

# GUIDE TO BONE MARROW AND STEM CELL TRANSPLANT



*What to Expect and How to Move Forward*  
*by Keren Stronach*

***n*bmtLINK**

National Bone Marrow Transplant Link

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## *What to Expect and How to Move Forward*

Note: this is a revised edition of “Survivors’ Guide for Bone Marrow/Stem Cell Transplant, What to Expect and How to Get Through It.”

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 sources are not intended to be endorsements.

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- Survivorship Guide for Bone Marrow/Stem Cell Transplant, Coping with Late Effects
- Caregivers' Guide for Bone Marrow/Stem Cell Transplant Practical Perspectives
- Voices of Hope & Healing
- The New Normal - Emmy Winning DVD

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Our team consists of master's level oncology social workers, nurses and health educators who are available by phone Monday through Friday, 9 a.m. to 9 p.m. (ET).

For a complete directory of our patient services programs, contact us at 800.955.4572 or [www.LLS.org/information specialists](http://www.LLS.org/information specialists) (Callers may request a language interpreter.)



## Guide to Bone Marrow and Stem Cell Transplant *What to Expect and How to Move Forward*

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Mike, transplant recipient at age 63, with his grandson

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# OVERVIEW OF THE BONE MARROW/ STEM CELL OR CORD BLOOD TRANSPLANT PROCESS

## FOREWARD



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, 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 people can find recommendations that speak to their own temperament and personality. Keep in mind that there is no "right way" to go through a transplant. Each person must find the path that is most appropriate for him or her.

As the primary writer, I have undergone two transplants from an unrelated donor. In addition to recounting some of my own personal experiences, I've included the experiences of several transplant patients, who took the time to answer an extensive questionnaire. This updated guide begins with a brief introductory section explaining the nuts and bolts of a bone marrow, stem cell transplant or cord blood transplant and follows the 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.

When I was first told that I would need a bone marrow/stem cell transplant (BMT), I mistakenly thought 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 the 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 1960'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 replace it with a donor's healthy marrow. Since then, the procedure has been refined and expanded to treat many other conditions, including cancers and diseases that do not involve 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 deciding to undergo a bone marrow/stem cell transplant, look into some of the promising treatments under investigation and educate yourself about treatment 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 diagnosis.

### 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 are 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, frozen 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

performed 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**

In an allogeneic transplant, the stem cells are taken from someone else. If the stem cells are taken from a sibling, the transplant is called a *related allogeneic transplant*. If the stem cells are taken from a person that is not related to you, the transplant 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 antigen (HLA) test that 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 develop GVHD.

A *non-myeloablative stem cell transplant*, sometimes referred to as a “mini” transplant, is a type of allogeneic transplant that uses lower doses of chemotherapy than those typically used in transplants. Discuss with your doctors whether a “mini” transplant may be right for you.

### **Cord Blood Transplant**

Stem cells are also abundant in the umbilical cords and placentas of newborn babies. A transplant that uses stem cells from an umbilical cord and placenta that is donated after the birth of a baby is referred to as a cord blood transplant. Cord blood transplants have an important and growing role in the treatment of leukemia, lymphoma, sickle cell anemia, myelodysplastic syndrome and severe aplastic anemia. One of the challenges in using cord blood is that there are relatively few stem cells in each umbilical cord and placenta which means that there are fewer stem cells available than in other types of transplants. However, cord blood transplants also

have advantages. The stem cells taken from cord blood are very versatile and can adapt to their new environment in the host’s body, which means that there is a lower risk of complications such as GVHD. It is therefore not as important to ensure a close genetic match between the donor and the host.

### **Haploidentical Transplant**

In cases where a patient cannot find a HLA-matched donor, new medical advances have made it possible to do a transplant referred to as a haploidentical transplant where only 50% of the HLA genes are a perfect match. The advantage of having a haploidentical transplant is that it increases the chance of finding a donor, as almost everyone has at least one parent, sibling or relative who is a 50% match and can provide stem cells for the transplant. When stem cells from a haploidentical donor are combined with cord blood, the combination produces an outcome that is, in many cases, as successful as that of a matched donor.

### **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 develop 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 you have and the hospital where you are receiving your care. Today, many autologous and some allogeneic transplants are done on an outpatient basis. In some cases, 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 that 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 that 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 or hematocrit 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 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 that were taken either from you or from your donor 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 methods. Traditionally stem cells were collected from a large bone such as the hipbone. 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.

Recently, *peripheral blood stem cell* (PBSC) transplants have become more common. In this case, the patient or donor donates stem cells 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*.

### 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 while 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 this guide. The intention of this book is to provide 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. It is hoped that you will feel less isolated in your journey and be able to utilize some of the coping methods 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 healthy diet, getting good dental care and maintaining an exercise routine. On a practical level, it may mean choosing a transplant center, determining caregiving arrangements, obtaining items for the hospital stay in addition to organizing legal, financial and insurance matters.

### EMOTIONAL PREPARATION

Facing the prospect of a transplant can be overwhelming—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 amount of information and new medical jargon can be mind numbing. As you prepare for the transplant, it is common to feel overwhelmed by emotions. You may experience feelings of anxiety, self-pity, hopelessness and self-blame. It is also normal to feel betrayed by your body and feel anger and jealousy toward others who do not have to face the same ordeals. At times, you may find that your feelings undergo intense fluctuations, alternating between hope, anticipation and fear.

You may experience denial. You may find yourself responding to the situation by becoming emotionally numb and very task-oriented. Be understanding and gentle with yourself. You are facing some of the most stressful situations you will ever experience. The transplant may also be seen as a new lease on life and 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 with 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 research all medical and alternative options yourself or hand over control to others, or a combination of the two. Be attentive and do whatever works for you, recognizing that your needs may change with time.

#### 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 talk to people who are helpful and 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 experience counseling people with life-threatening diseases can be 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 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 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.*

You can contact the National Bone Marrow Transplant Link (nbmtLINK) and request a connection to a transplant survivor who has been in a situation similar to your own. A trained peer support volunteer, who has undergone a transplant, will contact you personally. You can also ask a member of your medical team or your social worker to put you in touch with someone who has undergone a transplant.

Joining a support group (either in person or online) 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 other 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 provide relief to express one's emotions about these difficult issues and hear others express it:

*Getting cancer 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.*

*Cancer forced me to recognize that I am mortal, that life and death are inextricably intertwined – two sides of the same coin. And it is from this realization, the inevitability of death, that I have also come to better appreciate life. Knowing that the rug can be pulled out from under my feet any time, reminds me that life is to be LIVED and enjoyed now.*

Some survivors tend to blame themselves for their condition. Cancer is caused by complex reasons having to do with the environment, genetic, social and individual factors. Cancer can strike anyone. If a resource you are reading makes you feel upset, put it down.

### Explore Books, the Internet and Social Media

Reading books, watching videos, webcasts, and participating in social media are all helpful ways to learn about your disease and find out about ways to cope.

*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.*

*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. I also listened to relaxation tapes that helped me relax and fall asleep.*

*Someone showed up in my room with a DVD of "The New Normal." I watched it two or three times in a row. It was then that I realized just how limited my preparation for my transplant had been.*

*The Internet was an invaluable tool for me from the time of my lymphoma diagnosis through the recommendation of a bone marrow transplant. The research I did helped me better understand the transplant procedure and which transplant center would be best for me. It was critical for me to be able to speak with someone who had the same experience and finding the patient advocacy organizations with peer support programs was an additional blessing.*

*Twitter enabled me to keep up on what is happening around the globe as it relates to bone marrow transplant. I feel so fortunate to have social media tools such as Facebook, Instagram and Twitter to educate and keep me up on the latest information available.*

*I learned of a Facebook closed group for patients with GVHD. It was very helpful to be able to ask questions of other patients and feel uplifted through support. Facebook enables survivors like me to reach out when it is convenient and feel less isolated. I am so thankful for the friends I have made through social media.*

Another transplant patient recalls:

*A few days before entering hospital to start the process for a stem cell transplant, my wife handed me a story she had discovered on the Internet.*

*It was about a man going on a journey to the airport to meet and greet his stem cell donor for the very first time—to meet the man that saved his life! From that day forward I dreamed about the day when I would make a similar journey to meet my donor. The story inspired me and I kept a copy of the article with me to read from time to time as I aimed to do the same thing. Happily, I recently did meet my donor from Germany, when he came to visit me in the United States and it was one of the best days in my life.*

### Reduce Stress

It is helpful to think of ways that you can reduce 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 are ways to cope with the 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 it. One suggestion is to delegate tasks to family and friends who want to help.

Oftentimes, people around you will not know how to help and are grateful to you for providing them with concrete suggestions. Close contacts are likely to feel helpless in the face of your diagnosis and impending transplant. Giving them tasks will help you and help them feel useful.

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. I also asked people to send me a DVD of their favorite movie. It made my "down time" during transplant easier and it was interesting to see the taste my individual friends had in movies.*

*I found it incredibly helpful to have a blog to share transplant updates with my family and friends. I had two blogs. One was “public” for friends and people interested in my transplant progress and recovery. I posted every week or two to share what was happening and how I was doing. The second blog was private, requiring a password, and it was for my family. Here I provided daily updates with all the good, the bad and the ugly. It shared a higher level of medical details and personal information than I felt comfortable sharing publicly. It was a place for my family to go everyday and know exactly what was happening.*

*The blogs were a great way to keep everyone informed and connected. Both family and friends appreciated that I included lots of photos that gave everyone a sense of connection to me and my experience. And now, over a year post transplant, the blogs serve as a journal for me personally to look back on my journey.*

Another patient writes:

*Before the transplant, my husband and I participated in a holistic health program. The ten-week course helped me to gain emotional strength and to better understand my immune system.*

Some patients and caregivers find it helpful to use various websites referenced in the Resource Listing, located at the back of this book, to chronicle their journey, provide updates and organize support.

*Sometimes continuing with your normal routine is the most effective way of reducing stress.*

### **Practice Meditation and Relaxation Techniques**

Practicing stress reduction techniques such as deep breathing, muscle relaxation, meditation, hypnosis or guided 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. Meditation and guided imagery resources are increasingly available through various stress reduction apps and online recordings that can be downloaded. There are also many low cost meditation programs and retreats throughout the country.

*I went to a one-day cancer retreat that was helpful and also attended a two-day meditation retreat that did a lot to calm and relax me.*

### **Get in Touch with Your Spirituality**

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

*Prayer 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.*

*I find that being out in nature is the most powerful way for me to feel connected to the sacred – to the beauty and mystery of the world.*

### **Participate in Activities You Enjoy**

Reducing stress in your life can also be accomplished by doing activities that you find most relaxing, healing and fun. Consider making a list of all the things that bring meaning to your life, or that are simply pleasurable, and try to incorporate them into your daily, weekly or monthly routine.

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. I 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.*

*I decided to try to do one fun thing a day – sometimes it is just something small that made me laugh, or calling a friend I haven't spoken to in a long time, or going on a walk somewhere beautiful.*

### **Explore Creative Outlets**

Finding creative outlets for one's feelings or unique 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 that 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.*

### **Living Now and Planning for the Future**

Putting one's legal and financial affairs in order and designating someone to make health decisions for us if we are unable to do so is a way of providing security for ourselves and our loved ones. It is about documenting our wishes in a way that ensures that they will be respected and honored for the duration of our lives, and in the future. This is an issue that is relevant for everyone, regardless of whether or not they have cancer or will be undergoing a bone marrow transplant.

One way to do this is to have discussions with your most trusted friends and family and jointly sharing with each other what you would like to happen if you are unable to make decisions and speak for yourself. Your social worker or physician can also help you articulate your desires regarding critical care. These discussions, referred to as “advance care planning” are becoming increasingly routine. Your wishes can be documented in an Advance Directive, where you can state whom you designate to make decisions for you in the event that you cannot speak for yourself. Knowing that your wishes, whatever they happen to be, are documented and known 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. Advance Directives can easily be downloaded from the web and need the signature of two witnesses. Filling one out does not signify an anticipated negative outcome. Sometimes, by dealing with difficult issues in the event of one’s death, it helps put these issues aside in order to focus on more positive things.

One patient writes:

*When I was diagnosed, I wanted to make sure that my family knew what I wanted in the event that I would be in a situation that I couldn’t speak for myself, so I downloaded and printed several copies of an Advance Directive and everyone in my family filled one out – me, my parents, and my husband. Doing this was eye-opening as I realized that I had not known what they wanted, and that some of it was different than what I expected. I am grateful that they know what I want, and I know what each of them wants.*

One patient writes that to cope emotionally he did the following:

*I made efforts to put my business affairs in order, made final arrangements 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.*

Consider taking advantage of your benefits options such as Social Security Disability Benefits or the possibility of viatication, which is a process that allows you can sell your life insurance as a way of helping pay for medical and other expenses. 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 and 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 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 this probably has 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. There is a large amount of information available on the Internet. Be cautious when searching. Use reputable websites and realize not everything on the Internet is accurate. Talk to your doctors and former transplant patients. Visit transplant centers and call on different cancer organizations that employ knowledgeable staff that can respond to your questions and concerns. For more information about such organizations, please consult the Resource Listing. During your research, remember that it is always appropriate to pursue a second or even third opinion. Most doctors expect you to get a second opinion, and they will not feel hurt by your decision. If your doctor does have a problem with you seeking a second opinion, he/she is probably not the right doctor for you. When, where, and how you will be treated 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 with a physician, don’t hesitate to ask for information to be explained, if needed 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 or remembered the information correctly. Recording the medical sessions can also be helpful.

## Take Time for Yourself

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.

A wonderful essay by Stephen Jay Gould entitled “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.<sup>1</sup>

Keep in mind that being hopeful does not mean that you need to be positive all the time. You are 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 may 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, important to 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. It is important not to scare them with a lot of pessimistic information. Try to present the information realistically yet 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

<sup>1</sup> Stephen Jay Gould, “The Median is Not the Message,” DISCOVER/JUNE 1985, also available on [www.cancerguide.org](http://www.cancerguide.org)

and excellent physicians. Utilizing the help of professionals or a peer-support partner 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. 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 recording a favorite story so that your children can 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 can be an effective and tangible way to remind your children of your presence and caring. Of course, texts, email, Skype and FaceTime make it easier than ever to stay in touch.