loss immediately prior to treatment.

Generally the guidelines for maintaining good health, as recommended by the National Academy of Sciences and the American Cancer Society are as follows:

- Reduce dietary fats to less than 30% of total caloric intake.
- Eat plenty of fresh fruits and vegetables daily, particularly citrus fruits, green leafy vegetables, and carotene rich vegetables such as carrots and squash.
- Increase intake of certain fibers such as wheat bran.
- Consume alcohol in moderation, if at all, and completely refrain from smoking.

- Maintain your weight within normal range.
- Minimize your consumption of salt-cured, salt-pickled, and smoked foods.
- Cut your consumption of red meat. Protein alternatives include seafood, skinless poultry, legumes, tofu and low fat dairy products.

For some, the transition to a healthier diet is relatively easy; for others, it may require significant changes in eating patterns. If you are unfamiliar with a low fat diet, read some of the excellent vegetarian cookbooks that are widely available, consult with a dietitian, or ask your friends for good recipes. Taking time to find restaurants in your area that cater to customers interested in a low fat healthy diet may also be helpful.

Dental Care

Good dental care prior to transplant is an essential part of your overall preparation for transplant. Healthy gums and teeth prior to transplant can eliminate potential infections and some of the painful mouth sores that may develop during transplant. Meticulous mouth care prior to and during transplant can also provide protection against infections by limiting the number of open sores in the mouth. Taking care of lingering gum and tooth problems is also important because it is strongly advised that you refrain from any routine dental care for some time after your transplant until your immune system is fully functional again.

Ideally, mouth care should start at least two or three months prior to the transplant. When you visit your local dentist, explain the reason for your visit and the importance of getting your teeth and gums in the best possible shape prior to the transplant. Before initiating treatment, your dentist should contact your oncologist to discuss your medical condition and to determine whether you will need antibiotics or other precautionary measures before treatment. During this time, broken or problematic teeth should be removed or repaired. If you have braces, they should be removed and loose or poorly fitting dentures should be adjusted.

To have your mouth in the best shape possible before the transplant, you will need to adopt good personal oral hygiene. This may entail regular flossing and brushing as well as utilizing antiseptic mouth rinses. Before taking on a rigorous dental regimen of your own, however, it is a good idea to consult your dentist, to review the correct way to floss and brush your teeth, and to request a recommendation for a good toothbrush and mouth rinse.

Fertility

People undergoing treatment with total body irradiation and some forms of chemotherapy have a high risk of becoming infertile. If you are considering having children after the transplant, you may consider undergoing fertility treatment prior to receiving chemotherapy. For males, sperm banking is a possibility. This entails contacting a sperm bank in your area and freezing and storing sperm for use post-transplant. For women the process is more complicated. It requires them to freeze their fertilized eggs. In this process, women undergo hormonal treatment to induce ovulation. Once the eggs mature,

they are surgically removed, fertilized in a test tube with sperm, and then frozen for later implantation. Since the procedure is time consuming, it should be undertaken well before the transplant date. Before undertaking these procedures, anyone should make sure that their medical condition allows for the procedures involved.

At the time of this writing, new techniques are being developed that may allow women to freeze their eggs, and later thaw and fertilize them. There is also a new and still experimental option for women to freeze their ovary or a portion of it prior to transplant and to have it reimplanted post-transplant. It is possible that such a procedure may allow women who do this to regain ovarian function post-transplant and thus avoid the risks associated with early menopause. For more information about fertility clinics, please see the Resource Listing.

Although the majority of people undergoing a transplant will lose their fertility, some patients may in rare instances regain fertility.

Practical Preparations

Choosing a Center

Choosing a center is complex, and your choice may have to do with a combination of factors including the track record of the center, where you feel most comfortable, your support network, your finances as well as other personal factors. One important factor to consider is the size of the transplant center, the number of transplants performed for people with your condition and age group, the survival rates, and the experience of the doctors and staff. There are distinct advantages to having the transplant at a large experienced center with an excellent track record. If you have such a center close to home, the choice of where to do the transplant will be easy. If, however, this is not the case and there is no center near your home or it has a poor track record or has performed fewer than ten transplants of the kind you need, the choice may be more difficult.

Undergoing a transplant at a large transplant center with a good track record and a great deal of experience provides you with a sense of security that the physicians and staff will be able to handle unexpected complications if they arise. Bigger centers may, in some cases, also have the advantage of having access to large blood banks that can cater to the needs of transplant patients. However, large research centers may have the disadvantage of being more impersonal than small centers.

Having the transplant at a center close to home allows you to be close to family and friends and to have a stronger support system on hand. You will also save on travel expenses and will not have to deal with the hassle of moving to an unfamiliar place. Your life and the life of your caregiver will be less likely to be disrupted, and you may have the advantage of already being familiar with some of the doctors and staff.

Calling the National Marrow Donor Program (NMDP) to get a listing of transplant centers is an excellent way to get initial information about different centers. The NMDP guide contains phone numbers and addresses of most

transplant centers with information about the number and type of transplants performed at each center as well as some statistics about survival rates at each center. Contact the BMT Infonet for similar data.

In looking at these statistics, you need to be aware that the general statistics often include all categories of age groups and diseases and thus may be inapplicable to you. In order to really compare survival rates of different transplant units, you need to ask about the survival rate for your age group, your illness and the type of transplant you will undergo. Getting this information may be a difficult and frustrating process as some centers are reluctant to disclose this information. Since gathering this information can be stressful, you may consider recruiting friends or your doctor to help you with this task.

Signing on to bone marrow transplant information bulletin boards or online support groups on the Internet can be another useful way to get information. Many transplant survivors read these boards daily, answer questions and share information about their experience. Information about signing onto the Internet can be found in the Resource Listing.

Calling different centers to ask questions can provide useful information and give you a better sense of the transplant center and its atmosphere. Things you may wish to inquire about include the following:

1. How many transplants has the center completed for people with your specific condition? (Ideally, you should undergo a transplant at a center that has done at least ten transplants of the type that you need).
2. Are you going to have the same staff treating you throughout the transplant? (Most transplant centers have doctors and physician assistants rotate on a regular basis).
3. Will you be allowed to go outside, walk in the halls, or will you be confined to your room?
4. Will you have access to an exercise machine? Will you be visited by a physical therapist?
5. Will you have access to a social worker or counselor during the transplant?
6. Can the hospital accommodate your dietary needs? Can you ask for food at any time of the day or do you have to order it a day in advance? Are you allowed to eat raw fruits and vegetables? (Having a flexible eating schedule can be helpful as you may be nauseated and may not want to eat during conventional mealtimes).
7. What is the average time that the nurses have worked in the BMT unit?
8. How experienced are the physicians at the center and are there specialists available to handle complications should they arise?
9. Is there a support group for patients or their families?
10. What is the survival rate for patients with your condition in your age group undergoing your type of transplant?
11. How does the staff feel about patients putting up "Do Not Disturb" or "Please Knock" signs on the door?

12. Could someone who has undergone a transplant at the center contact you to tell you about their experience?
13. What is the visitor policy? How flexible is it? (Having your caregiver stay at the hospital overnight can be very comforting).
14. What living arrangements can be made for you and your family if you need to move away from your home to the transplant center? What will the cost of the living expenses be?
15. Can the center provide any assistance to defray some of the family's expenses?
16. Does the center have a long-term follow-up clinic that is easily accessible and will respond to questions once you leave the transplant center? (This is particularly important if your oncologist in your area of residence has very little experience with transplants).
17. Individuals undergoing a transplant from an unrelated donor should also inquire whether the center has a donor search coordinator and a quality tissue typing facility.

Visiting the transplant center before the transplant to familiarize yourself with the transplant setting and some of the staff is often comforting. While you are there, you might inquire if you can speak to patients undergoing transplants at the center to get their impressions, feedback and tips. One woman who did this, writes:

I remember visiting the BMT floor shortly before my transplant and being introduced to a woman who was on day 7 post-transplant. She was sitting on the bed, laughing profusely with two good friends. To me she looked like the picture of health. When I spoke to her, she assured me that she was feeling a lot better than she had expected. My visit to her did a lot to alleviate my fears.

If you need to travel to your transplant center, you may save money by contacting companies that provide discounts for medically necessary travel. Most of the major national cancer organizations will have information about these companies. Sometimes airlines will also provide discounted fares for patients and their caregivers. Organizations, such as The Leukemia & Lymphoma Society and Cancer Care will also often reimburse some travel expenses to and from medical centers. Please check the Resource Listing for more information.

Caregiving Arrangements

During the transplant, you will need at least one family member or a friend who can provide you with emotional and physical support. This person is often referred to as a caregiver. In many cases, it will only be possible for you to have one caregiver with you. If this is the case, you may consider arranging occasional visits by other family members or friends who can provide additional support during weekends so that the caregiving task does not fall on just one person. Ideally, however, you will be able to arrange to have more than one caregiver as the role can be very demanding. One woman who only had her mother as her primary caregiver while her husband continued to work and do household tasks commented:

In retrospect, I think both my mother and my husband were taxed beyond their limits. Though they didn't complain, I think it was a Herculean task they each assumed. I'm not sure what we could have done to improve the situation—it might just have been another one of those "tunnel situations" where one just has to keep putting one foot in front of the other to get through that tunnel.

Another man writes:

I did not like the fact that all of the burdens were on my wife. I worried about her as much as I worried about myself. All the extra worry, work and travel to and from the hospital each day was wearing her down. . . . This made me fight harder to get well faster so I could take over my part of our life together.

Even though many people successfully make it through the transplant with only one caregiver, having two or more caregivers is a real plus. When there are two or more caregivers, each one can have time to rest and can return to the hospital more refreshed. Having more than one caregiver is also helpful as it allows you to share your feelings and experiences with more than one person. Since caregivers often experience a high degree of anxiety, sharing the responsibility of caring for you can serve to alleviate some of the tension. Finally, having more than one caregiver provides a safeguard in the event that a caregiver gets sick and is unable to visit.

In organizing caregiving arrangements, think about the number of caregivers you would like to have. Some patients feel comfortable with many people, drawing support from visits of friends and relatives, whereas others prefer to see only few close relatives. One patient described her caregiving arrangement as follows:

I had four caregivers—my parents, my boyfriend and my cousin. One of my parents or my cousin would generally spend part of the morning and early afternoon with me and then my boyfriend would arrive in the early evening and spend the night in the room on a folding camping cot he bought to use in the hospital. He would generally stay until the doctors finished their rounds in the morning. Having him there during the morning rounds was very helpful because he would bring up issues and questions that I would forget to ask. Also it gave me the opportunity to discuss the medical issues with him and make sure that we both heard the same things. This system worked very well as it meant that no one caregiver was overburdened. Having different people was also great because I got a different kind of support from each of them. At times, though, having four caregivers was a little excessive as I felt pressured to see them all and give each of them equal time and attention.

Another patient writes:

There were several instances when one of my caregivers thought they might

have a cold. Knowing that there were other people there to take their place was comforting for all of us.

Considerations in Selecting a Caregiver

The most important consideration in selecting a caregiver is to make sure that your primary caregiver is someone who cares deeply for you and is someone you feel comfortable with. Other things you may wish to consider include whether or not the caregiver will feel comfortable in the hospital environment. It may be useful to think of caregivers with complementary skills. One caregiver may be better at listening and giving emotional support whereas another may be good at assisting in organizational tasks and helping with medical care. Do not be concerned if your caregiver is unfamiliar with some of the tasks he or she will be required to do. Most transplant units have workshops to train caregivers in necessary skills and are also able to provide additional help with certain tasks for those who need it.

Likely Responsibilities of a Caregiver During and Post Transplant³

The responsibilities of the caregiver may include the following:

- Providing emotional support
- Providing physical care during and post-hospitalization
 - care of the central line
 - helping the patient with the administration of oral medications
 - recording the medications taken
 - giving intravenous fluids and medications using a pump device
 - identifying changes in the patient's condition
 - obtaining medical care if needed
 - reporting symptoms to health care staff
- Gathering information
- Keeping family members and friends up-to-date about the patient's condition
- Monitoring the number of visitors
- Maintaining a clean home environment after hospitalization
- Preparing food
- Providing transportation to and from the hospital for follow-up care

What to Take With You To The Hospital

Bring whatever comes to mind, taking into consideration your hobbies and activities. Keep in mind that you will generally have less energy than usual, and it may, at times, be difficult to concentrate on doing all your usual activities. The following section provides a list of items that various patients have recommended to bring to the hospital.

- Answering machine—Having an answering machine is extremely useful as it allows you to screen calls while resting. It also enables you to leave a

daily message with an update of your condition for concerned friends and relatives who call in.

- An extra phone for caregivers and guests—During the time that your counts are low and you are vulnerable to infection it is nice to use your own personal phone and have guests use a separate one. In this way you are secure in the knowledge that the phone you are using is always clean.
- Address book and telephone numbers
- Favorite pictures and photographs to make the room feel comfortable and familiar
- Comfortable shirts and sweat pants—It is good to get materials that can be easily washed and put in the dryer. Also make sure to bring some warm button-down overshirts as it is fairly common to feel cold during the period of immuno-suppression even when the environment is warm. Button-down shirts will provide easy access to your central line, which is a small flexible tube in your chest that will be used to administer blood products and medications.
- Front buttoning pajamas (rather than nightgowns), as they allow you more modesty and provide easier access to your central line
- Comfortable walking shoes (Birkenstocks are great!) or slippers
- Many warm comfortable socks
- Portable PC computer to communicate with relatives, friends or work associates. Check with your transplant center to see if portable computers are permitted in the hospital room.
- Art materials (paints, needlework, knitting)
- Puzzles and games (scrabble, backgammon, crossword puzzles)
- Hats, scarves, wigs, turbans—even if you end up loving your bald head, it is nice to have some cozy warm covering.
- Something to make you laugh, such as a funny book or wig
- A tape deck or CD player with music or relaxation tapes you enjoy
- Good books or magazines—Books that can be read aloud by a caregiver are fun. Magazines and poetry books are also good options as they can be read at various intervals and do not require much concentration and long term memory.
- Paper, cards and pens to write letters
- A notebook—to jot down your feelings and experiences. Or use the notebook as a place to write notes to your family, taking it back and forth between the hospital and home as a place to exchange messages.
- Pre-addressed stamped envelopes to send home, particularly if you have small children
- A musical instrument for those who like to play music
- A camera

One survivor prepared for her transplant by creating a “chain of love” in the following manner:

In preparing for my hospital stay for my bone marrow transplant, I was concerned that there would be people that visited me that I would not remember had come. Also I knew that it would be helpful to me to have a constant reminder of all those who were praying for me and thinking of me. So, before my admission, I precut strips of multi-colored construction paper and got together a basket of markers. I set this in my room under a poster that instructed my visitors to write me a little note on a strip of construction paper; sign it, date it and staple it onto my growing chain of links. As my chain of support and love grew each day, so did my stem cells. On discharge day, my chain almost circled my entire room. Today, my links are carefully cut apart and compiled in a book which serves as a memoir of the beginning of my life as a cancer survivor.

THE TRANSPLANT PROCESS

Moving to the Transplant Center

Starting the treatment may evoke strong emotions. Your length of stay in the hospital will vary depending on the type of transplant you will be undergoing and your overall physical condition. In some cases the entire procedure is done on an outpatient basis and you will not be required to stay in the hospital overnight.

Patients undergoing a transplant from a donor can generally expect to stay in the hospital for four or more weeks and will need to stay in the area of the transplant center for approximately 100 days after transplant. Patients undergoing autologous transplants generally have shorter lengths of stay and, in many cases, have the entire transplant done on an outpatient basis.

The Hospital Environment

In the following section, you will find a description of a typical day during your transplant stay. It is very likely that the specific times and the details of the routine at your hospital may vary from the one described. The specific times of the activities mentioned, however, are not so important. The main point to note is that the days at the hospital are often full of activity. People will be coming in and out of your room throughout the day to check on you, to check medical equipment and to clean the room. When your energy level is low, interacting with the various members of the hospital staff that come in and out of the room and keeping up with the requirements for personal hygiene and exercise can take up a lot of your time and energy. Nevertheless, it is a good idea to have things available to do that you enjoy for the periods that you are alone and have free time and energy to spare.

A Typical Hospital Day (schedules will vary depending on patient's condition and medical regimen).

4–6 am: A nurse enters the room to draw daily routine blood tests.

7 am: A nurse aid checks daily weight.

8 am: A nurse comes in to take vital signs (every four hours).

8:30 am: Doctors and various team members enter the room for daily rounds.

9 am: Breakfast

11 am–3 pm:

- A person from housekeeping staff cleans the room.
- A nurse aid or nurse changes the bed.
- A physician assistant comes by to review general medical condition.
- Various people from the hospital staff come in to replenish the medical supplies in the room and check the status of the medical equipment.
- A nurse comes in at various intervals to administer medication, blood products and check vital signs.
- Once a week, patients are required to have a routine chest x-ray.

Lunch

4 pm: Vital signs are taken and medications replenished.

6 pm: Dinner

10–10:30 pm: Bedtime preparations

12 am: Vital signs are taken.

Various medications are administered throughout the night, either orally or through the central line.

Tip: Organizing a daily schedule of activities can be helpful. In addition to keeping you occupied, a daily schedule can motivate you to keep up important daily activities such as exercising and showering. During the day, you will also have the opportunity to watch movies, walk around the halls, have guests and rest. If the hospital schedule clashes with your desired schedule, discuss your preferences with a nurse to see if you can be accommodated.

Steps Through the Transplant

The Medical Evaluation

Upon your arrival to the transplant center, you will often undergo a general medical evaluation involving a physical exam and some lab and diagnostic tests to make sure it is safe to go ahead with the transplant and to provide a baseline for future comparison. These tests may include an eye and dental exam, heart and lung studies, a bone marrow aspiration, a spinal tap, a chest x-ray, as well as other tests. In certain instances, these tests may reveal certain underlying problems which need to be taken care of prior to the transplant.

Signing Consent Forms

During this period you will also be required to sign one or more consent forms for the transplant procedure. The consent form is a legal document which ensures that your physician has informed you of serious medical complications that can occur during and after your transplant. Therefore, be forewarned, the consent form often lists some of the most frightening and unsavory complications that may arise from the transplant, even those that may be quite rare.

If you are having your transplant at a large research institution, you may be asked to participate in several research protocols. Remember that you are entitled to do what is best for you and have no obligation to participate in a research protocol or clinical trial if you feel hesitant about doing so. If you are undecided as to whether to participate, consulting a physician from a different institution can be helpful.

Central Line

Before your transplant, you will have a small, flexible plastic tube inserted into the large vein above the heart. This is called a *central line*, *central venous catheter* or *Hickman catheter*. The central line is a highly useful device that allows blood samples to be withdrawn and drugs and blood products to be given painlessly. The procedure for installing the central line generally requires local anesthesia. For many patients this is a relatively simple and painless procedure whereas others find it more painful and difficult:

I found the fear associated with waiting for the placement of the catheter much worse than the procedure itself. I don't remember any part of the procedure and only had mild pain once the anesthesia wore off.

Bone Marrow or Stem Cell Collection

If you are having an autologous transplant, you will be your own donor and will have your own stem cells or bone marrow collected. If you are getting marrow from a donor, your donor will undergo the stem cell or bone marrow collection.

Bone marrow contains a high concentration of stem cells—the cells that give rise to all the cells that make up your blood. A small number of these stem cells are also released into the blood stream. Stem cells can, therefore, be collected either directly from the bone marrow or they can be obtained from the blood stream.

Bone Marrow Harvest

If stem cells are collected from the bone marrow, you or the donor will have to undergo a surgical procedure in which a needle is inserted into the hip bone several times. Marrow rich in stem cells will be withdrawn and stored until the time of the transplant. During the time of the surgery, you or your donor will be anesthetized and will not feel any pain, although the area of the surgery may be sore for a few days following the procedure.

Peripheral Stem Cell Collection

Stem cells can also be collected from the blood stream. The stem cells in blood are called peripheral blood stem cells. Like stem cells inside bone marrow, peripheral blood stem cells are able to make red blood cells, white blood cells, and platelets. Since the blood stream only has a small number of stem cells, you or your donor will need to take a daily injection to increase the number of stem cells in your blood. Once there are enough stem cells, they will be collected by a process called apheresis. In this process, blood will be withdrawn from a central

line and circulated through a cell separator. If your own stem cells are being collected, they will be stored until the time of transplant and given back to you. If stem cells are collected from a donor, the collection takes place the same day you receive the cells.

This process takes between three to four hours a day. Generally one to three days of pheresis are required to obtain an adequate number of stem cells for transplant.

Patients generally experience little, if any, discomfort during the pheresis procedure. Others experience numbness or tingling in their fingertips or toes, hand or leg cramps, lightheadedness, dizziness or chills. All of these are easily corrected.

One patient describes the experience as follows:

It was a walk in the park. They just hooked me up to the machines, fiddled a little here and there, and I didn't feel a thing... Once I was hooked up, it was just fascinating to watch the blood being separated and the stem cells being taken out.

Conditioning (Chemotherapy Treatment and/or Radiation)

The next stage of the transplant is *conditioning treatment* (also called preparative regimen), which involves several days of chemotherapy with or without radiation. The type and amount of chemotherapy and/or radiation you receive depends upon your disease and the type of transplant you are having. Regardless of your exact treatment protocol, the goal of the conditioning treatment is to destroy all the cancerous cells in your body.

The chemotherapy is often given through your central line and, in some cases, orally. Generally you will not feel anything during the administration of chemotherapy, but will experience the side effects later.

Many people fear undergoing the radiation treatment. The treatment itself, however, is painless. If you are anxious about the treatment, you may consider using the following strategies:

During the radiation, I found it helpful to relax, breathe and imagine the radiation rays killing the cancer cells and not hurting other cells.

I took music to the radiation room and pretended that it wasn't happening and that I was somewhere else.

The effects of the conditioning treatment range from mild to severe. Common symptoms resulting from chemotherapy and radiation include nausea, vomiting, diarrhea, hair loss, fatigue, loss of appetite and mouth sores. Some people develop all of these conditions whereas others develop only a few of them.

The conditioning treatment may also irritate the bladder and cause bleeding. Bladder irritation can be prevented by inserting a catheter through your urinary tract into your bladder and flushing out the bladder. Some people do not like the catheter, and should know that bladder irritation can be prevented through the

simple administration of medication. If you prefer to take medication rather than to have a catheter, let your medical provider know.

The Transplant

The day of the transplant is an exciting day that offers a chance at new life. However, the procedure itself is surprisingly simple, and, the experience of actually getting the transplant is often described as being anti-climactic. A bag of bone marrow or peripheral stem cells is infused through your central line just like any other blood product or medication. The stem cells migrate through the bloodstream into your bones where they begin to reproduce, giving rise to all the cells that make up your blood:

The transplant was a second birthday, a second chance at life.

Finally receiving the marrow of my donor was a tremendous relief. The transplant itself, however, was anti-climactic. A bag of blood was hung above my bed and infused over the course of several hours. A nurse monitored my temperature, pulse and blood pressure to make sure that it was all going ok.

Engraftment

Engraftment occurs when the newly infused cells begin to reproduce within your body. Often the first sign of engraftment is a rising white blood cell count. If you have had a peripheral stem cell transplant, engraftment will usually occur within 10-15 days post-transplant. If you have had a transplant with stem cells taken directly from the bone marrow, engraftment will usually take between 10 to 20 days. If you are someone who engrafts late, the waiting period can be trying and anxiety producing.

Throughout this period, your white count will be monitored carefully to check for signs of engraftment. Particular attention will be paid to your neutrophil count, also referred to as ANC (Absolute Neutrophil Count). Neutrophils, as mentioned earlier, are a common type of white blood cell which play an important role in fighting bacterial and yeast infections.

Many patients like to keep close track of their blood counts and keep a calendar in their room to mark off the days until engraftment. Celebrating the day of your engraftment with loved ones can be a good way to break the monotony of the hospital routine. Once your white count is above a certain level and you are free of infection and other complications, you can leave the hospital.

Physical Effects of the Transplant Process

The transplant process is characterized by tremendous change. In response to the chemotherapy, radiation and medications, your body will undergo many transformations. The changes will affect how you look, your energy level and strength as well as the functioning of different organs in your body.

Throughout the process, your blood counts and health status will be monitored carefully. Your weight will be checked daily and your vital signs—temperature, blood pressure and pulse—will be checked every few hours. Often you will be

given a diary to record the fluids and food you take in by mouth and your output as urine, vomit and stool. This close monitoring of your condition is necessary to ensure that any changes in your health status are detected and treated as early as possible.

Nausea

Nausea is a very common side effect which can range from moderate nausea for several days to severe nausea over the course of several weeks or even months. Fortunately there are some very effective medications for nausea. Some nausea medications may make you sleepy or cause hallucinations. If this is the case, or your medications are not reducing the nausea effectively, make sure to explore different options with your medical staff. You may also try relaxation or meditation to decrease nausea. Here are the accounts of two different patients:

On a physical level [the conditioning] made me puke every day for four weeks. I did not eat any food for that time. I got an infection and a fever of 105.8 and went to intensive care for three days. The doctors removed my chest catheter and put one in my neck—Yuck!

After four days of throwing up intermittently, I felt much better—although I was somewhat nauseated after meals. Ativan and Benadryl made me hallucinate terribly, so I switched to Marinol, which made me fully sane again and was highly effective in reducing my nausea. I was one of the few lucky ones who pretty much ate throughout the transplant.

Tips to Reduce Nausea

- Wear loose fitting comfortable clothes.
- Avoid overly sweet and greasy foods as they may increase your discomfort.
- Eat salty dry foods like crackers.
- Find ways to distract yourself with activities you enjoy.
- Practice relaxation and deep breathing techniques.
- Eat and drink small quantities throughout the day.
- Eat and drink slowly so that only small amounts of food enter your stomach at one time.
- Rest in a chair after eating and keep head elevated.
- Avoid eating very hot or very cold foods.
- Take anti-nausea medication regularly before the onset of nausea. Prevention is key!
- Avoid foods and smells you find unappealing.
- Refrain from eating your favorite foods during the period you are most nauseated as you may develop an aversion to these foods later on.

Mouth Sores

The conditioning regimens of chemotherapy and radiation often cause the tissues inside your mouth to become thinner and more delicate, leading to irritation and ulceration. In some cases, the whole digestive tract may become

irritated and painful. The extent of irritation will depend in large part on the type of treatment you receive and on your own unique reaction to the treatment. Many individuals experience changes in their sense of taste during the transplant or dry mouth, which may make it more difficult to eat. If you are experiencing painful mouth sores, physicians who specialize in pain management, psychologists and psychiatrists may be available to help you cope with pain and stress. As always, make sure to make your needs known. It is also helpful to keep in mind that the pain is transient and will subside once you engraft and have a better functioning immune system.

Here are two accounts from different patients:

I had a transplant from an unrelated donor, and despite all the warnings from doctors about the terrible pain I would get from mouth sores, I developed very few sores and only had pain for a day or two. It was much easier than I expected.

The pain in my mouth was the most acute physical suffering I encountered, but I knew it was for a limited amount of time. That helped.

Energy Depletion

The transplant procedure will tend to make you feel weak. Don't be surprised if you can only accomplish a limited number of activities during the day. Simple tasks like reading or writing a letter may seem very taxing at times. Patients have described their experience as follows:

Chemo that made me sick for seven days, 24 hours a day is memorable. . . . 1200 rads of total body irradiation (TBI) was no picnic. It was like an energy-zapping ray gun from an old '60's movie. . . .

I almost had to learn how to walk again because I was so weak. This was emotionally taxing me because it was so hard to do things that were so easy for me before the transplant.

The chemotherapy didn't make me as sick as I thought it would. I didn't get as horribly tired as I had thought I would, except for a few days. My recovery, except for my blood counts, was quicker than I had thought it would be.

During the transplant, I withdrew emotionally from everyone. I pretty much stopped talking, wouldn't take my telephone calls, or even read my mail. I really had nothing to say. It took all my energy to just keep putting one foot in front of the other to get through that tunnel. The only thing that helped me cope was just my mother's presence.

When I was too tired to read, listening to books on tape was a great way to pass the time.

Body Image

Coping with a changing body is an integral part of the bone marrow/stem cell transplant. You may begin the transplant with lots of hair on your head and will

then lose most or all of it. Some people lose their eyebrows and eyelashes whereas others don't. If you take certain immuno-suppressive drugs, your face, abdomen, hands and feet may become swollen and round for some time. Weight can fluctuate during the transplant. Although many people experience weight loss during the transplant, others gain weight due to water retention and bloating.

As you go through the transplant process other changes may take place. Once your hair starts coming back in, it may be a different texture or color than it was before. Medications, such as Cyclosporine, which is commonly used to treat graft versus host disease (GVHD) may cause additional hair growth. After your initial bald state, you may find that your hair, eyebrows, and eyelashes are thicker than ever. Some patients may grow additional body and facial hair. Here are two different perspectives:

One of the most difficult aspects of the transplant for me was having a lot of facial hair. I felt so unattractive, self-conscious and ugly.

I was amazed to find that I actually thought I was prettier bald than with hair! Once it started coming in, it was less attractive because it came in unevenly. I was horrified that it would stay that way. But it has come back thicker than ever—and curly too!

As you go through these transformations, remember to have a sense of humor. Suggestions by other patients include getting a funny haircut before your hair falls out, buying hats or wigs you like, marveling at the changes, remembering to laugh at yourself and keeping in mind that the changes are almost always temporary. Adjusting to a new and perpetually changing self may be difficult but it is helpful to remember that it is part of the necessary process you must undergo in order to recover and regain your health.

Graft Versus Host Disease (GVHD)—Allogeneic Transplant Patients

As your white count rises, you may experience *graft versus host disease* (GVHD). Graft versus host disease occurs when the white cells produced by your donor's transplanted cells do not recognize your organs and tissues as "self". This happens because there are some genetic differences between you and your donor. Because of these differences, your new immune system may identify your cells as foreign and will attack them. Patients getting an autologous transplant or getting a transplant from an identical twin do not get graft versus host disease. About half of the patients receiving a transplant from a related donor will develop some form of GVHD. Your chances of getting GVHD are higher if your donor is unrelated.

GVHD manifests itself in two forms: acute GVHD which develops in the first three months post-transplant, and chronic GVHD which develops any time after that. Acute GVHD primarily affects the skin, the digestive tract and the liver and can cause symptoms ranging from mild skin rashes that come and go to stomach pains, nausea, cramping of the intestines and diarrhea. In more serious cases, GVHD can affect major body organs and can be life-threatening. Acute GVHD

may resolve itself with treatment or, in some cases, it merges with the onset of chronic GVHD.

The effects of chronic GVHD include dry eyes, dry mouth, skin and joint problems or problems with organs such as the liver or lungs. The severity of GVHD varies dramatically from patient to patient, as does its time of onset and its duration. Some patients who receive marrow from a donor experience no GVHD whereas others experience extensive GVHD.

A variety of methods are used to prevent or reduce the incidence of GVHD. Patients receive immuno-suppressive drugs which weaken the immune system, thus reducing the severity of the attack on vital organs. Unfortunately, they also increase susceptibility to infections and prolong the period of immuno-suppression. These drugs may also affect one's emotional and mental state. While on these drugs, some patients experience drug induced depression, confusion, anxiety, roller coaster-like mood swings, and exaggerated feelings of anger or excitement. It is helpful to keep in mind that these effects are temporary and that many people do not experience these side effects.

Some BMT centers reduce the incidence of GVHD through the use of T-cell depletion. In this procedure some or all of the T-cells of the donor's marrow are removed, thus limiting the ability of the new immune system to orchestrate an attack on the host (the patient).

Other Changes

The following section highlights some of the experiences of different transplant patients. Keep in mind that not everyone goes through these changes. I have chosen to include the following experiences of survivors, as I think that it is useful to hear what others have been through, and to know that even despite the most difficult circumstances, people make it through, recover and return to normal active lives post-transplant:

It was months before I could sleep more than an hour at a time without getting up to pace the floor because of restlessness.

I needed a lot more sleep than usual and would take a three or four hour nap every day in the afternoon and would sleep like a log through the night.

I was told that I might have trouble concentrating on reading though I am an avid reader. It was true. I couldn't really read a book until two months after the transplant.

In general, restoring my digestive system to normal was the biggest physical challenge I faced. After the transplant, it was six months before I ate a normal meal in company, and even then I had to be very careful of what I ate.

It was very traumatizing to lose control of my hands to violent trembling because of medication. My handwriting was almost indecipherable for several weeks, but gradually returned to normal.

Boredom was a serious emotional challenge. I frequently lay awake at night

just listening to the sounds of my monitors. It was easy to become somewhat apathetic and depressed because of the routine nature of the days going by.

My memory while in the hospital was very bad. I still don't remember some of the things that I did or that happened while there.

My taste buds were off so everything tasted like cardboard.

I was unable to take food for a few days and an anal fissure that I had prior to the transplant was severely aggravated by repeated bouts of diarrhea. I also lost some weight both during and for six months after the transplant.

I got terrible hemorrhoids and had to sit on a pillow for about ten days. I suffered from diarrhea for about a week.

I had constant diarrhea which was the most debilitating effect and continued for eight months or more. I also vomited frequently. I still don't know how I coped with that. Just made sure I was near a bathroom, I guess.

Coping Emotionally

For some, going through the transplant is extremely difficult emotionally, whereas others find it easier than they expected. Some people are relatively alert and active during the transplant whereas others suffer greatly. Giving up control and losing one's independence and privacy is very problematic for many. Experiencing physical discomfort and adapting to physical and emotional changes can also be extremely taxing. In some cases, the medications you will take may affect your mood. Some patients find that while going through the transplant they lash out at the people who are closest and dearest to them. Dealing with a changed status and new role in the family may be difficult. You may find that other people are suddenly too protective or, in other cases, not as understanding as you wish. Taking it one day at a time and remembering to be gentle with yourself and others is helpful. Here are some excerpts depicting the experiences of different transplant patients:

The transplant was frightening because I had been told that I could have potentially fatal complications arise from the procedure. It was very difficult being separated from my family for such a long period of time, especially since I couldn't see my youngest until the very last week. I coped by constantly using the telephone as a life-line to my family. . . .the VCR tapes that my husband made for me helped me cope.

Suddenly becoming dependent on others was very difficult. Having no real privacy or independence and just dealing with the fear of something going wrong was hard. Not being touched and hugged and constantly worrying about some unseen bacteria was emotionally draining. I coped by accepting the situation and taking pleasure in what I could within the confined context of a hospital room.

Things that helped me through difficult periods were thoughts about the things that I would do if and when I got out of the hospital.

I listened to Guided Imagery and Affirmations tapes every day to help me relax and fall asleep.

The worst thing I did to myself was think I had to be strong all the time. As scary as it is to let yourself cry and feel your feelings, it is the best thing you can do for yourself and the people around you. I pushed people away because it was too scary to feel my pain. My way of being in control was holding in too much. I recommend others to let it out with family, friends, support groups or therapists. . . You owe it to yourself, you're worth it. Be proud of your story, it is pretty incredible.

I guess during the difficult times I drew on my inner resources, imagination, contact with my husband, videos, a few favorite TV shows. I also looked forward to visits on Sunday from a volunteer who had survived a transplant. She was a major inspiration. I also had a rigorous routine to follow to keep my body sterile and that took up time.

I found it helpful to talk to someone other than family. They can be unbiased and can let you get a lot off your chest without hurting anyone.

One of the things that helped was to get to know patients on the floor and talk about my feelings with them.

Make Your Needs Known—Be Assertive

Generally, the medical staff and your loved ones will want you to feel as comfortable as possible and will try to accommodate your specific needs and preferences. Make sure to articulate your preferences and needs to those around you. Things that may seem obvious to you may not be obvious to others. Let people know what you would like—what kind of food, what kind of schedule, what kind of care. Ask what your options are and find out what services are available to you.

It is not uncommon for the members of your medical team and other staff members to neglect to tell you about various services and options that are available to you. If you are interested in a certain service that was not mentioned, ask to find out if it can be made available. Remember, it never hurts to ask.

If you like your privacy respected, put a sign on your door requesting that medical personnel knock before entering. Or if there are certain hours that you would prefer not to be disturbed, let the staff know. If there are certain times of the day that you would like to be disconnected from your medication pump, discuss this with your nurse and organize a medication schedule that will allow you to be free of the pump during certain hours. If you are a vegetarian and the hospital menu is geared to meat eaters, see what can be done to accommodate you. One patient writes:

As a vegetarian, there was almost nothing on the menu that I could eat. After I made my needs known, several new items were added to the menu and my family was permitted to bring me food, even though I had not yet engrafted.

If you would like to have your spouse or parent stay the night in your hospital room, request a bed for them or buy a small folding camping bed and bring it to the hospital room. If having an overnight guest in the room is not allowed, see whether an exception can be made as was done in the case of the following patient:

My fiancée spent every night of my hospital stay with me during the transplant. When I returned to my home town, and had to be hospitalized again because of graft-versus-host disease, we both insisted that he stay in my room even though it was against the hospital policy. We knew that in my case there was no medical reason for him not to do so. The hospital staff was reluctant at first, but finally agreed. Having him there was a great source of comfort.

Communicate with your doctors and nurses. If there is some aspect of your care that you are not satisfied with, make this known, either by speaking directly to a member of your medical team, to a person in charge, or ask your caregiver to express your concerns. One patient writes:

When one of my doctors delivered information in a manner that was highly insensitive, my boyfriend and parents called him up to complain. It was great to have them as advocates because it meant that I didn't have to alienate my doctor. I continued being a "nice" patient, but he got the message anyway.

Maintain a Sense of Humor

Laughter and a good attitude can be powerful sources of support and healing. Clearly if you are not feeling well, this can be quite a challenge. To the extent possible, try to incorporate some fun into your days. Rent some funny movies or ask friends and family to send you videos of themselves. If you like to dance, turn up the music in your room and dance a jig or two. Try to incorporate a few things you enjoy into your day:

What helped me keep a positive attitude during the transplant was the realization that every day I had on this earth was incredibly precious. I felt I owed it to myself to make the most of this incredible gift of life. Every morning I made a commitment to myself to do one fun thing, one thing that would bring me joy that day—even if it was something as simple as calling a good friend or asking for a massage.

Caring For Yourself During The Hospital Stay

Following the conditioning treatment and the transplant, your immune system will be compromised and thus you will be at risk for infections. In order to minimize risk of infection, good hygiene, mouth care and exercise are all recommended.

Good Hygiene

The most effective way to minimize infection is to wash your hands and to require that all visitors and staff entering the room wash their hands. **Diseases**

are most commonly spread through hand contact and the importance of hand washing in minimizing the spread of infection cannot be stressed enough. As a patient, you should wash your hands regularly throughout the day, before meals, before taking your pills and after using the bathroom. Daily bathing is also highly recommended, as it will help to reduce skin bacteria.

Dental Care

One of the best things you can do for yourself during the transplant to reduce discomfort and infections is to take meticulous care of your mouth. The conditioning regimens of chemotherapy and radiation often cause the tissues inside the mouth to become thinner and more delicate, leading to irritation and ulceration (mucositis). By maintaining good oral hygiene during the transplant, you may reduce oral infection and bleeding gums.

Remember, optimal mouth care entails frequent mouth rinses throughout the day. You should also brush your teeth regularly with a soft nylon bristle toothbrush or a sponge toothbrush if the regular toothbrush hurts. While brushing, you should thoroughly rinse your mouth several times so as to remove bacteria and debris. Brush or rinse your mouth after taking any food as this will help minimize infection and pain. If you are good at flossing and are able to do so without injuring your gums, continue to do so.

Exercise

During days that you will feel weak and sick, it will be particularly tempting to curl up in bed and not move. However, exercising and moving is going to be your ticket to doing many of the things you will want to do when you are discharged. Exercising will mean more energy to carry out daily activities and is also likely to lower your risk of injury from falling or twisting an ankle. You do not need to be in top fitness to exercise. Many exercises and stretches can even be done in bed.

The benefits of exercise are manifold:

- Exercising promotes good circulation and encourages the continued normal functioning of your body.
- Exercise prevents or minimizes muscle atrophy from prolonged bedrest and steroid treatment.
- Exercise is associated with improved nutritional status as it promotes protein assimilation and decreases body fat.
- Exercising and deep breathing help prevent the accumulation of fluids in the lungs which can often lead to pneumonia.
- Exercise is known to combat depression and promote feelings of well-being as well as to enhance physical comfort.
- Exercise facilitates cardiac function and circulation.

During your time at the hospital and also as an outpatient, you may have visits from a physical therapist who will work with you in maintaining your strength and endurance and working on particularly important things like ankle strength and chest expansion. If you feel you need more information on exercises and

stretches, make your needs known and have a physical therapist visit you more often:

I was told that doing exercise would lower my chance of getting a lung infection—so I was on my exercycle almost everyday. I'd turn up the music, face the window and start pedaling.

Nutrition

Often the treatment will affect one's appetite and ability to eat and digest food. Eating may be difficult for some people because of changes in taste and smell, nausea, general dryness of the mouth or difficulty swallowing. If you are having difficulty eating, you will be fed intravenously through your central line so that your basic caloric and nutritional needs will be met. To the extent possible, it is recommended that you continue eating so that your digestive system continues to function and pass food. Depending on the center you are being treated at, there may be different food guidelines during the period of immuno-suppression, with some centers allowing fresh fruits and vegetables and others disallowing them. Good nutrition is particularly important post-transplant as your body will require additional calories, protein, vitamins and minerals to heal and recover.

Eating was really difficult for me. It took forever to chew food that normally would take minutes to consume. Some days I just couldn't eat anything at all.

Eating Tips

Although your nutritional requirements will be met through intravenous feeding, it is highly recommended that you try to continue eating, at least small amounts, throughout the period of the transplant. By eating and keeping your digestive tract active, the muscle tone and function of your digestive tract will be better maintained, thus making it easier for you to eat post-transplant. During this period, your dietitian can serve as an important resource in helping you find ways to meet your nutritional needs.

A helpful suggestion is to begin increasing your oral intake with small meals and snacks every few hours. Nutritious beverages are often well-tolerated and can be an excellent source of vitamins, minerals and calories.

In order to aid digestion and prevent heartburn, eat and drink slowly. Sitting up rather than lying down after meals can also help. If you are not experiencing much nausea, light exercise such as walking can promote digestion and may help you feel more comfortable.

Although there are no hard fast rules with regard to which foods to eat, a large number of people find that moist, bland, low fat soups, casseroles or noodle dishes are relatively easy to digest as compared to fried foods, meats and some raw fruits and vegetables. The best rule of thumb is to eat the foods that are most appealing to you. If there are particular foods you crave that are not on the hospital menu, see if they can be made available for you.

Finally, in order to reduce the probability of food-borne illness, wash your hands prior to eating meals and follow the food safety guidelines that are recommended by your dietitian.

Planning To Go Home

It is a good idea to prepare for your return home before leaving the hospital. This may entail organizing to have someone help you take care of your pet for the first 100 days post-transplant, organizing to have your house well-cleaned before you return, or arranging for a housecleaner to come in to clean the house at regular intervals until you can resume such activities. Getting family and friends to help with your return home can make the transition easier and smoother for you.

When I was at the hospital, all I could focus on was taking it one day at a time. Fortunately, my family prepared for my arrival by thoroughly cleaning the house and distributing various chores among friends and family so that no one would be too overburdened.

POST-TRANSPLANT

The Transition Home

We all look forward to the post-transplant period with great anticipation. Despite the joy that often accompanies leaving the security of the hospital and frequent doctor visits, the transition also brings up a lot of fears and anxiety. In fact, the overwhelming majority of respondents to the questionnaire found the recovery period and transition to the home as one of the more difficult phases of the transplant. One patient articulated her feelings as follows:

There were two periods which I found most difficult. The first was moving to outpatient status [at the transplant center] and having to deal with everyday stuff, and then it was returning home and having to deal with even more everyday stuff. Your limitations and lack of immediate support is tough. In the hospital everything is taken care of for you—if an unexpected glitch happens, care is right there. As joyful as I was to be out of the hospital, I experienced a lot of anxiety trying to acclimate back into the world again. What helped most for me was to try to communicate my needs and fears to family and friends. I learned that I had to ask when I needed something and not expect people to automatically know what it was that I needed.

The transition was very difficult because I was afraid of not having the nurses etc. at my finger tips. I had to develop a different type of responsibility for caring for myself. I felt I was breaking away from a safe, enclosed environment and having to face a world that did not know my condition. It was very scary.

I was not prepared for the extreme fatigue post-transplant and the amount of effort and energy it took to just take care of basic day to day tasks.

Outpatient Care Post-Transplant

In the first few months following the transplant, you are likely to visit the outpatient clinic several times a week or, in some cases everyday, for blood draws, physical exams, intermittent blood or platelet transfusions, as well as certain tests such as throat, urine and stool cultures to screen for infections.

Depending on your protocol, you may also undergo periodic x-rays, bone marrow aspirations, lumbar punctures or other procedures. This intensive follow-up care is necessary to monitor your progress and to treat complications should they arise. As the weeks and months progress and your condition stabilizes, your visits will become more infrequent.

Often the first few weeks out of the hospital can be tiring and difficult as well as exhilarating:

I was completely unprepared for how exhausting it was to be out of the hospital. Just going back and forth from my house to the hospital took a tremendous amount of energy. When in addition to that, I tried to organize and remember to take twenty or so pills a day, exercise, monitor and record my temperature, and keep all the hygiene requirements, I was overwhelmed. Getting out of the hospital was the best day of my life. Just being able to breathe fresh air, hug my kids and wife and be at home was incredible.

Readmission and Setbacks

Returning to the inpatient department of the hospital for treatment post-transplant is very common and is part of the recovery process. Although returning to the hospital or contracting an infection is discouraging, it is important to recognize that recovery is a bumpy road and that many patients experience small complications and may need to be readmitted for short periods to manage symptoms that cannot be safely taken care of in the outpatient department. One patient expressed this as follows:

The idea that I had to go back into the inpatient department was devastating for me at first. But then, after I talked to a former transplant patient who had to go back into the hospital many times, I realized that it was just one of the many steps involved in the recovery process...He made me realize that the recovery process isn't all smooth going. Sometimes you need to take one step backwards in order to take two steps forward.

Guidelines Post-Transplant

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 amount of immuno-suppressants being taken.

People who have had autologous transplants tend to be least immuno-compromised 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 have to 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 time 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 comes into contact with you should wash their hands frequently to minimize 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 in order to get them in the habit of using it.

- Carry latex gloves and alcohol wipes at all times 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 a milder soap can also reduce dryness and irritation. As part of general hygiene, towels and clothing should be changed daily.

Contact with People

In order 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 come into contact with 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 have to avoid public places altogether, it is probably wise to limit your exposure to large numbers of people. In particular, 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 foods were last prepared and to ask that foods 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 stir 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 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 a sun screen 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. A patient writes:

I used to tan so easily, it wasn't funny. Now I have stock in a sunblock company.

Swimming Pools

It is also recommended to avoid swimming in lakes or public pools until your immune system has reconstituted 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 foods 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 foods that have been sitting in the refrigerator for more than three days. A helpful way to keep track of 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 meats 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. In order 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

Nontraditional 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 greatest post-transplant. For this reason, you should avoid alcohol for the first six months post-transplant. If you are still taking medications 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 particular 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 as long as 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 lubricant. 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 the majority of 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 due to the effects 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 have to use a lot of lubricant and some positions are quite painful.

Caring For Yourself Post-transplant

Exercise

Regular exercise is an important part of the recovery process. By improving your stamina, muscle tone, and muscle strength, you will not only feel better physically, but also emotionally. Exercise can help counteract problems such as stiff joints, breathing problems, poor appetite and psychological lows. Seeing improvement in your physical state can be a real boost, particularly when you are adjusting to the stresses and difficulties of returning to a more normal lifestyle.

Initiating an exercise routine if your energy level is low and you are not feeling well may be difficult at first. A good way to begin exercising is to take walks outside or to visit the outpatient physical therapy department in your hospital where a physical therapist can work with you in selecting appropriate exercises and building your strength and stamina. You may also be able to get your doctor to write you a prescription to buy an exercise machine such as an exercycle. If this is the case, your insurance may cover a portion or all of the cost of the purchase. A doctor's prescription may also save you from paying sales tax on the purchase.

Physical exercise is particularly important if you are taking steroids. They may cause muscle wasting and weakness and thus regular exercise can be instrumental in maintaining muscle mass and strength. When taking steroids, however, choose low impact exercises to minimize stress on your joints since steroids can cause joint damage.

When exercising, pay attention to the messages your body gives you. You should challenge yourself, but should stop or slow down if you are experiencing pain. Between a scale of very light to very arduous, an optimal level of exercise is one that you would rank as moderately hard. The best way to regain strength is through regular exercise suited to your level of physical conditioning that builds slowly to progressively higher levels of activity.

Nutrition

After the transplant, your body will require many nutrients to regain strength and to recuperate. Your nutritional requirements will vary depending on your medical condition, the type of transplant you had and the medications you are on. Your nutritional needs post-transplant may increase, requiring you to take mineral and vitamin supplements. Herbal remedies and supplements should be avoided until discussed with your transplant team. During this period it is important to consult a dietitian about food choices to ensure that your nutritional needs are met.

If you are nauseated and find eating and drinking difficult, it is helpful to eat

and drink small amounts throughout the day rather than eating three large meals. Make sure to have a wide variety of appealing snacks at hand for the times that you do feel hungry. Eating in a pleasant setting or having an attractive food arrangement may also facilitate eating. During this time, you may also need to increase your fluid intake so as to prevent dehydration and to help flush the drugs and their residues from your bladder and kidney.

I had a terrible time remembering to drink enough. To alleviate this problem, I bought a water carrier and took a bottle of water or juice with me wherever I went. I also placed a bottle of water near my bed from which I drank every time I woke up during the night.

Recovery

For some, the recovery process is a smooth easy process, which entails relatively few adjustments. For others, the period of recovery is long and challenging. After a transplant, people are often changed – both physically and emotionally. The reintegration of this “new” post-transplant self into the old familiar world is often difficult. Figuring out how this new self with a changed body, changed physical capabilities, and changed sense of vulnerability fits into the pre-transplant world is a process that takes time. Generally, people who have undergone an autologous transplant tend to experience fewer physical problems and return to an active life more quickly. An encouraging video that addresses some of these issues is *The New Normal: Life After Bone Marrow/Stem Cell Transplant*. To order a copy contact the National Bone Marrow Transplant Link.

The hardest thing for me to realize was that recovery takes perseverance and patience. It is a process which isn't always smooth going. You do the transplant and want to put it all behind you, but there are continually medical issues and emotional issues that crop up.

The transition from the hospital to the outpatient setting was not difficult at all, probably because I was in pretty good shape compared to the shape that some other patients were in.

It is hard when you return home because everyone is ready for you to be okay again and they don't understand that your recovery is just beginning and it is a difficult journey. It is chronic and people get tired hearing about chronic.

In my mind I thought of the transplant like climbing a mountain and I was prepared emotionally for the hard climb. I was not prepared, however, for the fact that the climb down, after the transplant, would be just as hard, if not harder, than the climb up had been.

Physical Changes Post-Transplant

There is considerable variation among bone marrow/stem cell transplant survivors in physical, psychological and social functioning post-transplant. Some patients recover fully, returning to their old activity level several months after the transplant. For others, the recovery period is slow, and they never return to

old levels of vigor and health. For those who continue to suffer chronic health problems, it is sometimes hard to accept the physical changes post-transplant without mourning the loss of the vigor and strength prior to the treatment.

The extent of difficulty during the recovery process is often closely tied to the degree of physical difficulties post-transplant. Having repeated infections or chronic graft versus host disease can contribute to stresses and difficulties in returning to normal activities. Some of the potential problems that survivors may experience include fatigue, decreased strength, muscle cramps, difficulty concentrating, memory problems, sleep disturbances, numbness in hands and feet, cataracts, skin and joint problems, dry eyes or mouth, frequent infections and kidney or other body-organ dysfunction. Keep in mind when reading this list that not everyone will experience these problems. Generally these problems resolve themselves with time and most people return to productive and fulfilling lives post-transplant.

Some of the physical and mental changes post-transplant may also occur as a side effect of some of the drugs. Many of the drugs taken post-transplant can affect organ function, immune function, physical appearance and psychological well-being. Knowing that many of the changes are temporary can be helpful for everyone involved.

Dealing with a changed physical appearance due to bloatedness, excessive hair growth, or skin changes post-transplant can be traumatic for some people.

It has been very disconcerting to encounter old friends who find it difficult to recognize me because of changes in the color and texture of my hair and changes in the shape of my face.

I still have my "prednisone chub" in my cheeks and a little bit of facial hair from the cyclosporine a year post-transplant. It makes me realize how much I took my health and general appearance for granted before the transplant.

I used to feel that my mind and body were one . . . very much in tune, but now it feels as if my body is a stranger to me. We're getting re-acquainted but it's strange to get an ache or pain and be afraid of what it could mean.

Sometimes I am not sure what my body needs and that feels very foreign.

If you are having difficulty coping with a changed body image, programs such as the Look Good . . . Feel Better Program at the American Cancer Society may be able to offer some helpful suggestions. See Resource Listing for details.

Emotional Adjustment Post-Transplant

Going through a bone marrow/stem cell transplant changes us in many ways, requiring us to re-evaluate many aspects of our lives. Give yourself time to deal with the emotional impact of the transplant. Often people expect you to be over the experience in a month or two. In reality, however, the process may take much longer. Recovering from the transplant entails not only a physical process but requires also a mental shift from seeing yourself as sick to seeing yourself as healthy.

Some people experience recurring memories of the transplant which conjure up feelings of vulnerability, anxiety, or depression. You may find yourself going over the decisions you made, questioning the reasons for the transplant, and re-living the difficult times you had. Fear of relapse or complications are also not uncommon:

Once I got through the transplant and into the recovery stage, getting back to living was difficult. Physically I had limitations but also emotionally I felt very different. I experienced a feeling of loneliness and sadness. I guess one could label it a sort of depression. Even as I write this 10 months post-transplant, I still experience such overwhelming feelings. My therapist said that many times people going through such an intense trauma experience a sort of “aftershock” when they finally allow themselves to feel all the emotions they didn’t allow themselves to experience during the actual event.

If these fears cause a major disruption in your life or cause sleep disturbances, consider seeking some kind of outside help. Often speaking to a professional therapist or to members of a support group can help you put the experience in perspective and move on. Keeping in touch with someone who did the transplant with you can be particularly helpful.

Calling friends who did the transplant with me, comparing notes on how we were doing and just complaining together and knowing what the other person was going through helped me cope.

The transplant may also have a strong positive impact on one’s emotional well-being. Many people find that they emerge from the experience strengthened and more resilient:

*“I was changed by this, dramatically changed. It is a life-changing experience. It’s hard to believe that you will grow from this and that the change could be positive, but it is.” (from the nbmtLink video, *The New Normal: Life After Bone Marrow/Stem Cell Transplant*)*

I feel that I am now (five years later) able to face any health crisis that may confront me in the future. I didn’t have that confidence before. I can relax and enjoy the good things in life more now and don’t take them for granted. I have more faith in God that he will see me through the hard times and that I need not fear the future.

Changes In Self-Esteem

Making it through the transplant is a heroic accomplishment. However, many of us, upon emerging from the hospital, tend to compare our performance to our previous levels of activity or to the activity levels of our friends and colleagues. Our inability to accomplish as much as before or to be self-supporting may dash our self-esteem. As you begin the recovery process, set realistic goals for yourself and adapt your activities to your energy level instead of berating yourself for not being able to do more. Respect your need for rest and relaxation. One patient writes:

I had to realize my energy was not going to be the same as before so I read, did crafts, talked on the phone, rented videos and learned to do other things that weren't so physical. Also rides in the car and going to the park was wonderful.

Changes in Family Ties And Relationships

The transplant experience can also often result in changed relationships among family members. A working parent, for example, might take on virtually all of the household chores and child caring tasks during the transplant. Often these changes bring families closer, but, in some cases, the changes in roles increase tension and lead to additional strains. Here are the accounts of some patients:

I feel our whole family is on a more intimate level with each other because of all of the demands of my illness.

For the most part the transplant brought my family closer together, but at times I felt overprotected and at other times (even though so many people were around) I felt incredibly isolated.

The transplant experience has impacted negatively on the relationship between my son and me. We were very close, and in order to protect himself in case I died during the transplant, my son had to put some distance between us. It has been five years and we don't seem to be able to lessen the distance any, which makes me sad.

Friendships may also change or take on new meaning as you reflect on the people who were supportive of you during the transplant and those who were not. Some friendships will be enhanced and enriched whereas others may dissolve under the pressures of the transplant.

Some transplant patients have felt that the experience of having a life-threatening disease and undergoing the transplant has set them apart from their peers:

On an emotional level—I felt different from other people. I sometimes still find it difficult to talk to other people. I am most at home with cancer survivors and BMT survivors.

Changing Roles

Once out of the hospital, some patients find it difficult to perform many of the tasks they did before transplant. In the months following the transplant, both family members and the patient have to readjust to the new role and new capacities of the patient:

I had difficulty in letting others do housework and provide child care once I was home. My husband and I had a few arguments about that, but we managed to work it out.

Generally I am someone who is very independent. It drove me crazy to have everyone asking me if I was drinking enough, if I had put sun lotion on, if I

had consumed enough calories. . . . I suddenly felt I was being treated like a child again.

I'm not the breadwinner that I used to be, so the respect that I used to get has diminished some.

Recommendations for Coping During Recovery

Although, it is difficult to know ahead of time how the transition period from the hospital to the outpatient phase will be for you, keep in mind that recovery is a long-term process that does not always proceed in a smooth linear fashion. The following are suggestions by transplant survivors of how to cope during this transition period:

Let family and friends know that you don't just want to lie around—have them bring you things you can do; or else, plan ahead and have a project that you can work on for as little or as much time as you want while you are recuperating. Talk to your friends on the phone when you are feeling lonely and restricted.

I think what helps me to cope is having someone to talk to. For me, it has been a counselor and very few special people that I have felt have been able to understand all my complicated emotions. Second, having some type of daily, weekly and monthly goals helped to keep me going each day. The goals could be anything. For me it was learning to play the guitar, exercising, cooking . . . anything that I found enjoyable and lastly giving myself permission to feel sad and depressed—I think one needs to experience their emotions in order to work through them and then to move beyond them.

One survivor found the following attitude helpful:

I . . . work under the assumption that Murphy's Law is always in effect. That way blown veins, low platelet counts, and nonexistent white counts are to be expected . . . then I can be delighted when things go as planned. It's all in the attitude—and I'd rather laugh about it than drive myself up a wall worrying about what might happen.

Celebrate Landmarks

Often during the ups and downs of recovery, it is difficult to see the bigger picture and to appreciate how far you have come. Marking special dates such as your six month or one year anniversary with celebrations can serve as an important reminder of your progress:

I had a big party for my one year anniversary in which I invited all the people who had been involved and had sustained me through my difficult year. Seeing everyone I loved gathered in one room, all celebrating this momentous day, made me feel very privileged and helped me realize how much progress I had made.

Another way to mark your progress is to give yourself a special treat at the end of a designated period. One patient recommends the following:

I suggest that all BMTers set a reward goal for themselves. Early on I said that when I reach ten years out I'm buying myself a classic car. I am the proud owner of a 1956 Ford T-Bird! Make the reward a BIG ONE. It's earned. And you never know how much time ya got!

Contact Your Donor

Generally the bone marrow registry will not allow you to contact your donor directly until one year post-transplant. Until the one year time period is up, however, exchanging letters anonymously with your donor through the donor program can be very gratifying. Once you are given access to your donor's name and address a year post-transplant, meeting him or her can be very rewarding:

Finally getting the name and phone number of my donor was extremely exciting. I had wondered for so long who she was, what she was like, and what had motivated her to sign up for the registry and donate marrow. Being able to hear her voice and then to meet her, express my gratitude and solidify that bond was extremely meaningful.

Beyond The Transplant

Regardless of how long or how difficult the transplant process is for you, it is important to remember you can return to a normal and active lifestyle post-transplant. Survivors often report that the quality of their lives post-transplant is similar to or better than before the transplant. Others have some lingering effects, but do not experience significant deterioration in quality of life. A small number of people suffer from more significant handicaps resulting in the need to change their profession or to cease working altogether.

Although people are affected differently by the transplant, everyone, without exception, is changed as a result of the experience. Through the transplant, we are forced to look at ourselves and at our lives. We will inevitably suffer losses and hopefully also gain new strength and insights. Many of those who responded to the questionnaire reported a greater resilience and a greater appreciation for life. Here are some of the ways that people have come to view the world post-transplant:

I see life differently post-transplant. Being stuck in a hospital room for three months made me realize that even in the most confined and restrained settings, I can find joy and pleasure. I now know that the well-springs of joy are largely within me, and not only in the external environment.

Transplant has affected my life in so many ways ... both good and bad. I feel like I just played a game of pick-up-sticks with my life and all the sticks are all over the place—some pieces are new, some are missing and some are the same ... I still face my fears and issues but I am thankful to be alive and feel my experience has been a gift in many ways. I just try to live life one day at a time and be in the moment with whatever I am experiencing.

I live my life differently. I don't sweat the small stuff and worry about things I cannot change. The serenity prayer says it all [God grant me the serenity

to accept the things I cannot change, the courage to change the things I can, and the wisdom to know the difference]. I'm also more in tune to what I want out of life...

I try to live each day to its fullest and take one day at a time. There are so many people that live in the fast lane and think there will always be a tomorrow. I know how fast all of that can be taken away. I don't take things for granted anymore. I tell the people I love and care about how much they mean to me everyday.

Through the transplant, I have suffered many losses—lost fertility, lost friends, lost time—but I have also uncovered many treasures, gained invaluable insights and have become a happier, more hopeful person and more loving person.

The Journey Ahead

Thousands of people will undergo transplants in the upcoming year and will survive them. You are not alone in your journey. I have tried to chart my journey and that of others who generously shared their experiences. I know that by writing this guide and having the opportunity to read the experiences of others, I have personally benefited. I hope that by sharing my thoughts and the thoughts of others who have gone through the experience, you will be better prepared to face the road ahead.

At the time of this update, I am a survivor of eight years. Although I recognize that my life can never be the same as it was before the transplant, I know that it is only by accepting the transplant experience in its entirety with all of its hardships and rewards that I can grapple with the present, find joy in what I have, and move forward with determination and hope. I wish you all a safe journey with a healthy outcome at the end of the process.

If you have any comments about this guide or your transplant experience, please send them to:

Keren Stronach
c/o National Bone Marrow Transplant Link
20411 W. 12 Mile Rd., Suite 108
Southfield, MI 48076

RESOURCE LISTING

Bone Marrow/Stem Cell Transplant Information and Support

Autologous Blood and Marrow Transplant Registry (ABMTR)

IBMTR/ABMTR Statistical Center,
Medical College of Wisconsin
8701 Watertown Plank Road
P.O. Box 26509
Milwaukee, WI 53226
414-456-8325
Email: ibmtr@mcw.edu
www.ibmtr.org

Blood and Marrow Transplant Information Network

2900 Skokie Valley Road, Suite B
Highland Park, IL 60035
888-597-7674 or 847-433-3313
Email: help@bmtinfonet.org
www.bmtinfonet.org

The Bone Marrow Foundation

337 E. 88th St., Suite 1B
New York, NY 10128
800-365-1336 or 212-838-3029
Email: thebmf@bonemarrow.org
www.bonemarrow.org

National Bone Marrow Transplant Link (nbmtLink)

20411 West 12 Mile Road, Suite 108
Southfield, MI 48076
800-LINK-BMT (800-546-5268)
or 248-358-1886
Email: nbmtlink@aol.com
www.nbmtlink.org

Oncology Nursing Society

125 Enterprise Drive
Pittsburgh, PA 15275
412-859-6100
Email: customer.service@ons.org
www.ons.org

Bone Marrow Donor Information

Asians for Miracle Marrow Matches

231 E. Third St., Suite G107
Los Angeles, CA 90013
888-A3M-HOPE (888-236-4673)
Email: A3M@LTSC.org
www.asianmarrow.org

Caitlin Raymond International Registry

U Mass Memorial Medical Center
55 Lake Avenue North
Worcester, MA 01655
800-726-2824 or 508-334-8969
Email: info@crir.org
www.crir.org

HLA Registry Foundation, Inc.

70 Grand Avenue, Suite 103
River Edge, NJ 07661
888-HLA-DONOR or 201-487-0883
Email: info@hlaregistry.org
www.hlaregistry.org

National Marrow Donor Program (NMDP)

3001 Broadway, NE, Suite 500
Minneapolis, MN 55413
800-MARROW-2 or 800-526-7809
888-999-6743 (Office of Patient Advocacy)
www.marrow.org

Orchid Diagnostics

(formerly GeneScreen)
550 West Avenue
Stamford, CT 06902
800-543-3263
www.bonemarrowtest.com

Cancer Information and Support

American Cancer Society

1599 Clifton Road, NE
Atlanta, GA 30329
800-ACS-2345 or 404-320-3333
www.cancer.org

R. A. Bloch Cancer Foundation

4400 Main Street
Kansas City, MO 64111
800-433-0464 or 816-932-8453
Email: hotline@hrblock.com
www.blochcancer.org

Cancer Care, Inc.

275 Seventh Avenue
New York, NY 10001
800-813-HOPE or 212-712-8080
Email: info@cancercare.org
www.cancercare.org

Cancer Information Service National Cancer Institute

6116 Executive Blvd., MSC 8322
Room 3036A
Bethesda, MD 20892
800-4-CANCER
www.cancer.gov

Cancervive, Inc.

11636 Chayote Street
Los Angeles, CA 90049
800-426-2873 or 310-203-9232
Email: cancervivr@aol.com
www.cancervive.org

Candlelighters Childhood Cancer Foundation

P.O. Box 498
Kensington, MD 20895
800-366-2223 or 301-962-3520
Email: info@candlelighters.org
www.candlelighters.org

Coping with Cancer Magazine

P.O. Box 682268
Franklin, TN 37068
615-790-2400
Email: copingmag@aol.com
www.copingmag.com

Cure Magazine

Cancer Information Group
3535 Worth St., Suite 4802
Dallas, TX 75246
214-820-4754
Email: editor@curetoday.com
www.curetoday.com

Friends' Health Connection

P.O. Box 114
New Brunswick, NJ 08903
800-48-FRIEND or 732-418-1811
info@friendshealthconnection.org
www.48friend.com

Gilda's Club Worldwide

322 Eighth Avenue, Suite 1402
New York, NY 10001
888-445-9248
Email: info@gildasclub.org
www.gildasclub.org

National Childhood Cancer Foundation
440 E. Huntington Dr., Suite 300
Arcadia, CA 91066
800-458-6223 or 626-447-1674
info@ConquerKidsCancer.org
www.nccf.org

National Children's Cancer Society
1015 Locust, Suite 600
St. Louis, MO 63101
800-532-6459
Email: nccs@children-cancer.com
www.children-cancer.org

National Coalition for Cancer Survivorship
1010 Wayne Avenue, Suite 770
Silver Spring, MD 20910
877-NCCS-YES or 301-650-9127
Email: info@cansearch.org
www.canceradvocacy.org

National Family Caregivers Association
10400 Connecticut Ave., Suite 500
Kensington, MD 20895
800-896-3650
Email: info@nfcacares.org
www.nfcacares.org

Starbright Foundation
11835 W. Olympic Blvd., Suite 500
Los Angeles, CA 90064
800-315-2580 or 310-479-1212
Email: webmaster@starbright.org
www.starbright.org

Vital Options International TeleSupport Cancer Network
15821 Ventura Blvd, Suite 645
Encino, CA 91436
818-788-5225 or 800-477-7666
Email: info@vitaloptions.org
www.vitaloptions.org

The Wellness Community
35 East Seventh Street, Suite 412
Cincinnati, OH 45202
888-793-9355
Email: help@wellness-community.org
www.thewellnesscommunity.org

Well Spouse Foundation
P.O. Box 30093
Elkins Park, PA 19027
800-838-0879
Email: info@wellspouse.org
www.wellspouse.org

Women's Cancer Resource Center
5741 Telegraph
Oakland, CA 94609
888-421-7900 or 510-420-7900
Email: werc@werc.org
www.werc.org

Fertility

American Association of Tissue Banks
1350 Beverly Road, Suite 220-A
McLean, VA 22101
703-827-9582
Email: aatb@aatb.org
www.aatb.org

American Society for Reproductive Medicine
1209 Montgomery Highway
Birmingham, AL 35216
205-978-5000
Email: asrm@asrm.org
www.asrm.org

Genetics and IVF Institute
3020 Javier Road
Fairfax, VA 22031
800-552-4363 or 703-698-7355
Email: givf@givf.com
www.givf.com

Resolve Inc.
1310 Broadway
Somerville, MA 02144
888-623-0744
Email: info@resolve.org
www.resolve.org

Financial Assistance, Fundraising & Insurance Information

Cancer Legal Resource Center
919 S. Albany St.
Los Angeles, CA 90015
213-736-1455
www.lls.edu/community/clrc.htm

Children's Organ Transplant Association (COTA)
2501 COTA Drive
Bloomington, IN 47403
800-366-2682
www.cota.org

Health Insurance Association of America
1201 F Street, NW, Suite 500
Washington, DC 20004
202-824-1600
Email: webmaster@hiaa.org
www.hiaa.org

Jeffrey Katz Fund
(Southern California residents)
c/o Ronald McDonald House
4560 Fountain Avenue
Los Angeles, CA 90029
323-644-3000
www.larmh.org

The Medicine Program
P.O. Box 515
Doniphan, MO 63935
573-996-7300
help@themedicineprogram.com
www.themedicineprogram.com

My Friends Care Bone Marrow Transplant Fund
(Michigan residents)
148 South Main Street, Suite 101
Mount Clemens, MI 48043
586-783-7390
Email: mfc@mich.com
www.myfriendscare.org

National Association of Hospital Hospitality Houses
P.O. Box 18087
Asheville, NC 28814
800-542-9730 or 828-253-1188
Email: helpinghomes@nahhh.org
www.nahhh.org

National Foundation for Transplants
1102 Brookfield, Suite 200
Memphis, TN 38119
800-489-3863 or 901-684-1697
www.transplants.org

Nielsen Organ Transplant Foundation

(Northeast Florida residents)
580 West 8th Street
Jacksonville, FL 32209
888-749-4850 or 904-244-9823
nielsenfoundation@yahoo.com
www.geocities.com/nielsenfoundation

National Transplant Assistance Fund

3475 West Chester Pike, Suite 230
Newtown Square, PA 19073
800-642-8399 or 610-353-9684
Email: NTAF@transplantfund.org
www.transplantfund.org

Patient Advocacy Coalition, Inc.

777 East Girard Avenue
Englewood, CO 80110
303-744-7667
www.patientadvocacy.net

Patient Advocate Foundation

753 Thimble Shoals Blvd., Suite B
Newport News, VA 23606
800-532-5274
Email: help@patientadvocate.org
www.patientadvocate.org

Pharmaceutical Research and Manufacturers of America

Prescription Drug Patient Assistance Programs
1100 Fifteenth Street, NW
Washington, DC 20005
202-835-3400
www.phrma.org

Disease-Related Information

Anemia

Aplastic Anemia & MDS

International Foundation, Inc.
P.O. Box 613
Annapolis, MD 21404
800-747-2820 or 410-867-0242
Email: help@aamds.org
www.aplastic.org

Fanconi Anemia Research Fund

1801 Willamette Street, Suite 200
Eugene, OR 97401
541-687-4658
Email: info@fanconi.org
www.fanconi.org

Myeloproliferative Disease Research Center

115 East 72nd Street
New York, NY 10021
800-HELP-MPD or 212-535-4200
www.acor.org/mpd

Brain Tumor

American Brain Tumor Association

2720 River Road, Suite 146
Des Plaines, IL 60018
800-886-2282 or 847-827-9910
Email: info@abta.org
www.abta.org

National Brain Tumor Foundation

414 Thirteenth Street, Suite 700
Oakland, CA 94612
800-934-CURE or 510-839-9777
Email: nbtf@braintumor.org
www.braintumor.org

Breast Cancer

Adelphi New York Statewide Breast Cancer Hotline and Support Program

Adelphi Univ. School of Social Work
Garden City, NY 11530
800-877-8077 or 516-877-4444
Email: nysbchot@adelphi.edu
www.adelphi.edu/nysbreastcancer

National Alliance of Breast Cancer Organizations (NABCO)

9 East 37th Street, 10th Floor
New York, NY 10016
888-80-NABCO or 212-889-0606
Email: nabcoinfo@aol.com
www.nabco.org

The Susan G. Komen Breast Cancer Foundation

5005 LBJ Freeway, Suite 250
Dallas, TX 75244
800-462-9273 or 972-855-1600
Email: info@komen.org
www.komen.org

Y-Me National Breast Cancer Organization

212 West Van Buren, Suite 500
Chicago, IL 60607
800-221-2141 (English) or 800-986-9505 (Spanish)
Email: help@y-me.org
www.y-me.org

Immune Deficiency Disorders

Immune Deficiency Foundation

40 W. Chesapeake Ave., Suite 308
Towson, MD 21204
800-296-4433
Email: idf@primaryimmune.org
www.primaryimmune.org

National Organization for Rare Disorders (NORD)

P.O. Box 1968
Danbury, CT 06813
800-999-6673 or 203-744-0100
Email: orphan@rarediseases.org
www.rarediseases.org

Leukemia & Lymphoma

Children's Leukemia Foundation of Michigan

29777 Telegraph Road, Suite 1651
Southfield, MI 48034
800-825-2536 or 248-353-8222
leukemiamichigan@voyager.net
www.leukemiamichigan.org

Leukemia Research Foundation

(Illinois residents and those within a 100-mile radius of Chicago)
820 Davis Street, Suite 420
Evanston, IL 60201
847-424-0600
Email: LeukResear@aol.com
www.leukemia-research.org

The Leukemia & Lymphoma Society

1311 Mamaroneck Avenue
White Plains, NY 10605
800-955-4572 or 914-949-5213
Email: infocenter@leukemia-lymphoma.org
www.leukemia.org

**Lymphoma Research Foundation
(formerly Cure for Lymphoma)**

8800 Venice Blvd., Suite 207
 Los Angeles, CA 90034
 800-500-9976 or 310-204-7040
 or
 111 Broadway, 19th Floor
 New York, NY 10006
 800-235-6848 or 212-349-2910
 Email: LRF@lymphoma.org
 www.lymphoma.org

**National Leukemia Research
Association**

585 Stewart Avenue, Suite 18
 Garden City, NY 11530
 516-222-1944
 clra@childrensleukemia.org
 www.childrensleukemia.org

Multiple Myeloma**International Myeloma
Foundation**

12650 Riverside Drive, Suite 206
 North Hollywood, CA 91607
 800-452-2873
 Email: TheIMF@myeloma.org
 www.myeloma.org

**Multiple Myeloma Research
Foundation**

3 Forest Street
 New Canaan, CT 06840
 203-972-1250
 Email: themmrf@themmrf.org
 www.multiplemyeloma.org

Transportation**Air Care Alliance**

1515 East 71st Street, Suite 312
 Tulsa, OK 74136
 888-260-9707 or 918-745-0384
 Email: mail@aircareall.org
 www.aircareall.org

AirLifeLine

50 Fullerton Court, Suite 200
 Sacramento, CA 95825
 877-AIRLIFE or 916-641-7800
 Email: staff@airlifeline.org
 www.airlifeline.org

Corporate Angel Network

Westchester County Airport
 One Loop Road
 White Plains, NY 10604
 866-328-1313 or 914-328-1313
 Email: info@corpangelnetwork.org
 www.corpangelnetwork.org

National Patient Travel Center

4620 Haygood Road, Suite 1
 Virginia Beach, VA 23455
 800-296-1217 or 757-318-9174
 Email: mercymedical@erols.com
 www.patienttravel.org

Information on the Internet

The Internet is a valuable tool for cancer or medical research. It offers a wealth of information, some helpful, some misleading. Rely on credible sources for information like hospitals or medical associations. Proceed with caution when searching on the Internet. Evaluate material by asking:

- What is the source of this information?
- Is it factual or opinion?
- Is it based on someone's experience?
- How current is this information?
- Is this site set up to promote a product?

When evaluating Internet sites, check the address (URL). The final segment of the address offers a general idea of who is sponsoring the web site. Examples include:

- .edu...site sponsored by a university
- .gov...site sponsored by a government agency
- .org...site sponsored by a nonprofit organization
- .com...site sponsored by a commercial company

Cancer Web Sites

American Society of Clinical Oncology

www.asco.org
www.peoplelivingwithcancer.org

Breast Cancer Answers

www.canceranswers.org

Guide to Internet Resources for Cancer

www.cancerindex.org

Leukemia Links

www.acor.org/leukemia

Lymphoma Information Network

www.lymphomainfo.net

MEDLINEplus

www.medlineplus.org

Oncolink

www.oncolink.org

Physicians Data Query (PDQ)

www.cancer.gov

Clinical Trials Websites

www.cancer.gov/clinical_trials
www.cancercare.org
www.cancertrialshelp.org
www.centerwatch.com
www.cis.nci.nih.gov/resources/clinical.html
www.clinicaltrials.gov
www.oncolink.com

Additional Web Sites and Mailing Lists

AA-MDS-TALK

Listserv based mailing list in support of Aplastic Anemia and Myelodysplastic Syndrome patients, families, and care providers
www.aafa-ner.org

Association of Cancer Online Resources (ACOR)

Offers information and support mailing lists about many types of cancer and related disorders
www.acor.org

BMTnet

Portal to BMT resources, sponsored by seven international blood and marrow transplant organizations
www.bmtnet.org

BMT Support Online

Interactive chat for bone marrow transplant patients
BMT-support@BMTSupport.org
www.bmtsupport.org

BMT-TALK

Online communication forum
http://listserv.acor.org/archives/bmt-talk.html

Blood and Marrow Transplant Information Network

Lists an online database of over 250 transplant centers in the U.S. and Canada
www.bmtinfonet.org

Health Insurance Information

www.healthinsuranceinfo.net

National Center for Complementary and Alternative Medicine

Offers information about complementary medicine used in conjunction with standard treatments
www.nccam.nih.gov

Needy Meds

Information source for patient assistance programs
www.needymeds.com

BOOKS

Across The Chasm, A Caregiver's Story by Naomi L. Zikmund-Fisher (BMT Infonet)

Adult Leukemia: A Comprehensive Guide for Patients and Families by Barbara Lackritz

Anatomy of an Illness as Perceived by the Patient: Reflections on Healing and Regeneration by Norman Cousins

A Resource Guide for Bone Marrow/Stem Cell Transplant (nbmtLink)

Autologous Stem Cell Transplant: A Handbook for Patients by Sue Stewart (BMT Infonet)

Bone Marrow Transplants: A Book of Basics for Patients by Sue Stewart (BMT Infonet)

Cancer As A Turning Point: A Handbook for People with Cancer, Their Families, and Health Professionals by Lawrence LeShan

Cancer Talk by Selma Schimmel

Cancer Recovery Eating Plan: The Right Food to Help Fuel Your Recovery by Daniel Nixon, M.D.

Cancer Survivor's Nutrition and Health Guide by Gene Spiller, Ph.D. and Bonnie Bruce DR.P.H., R.D.

The Caregiver's Companion by Theola Jones

Caregivers' Guide for Bone Marrow/Stem Cell Transplant (nbmtLink)

Choices in Healing by Michael Lerner

The Courage to Laugh: Humor, Hope, and Healing in the Face of Death and Dying by Allen Klein

Everyone's Guide to Cancer Therapy, 3rd Edition, Malin, Md. Dollinger, et al

Finding the Money: A Guide to Paying Your Medical Bills by Diane Tolley

Full Catastrophe Living: Using the Wisdom of Your Body and Mind to Face Stress, Pain, and Illness by Jon Kabat-Zinn, Ph.D.

Getting Well Again by Carl O. Simonton, M.D., et al

Grace and Grit by Traya and Ken Wilbur

Guide to Stress Reduction by L. John Mason, Ph.D.

Healing into Life and Death by Stephen Levine

The Healing Power of Humor: Techniques for Getting Through Loss, Setbacks, Upsets, Disappointments, Difficulties, Trials, Tribulations, and All That by Allen Klein

Healing Yourself: A Step-by-Step Program for Better Health Through Imagery by Martin Rossman, M.D.

How to Live Between Office Visits by Bernie Siegel, M.D.

The Human Side of Cancer: Living with Hope, Coping with Uncertainty by Jimmie C. Holland, Sheldon Lewis

In the Country of Illness: Comfort and Advice for the Journey by Robert Lipsyte

Informed Decisions: The Complete Book of Cancer Diagnosis, Treatment, and Recovery by Harmon J. Eyre

It's Always Something by Gilda Radner

The Journey Through Cancer: An Oncologist's Seven-Level Program for Healing and Transforming the Whole Person by Jeremy R. Geffen

Kitchen Table Wisdom: Stories That Heal by Rachel Naomi Remen

Learn to Relax: A Practical Guide to Easing Tension and Conquering Stress by Mike George

Learning to Fall: The Blessings of an Imperfect Life by Philip Simmons

Love, Medicine and Miracles by Bernie Siegel

Making Informed Medical Decisions: Where to Look and How to Use What You Find by Nancy Oster

Minding the Body, Mending the Mind by Joan Borysenko, Ph.D.

Mom's Marijuana by Dan Shapiro

My Grandfather's Blessings by Rachel Naomi Remen

The New Cancer Survivors: Living with Grace, Fighting with Spirit by Natalie Spingarn

Not Just One in Eight by Barbara Stevens

Peace, Love and Healing by Bernie Siegel

Stem Cell Transplant, A Companion Guide for Breast Cancer Patients (nbmtLink)

Sexuality and Cancer: For the Man/Woman Who Has Cancer and Their Partner (American Cancer Society)

Sexuality and Fertility After Cancer by Leslie R. Schover

Share Care-How to Organize a Group to Care for Someone Who Is Seriously Ill by Cappy Capossela and Sheila Warnock

Supportive Cancer Care: The Complete Guide for Patients and Their Families by Ernest H., M.D. Rosenbaum, et al

Surviving Cancer Emotionally, Learning How to Heal by Roger Granet, M.D.

Survivor, Taking Control of Your Fight Against Cancer by Laura Landro

Take this Book to the Hospital with You: A Consumer Guide to Surviving Your Hospital Stay by Charles B. Inlander and Ed Weiner

Time On Fire by Evan Handler

Understanding Medical Information: A User's Guide to Informatics and Decision Making by Theresa Jordan

When a Parent Has Cancer: A Guide for Caring for Your Children by Wendy Schlessel Harpham, M.D.

Where the Buffaloes Roam by Bob Stone and Jenny Humphries

You Can Conquer Cancer by Ian Gawler



National Bone Marrow Transplant Link

Resources and Reassurance When You Need Them Most

The mission of the National Bone Marrow Transplant Link (nbmtLink) is to help patients, as well as their caregivers, families and the health care community meet the many challenges of bone marrow/stem cell transplant by providing vital information and support services.

Founded in 1992, the nbmtLink is an independent, non-profit organization funded entirely through the generosity of individuals, corporations and foundations.

Tax-deductible contributions are welcomed and vital to ongoing programs and services.

National Bone Marrow Transplant Link

20411 W. 12 Mile Road, Suite 108

Southfield, Michigan 48076

248-358-1886

Fax: 248-358-1889

Toll Free: 800-546-5268

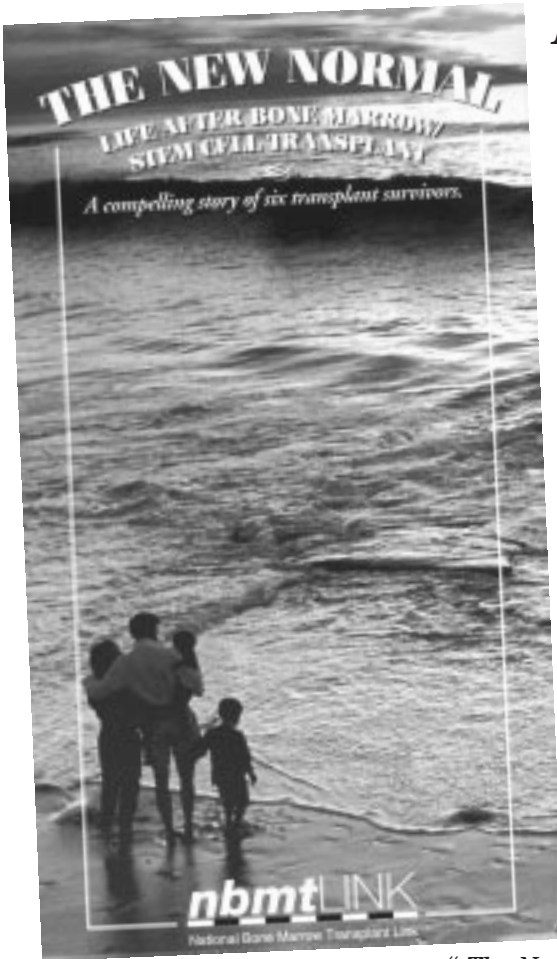
E-mail: nbmtlink@aol.com

www.nbmtlink.org

“A Second Chance at Life Is Our First Priority”

The New Normal: Life After Bone Marrow/Stem Cell Transplant

A video from the National Bone Marrow Transplant Link (nbmtLink)



Now available.....a remarkable 45-minute film for anyone whose life has been touched by bone marrow/stem cell transplant. *The New Normal* is an incredible story told through the voices of transplant survivors and their caregivers. Although no film can fully prepare an individual for what they will face during a bone marrow/stem cell transplant, *The New Normal* provides information, inspiration and hope.

Some thoughts on The New Normal...

“...each of the patients and their family members (in the film) were thoughtful, articulate, truthful, and tremendously helpful. The presentation ... gave reassurance by explaining that for every difficulty there are antidotes to minimize the effects...one emerges from the experience a deeper, more appreciative, more compassionate person.”

- Susan Vreeland, BMT survivor, author

“The New Normal is encouraging and inspiring.

This is a must for all patient education resource rooms and for every transplant patient.”

- Richard P. McQuellon, Ph.D.

Director, Psychosocial Oncology

Wake Forest University/Baptist Medical Center

Please Contact:

20411 W. 12 Mile Rd., Suite 108, Southfield, MI 48076

800-LINK-BMT (800-546-5268) 248-358-1886

Fax: 248-358-1889

e-mail: nbmtlink@aol.com Web site: www.nbmtlink.org



SURVIVORS' GUIDE FOR BONE MARROW/STEM CELL TRANSPLANT



What to Expect and How to Get Through It

by Keren Stronach

***nbmt*LINK**

National Bone Marrow Transplant Link