

# SURVIVORSHIP GUIDE FOR BONE MARROW/STEM CELL TRANSPLANT

~  
*Coping with Late Effects*  
by Keren Stronach

***n*bmtLINK**

National Bone Marrow Transplant Link

# SURVIVORSHIP GUIDE FOR BONE MARROW/STEM CELL TRANSPLANT

## ~ *Coping with Late Effects*

*I would like to thank the survivors and caregivers who responded to our survey and shared their personal stories, my husband, Josh, for his support and the spark he brings to my life, my children, Talia and Ben, for adding joy and laughter, and dear friends and family for making life rich and full.*  
–Keren Stronach

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The mission of the National Bone Marrow Transplant Link is to help patients, caregivers, and families cope with the social and emotional challenges of bone marrow/stem cell transplant from diagnosis through survivorship by providing vital information and personalized support services.

**The information in this guide should not be a substitute for medical advice, and the listed resources are not intended to be endorsements. Please consult with your physician regarding your medical decisions and treatment.**

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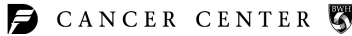
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- Survivorship Programs & Publications
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## PROLOGUE

I would like to imagine that over the years, I have become more expert at navigating uncertainty, at facing my mortality, at living a life that is so different from what I imagined. And for now, I feel lucky and blessed to be where I am – relatively healthy and alive. But I know that all this can change in an instant – a recurrence or another malignancy, a freak accident, or a broken limb. The following parable anchors me and gives me the courage to move on and face the future.

As many of you know, Itzhak Perlman is a famous violinist who contracted polio as a young boy. As a result, he walks with great difficulty and with the aid of crutches. One day, Perlman was scheduled to give a recital at Carnegie Hall. As usual, he came onto the stage with crutches, laboriously walking to his seat. A few bars into the concerto, one of his violin strings broke with a loud popping sound. The conductor stopped the orchestra, and the audience held its collective breath as it waited to see what would happen next. Would someone appear from backstage with a new violin? Would Perlman pull a new violin string out of his pocket? Instead, after a short pause, he nodded to the conductor to resume where he had left off.

The common wisdom is that it is not possible to play a violin with three strings. That evening, Perlman refused to know this. He played the entire concerto on three strings. When the concerto ended, the audience rose with thunderous applause, clapping and stomping and shouting. When the audience finally quieted down, he said:

*“It is the artist’s task to find out how much music you can make with the instrument that you have.”*

Survivorship is about living life fully with changed instruments: changed bodies, changed psyches, and changed perceptions. We all emerge from our transplant different than we were. Many of us are not as resilient. We may be changed physically or have an altered perception of our vulnerability and sense of mortality. The challenge is to figure out how to live as loudly, fully, and richly as we can, post diagnosis and post transplant. We may not be able to do as much or soar as high as we used to, but survivorship is about finding ways to live meaningful lives as we are today.

## INTRODUCTION

Before my first bone marrow transplant in 1994, I believed that my life would return to what I knew to be normal after the transplant. The information I was given about what to expect post transplant was minimal. Most doctors mentioned the possibility of long-term health problems resulting from the transplant, but they also told the stories of a few star patients who went back to their lives at full steam, returning to competitive tennis or running, just as strong as before. In my mind, I latched onto these positive stories, imagining myself a few years down the road, vigorous and healthy again. However, two transplants later, my body, skin, strength, stamina, and approach to life (and death) have profoundly changed. The new normal is both better and worse than I expected. My physical health and energy level are nothing like what they used to be. It is almost as if I am in a new body, which I have

had to get to know and identify with. Whereas before the transplant, I prided myself on being very athletic, healthy, and energetic, I am no longer these things. I deal with ongoing chronic Graft Versus Host Disease (GVHD) and take medications on a daily basis. And my energy, while allowing me to function normally, is a fraction of what it used to be. I certainly cannot travel to all the places I once hoped to visit or have the career I once imagined for myself. Emotionally, the story is more complex. Overall, I am content and happy, possibly more so than before the transplant. I appreciate life more; I am more accepting of my shortcomings; I treat myself more kindly; and I am more focused on enjoying this short life. I also still grieve the early loss of my health, vigor, fertility, appearance, and the imagined trajectory of my life had it not been for the aftereffects of the transplant

Navigating the bumpy post-transplant journey is not easy, particularly if we experience transplant aftereffects. Very few, if any, of our friends experience our symptoms. And often, the physicians caring for us outside of the transplant center are not savvy about the late effects of transplant.

This guide provides information and resources to help you on your journey in the years and decades following your transplant. Much of the information in this guide was obtained from surveys that were filled out by 61 long-term survivors, a few caregivers, peer-reviewed scientific journal articles, lectures by experts in the field, and discussions with survivors and medical personnel. The kaleidoscope of shared struggles, losses, and resilience speaks to the incredible capacity of individuals to weave together meaningful and rich lives despite adversity, and, in many cases, ongoing health problems.

**Keep in mind that the information, recommendations, survivor quotes, and products/medications mentioned in this booklet are not endorsements nor intended as medical advice. Always consult with your physician about your medical decisions and treatment. Please note that some of the survivor quotes have been modified or condensed for grammatical and space purposes.**

For readers who would like to learn about the basics of the transplant process, the booklet *Resource Guide for Bone Marrow/Stem Cell Transplant* is available from the National Bone Marrow Transplant Link. Please visit [www.nbmtlink.org](http://www.nbmtlink.org) or call 800-LINK-BMT to find out how you can receive a copy of this publication. The National Marrow Donor Program also has a booklet entitled *The Introduction to Marrow and Cord Blood Transplant* – available in English and Spanish. This can be ordered by calling 888-999-6743 or visiting [www.marrow.org/patient](http://www.marrow.org/patient).

## DEFINING LONG-TERM SURVIVORSHIP

**T**his guide is about long-term survivorship. It is about the years following the intensity of a transplant and the “new normal” that emerges. For the purposes of this guide, we are defining a long-term survivor as anyone who is two or more years after a bone marrow, peripheral blood stem cell, or umbilical cord blood transplant. Hematopoietic cell transplant (HCT) is the medical term encompassing all of these types of transplants. For the purposes of this book, we refer to them as “transplant” or “BMT.”

More than 50,000 such transplants are performed worldwide each year, of which 20,000 are performed in the USA. As treatment statistics improve and more individuals are added to the community of long-term survivors, the number of people experiencing chronic health conditions from the aftereffects of their disease and its treatment will grow as well. It is, therefore, increasingly important to provide a realistic picture of the post-transplant experience in all its complexity and diversity. The goals of this guide are to shed light on the challenges that individuals face after a transplant and to provide useful information and resources on how to cope with these challenges. Although many of us may continue to experience some chronic health problems as a result of the transplant, it is important to remember that we can live good lives despite post-transplant challenges. With persistence and good follow-up treatment, many of the aftereffects can be reduced.

## LATE EFFECTS OF THE TRANSPLANT

**T**he transplant experience can affect us physically, emotionally, mentally, and spiritually – with some people facing more effects than others. It can also affect our social relationships, our ability to work in the same profession or with the same intensity as in the past, and all this impacts our quality of life. Some survivors, once they are two or more years out, leave the transplant experience behind with few or no lingering problems. Others, however, may deal with ongoing challenges and complications that can affect many aspects of life.

A majority of transplant recipients do not experience a full restoration of health,<sup>1</sup> and it is estimated that at two years after transplant more than 25% of survivors have ongoing bothersome medical symptoms.<sup>2</sup> However, a recent study found that at ten years out, survivors are nearly as healthy as adults who have never had a transplant. Overall, survivors did not experience more hospitalizations or outpatient medical visits and had similar rates of conditions, such as asthma, diabetes, high blood pressure, and high cholesterol, as people who had not undergone a transplant. But, they did report a higher incidence of certain medical problems, including musculoskeletal complaints (stiffness and cramping), sexual problems, and a higher use of antidepressants and anti-anxiety medications.<sup>3</sup> Survivors are also more likely to experience cataracts, thyroid hormone deficiency, bone thinning (osteoporosis), and secondary cancers.<sup>4</sup>

Although some survivors view their health as worse than a typical person their age, they also report positive changes, such as greater personal growth,<sup>1</sup> an enhanced

appreciation for life, greater appreciation of friends and family, different priorities, and a shift in life expectations. How these gains and losses play out is different for each individual, with some people experiencing more of the benefits and others feeling the losses more acutely. Here is how several different survivors sum up their experience:

*I feel that I lead a more balanced life now. I definitely take more time to appreciate what life has to offer. However, I am constantly fearful of what health problems lie ahead (relapse, secondary cancers, etc.).*

*Since the transplant I have experienced physical problems as well as depression, fear, and profound anxiety that have been very debilitating.*

*Life after transplant is tough. I realize the transplant is always going to be part of my life. I have a scar where my Hickman catheter used to be; I have a bump on my scalp where a port was in my head. I wonder why I got sick since I had led such a healthy lifestyle before. I never even took aspirin before I got sick. My world has changed so much.*

*I feel mostly as strong and healthy today as before the transplant. The difference is that I can't push myself as hard. I need to take breaks when I start to falter (rather than work through it).*

*I feel better and healthier since the transplant. I am back 100%.*

## QUALITY OF LIFE POST TRANSPLANT

Quality of life is complex and is tied to many factors, including the extent of emotional support, personal belief system, financial resources, access to good medical care and other resources, as well as your own coping abilities. The presence of ongoing physical problems also greatly influences quality of life.<sup>5</sup> Assessing the change in quality of life before and after the transplant is complicated by the fact that shifts in expectations and priorities may change how a survivor evaluates his or her quality of life.<sup>6</sup> Also, deterioration in health or sexual functioning may be counterbalanced by strengthened social bonds or enhanced spirituality, all of which go into the general mix that makes up what we call quality of life.

Overall, survivors do more poorly on many measures of quality of life when compared to individuals who have not undergone a transplant.<sup>2,4</sup> Despite this, however, 60% of survivors are satisfied with their lives and report good to excellent quality of life in the initial years post transplant.<sup>2</sup> As survivors get further away from the transplant, they tend to report a better quality of life.<sup>5</sup>

Several survivors reflect on their quality of life after transplant:

*Before the transplant I took my good health and so much else for granted. Now, I deal with many small lingering health issues, but I use a different measuring stick to evaluate my life. What I once would have considered only acceptable, I now consider good, and I appreciate both the big and the little things more.*

*The transplant experience helped me grow as a person. I learned things about myself and fellow humans that I would not have considered prior to being sick. I think I am a better, happier person as a result of the experience.*

*Overall, I feel a bit depressed more often than before. I become anxious easily now in the face of unexpected changes in plans.*

*I am weaker in mind, body, and spirit. I continue to try to strengthen all and accept that both age and illness take their tolls.*

*I'm actually a happier and more well-balanced person than I was before the transplant. I treat myself better and try not to take things too seriously. I don't always succeed, but I do recognize when I'm blowing things out of proportion.*

## ADJUSTING TO THE NEW NORMAL

**F**iguring out how to incorporate the physical, emotional, and spiritual changes of the transplant into our lives is complicated and takes time. Often, our sense of who we are is challenged. We may need to discard some of the old notions that we had about ourselves, adjust some of our goals, and make some modifications to how we live. For some people, experiencing the new reality post transplant is extremely stressful. There is no easy template to deal with fear of recurrence, chronic health conditions, changed stamina, and changed perceptions of self. However, over time, a large majority of survivors do incorporate the changes of the transplant into their lives, and a new normal emerges.

*One of the greatest challenges for me after the transplant was learning to identify with and like my new self – the one who is not very athletic, who gets sick easily, who has bags under her eyes. For a long time, I kept wanting to apologize for this new self because, in some sense, I didn't see it as the real me. Now I can look at this new self with more acceptance, but liking the new me is still a work in progress.*

*I can no longer wind surf, kayak, mountain climb, mountain bike, downhill or cross country ski, or jog. I can walk, snorkel, swim, hike, garden, and bird watch.*

*The transplant tremendously impacted my perspective. I used to think I was invincible. The transplant was humbling.*

*The new normal is not a bad normal, just different. Perspective is everything. Life goes on. This is how I am now.*

## DEPRESSION AND POST-TRAUMATIC STRESS DISORDER (PTSD)

The extent to which your emotional health is affected by a transplant depends on a complex interplay of your health status and personality, genetic factors, social support, financial situation, and other concerns. For most people, emotions about their experience change and evolve over time. Typically, feelings of sadness or anxiety are transient. For some, however, these feelings may persist and interfere with daily life. Individuals who experience ongoing sadness, emptiness, or anxiety that does not go away may be suffering from depression or post-traumatic stress disorder (PTSD). Depression is an illness that can affect all aspects of life. It involves a persistent feeling of sadness, emptiness, and loss of joy. People with PTSD often have frightening thoughts or memories about their trauma. They may avoid the places or things that remind them of the traumatic event, may have angry outbursts, a feeling of being on edge, or a feeling of being emotionally numb. The symptoms of PTSD can develop shortly after the trauma or sometimes years later.

*I suffered from severe PTSD after the transplant. I had gone through a long period of cheerful façade – kept everyone feeling positive. After many setbacks, when things finally started looking up, I crashed emotionally, and it took a while to get back to being the positive, active, courageous person I was before.*

*I am sometimes inside for 3-5 days hiding from the world. I have a lot of anxiety. Everything involving confrontation is overwhelming. After calling to correct a billing error, I got so upset, I shook for hours afterwards.*

People with depression or PTSD often cannot “pull themselves together” and may need some type of treatment to resume a healthy emotional life. Treatments for continuing depression include talk therapy, counseling, and antidepressants. In cases of mild depression, alternative treatments such as acupuncture, guided imagery, relaxation, and other therapies can also provide relief.<sup>7</sup> PTSD is different from depression and is often treated with cognitive behavioral therapy that teaches people to separate their strong emotional reaction from the memories of the event.<sup>8</sup> A therapy called Eye Movement Desensitization and Reprocessing (EMDR) has also been found to be effective.<sup>9</sup> Other useful techniques for treating PTSD include group therapy<sup>10</sup> and relaxation tools such as guided imagery<sup>11</sup> and hypnosis. Medications to treat depression and anxiety may also be helpful in resolving PTSD.

*Therapy and antidepressants have been very helpful in dealing with my depression.*

*I was referred to a psychiatrist who was wonderful and put me on one antidepressant after another until we found the right one. I am still taking it.*

*Don't deny depression, anxiety, and post-traumatic stress disorder – get help when you need it.*

## EMOTIONAL WELL-BEING

**T**here is no magic pill to deal with the emotional effects of a transplant. However, there are things that we can do that can help make us more resilient to some of the challenges we face as long-term survivors. Here are some strategies that may be helpful in dealing with the long-term effects of transplant. Depending on your situation, you may choose to use multiple strategies together or focus on just one or two. Or, you may come up with your own particular strategy, suited to your personality and situation.

### Feeling One's Emotions

Our culture tends to emphasize feeling “happy” and having a “positive” attitude. Although there is value in taking a positive view of things, focusing only on the positive without allowing ourselves to feel the full range of emotions can be very constraining. Our emotions are an integral part of who we are. When we blunt our emotions and do not allow their full expression, we are cutting off important information about who we are and what we are experiencing. Sometimes we need to mourn our losses and express our grief in order to shift our expectations and make the necessary adjustments to our lives. In other cases, it is by mining the depth of our sorrow or grief that we can arrive at important insights. Expressing our “negative” emotions can be a way to clear them from our system and return to a balanced state where we can fully feel our joys.

*There is a myth that you need to put on a happy face. Emotions are there for a reason. They are useful and let us know what is happening.*

*I always try to feel my emotions, rather than to fear them and shut them out. My therapist told me something that has always stuck with me: change is inevitable. And, if you feel your emotions, they too will change, and you will move through them. If you fear your emotions, you are left with the constant emotion of fear.*

### Seeking Out Friends and Community

Just as it is nice to have friends to accompany you down a dark street, it is good to reach out to friends and community during difficult times. Our connection to friends provides a buffer against some of life's stresses. Close friends provide comfort, distraction, and understanding during difficult times.

*What has helped me most in dealing with the post-transplant experience is talking to friends about what I am going through. Not everyone can be there, but I have a special few whom I go to for feedback. They are really tuned into what is happening, and they give me perspective and support.*

If you already have close friendships and bonds, foster those friendships and keep them alive. If you don't have close friends or an intimate partner, consider expanding your social connections by joining a community with similar values and/or interests. Social networking on the Internet can be an effective way to find individuals with



similar interests. You might also find good companionship by joining a religious organization, such as a church, mosque, or synagogue. Or you might discover kindred spirits in a meditation group, survivor support group, a book club, a hikers' group, or another community organization.

### **Participating in Activities You Enjoy**

Focus on what you can do rather than on what you can no longer do. Ask yourself what makes you feel alive, joyful, and fulfilled – and go do it. This may mean taking a walk in nature, painting, dancing, singing, or sitting on the couch and watching a good movie. Be attentive to what is rejuvenating and brings you comfort and joy – and act on it.

*One of the things that has been helpful to me is to have a gratitude list. When I am down, I look at this list and realize that I have much to be grateful for.*

Take time to consider how you can reduce the number of activities that you dislike doing in your life. Although you may always have to do things that you do not like, there may be ways to cut down on these activities by delegating them to someone else (maybe paying someone to clean the house) or finding ways to reduce the amount of time you spend doing them.

### **Charting Your Priorities**

The following exercise may help you focus on certain priorities in your post-transplant life. Fold a piece of paper into four sections. On one side, list your favorite activities and think of ways to incorporate some of them into your life. On the other side, make a list of the things you dislike doing and consider ways to reduce the time you spend doing them, or ways to cut those activities out of your life. Your list may be comprised of small mundane things or can include a long-time dream. Carving out time for activities you enjoy may require you to change your priorities, or you might find that they can easily be accommodated in your daily routine. Below is an example:

<b>Things I love to do</b>	<b>Things I dislike doing</b>
• Hike in nature	• Clean the bathroom
• Practice yoga	• Pay my bills
• Spend time with friends	• Spend time on computer
• Spend time with my parents	• Go through the mail
• Watch movies	
• Go see performances	
• Get a massage	
• Swing in a hammock and read	

**Activities I will incorporate more into my life this month**

- Join a weekly yoga class
- Arrange to have a girls' night out after kids are asleep
- Find a good show that is coming to town in the next three months and buy tickets

**Things I can discard or change**

- Get a house cleaner to come every other week to clean
- Sign up for automatic bill payer with my bank, so I spend less time on bills

**Laughter and Humor**

Find ways to laugh, particularly if you are dealing with an unpleasant or difficult situation. One woman who hated waiting in the exam room for her doctor changed the situation by putting on ugly plastic glasses with a big plastic nose and a black mustache whenever she wore the white hospital gown. When her doctor or nurse would walk into the room, everyone would burst out laughing. With a little dose of creativity, she was able to transform a stressful situation into one that had an element of fun.

*When things are really tough, and life seems brutal, I try to bring to mind a funny joke or remember a funny situation, and, even though nothing has changed, it shifts my perspective just a little.*

Bringing humor to a situation doesn't negate the unpleasantness, but it can bring in a little light and make it more tolerable. Studies have found that viewing a funny movie of your choice can help reduce the need for pain medication.<sup>12</sup> Finding the humor in things, taking yourself and life a little less seriously, and finding the ways to bring more laughter to your life will probably not change the circumstances of your life, but may change your mood and how you cope.

**Befriending Uncertainty**

Finding a way to make peace with the unknown is one of life's biggest challenges. Although everyone faces the unknown and cannot know with certainty what tomorrow will bring, the transplant experience shines a light on these uncertainties and forces us to acknowledge, at some level, that the unexpected can happen anytime, and that some things are out of our control.

Years after the transplant, many of us still face uncertainty regarding how much of our stamina and health we will be able to regain. Many wonder about the risk of recurrence or a new malignancy. How we deal with uncertainty is different for each of us and may vary at different times in our lives. Sometimes, choosing distraction or denial to avoid thinking about uncertainty and the fears it brings is a very legitimate and appropriate way to cope.

At other times, it can be helpful to explore our fears with curiosity and to befriend the uncertainty. Sometimes it is by getting closer to that which we fear that we can lessen its power over us. One way to befriend our fears is to shed light on them. This

can include talking about them in a supportive atmosphere with a good friend or a therapist, or exploring them through writing or other forms of expressive art.

Living life while recognizing its inherent uncertainty requires us to have not only courage but compassion – the compassion to be non-judgmental, to give ourselves the time and space to experience and examine our fears, and to realize that even in unknown waters there can be solace, hope, and joy.

*Before the transplant, I would spend a great deal of effort trying to control the direction of my life. Now, I realize that many things are out of my control. So, I try to set my priorities and steer my life in a general direction. But if the river takes me in another direction, I don't try to fight the current as I used to. I go with the flow, knowing that life will lead me down many unknown paths. My challenge is to find ways to enjoy the ride.*

*When I am fearful, I stop myself and take stock of the moment. The moment is usually just fine.*

## **Finding Meaning**

How we interpret our challenges has a lot to do with how we experience life's obstacles. If we believe that our discomfort is for a good reason, our level of emotional suffering may be substantially less than if the reason for our suffering is not clear, or seems unfair or pointless. A marathon runner may experience a great deal of leg and foot pain in the last miles of a race but will push on through the pain with a feeling of accomplishment. However, if that same degree of leg pain were to be experienced without explanation, it would cause great suffering and distress. So, how we understand our physical experience affects our emotional response and also our level of suffering.

*Knowing that I am a more compassionate and caring person than I would have been had I not gone through the transplant helps me deal with all that I have to go through.*

*I get tremendous benefit from talking with other survivors and hearing their stories. I also benefit from mentoring others who find themselves needing a BMT. Every story inspires me in some way. I believe in the power of connection with other people on an emotional level.*

*I had set several goals when I was told of my cancer. I was not going to die before I had accomplished these goals. I have two left to do.*

Although we may not be able to change our medical conditions and general health, we can try to find meaning in the experience, reframe it, learn from it, or use it as an opportunity to do something that we wouldn't have done otherwise. And if there is some purpose for what we are going through, it is easier to find the courage to walk the twists and turns of our path.

Many survivors find purpose and meaning through volunteering. Volunteering allows survivors to put their experience to good use by making a difference in the lives of others.

*I have found that volunteering is the best way to deal with problems I have encountered. Finding ways to help other people always makes me feel more thankful for having been given a second chance at life.*

*Talking with other survivors, speaking at blood or platelet donor dinners, telling my story at schools, and participating in focus groups have been very helpful to me. If I can help one person, then I feel that the experience was worth it.*

## **Adjusting Expectations**

How much we suffer or enjoy a particular experience has a lot to do with our expectations. If it rains unexpectedly throughout a vacation, we may be very disappointed. If we go to a place like Scotland, however, where we expect a lot of rain, the same amount of rain will not detract from our sightseeing and enjoyment of the trip.

Similarly, if our expectation is that our health and strength will return to how it was pre-transplant, we may be more frustrated and disappointed than if we accept that our new normal may include discomfort associated with chronic health problems. Accepting that some health challenges may be part of life post transplant may allow us to cope with the setbacks with less frustration and fear. The key is to readjust plans to what is possible.

*A few days ago, I suddenly came to a point of acceptance, acceptance of my new life, the new normal. I realized that this is how my life is going to be, and it is time to stop hoping/fighting for something different. I felt so peaceful. And then, just a few moments later, I realized that this feeling of peace and acceptance will also pass. There will be days when I will accept the new normal and days when I'll rail against it.*

*It has been helpful for me to connect to others, keep low expectations, and find joy in the simpler, littler things in life.*

*The transplant killed my professional ambitions. The professional aspirations I had aren't compatible with working part-time. Sometimes I dream of the life that could have been without the transplant, then I remind myself that I probably wouldn't be alive. And, taking all into consideration, I feel fortunate to lead a pretty good life.*

## **Seeking Professional Guidance**

Many people find great comfort from seeing a therapist, counselor, or clergy person. Having a trusted person with whom you can share your experience, your feelings, and the changes you are going through can be very healing and helpful. Speaking to someone who can act as a sounding board and offer his or her own insights can help you make sense of your experience and find ways to deal more effectively with the challenges of life.

If the feeling of sadness or anxiety is overwhelming, it may be necessary to seek help from a psychiatrist who can prescribe medication to treat depression, anxiety,

and post-traumatic stress disorder. Medications can be used short-term or long-term, along with counseling to help individuals deal with a specific problem or with ongoing depression and anxiety.

*I found it helpful to see a therapist whose practice is limited to those who have had cancer. He taught me to meditate, focus on “the Now” and helped me to see the things that I have to be grateful for.*

*I had trouble seeing myself as a well person again. Seeing a therapist helped.*

Some survivors prefer to seek help from a support group at a local organization or hospital. You may also find practical advice and resources from books or the Internet. Some are listed in the Resource Listing at the end of this guide.

*The adjustments I needed to make after the transplant were nerve-racking. I found solace in support groups and close friends.*

### **Religion and Spirituality**

For some survivors, religious belief, ritual, and spiritual practice can be an important source of comfort and support post transplant. A belief in God, Jesus, Allah, Buddha, prophets, the wisdom of deeply rooted tradition, or a venerated teacher can support us and help us make sense of our experience, whatever it may be. Feeling that there is always someone to turn to can provide a great deal of security. Joining an established religious or spiritual community can provide opportunities to expand our network of friends, to feel part of a greater whole, and to get practical support when we need it. Many find that religion and daily prayer or spiritual practice is their most important source of sustenance.

*Religion, therapist, prayer, music, food, talking with close friends and sister, and caring for my dogs sustain me.*

*I fully rely on God and Jesus Christ for my comfort and strength ... and this faith is what keeps me constantly renewed each day.*

*During and after the second transplant and the CMV pneumonitis episode when I almost died, I became quite introspective and almost religious, but I “outgrew” that and am now back to my normal self.*

*The things that have helped me most are support groups, a healing group at my synagogue, and meditation.*

### **Awareness of Mortality**

Death is an intrinsic part of life. Everyone’s risk of death is 100%. Most people live the majority of their lives seemingly unaware of this fact. The experience of having a serious disease and a transplant often forces us to acknowledge our mortality. For many of us, this awareness is woven into the fabric of our lives post transplant, serving both as a source of inspiration and anxiety.

An awareness of our vulnerability can provide an added urgency and poignancy, serving as a well-spring for inspiration and an added appreciation of life. However, it

can also be a source of great anxiety and fear that interferes with our quality of life, and in some cases, our ability to function. How we deal with mortality is cultural and personal. How we feel about death is a lens into our world view and personality. It has to do with our beliefs about life and the afterlife, and with how we deal with uncertainty and the unknown. Our ability to cope with mortality is also shaped by how we see our lives, whether we have achieved our goals, and what we believe is our legacy. Our views on mortality often change over time; what we feel about death today may be different a few years from now, and may change again decades later.

*I worry that every ache is cancer coming back, and this heightens my anxiety. I am very afraid of death and dying.*

*My awareness of my mortality makes me more appreciative of life. I am less afraid to try new and more adventurous things. Heck, I survived a transplant, and that's huge.*

*I don't know what death brings. I just know that when my time comes, I want to die, embracing the dying life in me, celebrating all that was – warts and all. And I want, in my moment of passing, to step into the dark unknown, full of curiosity and wonder.*

*I try to do whatever I can to ensure my long-term health (get the follow-up treatment I need, eat healthy, exercise, etc.). And then, once I have done that, I don't worry because I know that I have done all I can do, and the rest is not in my hands. I try to savor all that I have, knowing that I might not be here to enjoy it in the future.*

### **OTHERWISE**

I got out of bed  
on two strong legs.  
It might have been  
otherwise. I ate  
cereal, sweet  
milk, ripe, flawless  
peach. It might  
have been otherwise.  
I took the dog uphill  
to the birch wood.  
All morning I did  
the work I love.

At noon I lay down  
with my mate. It might  
have been otherwise.  
We ate dinner together  
at a table with silver  
candlesticks. It might

have been otherwise.  
 I slept in a bed  
 in a room with paintings  
 on the walls, and  
 planned another day  
 just like this day.  
 But one day, I know,  
 it will be otherwise.

**Credit:** Jane Kenyon, "Otherwise" from *Collected Poems*. Copyright © 2005 by the Estate of Jane Kenyon. Reprinted with the permission of Graywolf Press, Minneapolis, Minnesota, [www.graywolfpress.org](http://www.graywolfpress.org).

## CHANGES IN APPEARANCE

**W**e emerge from a transplant changed. For some people, the changes can be seen; for others they are subtle and can be covered up, or they are invisible. Changes in appearance post transplant result from a combination of many factors. They can happen due to aging of the skin from radiation or the effects of GVHD, from hair loss or premature graying, or from organ damage. Also, certain medications can change how we look. Steroids may change how our body distributes fat, altering the shape of our face and waist. GVHD can cause changes in hair growth and skin tone. Even changes that are invisible to others, hidden under layers of clothing, can change how we feel about ourselves.

Living in a culture that values physical beauty makes it all the more difficult to cope with and accept these changes. How we look and the face we present to the world are closely linked to our identity. In some cases, changes in our appearance may make us feel ashamed, self-conscious, or anxious about our body and may challenge our sense of self-worth.

*In the first few years after the transplant, I was ashamed of how I looked and was reluctant to forge new friendships. I just couldn't imagine that someone would want to befriend me, given the fuzz of hair on my moon-shaped face, the dark circles under my eyes...I missed out on some potential friendships because of my own self-judgment. Now, even though I still don't like the way I look, I just try to act the way I would if I looked as I did before the transplant.*

*My hair has not filled in and is still baby-fine. So I have three wigs, a short one, another that is one inch longer, and another that is two inches longer, so it looks like I get haircuts.*

*I've gone from 180 to 160 to 245 to 180 again in weight. My hair has changed in color, texture, and volume. My face has made me unrecognizable to my own family. My skin has changed in many ways. It has impacted my life in every way imaginable and has messed with my self-esteem and identity in a profound way.*

*Every time I look in the mirror, I see someone different than the person I knew*

*during my life before transplant. The new me has circles under her eyes, thinner hair, skin with an uneven tone, aged skin. I try to tell myself that these scars tell the story of my life. They are my badge of courage. But I still miss the old familiar look that was me.*

*My appearance has changed. I got better looking (just kidding!). I do look different, but this has had no effect on my life.*

Changes in body image can cause great distress and can lead to feelings of shame, embarrassment, inferiority, or anger. These feelings can have a profound impact on quality of life and can restrict our activities in many ways including:

- Reluctance to leave the house
- Reluctance to date or meet new people
- Embarrassment to undress in front of others
- Shying away from intimate contact and sex
- Inability to accept the new self

### **Coping with a Changed Appearance**

It is helpful to remember that our appearance is only the tip of the iceberg of who we are. Most people appreciate us not just for our looks but for our actions, compassion, humor, skills, integrity, vulnerabilities, and strengths. In the end, it is behavior much more than looks that determines how well a person will do in social situations.

Here are some ways of coping that others have found helpful. You can try one or more strategies at the same time:

- As much as possible, stop comparing what you look like today to what you looked like before. Find ways to embrace and value the things that you still like about your appearance. Look at yourself with compassion, maybe a little humor and, to whatever extent possible, let go of self-judgment.
- Reframe the situation. Change your perspective and find ways to see beauty or meaning in the imperfection. What may be an ugly scar can also be seen as a badge of courage, a testament to all that you have gone through. As one person stated in their tag line, “Scars are like tattoos, but with better stories.”
- Continue to do the things that promote health and well-being such as maintaining an active lifestyle, exercising, eating well, sleeping enough, doing things you enjoy. A healthy lifestyle may not restore your appearance to what it once was, but it will help you look and feel better.
- Consider going to a makeup specialist, a stylist, or to a program such as the American Cancer Society’s Look Good Feel Better program ([www.lookgoodfeelbetter.org](http://www.lookgoodfeelbetter.org)) to help you spruce up your appearance through makeup and changes in hair style or clothing.
- If you can’t learn to love your new look, try to stop caring about what others may think about your appearance. This may require changing what you value about yourself, grieving what you have lost, and pushing yourself to change your priorities.



- Keep in mind that beauty is in the eye of the beholder, and it is subjective. Your body image is what you believe about your body but does not necessarily reflect what others see. What you find unattractive may be attractive (or not noticeable) to someone else.
- Have a sense of humor. One survivor with blotchy, discolored skin noted, “Guess I won’t be modeling bathing suits anymore, unless it is the leopard-skin print.”
- Continue pursuing relationships, friendships, and activities that you love. Relationships succeed or fail all the time based on things completely unrelated to appearance. How you behave and treat others is much more likely to affect your relationships than how you look. Although there is a possibility that a relationship won’t develop because of your appearance, there is a guarantee that it will fail if you don’t put energy into pursuing and maintaining it.
- Find a safe setting to discuss your feelings and fears with trusted friends. Finding ways to communicate your feelings with others can open the door to rich and meaningful exchanges that may bring you closer. Or find a support group or therapist with whom you can discuss your feelings and ways of dealing with a changed appearance.

#### **Imperfection – The Beauty of Cracked Pots**

There is a wonderful parable about a water bearer who carries two large water pots, which he hangs on either end of a pole on his neck. One of the pots has a crack in it and every day leaks out half of its water onto one side of the path. The cracked pot is ashamed of its imperfection and apologizes to the water bearer for being imperfect and not accomplishing its task. The water bearer responds that there is nothing to be ashamed of and points out that only one side of the path has flowers. He tells the pot that it is thanks to the water leaking out of its crack that one side of the path has been watered daily, thus allowing the beautiful flowers to bloom. He tells the pot that he has always appreciated the crack because it has allowed him to bring beautiful flowers to the house.

Moral: We all have unique flaws – our cracks and breaking points. It is sometimes in these cracks and broken places that beauty resides. Recognizing that part of being human is being “flawed” in some way opens the door to greater acceptance of oneself and others. Accepting our broken places may help us have compassion for the perceived imperfections of others. It can help us to reach out and make connections. Sometimes our vulnerabilities can be a source of inspiration or strength. And, regardless of how we feel about our broken places, they are part of what makes us uniquely ourselves.

## SEXUALITY AND INTIMACY

Much like self-perception, sexuality is complex. Feelings of desire and sexual drive are affected by a host of physical, emotional, and cultural factors. Some people think of sexuality as limited to intimate physical activity with a partner. However, many see sexuality as much broader, linked to our need for caring, intimacy, closeness, and touch. Our feelings around sexuality are influenced by hormones, energy level, the functioning of the sexual organs, feelings of love and closeness, how we were raised, and feelings about ourselves and our partner. Partner conflicts and miscommunication, as well as concerns about body image, can disrupt intimacy and sexual satisfaction. The transplant adds a whole new layer to this already complex picture.

A transplant can affect sexuality in many ways. It can change hormonal levels and sex drive. For men, neurovascular damage caused by chemotherapy or radiation may lead to erectile dysfunction. For women, the transplant may lead to early menopause and can reduce lubrication and elasticity. There can be inflammation of the skin or numbness and lack of sensation. In some cases, there is a narrowing or closing of the vaginal canal, which can make intercourse painful or impossible. Other factors, such as changes in our body image or concern about hygiene post transplant, can also affect desire and sexual activity. Even small changes in energy levels can reduce one's sexual drive.

Some individuals go through a transplant and experience no change in their sexual activity or sex drive. Others may find that they no longer desire or are able to have sex. And yet others find that once they make modifications and shift their expectations, they can resume an enjoyable and fulfilling sex life. How our sexuality is affected depends on many factors, including whether we are single or in a relationship, the nature of the relationship, and the extent to which our own sexual functioning has changed.

*My wife and I are closer than ever, but I can no longer achieve erection since radiation. This has not caused us to be less intimate or feel less close. We just can't have intercourse anymore.*

*The instant early menopause at 40 really messed with my physical and emotional balance. I feel my sex life ended at 40.*

*The biggest challenge post transplant is the day-to-day dealing with the sexual dysfunction, which is difficult on my marriage. While my spouse is extremely supportive, I feel guilty for having this "thing" to deal with every time we want to be intimate. We talk about it, but both of us deal with ongoing frustration over not being able to have the same level of spontaneity as in the past.*

*My vaginal canal is much narrower, shallower, and very dry, which makes sex more difficult.*

*I now enjoy sex more than ever!*

Studies on sexual dissatisfaction post transplant vary dramatically in their findings, reporting anywhere from 14% to 86% of survivors being dissatisfied after bone marrow transplantation.<sup>13</sup> A recent study of transplant survivors by the Fred Hutchinson Cancer Research Center showed approximately three-quarters of the men and a little over half of the women returned to their previous level of sexual activity pre-transplant. However, most women (80%) and nearly half of the men reported some sexual problems.<sup>14</sup> In the comparison group of people who did not undergo a transplant, fewer women and men reported sexual problems.<sup>14</sup>

### **Coping with Changes in Sexuality**

Regardless of whether we are married, in a committed long-term relationship, dating, or single, there are ways to enjoy intimacy in physical and non-physical, non-sexual ways. If sex is no longer pleasurable, you can enjoy warm bubble baths with your partner, soft caressing with massage oils or creams, cuddling, dancing, and talking. Erotic reading, movies, and sexual fantasy can be enjoyed in partnership or alone. If your body has changed, you might need to re-explore your body to discover what feels pleasurable and stimulating.

*When I am not really in the mood, I try to get into it by lighting candles, listening to music, and thinking about how I used to feel... I just bought KY Liquebeads and Astroglide upon the recommendation of my ob/gyn.*

*Vitamin E suppositories which provide moisture and lubrication have made a big difference in my ability to enjoy intercourse again.*

In some cases, finding sexual pleasure may mean longer foreplay or shifting the focus away from the genital area to other erogenous zones in the body, such as the neck, ears, inner thighs, feet, and toes. In the past, you may have felt desire spontaneously, but now you may need to plan in advance and initiate foreplay and physical touching in order to be aroused. Candles can help create a romantic atmosphere or can create a soft flattering light if you are uncomfortable with some of the physical changes from the transplant. If intercourse becomes uncomfortable, painful, or difficult, there are several approaches that are helpful. Men may need to take medication for erectile dysfunction before intercourse or use a penile implant. They may also benefit from some hormonal treatment. Women may need to use lubricants or vaginal moisturizers to enjoy sex. Hormone treatment can also improve sex drive and vaginal elasticity. If the vaginal canal has lost flexibility, shrunk, or closed up, vaginal dilators can be helpful. Vaginal dilators can often be obtained from the radiation department in hospitals.

*I am trying to let go of what used to be and am trying to figure out new ways to enjoy my partner; to give pleasure and get pleasure. It's different. It requires a willingness to trust that once we start touching, I will get aroused, rather than the other way around.*

*Since the hormone therapy, I want to make love more often than my husband does.*

## **Resuming Sexual Activity**

Reclaiming your sexuality post transplant can be difficult, particularly if you don't have a partner, or if you have not been sexually active with your partner for a long time. Sex, just like exercise, is harder to resume if you haven't been doing it. If you want to resume sexual activity, you may need to start slowly, find ways to initiate contact, and then build upon that.

If you are single and have concerns about dating, keep in mind that dating always involves risks, whether you are healthy or have chronic health conditions. Although it is possible that you will be rejected because of your cancer history or health condition, there are many people with serious health conditions or who have had transplants who find love. Finding partnership and love is about common interests, feelings of connection and trust, enjoyment of each other's company, as well as sexual attraction. There are dating websites to help you meet others with similar health histories and conditions.

Many people who are dating wonder when they should disclose their cancer history. There is no right or wrong answer, and the right time may vary depending on your level of comfort and trust in the other person, his or her personality, and the context in which you met. Unless the person you are dating already knows about your health history, you might feel more comfortable waiting until you have built a sense of mutual trust and affection before revealing your cancer history and sexual concerns. Once you feel that there is a connection, there are many ways to bring this up. You could broach the topic by mentioning that you had cancer treatment some years ago and ask how this might affect the relationship. Or, if you are concerned about changes in your sexual functioning, you might want to share that it now takes you longer to get aroused. Discussing these topics ahead of time can avoid future misunderstandings or hurt feelings.

If you have taken a long break from sexual activities and are nervous about it, it may be helpful to find non-physical ways to bring romance and intimacy into your life. You might want to embark on an old-fashioned courtship: go on several dates, watch the sun set, go on long walks, or exchange massages. Or, if you are in a long-term relationship, act as if you are courting all over again. Have some fun and enjoy the process, even if it is different from what was familiar and normal in the past.

## **Communicating Your Feelings and Preferences**

It is important to communicate with your partner, particularly if your sexuality has changed or intercourse is no longer as comfortable as in the past. Letting your partner know about these changes may help avoid feelings of rejection that can result from your lack of desire. Talking about your fears and concerns is the first step to finding ways to manage them. Open communication can lead to greater intimacy, regardless of whether sexual intercourse is possible or not.

If intercourse is painful or a certain kind of touching is uncomfortable, let your partner know either by guiding your partner's touches or discussing ways to create the most pleasure and avoid pain. If discomfort occurs, you may begin to associate physical intimacy with discomfort, which can reinforce your reluctance to have

intimate contact. Finding ways to communicate with each other about what is pleasurable and expanding your repertoire of ways to be intimate can strengthen your bond and reinvigorate your sexual life.

### **Seeking Advice from a Physician, Couple's Counselor, or Certified Sex Therapist**

Speaking to a medical professional about your sexual functioning can often be helpful. Generally, urologists (for men) and gynecologists (for women) can be a useful source of information regarding products to help with a variety of problems, including low sex drive/libido, erectile dysfunction, or vaginal dryness/narrowing. If you are embarrassed to talk about your sexuality, write your questions and concerns in advance and hand them to the doctor.

You may also find it helpful to speak to a couple's counselor or a certified sex therapist who specializes in helping individuals and couples deal with concerns about arousal, performance, pain or discomfort, or mismatched interest in sexual intimacy. The American Association of Sex Educators, Counselors, and Therapists can provide a listing of certified sex educators and counselors by state.

*For the first twelve years post BMT, my sexual desire was only 10% of what it used to be. This was very difficult on my marriage. But after couple's therapy, we are back.*

Sometimes treatments may not work, and your sexual dysfunction may continue to affect your life. This can be very frustrating. However, it is important to remember that intercourse is only one among many ways to express your sexuality, enjoy each other, and be intimate.

#### **ABCs of Love**

Always kiss each other upon departing.

Be there for her. Always.

Create an environment of love.

Do it. Now.

Escape from the kids.

Fight fair.

Give of your time.

Handle with care.

Inspire your partner with your love.

Judge not.

Keep your good memories alive.

Listen to her.

Make love with your partner's needs foremost.

Never go to bed mad.

Offer to handle an unpleasant chore.

Praise him.

Quality time isn't just for kids.

Respect her feelings.

Say what you feel when you feel it.

Tell her you love her every day. Every day.  
Every day. Every day.

Understand your differences.

Valentine's Day is every day.

Walk together. Talk together.

EXcite your partner as only you know how.

You can never say "I love you" too often.

Zero-in on his little passions.

## LONG-TERM RELATIONSHIPS WITH CAREGIVERS

Just as the transplant changes us, it can also profoundly affect our caregivers in both negative and positive ways. The effects of the transplant can change not only how our caregivers relate to us, but can also change their perceptions of themselves and their life goals. Many caregivers find that their feelings towards life and death, their sense of security, and their priorities are changed. Here are a few comments from caregivers about their experience:

*In addition to bringing me closer to my mother, the experience has left me with a clearer sense of priorities. It is a memory I can always invoke to remind myself of what really matters in life.*

*The transplant has completely changed our lives – physically, mentally, and financially. The doctors say that a stem cell transplant changes a body by aging it... The stress of being a caregiver also ages a person physically and mentally.*

*Although on the surface I think that I act about the same as before my daughter's diagnosis, underneath I am more pessimistic and bitter (But I don't think she feels that way at all).*

*I became for a time more hyper-clean and compulsively germaphobic than I like to admit... I also became more anxious and aware of the fragility of life, and that anxiety has diminished but still troubles me, even though my wife's health has improved and our post-transplant life has become more normalized.*

*Being a caregiver has impacted my career path... At the time of my mom's transplant, I was earning my PhD in English. I am now a professor in a unique program called Biomedical Humanities... The time I spent witnessing what life is like for a patient, how different professional caregivers interact with patients, how caregiving institutions work, etc., has definitely enriched the understanding and empathy I bring to the work that I do.*

For some caregivers, the late effects of the transplant may include post-traumatic stress, depression, and anxiety, while for others the transplant experience can lead to a greater sense of self-worth, meaning, pride, and improved sense of competence. The changes that are introduced into the relationship as a result of the transplant can pose serious challenges to relationships between survivors and their caregivers. Over time, these feelings evolve and change, sometimes bringing people closer, introducing strains, or, in some cases, tearing relationships apart. Below are some observations from caregivers on how their relationships have been impacted by the transplant:

*We are closer now more than ever (and we were extremely close before). I'm sure part of it was the forced opportunity to talk about the heavy, weighty subjects of life, meaning, and death, but a lot of it was just the time we were able to spend together.*

*Becoming a nurse to my husband has changed my perception of him. It is hard to go back to seeing him as I used to.*

*I am more protective of my daughter and worry more about her than I did before transplant. It probably affects me more than her.*

*The transplant and the changes it brought about in my husband were very challenging. Physical intimacy has continued to be difficult. Emotional closeness with my spouse is improving... Our social life has decreased with only a handful of friends with whom we are close.*

Dealing with the ripple effect of the transplant and its impact on our close relationships is complex, and requires good communication, compassion, and understanding. Recognizing that our caregivers have also been on their own cancer journey and have had to struggle in the process of supporting us can be useful. Like us, they too have suffered losses and made gains as a result of the transplant. And like us, when put to the test, they have struggled with their strengths and shortcomings, and have had to persevere to get to this point.

## PARENTHOOD OPTIONS POST TRANSPLANT

Both radiation and chemotherapy affect fertility, as does chronic GVHD. Although there have been documented cases of individuals conceiving and having children naturally post transplant, this is rare.<sup>15</sup> The vast majority of transplant recipients become infertile due to the effects of chemotherapy and radiation.

Your choices about having children will depend in part on the steps you took prior to your transplant. If you are male, you may have been offered the choice of freezing your sperm. Or if you are female, you may have chosen to freeze embryos or to undertake the more experimental procedure of freezing eggs or ovarian tissue. Even if you did not take these steps, there are still ways for you to have a family. New technologies, new ways to adopt, and changing societal norms have opened up a whole array of options for individuals who are infertile and wish to have their own children. Below are a few survivor experiences that you may find helpful:

*We have had an older daughter via adoption and twins born via a gestational surrogate. (I was able to freeze embryos before treatment.)*

*My gestational carrier is currently 15 weeks pregnant with my twins. My husband and I froze embryos before I began my treatments. The thinking was that I'd be able to have them myself. However, although I have been stable for a really long time, I still have a small indicator for the cancer, and the fear is that if it gets out of control again, we won't be able to get it back under control.*

*I used my sister's eggs and husband's sperm to create the embryos. Then we found a surrogate to carry the embryos to term. The process was long, expensive, and complicated. Although we found a great surrogate, the agency we used to find her was terrible, and we had to file a complaint against them.*

*The first fertility clinic we used was also problematic. We then switched to a fertility clinic at a large university hospital and now have two delightful children – a boy and a girl. My recommendation is to do as much research as you can about the agencies you plan to use.*

*We are trying to hire a surrogate to have our baby. Part of me wonders whether I should bring up a child if I am not healthy enough to carry one. I know that life is uncertain and healthy people can die, leaving young children behind. However, my life is REALLY uncertain.*

*We still are deciding. We may adopt or may consider egg donation.*

If you are interested in having a child that is genetically your own, or if you'd like to carry a baby to term, the first step is to talk to a fertility specialist or a reproductive endocrinologist. Take time to do some research about the topic, since centers vary in quality and experience. Survivors who are trying to conceive on their own should discuss this with their BMT physicians in advance to make sure that they are not taking medications that can have harmful effects on fetal development.

## **Adoption**

Adoption is an option that can be considered by most individuals. There are different types of adoption, including domestic and international. Some adoptions, known as open adoptions, allow the parents to know the identity of the birth mother and have contact with her both before and after the birth. A closed adoption refers to an adoption where the future parents and the biological mother have either very limited or no contact information about each other. Some individuals choose to try foster care and may adopt the child through this route.

## **RETURNING TO WORK**

**W**hether or not you go back to work after transplant depends on many things – your health, your stamina, your interest in your past profession, your budget, and your prioritization of life goals. For most of us, there is no right or wrong choice. In some cases, the decision to go back to work may be based on practical considerations, such as the need to maintain health insurance benefits. If work inspires you or helps you reclaim your sense of health and normalcy, you may want to jump right back in as soon as you can. If your job is stressful and/or you are still dealing with low energy, then taking your time and easing back into work slowly with a part-time schedule might be better, if this option is available. If you are still dealing with a variety of treatment aftereffects, then going back to work may not be an option at all.

*I feel that work is the thing that keeps me sane and feeling part of the world.*

*I have not been able to return to my pre-transplant work/life routine due to fatigue. This has been particularly frustrating as I remember what I used to be able to do and find that I am not able to work or do many of the things I used to enjoy.*



*Work helped take my mind off my health issues. I was really never tired and was able to go right back to work.*

*I was able to return to law school five years post transplant and start a free legal service for cancer patients. My professional life has been greatly influenced and directed by my medical experience.*

*After the transplant my confidence was shaken, and I wasn't sure if I could be independent financially. Luckily, I was able to find a good job and work full-time. Although I loved my job and was successful, it was also taxing, and I felt I had no reserve energy left for the rest of life. I now work part-time.*

*My main employer was very good in allowing me to come back at my own speed. I have fully resumed my career.*

### **Advocating for Yourself**

In our culture, independence and success are often measured by our professional achievements. This can make it more difficult to accept limitations or admit that we may need work accommodations. However, advocating for yourself and getting the accommodations you need is an integral part of ensuring that you are not compromising your hard-earned health by going back too soon or for too many hours. Sometimes it is difficult to know in advance how work will affect your energy level or how many hours you will be able to work. If you think that you need to ease into work slowly or that overwork is affecting your health, speak to your supervisor, human resources department, or personnel office to ask for changes that would make it easier for you to do your job.

*Be sure to be open with management about the need for gradual re-acclimatization. Before returning to work, let them know that you will need more frequent doctor visits and tests, and that their understanding is needed.*

### **Finding New Work**

If you have big gaps in your resume due to medical care, you might consider listing your jobs by skills and competencies rather than dates. Or, if you would like to include dates of employment but want to de-emphasize the gaps, list the other things that you did during the time you were not working due to illness, such as taking time to raise a family, listing an interest that you pursued, or noting volunteer work you performed.

Although employers cannot ask you specifically about your health, they can ask employees to take medical examinations as long as they are required for all employees. They may also ask disability-related questions as long as they are job-related and consistent with business necessity. However, the employer cannot take back a job offer unless the medical exam shows that you cannot perform the essential functions of the job (with or without reasonable accommodation). A job offer may also be withdrawn if the employer can prove that the job poses a threat to your health and safety, or to the health and safety of others. Employers may not ask disability-related questions or require medical examinations of job applicants prior to extending a conditional offer of employment.<sup>16</sup>

Although some people feel locked into a job because of their past health history, there are federal and state laws that are aimed at protecting people with medical conditions and disabilities from discrimination. Despite the existence of these laws, sharing your cancer history or health concerns with a new employer should be done only after careful consideration.

### **Do I Need to Tell My Employer About My Cancer History?**

Hiring, promotion, and treatment in the workplace should depend entirely on ability and qualifications. Unfortunately, some employers may discriminate against you if they know you have had cancer or another serious illness. In discussions with your future employer, emphasize your strengths and capabilities. Generally, it is recommended not to discuss any of the late effects of transplant or your medical history unless it directly affects your ability to perform your job. However, you should also make sure that the information you give is accurate. You do not need to tell the “whole truth,” but you do need to make sure that what you say or write does not contain any falsehoods. If you are caught lying on a job or insurance application, you may lose your job.<sup>16</sup>

If you know that you will require modifications to your job, you will need to notify your employer of your disability and the need for reasonable accommodation. You may ask for an accommodation at any point in the application process or during your employment. Your employer is only required to provide you with reasonable accommodations if you inform him or her that you have a disability. Reasonable accommodation may include changes such as a modified work schedule, telecommuting, or additional rest breaks. It does not include changes to the essential functions of the job. You are still required to perform these functions.

How much information you give about your health history and health status should be evaluated on a case-by-case basis. Although it is generally recommended that you disclose as little as possible, there may be exceptional circumstances in which your medical history may make you uniquely qualified for a job and may not be seen as a liability. However, revealing your health history before you are hired should always be done thoughtfully.

*After I was offered a job at a hospital, I told the HR department that I took immunosuppressants to manage GVHD. The offer was then withdrawn because all new hires were required to be fully vaccinated. Due to my immunosuppression, however, I was unable to get the mumps, measles and rubella (MMR) vaccine, which is a live vaccine. It was only after I appealed and threatened them with an investigation by the Equal Employment Opportunity Commission, that my job was reinstated.*

You may also be concerned about discrimination based on your medical condition when you already have a job. If you feel you are being discriminated against, a first step would be to familiarize yourself with your company’s policies and your legal rights. Your company’s policies are often spelled out in an employee handbook or on their intranet site. Equal Employment Opportunity and Family and Medical Leave Act policies also should be posted in your workplace. You can get additional

information about your legal rights from the Equal Employment Opportunity Commission (EEOC) at [www.eeoc.gov](http://www.eeoc.gov).

Speaking to your employer about the company's obligations and your expectations can sometimes resolve problems and prevent escalation. If you cannot reach a mutually acceptable solution through discussions with your employer, you will need to decide whether you'd like to invest the time and energy in litigation, which can be expensive and difficult, or if you should just move on and get another job. Sometimes pursuing legal action can be gratifying and can yield positive results. However, litigation can also be stressful and is often very expensive. If finances are a concern, there are a number of organizations that provide free and low cost legal services. Certain national organizations such as the EEOC can help in these situations, or you can do an Internet search on "cancer" and "legal assistance" or "legal referrals" for more local listings. Depending on the situation, you will need to decide what is best for you and how you'd like to proceed.

### **Americans with Disabilities Act**

The Americans with Disabilities Act (ADA) and the Family and Medical Leave Act (FMLA) are the two main federal laws that protect individuals from job discrimination.

The ADA applies to employers with 15 or more employees and to employees working at state and local government agencies. Under the ADA, you can't be fired or discriminated against because of a disability or because of a record of having a disability as long as you are able to fulfill your job duties. There may be additional laws in your state that provide protections as well.

In order to receive protection under the ADA, you need to qualify as a person with a disability. The definition of disability is broad and covers many different kinds of conditions.

Under the ADA, a person can qualify as disabled if they:

- Have a physical or mental impairment that substantially limits one or more major life activity(ies), such as concentrating, sleeping, eating, walking, caring for oneself, etc.
- Have a history of a physical or mental impairment which substantially limits one or more major life activity(ies), or
- Are regarded as having an impairment.<sup>12</sup>

Individuals with late effects of cancer and cancer treatment may fall into one or more of these categories. Employers are not required to lower job standards in order to make an accommodation. However, they are required to make reasonable accommodation unless they can prove it would be an undue hardship to do so.

Even if you do not think that you meet the ADA's definition of disability but believe you need accommodations, you can discuss this with your employer. Some employers will be willing and able to accommodate employees even if they do not meet the ADA definition. Furthermore, many state and local laws have a broader definition of disability than the ADA and also can require employers to make reasonable

accommodations. So even if you are not entitled to an accommodation under the ADA, you may be entitled to one under state or local law. For more information about the ADA, go to [www.ada.gov](http://www.ada.gov).

Reasonable accommodations may include:

- Getting reassigned to a less demanding job
- Restructuring a job
- Working flexible hours or part-time
- Obtaining a period of leave time

*I returned to work part-time at first, and my boss was wonderful in allowing me to modify my duties...I tired easily and didn't want to be exposed to many people. Fortunately, my boss was very understanding about this.*

### **Family and Medical Leave Act**

Patients and survivors, as well as their spouses, children, and parents, are also protected by the Family and Medical Leave Act (FMLA). This act allows individuals to take up to 12 weeks of unpaid medical leave from work in a year to care for their own medical needs or that of a seriously ill spouse, parent, or child. The FMLA applies only to employers with 50 or more employees. To be eligible, a person must have worked at the company for at least one year and a minimum of 1,250 hours in the year prior to the leave request.

Under the FMLA, employers must allow employees to return to their same position or an equivalent position with the same pay and benefits except in narrow circumstances, such as when a position is eliminated in a layoff. Although employees do not get paid during FMLA leave time, they may be able to qualify for short-term disability benefits or to use accrued sick leave or vacation time during their FMLA leave. During FMLA leave, employers are required to continue to pay their share of the health insurance premium for the employee. Employees must also pay their share of the premium, but can make arrangements to do so before, during, or after their leave.

Some states have more generous laws that allow cancer survivors and their families to extend their time off work beyond the 12 weeks required by FMLA. Even families that have obtained all the time off required by law may be able to obtain additional time off. How long an employer must hold someone's job depends on how much hardship it creates for the company, and also on the state in which the employee works.

For more information about the FMLA, go to [www.dol.gov/compliance/laws/comp-fmla.htm](http://www.dol.gov/compliance/laws/comp-fmla.htm).

### **Helpful Workplace Resources**

If you can no longer do the work you did in the past and need retraining, there are many resources available. Many states have a Department of Rehabilitation that can provide vocational training, or there are organizations that provide grants for job retraining. You can find resources for job retraining in your state by doing an

Internet search on “job retraining” or “vocational training” in your particular state. If you are on Supplemental Security Income (SSI), the Plan for Achieving Self-Support (PASS) allows you to set aside money to go to school, start your own business, or achieve other goals that help you become self-supporting.

If you feel you have been discriminated against, you can contact the EEOC through its website at [www.eeoc.gov](http://www.eeoc.gov) or call 800-669-4000. The EEOC offers live customer help and will provide free legal services if you have a legitimate claim. There are additional organizations that provide free or low cost legal advice and advocacy for cancer survivors. You can access these and other workplace-related resources in the Resource Listing under “Legal Rights and Workplace Issues.”

## CARING FOR YOUR BODY

As cancer survival rates improve and more of us live into old age, it is increasingly important to protect ourselves against developing new cancers and other chronic conditions. Although we can’t change our health or treatment history, there is a lot we can do to improve our overall health and reduce our future risk of disease and chronic conditions. Research has shown, for example, that what we eat can actually influence how certain genes are expressed and thus affect our cancer risk. Our level of activity can affect our weight and hormone levels, which impacts the risk of developing certain conditions. Even small changes in our day-to-day activities can lead to improvements in our overall health and well-being.

One of the main recommendations for reducing our risk for cancer is to maintain a healthy weight. Body fat, particularly fat around the waist, is associated with the development of various cancers, including post-menopausal breast cancer, colorectal cancer, endometrial, kidney, and pancreatic cancers.<sup>17</sup> The most effective way to maintain a healthy weight is through an integrated approach that combines healthy eating with regular exercise. In addition to reducing our future cancer risk, a healthy diet and regular physical activity can reduce the risk of chronic conditions, such as heart disease, stroke, diabetes, and osteoporosis (weakening of the bones). A healthy diet and regular exercise are also associated with improved overall vigor and mood, reduced stress levels, and a more resilient body.

The key recommendations of the American Institute for Cancer Research (AICR) are to:

- Choose mostly plant foods (fruits, vegetables, and beans) and limit red meat.
- Eat whole grains rather than refined grains, and limit processed foods.
- Be physically active in some way every day for 30 minutes or more.
- Aim to maintain a healthy weight throughout life.

### Healthy Eating

Depending on how well you know yourself and your relationship to food, you might want to make a big change in your eating habits all at once, or introduce change slowly, picking one or two items from the list below. Getting all the nutrients you need requires choosing a variety of foods. If you suffer from GVHD or have other

conditions that make it difficult for you to digest properly, maintain a healthy mineral balance, or consume a well-balanced diet, it is recommended that you consult with a dietitian. Think creatively about your food choices, introduce more healthy foods into your diet, and enjoy new tastes and flavors.

### **Eat Plant-Based Foods**

Shift your choices so that your diet includes more vegetables, fruits, whole grains, and beans. Include five or more servings of a variety of vegetables and fruits every day. By choosing fruits and vegetables that have different colors, you will get a fuller spectrum of nutrients. Fruits and vegetables are rich in vitamins, minerals, and other compounds that play a role in cell function, body regulation, and cell repair. Their high fiber content also contributes to a feeling of satiety and helps food and waste move through the digestive system. Some forms of fiber also play a role in lowering cholesterol. Fruits and vegetables have the added benefit of being relatively low in fat and calories.

### **Choose Whole Grains Over Refined Grains**

Whole grains and the flour made from whole grains provide far more nutrients and fiber than refined grains, where the nutrient-rich outer covering of the grain has been removed. Whole grain products include breads, cereals, and pastas, where the flour that is used is made from 100% whole grains. You can get the benefits of whole grains by eating foods such as popcorn, oatmeal, brown rice, and wild rice, and dishes that include quinoa, barley, kamut, and rye, among others.

### **Reduce Your Consumption of Red Meat and Processed Meats**

Although meats are a good source of high quality protein, they contribute to high levels of saturated fat and cholesterol in the diet.<sup>18</sup> Red meat in particular tends to be high in saturated fats and can contribute to higher cholesterol and blood pressure. Consumption of red meat is also associated with a higher cancer risk.<sup>17</sup> Examples of red meat include beef, pork, lamb, and goat. Processed meats are not recommended because they often have chemical preservatives and other additives that are known to be harmful. Processed meats include ham, bacon, salami, hot dogs, sausages, and meats that are preserved through salting, curing, or smoking.<sup>17</sup> The AICR recommends that we consume 18 oz. of red meat or less per week and strictly limit or avoid processed meats.<sup>17</sup> If you do choose to eat red meat, it is recommended that you eat meat from animals that have been grass fed, trim the fat off the meat before cooking,<sup>19</sup> and avoid cooking it at very high temperatures. Cooking meat at very high temperatures can produce chemicals known as heterocyclic amines which may increase cancer risk.<sup>20</sup> It is, therefore, advised to bake, stew, braise, or poach meats rather than to grill, broil, or fry them at very high temperatures.<sup>18</sup> When eating meat, choose poultry or fish more often.<sup>18</sup>

### **Replace Unhealthy Fats with Healthier Fats**

Fats are found in many of the foods we eat. Some fats contribute to our health while other fats are associated with heart disease and other conditions. If you have lost weight or are underweight, a higher fat diet may be necessary to achieve a healthy weight. Choosing fats wisely allows us to continue to enjoy the flavors that

they contribute to food without the negative effects. The key is to replace unhealthy fats with healthier fats.

#### *Healthier Fats – Monounsaturated and Polyunsaturated Fats*

The unsaturated fats – monounsaturated and polyunsaturated – can have a beneficial effect on health when consumed in moderation and when used to replace unhealthy fats. Monounsaturated fats are found in olive oil, canola oil, avocados, almonds, hazelnuts, and peanuts. It is also possible to find non-hydrogenated soft margarines that are made with unsaturated fats.

Polyunsaturated fats include omega-3 fatty acids. Consumption of foods rich in omega-3 fatty acids is associated with lower rates of heart disease.<sup>21</sup> Good sources of omega-3 fatty acids include cold water fish (salmon, sardines, halibut, and others), algae, chia seeds, flax seeds, walnuts, and canola oil.

#### *Unhealthy Fats – Saturated and Trans Fat*

Saturated fat is associated with increased risk for heart disease, obesity, diabetes, and certain types of cancer. Saturated fat is found in animal products such as meat and dairy. Common sources of saturated fat in the diet include meat, baked goods, mayonnaise, milk (other than skim milk), and other dairy products such as cheese and butter. Unfortunately, many popular foods, such as pizza, hamburgers, lasagna, tacos, and ice cream have high levels of saturated fats. To reduce your intake of saturated fats, you can choose low-fat dairy products or non-fat dairy products that contain no saturated fats.

One type of fat that is particularly bad for our health is trans fat. Trans fat both raises overall cholesterol and lowers our level of the good cholesterol (HDL) that protects against heart disease. Trans fat can also trigger inflammation,<sup>22</sup> an overactivity of the immune system that has been implicated in heart disease, stroke, diabetes, and other chronic conditions. Some trans fat occurs naturally in meat and dairy. But most is created in the manufacturing process when liquid oils are processed and turned into solid fats like shortening and margarine. Many types of fast foods, processed foods, cookies, donuts, and muffins contain trans fat. Read labels to avoid products with trans fat and high levels of saturated fats.

#### **Drink Plenty of Water and Reduce Sugary Drinks**

Water helps flush out toxins and keeps your kidneys and other organs in good shape. It is best to get most of your fluids from drinks that are either not sweetened or only slightly sweetened. Many of the drinks with added sugar have lots of calories but little nutritional value. Getting most of your fluids from sugary drinks increases the likelihood of weight gain. It is generally recommended to stay well-hydrated. Your needs may vary depending on your body size, the weather, your level of activity, and your diet.

#### **Limit Alcohol**

Alcohol is associated with increased risk of several types of cancer, including breast, colon, esophagus, mouth, and liver cancers. Heavy drinking is also associated with a variety of conditions, such as liver damage and heart disease.

Although modest amounts of alcohol may have a protective effect on heart health, cancer risk increases with the amount of alcohol consumed.<sup>23</sup> If you do choose to drink alcohol, women should limit their consumption to one drink or less a day, and men to two drinks or less a day.<sup>17, 18, 19</sup>

### **Cut Down on Salty Foods**

Consuming too much salt can be harmful to our health, increasing our risk of high blood pressure and stomach cancer. Many processed foods, including some canned goods, as well as cookies and foods that are sweet, may have high levels of salt as well. Read the labels and limit your consumption of salt (sodium) to less than 2,400 mg a day.<sup>17</sup>

### **Get Your Nourishment from Food Rather than from Supplements**

Aim to get your required nutrients by eating a healthy, well-balanced diet. However, there are situations when you may need to supplement your diet with vitamins or compounds. If you are post-menopausal, for example, you may need to supplement with calcium and vitamin D to prevent bone loss. Long-term survivors who do not get enough exposure to the sun may need to supplement with vitamin D. There is a growing body of evidence that vitamin D deficiency is associated with increased risk of cancer progression or recurrence.<sup>18, 24</sup> Given the complexity of the post-transplant picture, it is advisable to consult with a dietitian to make sure that you are meeting your nutritional needs. Supplements vary greatly in their quality. It is therefore important to make sure that the active ingredients listed are actually present in the supplement. Consumerlab.com is an independent organization that verifies the content and quality of the manufacturer.

### **Exercise**

Think creatively about ways to increase your activity level. This could involve signing up for a gym or an exercise class but could also simply entail a commitment to walk or bicycle more often, use the stairs instead of the elevator, or regularly park a few blocks from your intended destination. In addition to helping us maintain a healthy body weight, exercise can help to improve our mood and reduce depression and anxiety.<sup>25</sup>

Regular exercise can help increase strength, maintain muscle mass, and promote flexibility. Research also shows that people who exercise regularly have a lower risk of developing breast and colon cancer, as well as diabetes.<sup>26</sup> Activities that include weight-bearing exercises can also help to improve bone density and reduce the risk of osteoporosis, which is a thinning of the bones. Bones are living tissues, and like muscles, gain strength and density when they are put to work.

The key to exercising is to plan it into your schedule and find as many ways as possible to incorporate it into your everyday life. If you would like more company, weave exercise into your social activities. Keep in touch with a good friend by scheduling a weekly time to walk and talk. Instead of driving to a restaurant, invite friends to walk there with you. If you crave time to read, take your newspaper or book and read it on the exercise bike instead of on the couch. If you are a homebody,



consider purchasing a few exercise videos to do at home. If you belong to a gym, arrange to have one of the trainers work with you to design a workout that will help you build strength, stamina, and flexibility.

The Centers for Disease Control recommends at least 30 minutes of exercise five times a week. If you find it difficult to exercise for a 30-minute time block, you can still derive benefit by doing 10 minutes of exercise three times a day. Studies show that quality of life and fitness levels can improve with even a small increase in activity.

Ideally, an exercise program should include activities that improve flexibility, cardiovascular health, strength, and bone density. Many activities provide overlapping benefits. Weight-bearing exercises that strengthen bones, such as weight lifting, jogging, brisk walking, racquet sports, and stair climbing, are also good for cardiovascular fitness and stamina. Even activities, such as yoga and T'ai Chi, which are often associated with improving flexibility, have poses that put weight on the bones and can improve bone density, strength, and stamina, if done regularly.

<u>Weight Bearing/Strength</u>	<u>Cardiovascular/Stamina</u>	<u>Flexibility/Posture</u>
Weight lifting	Weight lifting	Yoga
Jogging	Jogging	Pilates
Brisk walking/hiking	Brisk walking/hiking	T'ai Chi
Racquet sports	Racquet sports	Stretching
Stair climbing	Stair climbing	Dance
Dance	Dance	
Using elastic exercise bands	Bicycling	
	Swimming	
	Water aerobics	

### **Exercising Tips**

Start slowly and increase your level of activity over time. Overdoing it can be taxing and harmful to your body. **Remember to consult your physician before beginning a new exercise program.**

If you have osteoporosis or other underlying medical conditions, consult with your doctor or a physical therapist about any limitations. If your condition stops you from meeting the guidelines of 30 minutes, five days a week, come up with a physical activity plan that meets your abilities. In general, getting *some* exercise is better for you than getting *no* exercise.

Exercise can energize and can be helpful in combating fatigue. Even on days when you feel reluctant to exercise, pushing yourself to engage in some moderate activity can often feel refreshing and invigorating.

*I lost so much flexibility after the transplant. Sometimes it can be depressing to compare my flexibility today to what it was. Instead, I focus on maintaining and increasing my flexibility by doing yoga a couple times a week. I remind myself that even though I am not as flexible as I used to be, I am so much more flexible than I would be if I did not stretch regularly.*

*For people who were never gym rats, it is the time to become one. Exercise has been so helpful to me to help me return to my strength levels and stay there.*

## COMPLEMENTARY AND ALTERNATIVE MEDICINE (CAM)/INTEGRATIVE MEDICINE

Complementary and Alternative Medicine (CAM) refers to healing practices that fall outside of the conventional model of medicine that is practiced in most U.S. hospitals. CAM includes practices such as Traditional Chinese Medicine, yoga, and meditation that have been used for thousands of years, as well as newer practices such as homeopathy, guided imagery, and nutritional supplements.

There are so many different types of complementary and alternative medicines that it is hard to generalize about their effectiveness. Many types of CAM have never been studied scientifically, and there is no data on their effectiveness, or, in some cases, there is evidence that certain alternative medicines can be harmful. However, there is a growing body of research showing that many forms of CAM are effective at treating certain conditions. Integrative medicine combines conventional treatment with CAM. A growing number of doctors and hospitals are adding CAM practices, such as meditation, acupuncture, guided imagery, and biofeedback into their practice. The settings where treatment includes both conventional and CAM are often referred to as Integrative Care Centers. If you are interested in learning more about CAM, talk to your doctor, or visit the National Center for Complementary and Alternative Medicine (NCCAM) website, [www.nccam.nih.gov](http://www.nccam.nih.gov).

Some types of CAM are not intended as a form of medicine but are primarily used to affect mood, bring about relaxation, and/or change body alignment and energy. Since our minds and bodies are connected, changes in our state of mind can affect our physical well-being and vice versa. An easy way to understand the mind-body connection is to think of the powerful physiological effect that a simple mental image can have on our body. Just as imagining or remembering a scary situation can raise blood pressure, imagining a peaceful, relaxed setting can activate a strong relaxation response that brings blood to the fingertips and reduces heart rate, blood pressure, and anxiety.

Many survivors use CAM modalities to improve their sense of well-being, reduce anxiety, or improve physical fitness.

*Nothing relaxes me as completely as going to my acupuncturist. Whenever I feel I am under the weather and getting a cold, I make an appointment to see him. I feel like I gain a whole night's sleep in the short hour that I see him and have avoided many full-blown colds.*

*I practice a yogic breath called Pranayama, which has been very helpful. I also do acupuncture and meditate. I am not on any special diet, but I eat well and take vitamin supplements.*

*I have tried many different alternative forms of care to treat my GVHD – acupuncture, biofeedback, meditation, and guided imagery, and none has been very effective. However, they have been useful in improving my general health and sense of well-being.*

## **TRANSITIONING YOUR CARE TO A PRIMARY CARE DOCTOR**

**G**ood medical care and accurate information are crucial in the years and decades following a transplant. Long-term survivors are at risk for certain health complications resulting from the transplant long after they have recovered and regained their strength.

Ideally, in the years following your transplant, you will continue to have a connection to both your oncology team and primary care medical providers. Even if you have a very good primary care physician dealing with your routine medical care, it is helpful to have occasional visits with an oncologist who knows about your treatment and its aftereffects. At first, the transition to primary care can be stressful, particularly if your primary care doctor is not familiar with post-transplant issues or does not communicate with your oncologist on a regular basis. As the years go by, more of your care will probably transfer to a primary care physician.

*My internist takes care of routine care, but even after 20 years, I always have questions for my hematologist/oncologist at my annual visits.*

*I was disappointed that my primary care physician was neither very interested nor knowledgeable about the transplant and possible problems related to it. For example, when I went to her after transplant because my tongue was all white-coated, she immediately diagnosed thrush and gave me a mouthwash and medicine. I called my transplant doctor who had me come in right away and saw that my GVHD was back.*

*The transition to a primary care physician was more difficult psychologically than physically at first, partly because of the volume of details to transfer and translate to my everyday doctor. With every new situation, there were pharmacological or physiological issues that related back to the BMT. It took quite a few years to get on the same page.*

*It has been extremely frustrating trying to get care for GVHD. I have had to seek help from various sources outside of my medical plan.*

As you begin to shift your care from oncology to primary care, there are a number of things you can do to ease the transition. You will have to figure out what is possible, given your situation, your health insurance, and the health care system in which you receive your care.

## Choose a Doctor Who is Right for You

If your health care plan has a selection of doctors to choose from, do some “detective” work to find one that you feel comfortable with. There is no foolproof way of finding a doctor that you like, but there are a variety of things you can do to improve your chances of success. Don’t overwhelm yourself. Choose a few things that seem “do-able” and easy for you.

- Ask your oncologist, nurse practitioner, or other trusted person in the health care setting who is familiar with many doctors for a recommendation. Let the person know what qualities you are looking for – someone good at dealing with complex medical issues, who is responsive, a good communicator, etc.
- Ask friends and co-workers for a recommendation. Ask them what they like and don’t like about their doctor and the doctor’s office.
- Get information about the doctor’s training and experience. You can do so by calling the doctor’s office to request a brochure or biography. Sometimes you can find this information online by going to the webpage of their medical office. Or you can do old-fashioned sleuthing and visit your local library to look up potential doctors in the Directory of Medical Specialists, which lists doctors, their training, and licensing status.
- You can check to see if there are any registered complaints or disciplinary actions against a particular doctor. This information is available on the DocFinder website ([www.docboard.org](http://www.docboard.org)) or can be found on the website of your state’s medical licensing board.
- Once you have narrowed down your search to a few doctors, contact their offices to find out how easy it is to get in touch with them. Ask about their open hours and how to communicate with them or get care after hours. How easy is it to be seen on days when appointments are not available? Find out if you would visit with the doctor or someone else, such as a nurse practitioner.
- Make an appointment to get acquainted with the doctor you’ve selected. Ask if there is a direct way for you to communicate, such as email, if you have questions. Ask if the doctor would be open to consulting with your oncologist about medical issues that might come up.

*I found a general medicine physician who opened a practice primarily for cancer survivors. After the transplant, I had a cardiologist, a neurologist, a rheumatologist, and a gynecologist, but each of them only cared about their specific part of me. I need someone to put all the pieces back together and treat me as a whole person with special needs. Finding her has allowed me to put all my health care cards back in one hand.*

*When I switched health care plans, I asked the receptionist in the oncology center which doctor seemed the most caring and kind, and who would be willing to take direction from another doctor. Although I don’t think she was supposed to tell me, she directed me to a lovely woman who is still my physician.*

*It has taken me four years to locate a gynecologist who acknowledges the effects of the transplant. She gave me a lubricant, exercise band, plus instructions to do Kegel exercises to strengthen and also learn to relax my vaginal muscles.*

### **Communicate with Your Doctor and Health Care Team**

Communicating well is not always easy. This situation can be made worse by the health care setting, where physicians are often under a great deal of pressure to see many patients. Regardless of how busy your doctor is, you have the right to have all your questions thoroughly reviewed and your concerns addressed. You can facilitate good communication by making sure that you are doing your part to communicate well. Write down your questions before the office visit and give a copy to your doctor so that your questions will get addressed no matter how hurried the doctor is. You may want to ask your physician what symptoms warrant contact with him or her. Also consider taking a tape recorder or another person with you to appointments to take notes to make sure you get all the information you need from the physician.

If your financial situation has changed, and you are finding it difficult to pay for your office visits or medications, notify your doctor and any other relevant staff in the doctor's office. There may be ways for you to get medications at a lower cost or to reduce the cost of your office visit.

Talk with your doctors about the best way to reach them if you have a time-sensitive question or concern. Advocate for yourself. If there is a mode of communication that you would prefer, such as email, let your doctor know. If your doctor is reluctant to provide an email address, it is sometimes helpful to tell him or her that you will not abuse the privilege and will use it sparingly.

Think about facilitating conversation amongst your doctors so that everyone is on the same page. You can do this by putting together a list of all your physicians with their contact information. Give each of your physicians a copy of the list. You can also note on the sheet the best times and ways to reach you.

*When I have a question about a new symptom or problem, I copy all my doctors on the email (even my acupuncturist!) so that they can all weigh in on the issue and be in communication if necessary. I've also found this to be an effective way of getting a response from an unresponsive doctor.*

*Communication from my BMT providers to my primary care physician has been nonexistent. I have had to be the go-between.*

*I always make sure that there is close coordination between my oncology team and my primary care team. Whenever I have a concern or question, I email it to both of them, so that they can each see the response of the other. I also make sure that my test results go to both of them.*

*I write down issues as they occur. Then, I take a second copy and give it to my doctor. This works better than relying on my memory to explain what is going on.*

*If my dentist or other doctors wish to get an x-ray or a scan, I always remind them of my radiation history. Given that radiation is cumulative, I make sure to be a strong advocate for myself and to avoid exposure to radiation unless absolutely necessary.*

### Track Your Health History and Health Status

One of the most important things you can do as you shift your care from an oncologist to a primary care physician is to ensure that the primary doctor is informed of your past health history and current health concerns. You can facilitate this by writing up a short summary that includes:

- Your diagnosis prior to transplant
- Date and type of transplant (autologous, sibling donor, unrelated, cord blood, etc.)
- Type of conditioning regimen you received – chemotherapy, radiation, or other
- Name of transplant center
- Contact information for transplant center (name of doctor, telephone, or pager number, etc.)
- Health problems and treatments post transplant
- Current health concerns
- Questions for your doctor
- Best way to reach you

Update this list regularly as you progress through the years, noting changes in your treatment or health. Having such a summary is useful, as it allows your doctors to see at a glance what your past treatments and health problems have been. It is also a great way for you to keep track of treatments and the bigger health concerns and issues that have come up over the years.

### List Your Medications

It is also helpful to keep a list of the current medications you are taking and their dosage. Include vitamins and other supplements. This should be updated regularly and brought to your medical and dental appointments. Please use the example list below as a guide for creating your own list:

Current Medications*	Dosage	Refill Information
Acyclovir 800 mg	2 a day	2535382704
Calcium Mg + Vit D (500 mg Ca)	2 a day	Local pharmacy
Estradiol 1 mg	1 a day	2531505844
Fosomax 70 mg	1 a week	1241005571
Nordic Naturals (fish oil)	Every day	www.abcwebsite.com

\* The above names, doses, and refill information are provided as examples. Your medication list will depend on your condition and should be developed in consultation with your doctor.

Having this information on hand allows you to make the most of short office visits and will ensure that your doctors are aware of your past concerns, as well as your current health and medications. Sending this information before your office visit may allow you to use the short time that you see your doctor more effectively.

*I have created several documents (meds list, allergies list, hospitalization list) that I have given to all my doctors and any new doctor that I need to see. This includes my dentist. I think that this information helps doctors feel that they are part of a team. If I find a doctor who is not a “team player,” I do not keep that person.*

*New doctors always appreciate getting my concise medical summary. At the end of my summary, I always add my questions for the visit. This gives them a heads up about what my concerns are. The added benefit is that when doctors see that I am organized and am willing to invest time in making it easier for them, they treat me with added respect.*

### **Track Your Symptoms**

Inform your doctor of your symptoms or changes in your health by using a symptom log like the one below. Or you can record your symptoms on a calendar or in a memo on your phone or other hand-held electronic device.

<b>Date</b>	<b>Symptom</b>	<b>Medication</b>
4/14/09	Fever 102, threw up in morning + diarrhea – Resolved by evening	None
6/5/09	Skin GVHD worsened. Red, itchy, raised blisters that scab.	Apply Protopic twice a day
9/7/09	Eye infection	Ofloxacin 0.3% - twice a day for 5 days

## **FOLLOW-UP CARE**

**E**ven if you are healthy, it is important that your doctor be made aware of the recommended guidelines for follow-up care. Complications from a transplant can happen many years afterwards. It is possible that you will never develop any of the long-term side effects of the transplant. However, routine testing is important so that potential problems are caught early when treatment is more likely to be effective. In addition to maintaining a healthy lifestyle and getting the routine check-ups that are recommended for the general population, transplant survivors need to do additional monitoring and screening.

If you are experiencing symptoms that you think might be related to your transplant, it is important to be seen by a specialist who is aware of the late effects of transplants and the most promising treatments. This may mean making an appointment with your BMT specialist, or, in some cases, **if your symptoms do not resolve, seeing a specialist at one of the larger transplant centers where**

**physicians are knowledgeable about long-term survivorship issues and up-to-date on cutting-edge treatments.** Being proactive is a very important step in getting the treatment you need.

To date, there is no one clearinghouse for information regarding long-term survivorship centers. However, there are some good resources on transplant-specific care including the National Marrow Donor Program ([www.marrow.org](http://www.marrow.org)). The National Bone Marrow Transplant Link (800-546-5268) can also provide assistance in locating a survivorship center near you. Other sources of information that are not transplant-specific, but which can help you locate well-regarded cancer centers, include the National Comprehensive Cancer Network ([www.nccn.org/members/network.asp](http://www.nccn.org/members/network.asp)) and the National Coalition for Cancer Survivorship ([www.canceradvocacy.org](http://www.canceradvocacy.org)).

To find institutions that are tailored to meet the needs of transplant survivors, you can also do an Internet search using terms such as “bone marrow transplant” or “stem cell transplant” and “survivorship center.” Depending on your needs, you may also want to search for a chronic GVHD comprehensive evaluation program or a clinical trial in chronic GVHD.

The following sections provide some general recommendations for long-term transplant survivors. Your physician may have additional recommendations that are specific to your needs. More detailed guidelines for follow-up care are summarized in two helpful guides, *A Guide to Protecting Your Health After Transplant, Recommended Tests and Procedures (Autologous)* and *A Guide to Protecting Your Health After Transplant, Recommended Tests and Procedures (Allogeneic)*. These were produced by the Consumer Advocacy Committee of the CIBMTR based on guidelines developed by the large transplant societies, ASBMT, CIBMTR, and EBMT. These guides also include a handout for your primary care physician entitled “Recommended Screening and Preventive Practices for Post-Transplant Patients.” You may obtain your free copy by calling 866-647-7750 or by visiting the CIBMTR’s website ([www.cibmtr.org](http://www.cibmtr.org)).

## **Cancer and Disease Prevention**

Supplement the routine screenings at your doctor’s office with self-exams at home. Note any changes in your skin, sores or symptoms that do not heal by themselves, or any lumps in your breasts or testes. Discuss your symptoms or changes in your health or energy level with your doctor.

You can do all the things recommended to the general public for disease prevention: Choose a healthy lifestyle. Invest time in developing and maintaining close friendships and a strong social support network. Avoid tobacco and excessive exposure to the sun. Wear a hat, long-sleeved shirt and full-length pants, and use sunscreen on areas of the body that are directly exposed to the sun, particularly your face and neck. Incorporate exercise and a healthy diet into your daily lifestyle.

## **Routine Care**

Visit your doctor every year or as required for a complete history and physical examination, which could include:



- Blood tests (complete blood count, glucose level, lipid levels, BUN/creatinine testing, etc.)
- Thyroid hormone levels
- Test for blood in stool
- Cardiovascular risk assessment (blood pressure, cholesterol, etc.)
- Clinical pulmonary (lung) assessment
- Women: Pap smear and mammogram based on current guidelines and in consultation with your doctor, monthly breast self-exam. If you are taking estrogen or progesterone, review the benefits and risks with your gynecologist.
- Men: Annual prostate exam over the age of 45 and testes self-exam
- Regular skin self-exam; notify your doctor of any changes or unusual symptoms
- Discussion of sexual function, noting changes or problems
- Annual flu vaccine
- Screening colonoscopy starting at age 50, or if there is a family history of colon cancer, 10 years before the age your close family relative was diagnosed with colon cancer. Follow-up based on doctor's recommendations.

### **Dental**

Have a dental exam and cleaning every six months. If you have mouth GVHD or are immunocompromised, you may need to take antibiotics prior to dental work to reduce your chance of infection. Consult with your transplant center or dentist regarding appropriate guidelines. Make sure that your dentist screens you for mouth cancer.

### **Eyes**

Have an eye exam annually to check for cataracts or problems resulting from GVHD. If you have GVHD or are on immunosuppression, get a Schirmer's test to measure tear production. Take along your medication list, as some medicines can affect eye health.

### **Special Tests**

#### *Pulmonary (Lung) Function Test*

This should be done one year post transplant and then again five years post transplant. If tests are abnormal, if you have symptoms, or are being treated for chronic GVHD, you may need to have additional pulmonary lung function tests.

### **Vaccinations**

Childhood immunizations should be done after transplantation, usually at one year post transplant. However, your timing might be different depending on your immune recovery. Live vaccines for diseases such as measles, mumps, and rubella should be given only after you have been off immunosuppressive treatment for a year or more. Vaccines, such as the pneumococcal vaccine, which is derived from the dead form of the bacteria, can be given regardless of your immune status. Consult your BMT team for the most up-to-date recommendations, as there may be requirements to receive seasonal vaccines (flu shots, H1N1 or "swine flu"). Consult

a travel clinic for preventive recommendations if you plan to travel abroad.

### **Hepatitis C Virus**

You should get tested at some point after the transplant for the hepatitis C virus, particularly if you had transfusions before 1991.

### **Chronic Myeloid Leukemia (CML)**

Patients who had CML prior to their transplant should get a blood test annually to be screened for the presence of leukemia cells.

### **Bone Density**

Loss of bone mass after transplant can occur due to low hormone levels, use of certain medications, as well as inactivity. A bone density scan should be done at least once after the transplant and followed up with additional screening and treatment if warranted.

### **Adrenal Function**

When treatment with prednisone is being tapered or discontinued, your physician may need to check your adrenal hormone levels.

### **Guidelines for Chronic GVHD or Immunosuppression**

- Prevent and minimize bone loss by getting enough calcium and vitamin D, taking medications if prescribed, and doing weight-bearing exercise. Get bone density tests as needed to screen for osteopenia and osteoporosis (bone thinning).
- Regular antibiotics must often be taken to reduce your risk of bacterial infections, such as encapsulated bacteria and *Pneumocystis carinii* pneumonia (PCP), which is also known as *Pneumocystis jiroveci*.
- Get screened for muscle weakness that may be caused by corticosteroids and get physical therapy if necessary.
- Some physicians also recommend taking medication to prevent fungal infections and recurrent symptoms from the herpes simplex virus and varicella zoster viruses.

### **Ongoing Testing**

Ongoing testing may be required if past tests were abnormal or symptoms develop:

- Liver function test
- Ferritin testing (testing for iron in the blood)
- Bone density tests
- Urine protein screening
- Neurological clinical evaluation
- Thyroid function testing
- Chest x-ray
- Evaluation for depression, anxiety, PTSD, or other psychological issues

## Getting a Second Opinion

A second opinion from a BMT specialist may provide valuable information about managing late effects from the transplant, or it may reassure you that the treatment you are getting is appropriate. Ideally, your doctor will welcome the input of another physician. However, some doctors may be reluctant to refer you outside the covered network, and some insurance companies may deny authorization for a second opinion due to cost concerns.

If your doctor refuses to authorize a second opinion to see a specialist, or your insurance doesn't cover it, you can choose to pursue this further with the insurance company (please see below for more information) or to pay for the visit yourself.

*I thought that my oncologist was offering me the best treatment for my ongoing skin GVHD. However, my GVHD continued to get worse, despite my continued use of prednisone and cyclosporine. It got to the point that I was experiencing severe itching and blistering all over and was getting sick every other week with some new bug. In desperation, I finally made an appointment with the Long-Term Follow-Up Department at a nationally recognized BMT Center. The doctor there made clear that the regimen I had been on impeded my immune system's ability to build tolerance to my body. She put me on a completely different protocol, with a clear plan to taper my immunosuppression. A year later, I still have GVHD, but it is so much more manageable!*

## Appealing Your Case

If your request for a second opinion or type of treatment has been denied, you can sometimes overturn the denial by resubmitting your request with a strong claim (with valid medical reasons) for why the service should be authorized.

*After my doctor denied my request to go out of network, I sent two appeal letters, and then my request was approved. Persistence pays off.*

You can also contact your health plan's customer relations department to discuss your request. If you do not agree with the results of the review, you can often appeal the decision to a panel of individuals who were not involved in the initial decision.

If you cannot resolve this within the framework of your health care plan, you may be able to have your case reviewed by your state's external review program. Most states have review programs, but programs vary from state to state. More information about ways to appeal your case can be found in the legal departments of your health care institution or on the Kaiser Family Foundation website: [www.kff.org/consumerguide/7350.cfm](http://www.kff.org/consumerguide/7350.cfm).

*If you are having difficulty getting the care you need, recruit a friend or professional health advocate to help you.*

## CHEMOTHERAPY AND RADIATION – LATE EFFECTS

The high-dose chemotherapy and/or radiation that you may receive prior to, during, or after your transplant can cause long-term damage to healthy cells and organs, and in turn this can affect your future health and well-being. The extent of the damage depends on many factors, including the type and extent of chemotherapy, the amount of radiation, and the ability of your damaged organs to heal themselves.

<b>Aftereffects of Chemotherapy</b>	<b>Aftereffects of Radiation</b>
<ul style="list-style-type: none"> <li>• Fatigue</li> <li>• Early or premature menopause</li> <li>• Infertility</li> <li>• Changes to the heart</li> <li>• Reduced lung capacity (difficulty breathing)</li> <li>• Kidney and urinary problems</li> <li>• Neuropathy (numbness, tingling, and other sensations in areas of the body, especially hands and feet)</li> <li>• Muscle weakness</li> <li>• Cognitive problems such as memory loss or inability to focus</li> <li>• Osteoporosis</li> <li>• Changes in texture and appearance of hair and nails</li> <li>• Secondary cancers</li> </ul>	<ul style="list-style-type: none"> <li>• Cataracts (if radiated near eyes)</li> <li>• Permanent hair loss (if scalp is radiated over certain dose levels)</li> <li>• Dental decay, tooth loss, receding gums (if radiated near mouth)</li> <li>• Loss of tears and ability to produce saliva (if head/face radiated)</li> <li>• Problems with thyroid or adrenal glands (if neck or kidney area radiated)</li> <li>• Slowed or halted bone growth in children (if bone radiated)</li> <li>• Decreased range of motion in the treated area</li> <li>• Skin sensitivity to sun exposure (in the area of skin that was radiated)</li> <li>• Problems with the digestive system (if abdomen was radiated)</li> <li>• Secondary cancers (in area radiated)</li> <li>• Infertility (if ovaries or testes were directly radiated)</li> </ul>

This chart was adapted from a number of sources that can be found in the reference section.

### Graft Versus Host Disease

Another common and serious long-term BMT side effect is Graft Versus Host Disease. GVHD is a condition in which the donor's immune system (the graft) attacks the transplant recipient (the host). Immune systems are designed to distinguish between self and other and to attack foreign invaders such as viruses and bacteria. GVHD is caused by the genetic differences between the donor's immune system and that of the recipient. Because of these differences, the new immune system (the graft) does

not recognize the transplant recipient (the host) as self, and therefore launches an attack. Additional information on GVHD can be found on the National Bone Marrow Transplant Link's website at: [www.nbmtlink.org/webcasts](http://www.nbmtlink.org/webcasts).

In the case of autologous transplants or a transplant from an identical twin, the donor and recipient are genetically identical, and there is generally no GVHD. In allogeneic transplants where the donor is related, approximately 30-40% of individuals experience GVHD. In transplants from an unrelated donor, where the donor and recipient are genetically more different, approximately 60-80% of transplant recipients experience GVHD.<sup>28</sup>

In the case of transplants from unrelated donors, GVHD tends to be more severe than with related transplants because of the genetic differences between the donor and the recipient. Depending on the characteristics of the population being studied, about one-third to one-half of the people receiving a transplant from an unrelated or sibling donor have some active GVHD two years post transplant.<sup>29</sup> Treatment for chronic GVHD takes two to three years on average, and in most cases, resolves within five years. Generally, individuals with active GVHD report more problems with physical and mental health. However, once GVHD resolves, there is no reported difference between those who had chronic GVHD and those who never had GVHD.<sup>29</sup>

Although severe GVHD is very debilitating, mild GVHD can be considered beneficial. When the new immune system attacks the host cells, it also targets any remaining cancer cells, thus reducing the risk of recurrence. This is known as the "Graft Versus Leukemia Effect" or "Graft Versus Tumor Effect." Because of this, doctors must often tread a fine line, trying to reduce severe GVHD while maintaining the benefits of the anti-cancer effect of mild GVHD.

GVHD can occur any time after transplant. GVHD that occurs in the first 100 days post transplant usually causes a red and raised skin rash, diarrhea, or liver inflammation and is called "acute GVHD." GVHD that occurs more than 100 days post transplant can be either a form of late acute GVHD or may be chronic GVHD. Acute and chronic GVHD are different in the symptoms they cause and in how they respond to treatment.

### **Symptoms of Chronic GVHD**

GVHD can affect any part of the body. Areas that are commonly affected include the skin, eyes, mouth, digestive tract, joints, lungs, and liver. In addition to damaging organs and various body parts, GVHD may also cause immunosuppression and fatigue. Because of its attack on your immune system, GVHD can make you more vulnerable to a wide variety of infections and diseases.

**Chronic GVHD Symptoms**<sup>28,30</sup>

<b>Organ</b>	<b>Symptoms may include:</b>
Skin	Itchy, raised rash, dark spots, tautness of skin, skin scarring and thickening (sclerosis), impaired joint mobility, and limited or no sweating (leading to heat intolerance)
Liver	Abnormal liver function leading to jaundice (yellowing of skin and eyes), severe liver disease
Eyes	Dry eyes leading to burning sensation, redness and general irritation, sensitivity to light, possible vision impairment
GI Tract	Problems with digestion, diarrhea, heartburn, stomach pain, difficulty swallowing/eating, weight loss
Mouth	Dry mouth, sensitivity to spicy or acidic foods, sores in mouth, dental cavities, weight loss, difficulty swallowing due to less saliva
Lungs	Shortness of breath, hard to take deep breaths, difficulty breathing, wheezing
Joints, tendons, and muscles	Pain and tightening around the joints, muscle weakness, contractures of the tendons that make extending and contracting arms and legs difficult
Genitourinary	Vaginal dryness, tightness, or stricture
Immune function	Increased risk of infections – bronchitis, pneumonia, and other types of infections
Derma appendages	Hair loss, including scalp hair, eyelashes, and eyebrows, premature graying, ridging of nails

**EYES**

**E**xtensive chemotherapy and radiation to the head, as well as GVHD, can damage the glands in your eyes that produce tears. As a result, your eyes may not produce enough tears or the right mixture of oils and moisture to keep them healthy and comfortable. Sometimes the damage to the eye glands is permanent, and dryness may persist long after treatment and after the GVHD is resolved.

Some of the potential late effects of a transplant on your eyes can include dry, burning, or gritty eyes, itching, general eye pain, difficulty opening your eyes in the morning, sensitivity to light and wind, halos around lights, excessive tearing, and reduced visual clarity and/or blurring.<sup>31</sup>

*I really miss my tears. I miss the satisfaction of feeling tears rolling down my cheeks during a good cry or a touching part of a movie. My eyes feel very, very dry – like I have sand in them when I wear my contacts, which I can't really do anymore. Wind, or anything blowing on them, is uncomfortable.*

*My eyesight went from 1.25 to 2.75 after the transplant. I have also become extremely sensitive to light. I now wear sunglasses even to watch TV. I always wear wrap-around sunglasses when I go outdoors, even for a few minutes. Light is piercingly painful.*

*Other than needing reading glasses (I'm 45), my eyes are in good shape. They were dry for a couple of years post transplant but are fine now.*

## **Cataracts**

Cataracts can develop after transplant as a result of exposure to radiation or as a side effect of taking certain steroids. Cataracts occur when the normally clear lens of the eye becomes cloudy or opaque. You can live with cataracts with very little visual impairment, or you may experience blurring and loss of visual clarity. Cataracts generally develop slowly. If you have cataracts, you can benefit from glasses or better lighting. If your vision becomes impaired, you can also undergo a simple and relatively painless surgical procedure where the cataracts are removed. Most ophthalmologists will perform cataract operations even in people with chronic GVHD or extremely dry eyes.

*When I had the cataracts, it was very difficult to see things where there was a direct light source shining on my face. Having the cataract surgery really helped.*

*I had surgery in each eye but still have some blur and light refraction problems (poor night vision).*

*I recently discovered that the Light House for the Blind has yellow tinted glasses designed especially for low light situations. The glasses have really helped cut down the glare from night lights.*

## **It's Never too Early – and Never too Late – to Protect Your Eyes**

We are all exposed to ultraviolet (UV) light, a form of radiation, every day when we go outside. The effect of UV light on the eyes is cumulative, so if you have had radiation to the head area, it is good to be extra vigilant and protect yourself by wearing eyeglasses with lenses that block UV rays. An eye care professional can help you choose what lens is best for you.

Getting appropriate treatment for your eyes is important because permanent eye damage may result from dry eyes that are left untreated. If you are experiencing eye discomfort, make sure to see an eye specialist, such as an ophthalmologist, who can determine the extent and cause of the dryness and recommend treatments. In some cases, dryness may be caused by low tear production. In other cases, it can be caused by changes in the composition of the tears, making them evaporate faster than normal. Excessive tearing may also be a symptom of irritation resulting from excessive dryness of the eyes.

If you are experiencing only mild dryness, your doctor may recommend something as simple as the use of over-the-counter artificial tears several times a day. Many transplant survivors who use artificial tears regularly recommend ones that are pre-

servative free because the preservative can irritate your eyes. Survivors also report that some brands seem to work better than others. Lubricating tear ointments that tend to be thicker and oilier than artificial tears can also provide relief. Since these ointments can temporarily blur vision, it is better to apply them just before bedtime.<sup>32</sup> There are also topical steroids or cyclosporine in the form of eye drops that may be helpful.

*I use homeopathic eye drops with no preservatives (Similasan) several times a day. However, when my eyes get very dry, I need to supplement with a night ointment, like Refresh PM, which is thick and goopy, but which provides the added protection I need for the long dry night.*

*I've tried many different drops. The ones that work best for me are Tears Naturale II. And, I always use an ointment at night.*

If artificial tears and ointments do not provide sufficient relief, tear ducts can be plugged with tiny silicone plugs. This reduces how fast the tears drain from your eyes and serves to conserve your natural tears and any artificial drops that you have added. In some cases, a temporary plug made from collagen that dissolves can be tried first to make sure that the permanent ones will not cause excessive tearing.

Other recommendations include applying very warm compresses over the eyes several times a day, avoiding very dry environments if possible, and adding moisture to the environment by using a humidifier in your house or office. There are also specially designed glasses that can create a moisture chamber around your eye to minimize drying. Some survivors have created the same effect by using swimming goggles to retain moisture around their eyes.<sup>32</sup> There is also some evidence that a high dietary intake of omega-3 fatty acids (found in fish oil and flaxseed oil) may improve dry eyes.<sup>32</sup> For individuals with very dry eyes, other possibilities include using autologous serum eye drops, which are produced from your own blood. The serum drops, which are biochemically most similar to your own natural tears, have many of the same healing properties as natural tears and can provide extended relief.<sup>33</sup> People with severely dry eyes may also benefit from the Boston Scleral Lens, a customized contact lens that creates a fluid-filled layer over the eyes, thus preventing them from drying out.<sup>34</sup> The key is to see an eye specialist who can review your situation and make the best recommendation for you.

*Nothing has worked for my severely dry eyes except for my own blood serum. I've tried everything the doctors recommended for the last five years, but my own serum eye drops have been the best medicine.*

*I get relief from using Boston Scleral Lenses. I can't imagine a day in my life without them. The only time I have any discomfort is when I remove them at night.*

*My ophthalmologist used laser and sutures to close my tear ducts to help me retain the tears I produce. And I use drops in my eyes every day.*



*Staying well-hydrated helps. I also always wear sunglasses outside because the sun makes my eyes feel worse. I also try to avoid air conditioning.*

### **Dry Eye Solutions Summary**

- Eye drops
- Nighttime eye ointments
- Sunglasses with lenses that block UV rays
- Humidifier (at home and at work)
- Glasses or goggles that create a moisture chamber around the eyes
- Serum eye drops made from your own blood
- Boston Scleral Lens (customized fluid layer over the eye)
- Silicone plugs to block tear ducts
- Flaxseed oil
- Topical steroids
- Cyclosporine
- Proper hydration

## **SKIN AND JOINTS**

Radiation can cause long-term discoloration and aging of the skin.<sup>35</sup> Chronic GVHD can also affect the skin in a variety of ways, causing blotchy, discolored skin, a dry, itchy rash, poor wound healing, or sometimes a tightening and thickening of the skin, known as sclerosis.<sup>36</sup> Sclerosis varies in its severity and can remain confined to the skin or it can spread across joints and tendons. This tightening of the joints and tendons can limit your range of motion and can make it difficult to bend and straighten your arms, legs, and other joints.

*I can no longer stretch out my arms because of all the skin GVHD, and certain areas of my skin feel slightly numb.*

GVHD can also lead to inflammation called lichen planus, which can appear as a rash, lesions, or flat, purplish bumps. This inflammation may or may not be itchy or painful. GVHD can also damage the sweat glands, leading to heat intolerance. Skin injury and scarring may lead to hair loss all over the body and premature graying. Nails may become more brittle or may have ridges or cracks. Skin GVHD should be examined by a specialist and treated promptly to prevent its spread and minimize damage.

*My skin GVHD migrates around my body with no rhyme or reason. A few years ago, I had it mostly on my back. Then it moved to my hands and shins where it manifested as painful, itchy blisters. It looked and felt like a bad case of poison oak. Some days I wanted to cut my fingers off to stop the itching. And now my hands are much better, but I have it on my upper arms and shoulders.*

*Before the transplant, I loved hot weather. Now that my sweat glands no longer function well, I wilt in the slightest heat. I try to avoid going out when it is hotter than 80 degrees.*

## Caring for Your Skin and Joints

Radiation and skin GVHD, as well as some of the medications to treat GVHD, may make your skin more sensitive to the sun and more susceptible to dryness. Even long after treatment and after the GVHD is resolved, you may continue to experience skin sensitivity. It is therefore important to:

- Regularly use a sunscreen with an SPF of 30 or more
- Avoid prolonged sun exposure and wear long sleeves, pants, and a hat
- Use an oil-based moisturizing lotion regularly, especially after bathing
- Avoid very hot showers and baths
- Use humidifiers to moisten the air in your home or office, particularly in cold winter climates
- Stretch regularly to maintain flexibility.

*After spending a day kayaking, my skin GVHD worsened significantly, and I needed to go up on my steroids for months. Much as I love kayaking, it was not worth it. Now I dress like the ultra-orthodox making sure to wear long-sleeved shirts and pants and a wide-brimmed hat when I am outdoors in the sun. Luckily, I look good in hats!*

## Topical Treatments and Systemic Immunosuppressants

Topical steroids are often used for mild skin GVHD. They vary in strength and can cause the skin to become thinner and more fragile. Check with your health care provider about the strength of the steroid cream you are applying and how often and where it can be applied. Strong steroids should not be applied to delicate areas, such as the face, where the skin is more absorbent and fragile. For such areas, steroid sparing creams can be used effectively.

If topical creams are not sufficient, then systemic immunosuppressants such as prednisone, cyclosporine or tacrolimus, or mycophenolate mofetil (MMF) are often used. Although these can be very effective, they also have various side effects and can weaken your immune system's ability to fight off infection. **The medications mentioned are not intended as recommendations. Discuss any questions about medications with your physician.**

## Extracorporeal Photopheresis (ECP)

Extracorporeal photopheresis (ECP) is a promising therapy for chronic skin GVHD. In this procedure, blood is removed from your body, treated with a chemical and radiation to kill certain white blood cells, and is then returned to your body. The mild side effects of ECP include an intermittent drop in blood cell counts. Surprisingly, this treatment does not seem to cause immunosuppression and has the added benefit of being much less toxic than other treatments, since the exposure to radiation takes place outside of the body. The main drawback of the treatment is that it requires a substantial time commitment and several months of therapy before it can be determined whether or not it is effective. Although ECP is often covered by insurance, the amount you would be expected to pay should be discussed and considered prior to beginning treatment.

*I found the benefit of ECP to be marginal. I did not experience much improvement in my eyes, but my blotchy skin cleared up quite a bit.*

*For a 16-gauge size needle, ECP doesn't hurt that bad. The nurses apply a numbing cream and, at this point, I hardly feel the needle any more.*

*The ECP is a slow process, but it has been very effective for me and has really improved my range of motion and my skin in general.*

### **Psoralen Ultraviolet A Radiation (PUVA) Treatment**

PUVA treatments are also used to treat chronic skin GVHD. In this treatment, a substance called psoralen (or psoralene) is used to sensitize your skin to ultraviolet radiation. The skin is then exposed directly to UV light. Although PUVA is often effective in treating skin GVHD, it also increases an individual's risk of developing some forms of skin cancer.

### **Exercise and Stretching to Maintain Skin and Joint Flexibility**

People with sclerosis (thickening and hardening of the skin) can benefit from stretching exercises under the direction of a physical or an occupational therapist to increase their range of motion. Exercising regularly will improve circulation to the affected areas and will help you maintain and possibly increase your range of motion. Discuss your exercise plans with your physician prior to beginning a workout routine.

### **Massage**

Individuals with fascial sclerosis, which is a hardening of the connective tissues, can benefit from a deep tissue massage called myofascial release massage that incorporates stretching and massage of connective tissues (fascia).<sup>22</sup>

## **MUSCLES AND NERVES**

**G**VHD can also affect your neuromuscular structures. This causes nerve pain, muscle weakness, and cramping. Muscle cramping can also be caused by some of the medications used to treat GVHD. However, for reasons that are not fully understood, muscle cramping can persist years after GVHD has resolved and can also occur in individuals who have never experienced GVHD.

*My muscle cramping is so bad that I sometimes wake up crying out in pain. Even simple things, like holding a pen, are now difficult.*

*I have neuropathy in my lower legs and feet. It feels like my legs are going to sleep. My balance is affected, and I use crutches to walk far. Foot and calf massages help alleviate the symptoms of peripheral neuropathy.*

*For the first five years after the transplant, I used to have muscle cramps every night that required me to get up out of bed several times to walk it out. But that has now resolved, and I can no longer remember when I last had a muscle cramp.*

Muscle cramping post transplant usually does not resolve with typical muscle

relaxants and pain medications. Tonic water, which contains quinine, can sometimes provide relief as can certain prescription drugs that can be used alone or in combination with quinine. Talk to your doctor about possible treatments. Specific guidelines for treatment can also be obtained from larger transplant centers with departments dedicated to long-term care post transplant.

## MOUTH AND ESOPHAGUS GVHD

Radiation that is given as part of the conditioning regimen before a transplant can reduce saliva production, as can GVHD.<sup>37</sup> Saliva has several important functions, including protecting against the bacteria that contribute to cavities, lubricating and breaking down food so that it can be tasted, moisturizing and binding food so that it can be easily swallowed, and initiating digestion. When the amount of saliva is reduced, people are at greater risk for dental cavities. They may also experience greater difficulties with tasting and swallowing.

GVHD can attack the cells lining your mouth causing mouth sores, irritation of the gums, ulcers, dryness, and chapped lips. This in turn can lead to a burning sensation and pain when you eat spicy foods or use toothpaste. Sometimes GVHD manifests as lichen planus, which appears as white, lacy streaks, bumps, or ulcerations in the mouth or on the lips. Good oral hygiene is very important to prevent infections and to maintain the health of your gums and teeth. Using a mouth rinse or toothpaste with corticosteroids may improve the symptoms of chronic GVHD of the mouth.

GVHD can also affect the esophagus, making it more difficult to swallow. If you have trouble swallowing, you may benefit from consulting with a physician specializing in problems of ears, nose, and throat or with a speech-language pathologist trained in problems of the esophagus.

*My mouth is very dry, and I have had a lot of tooth decay. I now have numerous crowns.*

*I have sores in my mouth, my tongue feels swollen, and it is difficult to swallow. Even my speech is affected. I am going to see a GI specialist to see if my esophagus is constricted and if it can be stretched.*

### Caring for Your Mouth

Keeping your mouth clean and free of dental cavities is an important part of preventing infection and maintaining your general health. Make sure to consult with a dentist about the best way to care for your mouth, particularly if you are experiencing GVHD or other late effects from your transplant. In addition to letting your dentist know that you have had a transplant, you should also keep him or her informed of any medications you are taking. Certain medications may affect your gums or saliva and can affect your oral health. Getting a full list of the medications you are taking will help your dentist or oral hygienist better understand the changes in your mouth.

Good Oral Hygiene includes:

- Regular brushing two times a day. An electric toothbrush with a two-minute timer is recommended by many dentists to remove plaque.
- Daily flossing or cleaning with an interdental cleaner. This helps to remove plaque from between your teeth and under your gum line.<sup>38</sup> An oral irrigator (Waterpik) that uses a fine, high-pressure jet of water to clean the gum line and the spaces between the teeth is also effective.
- Using a tongue scraper to remove food debris and bacteria from your tongue. A tongue scraper is a simple device that takes just a few seconds to stroke a few times across your tongue. Many of the bacteria that lead to plaque, tooth decay, and gum disease reside on the tongue. Regular tongue cleaning with a scraper can help reduce the coating on the tongue, and can improve bad breath and taste perception.<sup>39, 40</sup> Tongue scrapers may be made of plastic, metal, or wood. Many can be purchased very inexpensively, or they can sometimes be obtained free of charge from your dentist.
- Get dental check-ups and cleanings at least twice a year. Make sure that your dentist or oral hygienist does a cancer screen by looking and feeling around your mouth for any unusual bumps or spots. If you are still taking immunosuppressants, and your dentist recommends prophylactic antibiotics, make sure you follow the directions about the appropriate doses and timing. You may be able to get the prescription and the antibiotics at your dentist's office.

*Ever since the transplant, my gums have been receding continuously. After several consults with dentists, I now have a regimen that seems to be keeping the progression at bay. I now spend close to ten minutes every night caring for my teeth – brushing for two minutes with a sonic toothbrush, flossing, then using an interdental cleaner to get remaining plaque, and cleaning with a tongue-cleaner.*

### **Dry Mouth Solutions**

- Get adequate hydration. This can include water with lemon juice and herbal teas.
- Eat foods that have a lot of liquid, such as soups and stews. Moisten your food by adding sauces and broths.
- Take frequent sips of water and rinse your mouth regularly throughout the day.
- Avoid alcohol and caffeine as they may aggravate dryness. Avoid hidden sources of alcohol in mouthwashes and medicines.
- Moisten the air around you with a cool-air vaporizer to add humidity.
- Use saliva substitutes, moisturizing gels, and special dry mouth toothpastes to provide temporary relief. Your dentist should be able to recommend helpful products.
- Take medications to increase your saliva production. Consult with your physician or dentist about appropriate medications.

- Chew on sugarless gum or suck on a piece of sugarless candy to stimulate salivary glands throughout the day.
- Pure papaya and pineapple juice are known to break up thick saliva. Other fresh fruit can also help.<sup>20</sup>
- Certain acupuncture points may help stimulate saliva production.<sup>41</sup>

## GASTROINTESTINAL TRACT (GUT) GVHD

Your gastrointestinal tract or gut is the system that digests and absorbs food and then expels waste matter. The gut also contains many immune system cells and serves to protect the body from infection. When the cells that line the gut are damaged by GVHD, they are less able to absorb nutrients and to protect the body from infection. The symptoms of gut GVHD vary based on where in the gut the disease occurs and on the severity of the GVHD. Symptoms may include difficulty swallowing, heartburn, nausea, vomiting, abdominal cramps, poor absorption of nutrients, problems with gut motility, weight loss, and diarrhea.

*Gut GVHD is a totally unique feeling, unlike normal nausea or abdominal pain. It is a very sharp pain, like an animal eating my gut, with bloating, diarrhea, and indigestion. Gut GVHD is the worst part of my post-transplant life.*

*I have chronic diarrhea, but it has not affected my health. I usually am able to control the diarrhea with medication.*

*My esophagus burns from the throat down to the sternum, particularly when I consume anything spicy or processed. The pain lasts 6-24 hours, even with Prilosec.*

*I have noticed changes to my GI system, but nothing serious enough to go to doctors with.*

Gut GVHD affects not only the absorption of foods but also absorption of medications. If you have GI symptoms, it is very important for you to consult with a knowledgeable physician and to get nutritional counseling.

## LIVER CONDITIONS

The liver performs a variety of essential functions, including breaking down medications so that the body can use them, removing toxins, producing proteins that play a role in blood clotting, producing bile that aids in digestion, and removing bilirubin, which is produced when red blood cells die. Liver function can be damaged by many factors after a transplant, including GVHD, viral hepatitis, bacterial and fungal infections, iron overload from multiple red blood transfusions, and drug toxicity. If liver inflammation (hepatitis) develops, it is important to determine whether it is caused by GVHD, a viral infection, or another condition, so that it can be treated appropriately. In some cases, liver damage can result from more than one condition. A liver biopsy can be helpful in determining the main cause of the damage.

If your liver damage is minimal, there are often no symptoms, and the only signs of the damage are elevated levels of blood bilirubin and liver enzymes. When damage to the liver is mild or moderate, it tends to be temporary and reversible with treatment. If liver disease progresses, additional symptoms can include jaundice, which is a yellowing of the skin and eyes, itching, and loss of appetite.

*My liver enzymes have been high for a number of years, but the good news is that I have no symptoms.*

## VAGINAL CONCERNS

Many women report vaginal dryness, skin irritation, and pain with intercourse following transplant. The vaginal skin may be more prone to inflammation and tearing from many factors. Low estrogen levels due to premature menopause can cause drying and thinning of the vaginal lining. Radiation treatments to the pelvic area and GVHD can have the same effect and can also lead to vaginal stenosis, a condition where the vaginal opening becomes narrower, shorter, and less flexible. Vaginal stenosis can make intercourse and clinical examinations more painful or impossible. Regular intercourse and vaginal dilators can help prevent and in some cases treat vaginal stenosis. Women should see their gynecologist if they develop pain with intercourse so that they can be treated early before the condition progresses. Topical estrogen or immunosuppressive creams may also be helpful. If vaginal adhesions form, surgery may be required.

Inflammation of the genital area can also be caused by a skin condition called lichen planus, which can result in itchy, painful lesions. Although there is no cure for lichen planus, it can become dormant with treatment.

*After the transplant, I quickly found out that intercourse with my husband was very painful. It turns out that you can get strictures not only in your esophagus, but also in your vagina!*

*I have had extensive vaginal GVHD and have also lost most of my pubic hair. After I developed a vaginal constriction, surgery made things better, but still left me uncomfortable.*

## BONES

Two of the most common reasons for bone pain post transplant come from osteoporosis-related fractures and avascular necrosis. If you are experiencing bone pain, it is important to follow up with your doctor to determine the cause of the pain and to treat it. Bone deterioration may occur without symptoms. Pain may slowly increase or erupt suddenly due to bone fracture or collapse. The earlier that bone deterioration is caught, the more effectively it can be treated.

### **Osteoporosis and Osteopenia**

Osteopenia is a condition where bone mineral density is lower than normal. Individuals with osteopenia are at risk for developing osteoporosis, which is a

condition where there is further bone loss and a high risk of bone fractures. People with osteoporosis will often not experience any symptoms until there is a bone fracture. Bone fractures are painful and can occur anywhere in the body, including the spine.

*Years of prednisone use has created osteoporosis, and I am at very high risk for bone fractures. I have had four stress fractures including my left hip, which has three titanium pins holding it together. I was on crutches for ten weeks after the surgery to repair my hip. My various orthopedic fractures required me to walk in special “ortho” boots, and that threw my hips and back out of whack. Physical therapy and yoga have helped me greatly in regaining my strength and balance. I take vitamin/mineral supplements as well as two bone density drugs, one of which I inject daily.*

Transplant survivors are at higher risk for developing osteoporosis because of their exposure to radiation, chemotherapy, and the use of steroids, such as prednisone. Early menopause and low estrogen levels can also contribute to bone thinning. All transplant survivors should have their bone density checked so that bone loss can be detected early and treated.

The best treatment for osteopenia and osteoporosis is a holistic approach that includes medication, nutritional changes, and exercise. There are a number of effective medications that can slow down, prevent, and, in some cases, reverse bone loss. These medications should be supplemented with daily calcium and vitamin D, which are important for bone health. Weight-bearing exercises to strengthen the bones should also be incorporated into your daily routine. Weight-bearing exercises include brisk walking, weight training, dancing, jogging, and aerobics. Virtually every gym has a trainer who can help you design a fitness program to meet your needs.

If you already have some bone loss, it may be important to avoid high impact exercises that carry a high risk of falls or bone fracture. The risk of falls and injury can also be reduced by engaging in exercises such as yoga and T'ai Chi that improve balance, core strength, and flexibility. Talk to your doctor to make sure that your exercise routine is appropriate, and then go get that body moving!

For post-menopausal women, hormone replacement therapy with estrogen is also an effective way to slow bone loss. However, given the controversy around estrogen therapy, treatment with estrogen should only be started after careful consideration and in consultation with your doctor.

### **Avascular Necrosis (AVN)**

Avascular necrosis (AVN) is a condition that occurs when the blood supply to the bones is damaged, causing them to break down faster than the body can rebuild them. Left untreated, bone tissue can die and collapse. Joint pain is usually the first symptom of AVN. It tends to start in the hips, but can also occur in other joints such as the knees, shoulders, ankles, and wrists. AVN in long-term survivors is generally caused by the use of high-dose steroids, such as prednisone.



*My right hip is very painful because the right femoral nerve is dead, so the hip is dying and getting worse. I have avascular necrosis in both hips and my right thigh is totally numb. I guess there is no choice but to learn to live with this stuff.*

*I had avascular necrosis of the hip a couple of years ago, and then had my hip replaced the following year. I am now doing well.*

Treatments for AVN include medication to prevent bone degeneration, use of crutches or braces to reduce weight and pressure on the joint, range of motion exercises, and treatments such as electrical stimulation to promote the growth of new blood vessels and bone tissue.

If AVN is caught early, a surgical procedure called core decompression can also be used. In this procedure, a limited amount of dead bone can be removed from the joint to relieve pressure, helping the body to restore blood supply to the bone. Certain centers will also replace the dead bone tissue that is removed with healthy bone taken from a different part of the body to strengthen and bring more blood to the injured joint. Total joint replacement is also an option if AVN is more advanced.

## OTHER HEALTH CONCERNS

In addition to targeting organs, GVHD can target the immune system itself, including the bone marrow and the thymus, where certain white blood cells known as T-lymphocytes mature. By attacking the immune system, chronic GVHD can impact a person's general immune function and ability to fight infections.

Lung damage following transplant can be a result of damage from radiation, chemotherapy, or from GVHD. When lung damage is mild, there are often no symptoms, and the only evidence is poor results on pulmonary function tests. Symptoms of lung GVHD may include coughing, wheezing, labored breathing, and bronchitis. Early recognition and treatment of the inflammation is important.

## CONCLUDING REMARKS

Regardless of how we are faring post transplant – whether our health is fully restored or we continue to grapple with physical and emotional challenges – we are here to tell the tale. The transplant may have changed the direction of our lives in ways we never imagined. Each of our stories is unique and is part of a larger tapestry of stories of tragedy and triumph, of loss and hope. The challenge each of us faces is to find ways to live this complicated, beautiful, painful, and miraculous life to the best of our abilities. Itzhak Perlman played an entire concerto on a violin with only three strings. Given who you are today, how much music can you make? What are you going to do to live your one precious life as richly and fully as possible?

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## RESOURCE LISTING

The following list of resources may be helpful to BMT survivors, their caregivers, and families. They are not intended to be endorsements. While the Internet may be a valuable tool, it may also contain misleading or inaccurate information. **Remember, the best source of medical advice is your physician.** Additional information and resources may be found on the National Bone Marrow Transplant Link website at [www.nbmtlink.org](http://www.nbmtlink.org).

### **Bone Marrow/Stem Cell Transplant Information and Support**

#### **National Bone Marrow Transplant Link**

800-LINK-BMT (800-546-5268) or  
248-358-1886  
[www.nbmtlink.org](http://www.nbmtlink.org)

#### **National Marrow Donor Program**

Office of Patient Advocacy  
888-999-6743 or 612-627-8140  
[www.marrow.org/patient](http://www.marrow.org/patient)

#### **American Society for Blood and Marrow Transplantation (ASBMT)**

847-427-0224  
[www.asbmt.org](http://www.asbmt.org)

#### **Blood and Marrow Transplant Information Network**

888-597-7674 or 847-433-3313  
[www.bmtinfonet.org](http://www.bmtinfonet.org)

#### **The Bone Marrow Foundation**

800-365-1336 or 212-838-3029  
[www.bonemarrow.org](http://www.bonemarrow.org)

#### **Center for International Blood & Marrow Transplant Research (CIBMTR)**

414-805-0700  
[www.cibmtr.org](http://www.cibmtr.org)

### **Bone Marrow Donor Information**

#### **Be the Match Registry<sup>SM</sup>**

Operated by the National Marrow Donor Program  
800-MARROW2 (800-627-7692)  
[www.bethematch.org](http://www.bethematch.org)

#### **Asians for Miracle Marrow Matches**

888-A3M-HOPE (888-236-4673)  
[www.asianmarrow.org](http://www.asianmarrow.org)

#### **Bone Marrow Donors Worldwide**

[www.bmdw.org](http://www.bmdw.org)

#### **The Caitlin Raymond International Registry**

800-726-2824 or 508-334-8969  
[www.crir.org](http://www.crir.org)

#### **DKMS Americas**

866-340-3567  
[www.dkmsamericas.org](http://www.dkmsamericas.org)

#### **Gift of Life Bone Marrow Foundation**

800-9MARROW or 561-982-2900  
[www.giftoflife.org](http://www.giftoflife.org)

### **Alternative, Complementary and Integrative Medicine**

#### **Complementary/Integrative Medicine Education Resources**

MD Anderson Cancer Center  
877-MDA-6789 (877-632-6789)  
[www.mdanderson.org/departments/CIMER/](http://www.mdanderson.org/departments/CIMER/)

#### **Integrative Medicine – Herbs, Botanicals and Other Products**

Memorial Sloan-Kettering Cancer Center  
212-639-2000  
[www.mskcc.org/mskcc/html/11570.cfm](http://www.mskcc.org/mskcc/html/11570.cfm)

#### **National Center for Complementary and Alternative Medicine**

888-644-6226  
[www.nccam.nih.gov](http://www.nccam.nih.gov)

### **Cancer/Multi-Service**

**American Cancer Society**  
800-ACS-2345 (800-227-2345)  
[www.cancer.org](http://www.cancer.org)

**CancerCare, Inc.**  
800-813-HOPE (800-813-4673)  
[www.cancercares.org](http://www.cancercares.org)

**National Cancer Institute**  
Cancer Information Service  
800-4-CANCER  
[www.cancer.gov](http://www.cancer.gov)

### **Caregiver Support**

**National Alliance for Caregiving**  
301-718-8444  
[www.caregiving.org](http://www.caregiving.org)

**National Family Caregivers Association**  
800-896-3650 or 301-942-6430  
[www.thefamilycaregiver.org](http://www.thefamilycaregiver.org)

**Rosalynn Carter Institute for Caregiving**  
Georgia Southwestern State University  
229-928-1234  
[www.rosalynncarter.org](http://www.rosalynncarter.org)

**Well Spouse Association**  
800-838-0879 or 732-577-8899  
[www.wellspouse.org](http://www.wellspouse.org)

**Young (Cancer) Spouses**  
[www.youngcancerspouses.org](http://www.youngcancerspouses.org)

### **Children/Adolescents/Young Adults**

#### **Beyond the Cure**

(National Children's Cancer Society)  
800-5-FAMILY (800-532-6459)  
[www.beyondthecure.org](http://www.beyondthecure.org)

#### **Cancer Survivors' Fund**

281-437-7142  
[www.cancersurvivorsfund.org](http://www.cancersurvivorsfund.org)

#### **Candlelighters Childhood Cancer Foundation**

800-366-2223 or 301-962-3521  
[www.candlelighters.org](http://www.candlelighters.org)

#### **CureSearch**

(National Childhood Cancer Foundation and Children's Oncology Group)  
800-458-6223  
[www.curesearch.org](http://www.curesearch.org)  
[www.survivorshipguidelines.org](http://www.survivorshipguidelines.org)

#### **I'm Too Young for This! Cancer Foundation**

877-735-4673  
[www.i2y.com](http://www.i2y.com)

#### **Planet Cancer**

512-452-9010  
[www.planetcancer.org](http://www.planetcancer.org)

#### **Ronald McDonald House Charities**

630-623-7048  
[www.rmhc.org](http://www.rmhc.org)

#### **The Sam Fund for Young Adult Survivors of Cancer**

866-439-9365 or 617-938-3484  
[www.thesamfund.org](http://www.thesamfund.org)

#### **SuperSibs!**

866-444-7427 or 847-705-7427  
[www.supersibs.org](http://www.supersibs.org)

#### **Survivor Alert**

A Lion in the House  
937-767-1924  
[www.survivoralert.org](http://www.survivoralert.org)

#### **The Ulman Cancer Fund for Young Adults**

888-393-3863 or 410-964-0202  
[www.ulmanfund.org](http://www.ulmanfund.org)

#### **Working Against Cancer**

[www.workingagainstcancer.org](http://www.workingagainstcancer.org)

**Clinical Trials**

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**Cancer.gov** (National Cancer Institute)  
www.cancer.gov/clinicaltrials

**CenterWatch Clinical Trials Listing Service**  
www.centerwatch.com

**Coalition of National Cancer Cooperative Groups, Inc.**  
www.cancertrialshep.org

**EmergingMed**  
www.emergingmed.com

**National Institutes of Health**  
www.clinicaltrials.gov

**Disease-Related Information**

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**American Sickle Cell Anemia Association**  
216-229-8600  
www.ascaa.org

**Aplastic Anemia & MDS International Foundation, Inc.**  
800-747-2820 or 301-279-7205  
www.aamds.org

**Fanconi Anemia Research Fund, Inc.**  
888-326-2664 or 541-687-4658  
www.fanconi.org

**American Brain Tumor Association**  
800-886-2282 or 847-827-9910  
www.abta.org

**National Brain Tumor Society**  
800-934-CURE (800-934-2873)  
www.braintumor.org

**Immune Deficiency Foundation**  
800-296-4433  
www.primaryimmune.org

**National Organization for Rare Disorders (NORD)**  
800-999-6673 or 203-744-0100  
www.raredisorders.org

**The Leukemia & Lymphoma Society**  
800-955-4572 or 914-949-0084  
www.lls.org

**Children's Leukemia Foundation of Michigan**  
800-825-2536 or 248-530-3000  
www.leukemiamichigan.org

**Leukemia Research Foundation** (Illinois residents and Chicago vicinity)  
888-558-5385 or 847-424-0600  
www.leukemia-research.org

**Lymphoma Research Foundation**  
800-500-9976 or 310-204-7040  
www.lymphoma.org

**International Myeloma Foundation**  
800-452-2873 or 818-487-7455  
www.myeloma.org

**Multiple Myeloma Research Foundation**  
203-229-0464  
www.multiplemyeloma.org

**Fertility, Sexuality, and Intimacy**

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**The American Association of Sex Educators, Counselors, and Therapists**  
804-752-0026  
www.aasect.org

**American Society for Reproductive Medicine**  
205-978-5000  
www.asrm.org

**Female Sexual Medicine Program**  
650-723-7243  
www.womenshealth.stanford.edu/fsm/

**Fertile Hope** (Now part of LIVESTRONG)  
866-965-7205  
www.fertilehope.org

**Genetics and IVF Institute**  
800-552-4363 or 703-698-7355  
www.givf.com

**Resolve: The National Infertility Association**  
703-556-7172  
www.resolve.org

**Financial and Fundraising**

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**Cancer Financial Assistance Coalition**  
www.cancerfac.org

**The Max Foundation**  
888-462-9368 or 425-778-8660  
www.themaxfoundation.org

**National Association of Hospital Hospitality Houses**  
800-542-9730 or 828-253-1188  
www.nahhh.org

**National Foundation for Transplants**  
800-489-3863 or 901-684-1697  
www.transplants.org

**NTAF** (formerly National Transplant Assistance Fund)  
800-642-8399 or 610-535-6105  
www.ntafund.org

**Patient Access Network Foundation**  
866-316-7263  
www.patientaccessnetwork.org

**Patient Advocate Foundation**  
800-532-5274  
www.patientadvocate.org

**Insurance and Prescriptions**

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**Foundation for Health Coverage Education**  
800-234-1317  
www.coverageforall.org

**Medicare**  
800-MEDICARE (800-633-4227)  
www.medicare.gov

**Medicare Rights Center**  
800-333-4114  
www.medicarerights.org

**NeedyMeds, Inc.**  
www.needymeds.org

**Partnership for Prescription Assistance**  
888-477-2669  
www.pparx.org

**Legal Rights and Workplace Issues**

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**American Bar Association**  
800-285-2221  
www.abanet.org

**Americans with Disabilities Act**  
800-514-0301  
www.ada.gov

**Cancer and Careers**  
212-685-5955 ext. 132  
www.cancerandcareers.org

**Cancer Legal Resource Center**  
866-843-2572 or 213-736-1455  
www.cancerlegalresourcecenter.org

**Equal Employment Opportunity Commission**  
800-669-4000  
www.eeoc.gov

**Patient Advocate Foundation**  
800-532-5274  
www.patientadvocate.org

**Managing Side Effects**

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**American Pain Society**  
847-375-4715  
www.ampainsoc.org

**Boston Foundation for Sight**  
781-726-7337  
www.bostonsight.org

**The Cancer Journey** (Oncology Nursing Society)  
866-257-4667  
www.thecancerjourney.org

**National Bone Marrow Transplant Link**  
Coping with Chronic GVHD  
Telephone Education/Support Group and Webcasts  
800-LINK-BMT (800-546-5268) or 248-358-1886  
www.nbmtlink.org

**National Lymphedema Network**  
800-541-3259 or 510-208-3200  
www.lymphnet.org

**National Sleep Foundation**  
202-347-3471  
www.sleepfoundation.org

**The Neuropathy Association, Inc.**  
212-692-0662  
www.neuropathy.org

### **Nutrition**

**American Institute for Cancer Research**  
800-843-8114 or 202-328-7744  
www.aicr.org

**Food and Nutrition Information Center**  
www.nutrition.gov

### **Survivorship**

**Association of Cancer Online Resources (ACOR)**  
212-226-5525  
www.acor.org  
BMT Talk:  
listserv.acor.org/archives/bmt-talk.html  
GVHD:  
listserv.acor.org/archives/gvhd.html

**R.A. Bloch Cancer Foundation, Inc.**  
800-433-0464 or 816-854-5050  
www.blochcancer.org

**Cancer.Net (American Society of Clinical Oncology)**  
888-651-3038 or 571-483-1780  
www.cancer.net

**Cancer Hope Network**  
877-467-3638 or 908-879-4039  
www.cancerhopenetwork.org

**Cancer Support Community**  
(Formerly Gilda's Club and the Wellness Community)  
888-793-9355  
www.cancersupportcommunity.org

**LIVESTRONG Lance Armstrong Foundation**  
866-673-7205  
www.livestrong.org

**National Cancer Survivors Day Foundation**  
615-794-3006  
www.ncsd.org

**National Coalition for Cancer Survivorship**  
888-650-9127 or 301-650-9127  
www.canceradvocacy.org

**Oncolink**  
www.oncolink.com

**Planet Cancer**  
512-452-9010  
www.planetcancer.org

**Vital Options International**  
818-508-5657  
www.vitaloptions.org

### **Transportation**

**Air Care Alliance**  
888-260-9707  
www.aircareall.org

**Air Charity Network**  
877-621-7177  
www.aircharitynetwork.org

**Corporate Angel Network, Inc.**  
866-328-1313 or 914-328-1313  
www.corpangelnetwork.org

**National Patient Travel Center**  
800-296-1217  
www.patienttravel.org

### **CDs/DVDs/Videos**

**Coping with Chronic GVHD in Adults and Meeting the Challenges of Chronic GVHD in Children & Adolescents**, National Bone Marrow Transplant Link, 2009

**Decisions. Support. Possibilities. Transplant as an Option When You are 50 and Older**, National Marrow Donor Program, 2007

**Discovery to Recovery: A Child's Guide to Bone Marrow Transplant for Children Ages 5-9**, National Marrow Donor Program, 2005

**Forward! Living Life After Transplant** (teens, young adults), National Marrow Donor Program, 2007

**Guided Visualization: Working with the Healing Power of Your Immune System**, Aquarius Health Care Media, 2003

**The Healing Attitude: The Empowered Patient**, Aquarius Health Care Media, 2007

**The New Normal: Life After Bone Marrow/Stem Cell Transplant**, National Bone Marrow Transplant Link, 2001

**Stress Relief Healing with Dr. Russ Greenfield**, Aquarius Health Care Media, 2006

**Words of Experience. Stories of Hope. A Guide to Marrow and Cord Blood Transplant for Patients and Caregivers**, National Marrow Donor Program, 2008

### **Books and Magazines**

**100 Questions & Answers about Life after Cancer: A Survivor's Guide**, by Page Tolbert, 2008

**100 Questions & Answers about Cancer and Fertility**, by Kutluk H. Oktay, 2008

**After the Diagnosis: How to Look Out for Yourself or a Loved One**, by Donna L. Pikula, DDS, 2006

**American Cancer Society Complete Guide to Complementary and Alternative Cancer Therapies**, 2nd edition, 2009

**The Anatomy of Hope: How People Prevail in the Face of Illness**, by Jerome Groopman, 2005

**Anatomy of an Illness as Perceived by the Patient: Reflections on Healing and Regeneration**, by Norman Cousins, 1958

**Breaking the Silence: Inspirational Stories of Black Cancer Survivors**, by Karin L. Stanford, PhD, 2005

**Cancer Caregiving A to Z: An At-Home Guide for Patients and Families**, American Cancer Society, 2008

**Cancer Dictionary**, by Michael J. Sarg, 2007

**Cancer Etiquette: What to Say, What to Do, When Someone You Know or Love Has Cancer**, by Rosanne Kalick, 2005

**Cancer Fitness: Exercise Programs for Patients and Survivors**, by Lance Armstrong and Anna L. Schwartz, 2004

**Cancer in Context: A Practical Guide to Supportive Care**, by James Brennan, 2004

**Cancer Survivor's Almanac: Charting your Journey**, National Coalition for Cancer Survivorship, edited by Barbara Hoffman, 2004

**The Cancer Survivor's Guide: The Essential Handbook to Life after Cancer**, by Michael Feuerstein, PhD and Patricia Findley, 2006

**Caregivers' Guide for Bone Marrow/Stem Cell Transplant: Practical Perspectives**, National Bone Marrow Transplant Link, 2007

**Childhood Cancer Survivors: A Practical Guide to Your Future**, by Nancy Keene, 2007

**Crazy Sexy Cancer Tips**, by Kris Carr, 2007

**Creative Visualization: Use the Power of Your Imagination to Create What You Want in Life**, by Shakti Gawain, 2009

**Chronic Graft Versus Host Disease: Interdisciplinary Management**, by Georgia B. Vogelsang, MD and Steven Z. Pavletic, MD, 2009

**Coping with Cancer Magazine**, [www.copingmag.com](http://www.copingmag.com)

**Coping with Prednisone (and Other Cortisone-Related Medicines)**, by Eugenia Zukeman and Julie R. Ingelfinger, MD, revised and updated 2007

**CURE Magazine**, [www.curetoday.com](http://www.curetoday.com)

**Diagnosis: Cancer**, by Wendy Schlessel Harpham, 2003

**Eating Well Through Cancer**, by Holly Clegg & Gerald Miletello, MD, 2008

**Eating Well, Staying Well During and After Cancer**, edited by Abby Bloch, PhD et al. American Cancer Society, 2004

**Everyone's Guide to Cancer Supportive Care: A Comprehensive Handbook for Patients and their Families**, by Ernest Rosenbaum, MD and Isadora Rosenbaum, 2005

**Everyone's Guide to Cancer Survivorship: A Road Map for Better Health**, by Holly Gautier, RN and Ernest H. Rosenbaum, MD, 2007

**Everything Changes: The Insider's Guide to Cancer in Your 20's and 30's**, by Kairol Rosenthal, 2009

**Full Catastrophe Living: Using the Wisdom of Your Body and Mind to Face Stress, Pain, and Illness**, by Jon Kabat-Zinn, PhD, 2009

**Handbook of Cancer Survivorship**, by Michael Feuerstein, PhD, 2007

**The Healing Power of Humor: Techniques for Getting Through Loss, Setbacks, Upsets, Disappointments, Difficulties, Trials, Tribulations, and All That Not-so-funny Stuff**, by Allen Klein, 2003

**Kitchen Table Wisdom: Stories That Heal**, by Rachel Naomi Remen, MD, 2006

**The Lonely Patient: How We Experience Illness**, by Michael Stein MD, 2007

**Mapping the Maze: A Personal Financial Guide to Blood Stem Cell Transplants**, by National Marrow Donor Program, 2003

**Nutritional Issues in Cancer**, edited by Valerie J. Kogut, MA, RD, LDN, 2005

**One Bite at a Time Nourishing Recipes for Cancer Survivors and Their Friends**, by Rebecca Katz with Mat Edelson, 2nd edition, 2008

**Picking Up the Pieces: Moving Forward after Surviving Cancer**, by Sherri Magee and Kathy Scalzo, 2007

**Resource Guide for Bone Marrow/Stem Cell Transplant: Including Bone Marrow, Peripheral Blood, and Cord Blood**, National Bone Marrow Transplant Link, 2006

**Sexuality and Cancer: For the Woman Who Has Cancer and Her Partner**, American Cancer Society, 2005

**Survivorship Guide for Bone Marrow/Stem Cell Transplant: Coping with Late Effects**, by Keren Stronach, National Bone Marrow Transplant Link, 2010

**Understanding Cancer Therapies**, by Helen S.L. Chan, 2007

**What Helped Get Me Through: Cancer Survivors Share Wisdom and Hope**, edited by Julie K. Silver, MD, American Cancer Society, 2009

**When Bad Things Happen to Good People**, by Harold S. Kushner, 2004

**You Can Conquer Cancer: Prevention and Management**, by Ian Grawler, 2005

**YOU: The Smart Patient: An Insider's Handbook for Getting the Best Treatment**, by Michael F. Roizen, MD, and Mehmet C. Oz, MD, with the Joint Commission, 2006

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Please take our five-minute survey online at  
<http://www.zoomerang.com/Survey/?p=WEB22A3DRFVB6B>

You can also call 800-546-5268 for a print version of the survey.

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**NATIONAL  
MARROW  
DONOR  
PROGRAM®**

OFFICE OF PATIENT ADVOCACY

**The transplant process is a journey. We are here to help guide patients and families along the way.**

The case managers at the National Marrow Donor Program® (NMDP) are more than good listeners. They are knowledgeable professionals who are dedicated to helping patients and their families navigate the transplant journey, from diagnosis to survivorship.

Our Office of Patient Advocacy provides information to anyone seeking answers about marrow or cord blood transplantation. We provide and connect you to the resources and services you need—whether you are planning for transplant or are a survivor like Betsy.



**Betsy:** three years after her marrow transplant, Betsy is cancer-free and active. Along with raising her two young daughters, she now volunteers to help educate patients about transplant and to raise awareness of our Be The Match Registry.<sup>SM</sup>

1.888.999.6743 | [marrow.org/patient](http://marrow.org/patient)

**Let us help you.**

# SURVIVORSHIP GUIDE FOR BONE MARROW/STEM CELL TRANSPLANT



*Coping with Late Effects*  
by Keren Stronach

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National Bone Marrow Transplant Link