

# CAREGIVERS' GUIDE FOR BONE MARROW/STEM CELL TRANSPLANT



*Practical Perspectives*



***nbmt*LINK**

National Bone Marrow Transplant Link

# CAREGIVERS' GUIDE FOR BONE MARROW/STEM CELL TRANSPLANT



## *Practical Perspectives*

There are only four kinds of people in the world:

Those who have been caregivers

Those who are currently caregivers

Those who will be caregivers

Those who will need caregivers.

– Rosalynn Carter, *Helping Yourself to Help Others*

This booklet is dedicated with admiration to BMT caregivers,  
past, present and future.

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

Founded in 1992, the nbmtLINK is an independent, non-profit organization funded entirely through the generosity of individuals, corporations and foundations. Tax-deductible contributions are welcomed and vital to ongoing programs and services.

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

For additional copies of this booklet, please contact:

National Bone Marrow Transplant Link

20411 W. 12 Mile Rd., Suite 108

Southfield, MI 48076

Phone: 248-358-1886

Toll Free: 800-LINK-BMT (800-546-5268)

Fax: 248-358-1889

[info@nbmtlink.org](mailto:info@nbmtlink.org)

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

The National Bone Marrow Transplant Link (nbmtLINK) would like to acknowledge the transplant patients, survivors, caregivers, and health professionals who generously shared their experiences and recommendations, and the other individuals who reviewed and edited sections of this booklet's earlier edition.

The nbmtLINK would also like to acknowledge the editors, reviewers, and nbmtLINK staff who helped update this second edition of the *Caregivers' Guide*.

**Co-editors:**

**Myra Jacobs, MA**

National Bone Marrow Transplant Link

**Jean Jones**

National Bone Marrow Transplant Link

**Advisors/Reviewers:**

**Muneer H. Abidi, MD**

Barbara Ann Karmanos Cancer Institute

**Kari Bailey, MBC**

National Marrow Donor Program

**Michelle Burda, MLS**

University of Pittsburgh Medical Center

**Sarah Christensen, MA**

Mayo Clinic Cancer Center

**Jill Dowdy, MLIS**

Mayo Clinic Cancer Center

**Katy Fasl, MSW**

University of Michigan Health System

**Heather Sikora James**

National Marrow Donor Program

**Emily McChesney, MSW, LICSW**

National Marrow Donor Program

**Tiffany Rowe, MBA**

National Bone Marrow Transplant Link

We are also grateful to our dedicated nbmtLINK office volunteers  
who helped make this booklet possible:

**Lori Strager, Chris McClellan, Peg McIvor, and Marilyn Beckham**

We gratefully acknowledge the financial support  
for this *Caregivers' Guide* from the following:

---

## **Sustaining Partners**

---

**American Society for Blood and Marrow Transplantation**



**The Blood and Marrow Transplant Program at Northside Hospital**



**Children's Hospital of Michigan**



**City of Hope Cancer Center**

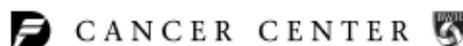


**Community Cancer Care Specialists**



**Dana-Farber/Brigham and Women's Cancer Center**

**DANA-FARBER/BRIGHAM AND WOMEN'S**



## Fred Hutchinson Cancer Research Center/Seattle Cancer Care Alliance



Fred Hutchinson Cancer Research Center  
UW Medicine  
Children's Hospital and Regional Medical Center

*Working together to cure cancer*

## Henry Ford Macomb Hospitals



**HENRY FORD  
MACOMB HOSPITAL**

## Henry Ford Transplant Institute



**HENRY FORD TRANSPLANT INSTITUTE**

## J.P. McCarthy Foundation



## Karmanos Cancer Center

BARBARA ANN  
**KARMANOS**  
CANCER CENTER

At the Detroit Medical Center

## Memorial Sloan-Kettering Cancer Center



## National Marrow Donor Program

**NATIONAL  
MARROW  
DONOR  
PROGRAM®**

## OHSU Center for Hematologic Malignancies



## University of Michigan Comprehensive Cancer Center



## The University of Texas M. D. Anderson Cancer Center



---

## Supporting Partners

---

Gift of Life Bone Marrow Foundation



The Leukemia & Lymphoma Society



Siteman Cancer Center at Barnes Jewish Hospital  
and Washington University School of Medicine



UPMC Cancer Centers/Stem Cell Transplant Program



---

## Collaborating Partners

---

Aplastic Anemia & MDS International Foundation

Gilda's Club Worldwide

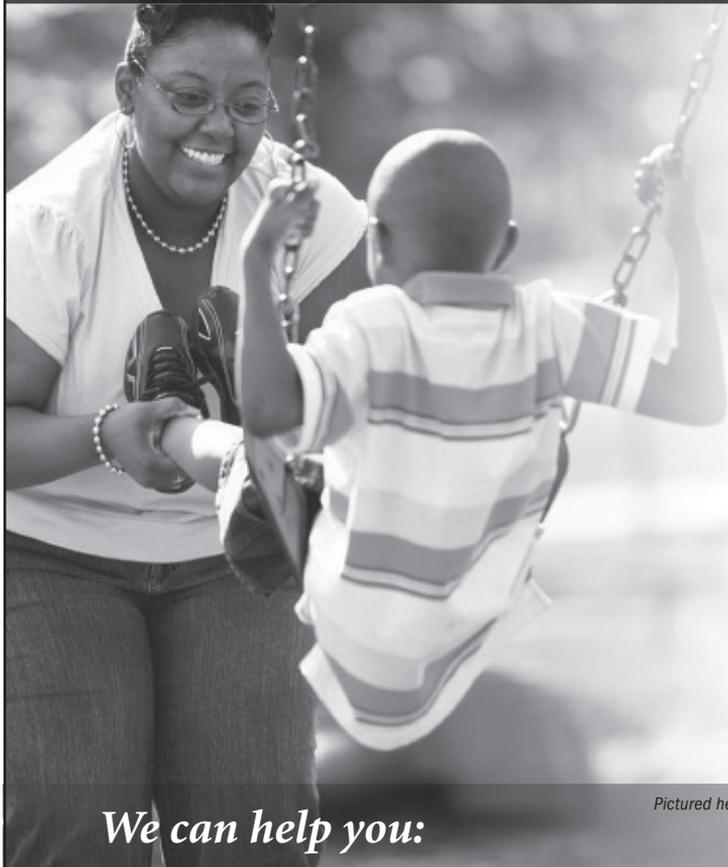
The Nebraska Medical Center

Rosalynn Carter Institute

Rocky Mountain Blood and Marrow Transplant Program

# Marrow or cord blood transplant?

*We're here to help.*



**The National Marrow Donor Program (NMDP)** helps people who need a life-saving marrow or cord blood transplant. We are committed to helping more people live longer and healthier lives.

**Our Office of Patient Advocacy** can support you and your family every step of the way, from diagnosis through survivorship.

*We can help you:*

*Pictured here: Danielle, transplant in 2004, with her son, Jaylen*

- Learn about treatment options
- Understand the transplant process
- Overcome financial barriers
- Find the transplant center that is best for you
- Maximize recovery after transplant

***Call us. All of our services are free and confidential.***

Toll-free in the United States: **1 (888) 999-6743.**

Outside the United States: **1 (612) 627-8140.**

E-mail: **patientinfo@nmdp.org**

To learn more, visit us online at: **www.marrow.org/patient**

**NATIONAL MARROW DONOR PROGRAM®**

*Creating Connections. Saving Lives.®*

## **Reassurance, Understanding and Peer Support for Bone Marrow/Stem Cell Transplant (BMT) Caregivers**

**“Peer Support on Call”**– is a free service offered by the National Bone Marrow Transplant Link

Caring for someone having a Bone Marrow/Stem Cell Transplant (BMT) is a unique commitment that requires extraordinary physical and emotional effort. It is the goal of the National Bone Marrow Transplant Link (nbmtLINK) to reinforce the important role of BMT caregivers and to help them meet the many challenges they face. Through the “Peer Support on Call” program, emotional support is available through one-on-one conversations with trained peer support volunteers, caregivers themselves, who have successfully faced the BMT experience and cared for their loved one. They understand a caregiver’s feelings and can provide an empathetic point of view.

If you would like to request a phone call from a peer support volunteer, please call our office at **800-LINK-BMT (800-546-5268)**.

For additional nbmtLINK resources, visit our website at [www.nbmtlink.org](http://www.nbmtlink.org)

***nbmt*LINK**

National Bone Marrow Transplant Link

# CAREGIVERS' GUIDE FOR BONE MARROW/STEM CELL TRANSPLANT

  
*Practical Perspectives*

## **Table of Contents**

Foreword.....	1
Why a Special Booklet for BMT Caregivers?.....	3
My Gift to Mom for Her Second Birthday: An Adult Daughter's Perspective.....	7
Tackling the Challenge: A Husband's Perspective.....	11
Cancer Etiquette: A Survivor's Perspective on Effective Communication.....	15
Top Tips for Parent Caregivers: A Mother's Perspective.....	19
Another Way to Say I Love You: A Wife's Perspective.....	31
Emotional Aspects of Caregiving: An Oncology Social Worker's Perspective.....	35
Relying On a Family of Strangers: A Patient's Perspective.....	41
Symptom Management for Caregivers: An Oncology Nurse's Perspective.....	45
How to Be a Successful Family Caregiver: An Advocate's Perspective.....	51
Resource Listing.....	55

---

~

# Foreword

~

by Dr. Mary Horowitz



*Mary Horowitz, MD, MS, joined the Center for International Blood and Marrow Transplant Research (CIBMTR) [formerly the IBMTR/ABMTR] in 1986 and has served as Scientific Director since 1991. She received her MD in 1980 and MS in Biostatistics/Clinical Epidemiology from the Medical College of Wisconsin (MCW) in 1991. Dr. Horowitz currently holds the Robert A. Uihlein, Jr. Chair in Hematologic Research and is a tenured Professor of Medicine in the Division of Neoplastic Disease at the Medical College of Wisconsin, where she is also an active blood and marrow transplant physician. She is a member*

*of numerous professional societies and received MCW's Distinguished Service Award in June 2006, MCW's highest honor. She was selected to give the Mortimer M. Bortin lecture at the 2007 BMT Tandem Meetings.*

*Dr. Horowitz is a member of the editorial boards of the journals Blood, Bone Marrow Transplantation, and Biology of Blood and Marrow Transplantation. She has served on the Board of Directors of the National Marrow Donor Program (NMDP) and on the National Cancer Institute's Cancer Clinical Investigation Review Committee. She is the Principal Investigator of the Data and Coordinating Center of the U.S. Blood and Marrow Transplant Clinical Trials Network. She is also the Research and Project Director of the U.S. Stem Cell Therapeutic Outcomes Database, a component of the C.W. Bill Young Cell Transplantation Program, charged with collecting and assessing outcome data for all U.S. allogeneic transplants.*

**A**s a transplant physician for almost 20 years, I have had the opportunity to work with many wonderful people. Caring for patients through the transplant procedure and beyond requires a multidisciplinary team of physicians with expertise in multiple specialties, highly-trained nurses, pharmacists, nutritionists, physical therapists, social workers and others. Without these colleagues, it would not be possible to provide the highest levels of care to my patients. Patients themselves are an important part of this team with a very difficult role—complying with complicated

therapeutic regimens despite fatigue, pain and side effects. Their courage and persistence inspire and motivate us.

An equally important, but sometimes more overlooked member of this team is the caregiver. Most often a spouse, parent or child but sometimes other relatives or friends, caregivers play an irreplaceable role in care and recovery of patients. Most come to the transplant procedure with little medical knowledge or skill but quickly gain competence in the language of cancer and transplantation, acquire expertise in the identification and dispensing of medicines, and become able providers of a considerable amount of hands-on medical care. And caregivers provide things that the medical team cannot provide nearly as well—love, hope, encouragement, understanding, a knowledge and appreciation of the patient that goes beyond their illness. When patients are too tired or too sick to effectively communicate their needs, caregivers are their advocates.

Several scientific studies show that patients with supportive relationships fare better than those without caregiver support—and this is true for both children and adults. Though not so scientifically rigorous an evaluation, I know from personal observation that the pain and discomfort of the transplant procedure are borne more easily by those with family and friends to lean on. I feel much more comfortable discharging a patient when I know he or she has a strong support system. I also know that this support is not so easy to give. Caregivers often sacrifice much for their loved ones. There are long days and long nights; there is fatigue and discouragement. Careers and usual social and family roles must sometimes be put aside for long periods. Additionally, the difficulties faced by the transplant recipients are often acknowledged and are the source of sympathy and empathy from the medical team, friends and relatives. However, the difficulties of those sharing the experience with them may be overlooked or minimized.

Yet, there are also rewards. Helping the person you love overcome their illness is the most obvious. Additionally, families and friendships may achieve new levels of intimacy as hardships are faced together. Individuals sometimes find they have strength and skills they never imagined possible. But there are days when it is hard to see the rewards—and only too easy to be discouraged by the difficulties. This book gives you practical suggestions for getting through the hard days from people who have been there. Hopefully, it lets you know that you are not alone, that it is worth the struggle and that your role is critically important and appreciated.

Why a  
Special Booklet  
for BMT Caregivers?

by Myra Jacobs and Michelle Bishop



**Myra Jacobs, MA**, is the Founder and Executive Director of the National Bone Marrow Transplant Link (nbmtLINK). She has been involved in non-profit management, program development and fundraising for over 30 years. Her interest in bone marrow transplantation began while on staff at the Children's Leukemia Foundation of Michigan for over 10 years. Inspired by the plight and courage of bone marrow transplant patients and families and recognizing their need for information and support, she founded the National Bone Marrow Transplant Link in 1992.

In 2004, Myra received the National Public Service Award from the American Society for Blood and Marrow Transplantation. She is currently a member of the Consumer Advocacy Committee of the Center for International Blood and Marrow Transplant Research (CIBMTR). She is a graduate of the University of Michigan and holds a Master's Degree in Guidance and Counseling from Oakland University.



**Michelle M. Bishop, PhD**, is Research Assistant Professor in the Departments of Medicine and Clinical and Health Psychology, at the University of Florida, Gainesville, FL. A licensed clinical health psychologist, Dr. Bishop has 12 years of clinical experience helping patients and families with the psychosocial aspects of acute and chronic illness and its treatment, particularly cancer and blood and marrow transplantation (BMT). She served for four years as the project coordinator of the largest study to date of the long-term quality of life (QOL) of BMT survivors and their spouses, a multi-site

project funded by the National Cancer Institute (NCI) involving 40 BMT centers in North America. She recently received her own grant from NCI to conduct an in-depth follow up study of the couples enrolled in the aforementioned study to better understand

*the losses and gains they experienced. She also has conducted qualitative expressive writing studies with BMT spouse-caregivers in the transition phase home after BMT. She currently serves on the Late Effects/QOL subcommittee for the Blood and Marrow Transplant Clinical Trials Network State of the Science Committee and is a member of the Late Effects/QOL committee of the Center for International Blood and Marrow Transplantation Research. Dr. Bishop has received several awards for her research and has presented her work at a variety of state and national meetings. Her research interests include the long-term QOL, health behaviors, and positive changes experienced by cancer/BMT survivors, as well as, the short-term and long-term impact of cancer/BMT on the QOL of spouse-caregivers and the development of support services for BMT families.*

There are multiple reasons for publishing *Caregivers' Guide for Bone Marrow/Stem Cell Transplant, Practical Perspectives*. Since its founding in 1992, the National Bone Marrow Transplant Link (nbmtLINK) has had the opportunity to work with a host of remarkable people who filled “caregiver shoes.” Early on, we were inspired by stories of BMT caregivers that demonstrated incredible spirit, dedication and perseverance. We asked ourselves, “How could the nbmtLINK address the unmet needs of BMT caregivers?” and “What could the nbmtLINK do to recognize and support the efforts of these caregivers?”

It is well known that in this environment of increasing outpatient care, the caregiver's responsibilities become closely woven into the BMT process itself. In addition, the health care team actually relies upon the caregiver to provide services for the patient. Studies have shown that the caregiver role is critical to the health, adjustment, and quality of life of the BMT survivor. Yet, the physical, emotional, and social impact of the disease and BMT treatment on the family often are not acknowledged. In fact, caregivers experience the same, if not more, distress than the survivors themselves and are usually less likely than survivors to get the help they need.

After much observation and discussion, we concluded that the creation of a special booklet was needed. By focusing on various perspectives, the booklet would offer insights into the BMT caregiver role while acknowledging and affirming its importance. In reality, caring for someone having a BMT is a unique commitment requiring extraordinary physical and emotional effort. The primary medical focus, of course, is directly on the patient, with the hope for a positive treatment. However, the challenge of a BMT for the caregiver becomes life-changing as well. BMT caregiving, depending on the type of transplant, may consume one's daily living for an extended time. Families may be subjected to intense emotions and challenges in the wake of BMT. Treatment may require lengthy stays at a specialized care center hundreds of miles from home. Families often face financial hardship as careers are put on hold and health care costs accumulate. Many caregivers struggle to balance caring for the survivor with raising children and tending to the household. The caregiving role is not a

casual responsibility. It is a serious and ongoing promise. BMT caregivers may “wear the hat” of coach, nurse, nutritionist, companion, aid, driver, administrative assistant, spiritual counselor, advocate, and more. They may be signing on for weeks, months or even years of duty. It can be a sobering challenge and responsibility but clearly one worth the effort.

With regard to the long term picture, BMT family caregivers may continue to feel the impact of the cancer/BMT for months or years after the active caregiving stage is over. Although most are remarkably resilient, a substantial minority continue to be negatively impacted by the personal, family, and life changes that occur. Studies have shown that approximately 20% of BMT spouses report symptoms of depression many years after BMT. Many feel lonely with limited social support for themselves and describe fewer of the positive changes, such as new life meaning or personal growth, which many BMT survivors describe. It is important that BMT caregivers be aware that, like BMT survivors, they may experience long term “side effects” of the experience and should seek the help and support that they need and deserve.

In creating this booklet, we hope to address the educational and emotional needs of BMT caregivers to help them successfully cope with their caregiving journey and to know that they are not alone.

Through this publication, we hope to:

- Elevate and legitimize the role of the caregiver.
- Encourage interventions that permit the BMT caregiver to participate as a member of the health care team.
- Encourage family members, friends, and the community to support the caregiver’s efforts and provide some release from daily responsibilities.
- Empower caregivers to seek psychological counseling for themselves when needed. It is a sign of strength, not weakness to ask for help.
- Encourage caregivers to utilize community resources for educational and emotional support.
- Educate caregivers as to why it is vital to take good care of themselves.
- Recognize the potential rewards of the caregiver role in terms of personal growth, family cohesion, and a new appreciation for life.
- Reinforce the fact that caregivers are not alone in their circumstances.

While BMT patients may follow an arduous road to recovery, BMT caregivers walk a parallel path with their own set of unique challenges. With this booklet of practical perspectives, we hope we have made the caregiver journey an easier one.

# My Gift to Mom for Her Second Birthday

## An Adult Daughter's Perspective

by Erin Gentry



*Erin Gentry was the primary caregiver for her mother, Martha, during her autologous stem cell transplant for non-Hodgkin's lymphoma at the University of Nebraska Medical Center in Omaha in 2004. She currently resides in Durham, NC and very much hopes that by the time you are reading this, she will have completed her PhD in English. Her caregiving experience has changed her life in many ways: she has become a regular platelet donor; she ran a half-marathon as a fundraiser for The Leukemia & Lymphoma Society; and she is the recipient of a beautiful gift of perspective that regularly reminds her how wonderfully lucky she*

*is to have her mother, alive and healthy, in her life.*

I had just started my third year of graduate school when my mother was diagnosed with Diffuse Large B-Cell Lymphoma and a tumor in her abdomen the size of a grapefruit. My mom and I have always been intensely close, and being 1200 miles away as she experienced the repeatedly disappointing results of three increasingly aggressive chemo protocols was, well, gut-wrenching. My first response was to join the National Marrow Donor Program Registry and to cut my long hair and donate it to Locks of Love to be made into a wig for someone; but I was having a hard time just getting out of bed in the mornings because I felt so frustratingly helpless. When the stem cell transplant loomed on the horizon, there was some question as to who would be the primary caregiver. I certainly had the most flexible schedule in my family, and it was with great relief at finally being able to DO something that I took a leave of absence from school and moved back home to Nebraska for four months.

As grateful as my mom was that I could be her caregiver, it was not an easy thing for her—or any parent—to accept. Parents want to do the caregiving, and they want to make things *easier* and *better* for their children. My mother felt guilty about “uprooting” my life. It took some time for her to be able to accept that—emotionally—I needed to

be there just as much as she needed me there. And let's face it: as soon as the diagnosis of "Cancer" is made, everyone's life gets "uprooted" as plans change and priorities dramatically shift.

Caregiving for a transplant patient disrupts the rhythms of your normal life, substituting doctors' appointments, blood draws and medication schedules. Time is a funny thing in the transplant world. It is what you are fighting so desperately for more of, and yet what often passes monotonously in waiting rooms in anticipation of the next set of "results." But time is all about how you choose to fill it. Mom and I carried a favorite word game with us wherever we went (mom still claims it helped with "chemo brain"! ) to fill in those waiting spaces. And since both of us are workaholics at heart, we unexpectedly found ourselves with time for leisurely conversations and with bonafide excuses to "goof off" in whatever ways we could invent. We had the kind of time to spend together that grown children and their parents rarely get. Despite the hard, scary and ugly moments, we both remember this time as one of the greatest gifts the transplant process gave us. (Yes, it does give gifts!)

But, along with the gifts, there were most definitely, hard, scary and ugly moments, all requiring different sorts of coping. One of the hardest things for me was my mom's need to talk about death. People cope with the ever-present specter of death in different ways. My mom, the scientist, needed to face it openly and talk about contingencies, and she needed to know that if it came time, I would let her go. I felt my job as a caregiver was to revive her spirits when they flagged, to cheerlead, to help her fight the fight, and it was hard not to feel failure and despair when my mom talked about her death. But I learned that being able to talk about death was just as much a part of caregiving for my mom as crusading against it. We compromised: I promised I would let her go if it came time, as long as she promised she would fight her hardest until that time came.

The scary moments were of the mind-numbing "this can't really be happening" variety. It was frightening enough that they predicted a 15% chance of success going into the transplant due to her tumor's classification as "chemoresistant." But it was utterly terrifying when mom ran a dangerously high fever for several days, when her lungs filled with fluid, and when her heart rate soared off the charts. Most of all, it was when she stopped being "mom." The full impact of our role-reversal didn't hit me until she was so sick that I was no longer just holding her up but was shouldering the decision-making without her input.

During those early post-transplant days, I wondered if I would ever see "mom" again. Those were the lowest days, the kind that had me asking if I was strong enough for this. I was. And I promise, you are, too. Whether you call on faith, on hope or on will, you will find it there when you need it most. And never stop believing. My mother—who bounced back from heart failure in a matter of days and is nearing three years in remission—is proof that statistics are only numbers.

Sometimes it was difficult for me to cope with my own feelings. I felt frustrated, angry, helpless, sorry for myself, then guilty about having any of these feelings in the first place. I was very blessed not to have a job at risk, or a family of my own needing care, and was additionally blessed that my stepfather was also there to provide caregiving respite and to handle all the financial matters. Most people caregiving for a parent have many more needs to juggle and sacrifices to make. Yet, even in my situation, caregiving had its strains, and I had to learn the importance of taking time off and taking care of myself. I still felt guilt: after all, my mom couldn't ever take "time off" from having cancer! But by allowing myself time to visit old friends or catch a movie—and in so doing, to re-gather my spirits and relieve my frustrations—I was being the very best caregiver I could be. As selfish as it sounds, caregivers need to put themselves first sometimes. And they need their own caregivers, especially someone who is wholly invested in their well-being (as opposed to the patient's), someone to whom they can admit all their frustrations without fear of judgment and who can remind them to take time for themselves. Support groups, and even other caregivers, can be great sources for letting off steam; just make sure you have *someone*!

Beyond helping with medications, meals, etc., and keeping that ever-important notebook of details and questions, I found there were other ways I could make a significant difference for my mom's experience. One such way was in keeping friends and family updated on my mom's progress. We found an online blog (we used [livejournal.com](http://livejournal.com), but [caringbridge.org](http://caringbridge.org) is another great, free site) where we could post daily updates and visitors could leave comments, the most efficient and easiest way to do this. I could also help by supporting my mom as she searched for meaning in this journey (her way of answering the "why me?" question). For my mom, that meant giving back and making something beautiful out of the experience and wisdom she was gaining.

To this day, when my mom reads back over our "livejournal" of the transplant experience, she is shocked by many of the entries I wrote during her sickest moments. The details are wholly unfamiliar to her; she simply has no recollection of them. This is the best gift I can offer to any of you embarking as caregivers on the transplant journey: those days when your loved one is in the most pain, is the most miserable, and you ache the most for them... these are the days they are least likely to remember. It truly is a second birthday for them, and you, too, one day farther along in the healing process, may be able to look back on the experience not with memories of the struggle, but with joy and thanks for the new life it enabled.

# Tackling the Challenge

## Caregiving from a Husband's Perspective

by Chris Johnson



*Chris Johnson assumed the role of primary caregiver for his wife, Sheryl, when she was told that an autologous stem cell transplant would be the treatment of choice for her breast cancer. (Please note that although stem cell transplant is no longer commonly used for the treatment of breast cancer, the caregiving perspectives in this chapter are nevertheless valuable.) In addition to caring for Sheryl, he also managed parenting responsibilities for their two teenage children. Chris is an attorney and works as General Motors North America Vice President and General Counsel. He is a graduate of West Point*

*and served in the U.S. Army receiving the Army Commendation Medal for Meritorious Service.*

### ***“You have Cancer.”***

**W**hen you first heard those words come out of the doctor’s mouth concerning your spouse, child, parent, or loved one, you probably marked it as one of those days when your life changed forever. Although not the patient, I abruptly moved into a world where I did not speak the language, often felt overwhelmed by the number of decisions to be made, and within a short time, assumed a full schedule as primary caregiver.

After 25 years of marriage, I felt a wide range of emotions. Among these strong feelings, I experienced a huge sense of loss of control. One close friend said, “I feel like our lives have been hijacked.” At the highest level, it goes to loss of control over your destiny. At the most basic level, it goes to what you can eat, drink, and think about day and night. The difficulty and strain of dealing with many of the medical treatments is woven throughout all of the experience.

One of the most promising, as well as challenging treatments for selected cancers and other diseases is a bone marrow/stem cell transplant (BMT). When my wife and I first

heard the diagnosis and treatment options for her, we almost fell out of our chairs! BMT is a demanding treatment, but it offered us hope. Still, there is, with a BMT, like other treatments, that loss of control. It included an extended hospital stay and convalescent period among many other inconveniences that accompany the procedure.

The one positive aspect of a BMT that stood out in my mind was that the patient needs a caregiver. In our case, that was going to be my role. You might question, “Why is that such a good thing?” My immediate answer—it gave me back some of what I felt was lost when we heard that dreaded diagnosis. I was gifted back some personal control over the situation. For the first time since my wife had been diagnosed with cancer, some two years prior, I played a clear and defined role in her treatment. I was to be an important part of this experience. No longer was I just a bystander. No longer was I just a conduit to the nurse or doctor, but rather, I was an integral part of the team. That made me personally feel that I had some control over this “thing” that had taken possession of our lives.

Being on this BMT team comes with a lot of responsibility, and it takes time, courage, stamina, and everything else you have needed to tackle other life challenges. As I think back, I never thought I would find anything that could compare remotely to my plebe year at West Point, or negotiating the “deal of the century” as a successful corporate lawyer, but this BMT experience put all of that to shame. It was, and will remain, the challenge of my lifetime.

I moved into the role of caregiver with gusto. I was empowered being able to serve my wife in this manner. Of course, I had the same emotional concerns as many caregivers. I sometimes felt that strange sense of guilt of being in a hospital and being healthy. It is naturally difficult, sometimes beyond words, to watch your loved one feeling so desperately ill. You, as a caregiver, may wonder, as I did, if you are up for this momentous challenge. Believe me, you are.

What I can recommend to you from my own experience is a playbook, of sorts, just like a football player or coach relies on in sports. Knowing what “plays” you can call and ones that you cannot becomes valuable. It helped me immeasurably to have a flexible “game plan” regarding my caregiving role. An organized notebook is a must! It might include a general written outline that captures everything from medical concerns and questions to keeping a journal recording the emotional journey your patient is taking. I kept track of some special needs including financial issues that arose during the BMT.

It is easy for caregivers, as well as the patient, to experience “information overload” given the circumstances of a BMT. There is plenty of information to track. Being organized was made simplest for me with a caregiver’s notebook. Included in the notebook were calendar pages that permitted entries. It will become, as it did for me, a valued tool. I could, when my mind was “too crowded” with details or the constant flow of information, always refer back to my notebook for reinforcement. Create your

own notebook or purchase one at a bookstore. You can also look online for special caregiver notebooks.

The BMT spousal caregiver experience is, without doubt, the challenge of a lifetime. Being organized, “in control” as much as is possible, and ready to be a team player will serve you well.

---

≈

# Cancer Etiquette

## *A Survivor's Perspective on Effective Communication*



by Rosanne Kalick



*Rosanne Kalick, MA, MLS, is a two-time cancer survivor. She was diagnosed with multiple myeloma in 1993, had two stem cell transplants and has been in partial remission ever since. In 2000, she was diagnosed with breast cancer which was treated by a double mastectomy and chemotherapy. Rosanne was a high school English teacher and then became a college librarian and chairperson of the Library and Learning Resource Center at Westchester Community College in Valhalla, New York. After retiring, she began work on her book, "Cancer Etiquette: What to*

*Say; What to Do When Someone You Know or Love Has Cancer." Her research, her volunteer work, and her five grandchildren keep her out of trouble.*

### **The Words**

**E**tiquette books abound. You can learn how to fold napkins, what to wear on the golf course, how to behave in a church where the rituals are new to you. We want to say and do the right thing. We look for standards for our behavior. When it comes to cancer, however, we have few guidelines. Too often our emotions take over, and we say or do the inappropriate thing.

Years ago we spoke in whispers about cancer, and there was little we could do as friends, family, or colleagues. Today we speak openly about the disease, and there is much we can do to communicate more compassionately. Words and deeds are powerful.

Often people say the most damaging words during the period just after diagnosis. The shock, memories of family members who had cancer, the individual's fear of getting cancer cause him to speak before he's thought of the consequences of his words.

One young woman diagnosed with breast cancer received a sympathy card from her mother. A casual acquaintance asked someone who had a colostomy whether the bags

were paper or plastic. At a luncheon, one woman turned to another and told her not to touch the glass of another guest because “she has cancer.”

Those are examples of words said, words that hurt. There are many, many others. If we begin to think in terms of cancer etiquette, we are less likely to err in our words. “Do I really need to say this?” or “What would I want someone to say to me?” may prevent verbal errors.

It is not uncommon for someone to say to the patient, “You will be fine.” Of course, you want everything to be fine, so does the patient. By saying that, however, you’re ignoring cancer reality. The high dose chemotherapy in the bone marrow transplant process and the threat of infection are part of that reality. While the transplant success rate is good, there are likely to be setbacks along the way. That is part of the process. Saying “I hope everything will be all right” or “You’re in an excellent program; you’ll be getting excellent care,” are better choices. The patient is facing the greatest medical challenge of his or her life. Your saying everything will be fine doesn’t give the patient any “wiggle” room. How can he or she speak to you openly unless you are realistic about the medical situation? This is true of most of our questions and words. Always leave the door to communication open so that the patient can be honest, can raise issues of concern to him, can speak of his anger, his fears, his family concerns.

“How are you?” Usually we’re expected to give the standard, “OK, fine or great.” The question and the response aren’t taken too seriously. It’s part of the daily exchange of words. In the cancer scenario, however, that question is significant. If you’re going to ask this or any other question, be prepared for the answer. It may be better to say, “How are you today?” The patient can then speak honestly of how he feels at the moment. He can speak of how he feels today compared to yesterday.

Be careful, too, about commenting on how the patient looks. Don’t tell the patient how great he looks. The transplant patient will not look great much of the time. He knows that. Saying, “You’re looking stronger” or “I’m glad to see you’re walking around” are better choices. There are two areas that are particularly sensitive. Hair loss is one. High dose chemotherapy causes the patient to lose his hair. Eyebrows, eyelashes, and pubic hair can disappear. It will be months before hair growth returns. Seeing oneself bald every day isn’t easy. Don’t ask how it feels to be bald.

If the patient should make a comment such as, “I’m really worried about dying,” and you respond, “You’re not going to die,” again, you may be “clogging a verbal artery.” The patient wants to live. She wants to live to see her children grow up. He wants to live long enough to meet his grandchildren. Fears about death, pain, finances, permanent damage to the immune system are natural for the transplant patient. Your responsibility as caregiver, friend, family member, or colleague is to listen. Listening totally, listening without interrupting the patient, listening without planning your response will be extremely helpful.

If you're a close family member or friend, probably the most important words you can say are, "I love you." Joseph Telushkin tells the story of an old man whose wife had just died. The scene is the cemetery. All the guests have left, and only the man and the rabbi are present. The old man keeps repeating, "I loved my wife, I loved my wife" again and again. The rabbi keeps telling the old man that it is time to go. The old man finally says, "But you don't understand. I loved my wife, and once I almost told her." During the long transplant period, the two greatest gifts you can give will be your presence and your words of love. Never underestimate the power of a hug, the power of silence, the power of a touch.

Don't ask questions now that you wouldn't have asked before the diagnosis. If you discussed your sex life with the patient before his treatment, fine. However, just because your uncle has had prostate surgery doesn't give you permission to ask about impotence now. If you talked about problems with your teenage daughter before the patient started treatment, you can do so now. If the patient is too tired, she can ask that you talk about it some other time. If you value your friend's advice about business, you can still ask for it. The fact that he's having treatment doesn't mean he is any less intelligent than he was before. There may be times when the drugs will give him a sense of "chemo brain." Obviously if he seems disoriented or excessively fatigued, postpone the question. When in doubt about what to say, don't say it. Think before you speak.

Equally personal is the faith question. Again, if you've discussed faith with the patient before her illness, it's probably all right to discuss it now. It's best to wait for the patient to raise the issue. If you have strong religious views, and you're not sure of the patient's, don't speak about how faith will heal. You may be intruding into an area that is too difficult for the patient at this time.

Generally, your presence is more important than your words. In our society, we seem to think we need to talk whenever we're with someone. There will be times when silence may be the best connector.

### ***The Deeds***

"If you need me, I'm here." "If you need anything, just call." Variations on these words are common. There are better ways to offer help. Be specific. "Do you want me to bring dinner on Tuesday or Thursday? Do the kids prefer chicken wings or roast chicken?" "I'm going to the library tomorrow. I can return your library books and pick up picture books for the kids."

Patients undergoing a transplant may feel their life is out of control. Anything you can say or do to restore a sense of control is good. That's why asking rather than telling works. It gives the patient a chance to make a decision, to assert control. Specific areas of help include planning schedules for carpooling, travel (especially important if the patient is being treated at a cancer center far from home), arranging food shopping and preparation. Remember, bringing dinner means cleaning up as well. Often two or more people need to coordinate these schedules.

Here are some guidelines for gifts:

- Buy pajamas or nightgowns that open in the front. This makes it easier in terms of the catheters the transplant patient has.
- Moisturizers are good, but no gift should be heavily scented. Strong smells can add to the patient's discomfort.
- Snacks can be great. The patient's appetite will need stimulation. Providing the doctor approves, almost anything that the patient enjoys is acceptable. Ice cream in the morning? Why not? Interesting teas, nutritional home shakes, and hot chocolate may stimulate a weak appetite.
- Bring CD's or books that are short and light.
- Consider a magazine subscription for the patient or her children.
- Give a gift certificate for dinner or a manicure/pedicure, a day at the spa, or a cleaning service for one day.
- A gift to a cancer organization honoring the patient is appreciated.
- During the neutrapenic period, do **not** give gifts of flowers or certain fresh food.

The patient will be undergoing treatment for several months. One card or one casserole will not do the trick. E-mails, notes, jokes, videotapes, computer games are all good possibilities. Remember the caregiver with small gifts. Plan for the long haul. Work in community. Your neighbors, church or synagogue, or office mates can collectively do more as a group than you can as an individual.

If there is a mantra for cancer etiquette it is "Stay connected; stay connected; stay connected." You'd be surprised at how many people "disappear" when someone gets cancer. Understand that you won't be able to do everything, but you can do something. Cancer etiquette is like a puzzle. What will fit one moment won't the next. Just keep trying. You can do it!

≈

# Top Tips for Parent Caregivers During the BMT Process

## Caregiving from a Mother's Perspective



by Melanie Goldish



*Melanie Goldish, MA, is the mother of a bone marrow transplant survivor. In May 1998, her five year old son Travis was diagnosed with Acute Lymphoblastic Leukemia (Philadelphia Chromosome). Travis received an unrelated marrow donor transplant in September 1998 from their "hero" donor Marj. Melanie is the Executive*

*Director of SuperSibs!—a nonprofit organization to honor, support and recognize siblings of children diagnosed with cancer ([www.supersibs.org](http://www.supersibs.org)). She also serves on the National Marrow Donor Program Board of Directors and The Marrow Foundation Advisory Board. She holds a Master of Arts degree from the University of Minnesota and is the proud mother of two miracle sons, Travis and Spencer.*

**A**s a parent who was instantly transformed from a typical devoted and loving, working mother to a “BMT Mom,” I learned firsthand about the immense multi-tasking and perseverance required to manage through the emotionally and physically draining transplant journey. On its own, parenting is a formidable task. Parenting, self-care, and caregiving for a child before, during and after his transplant is a huge endeavor—one that requires more than a single individual can ever manage alone. Fortunately, many parents have blazed this trail with positive outcomes and shared their experiences so that others may benefit. In the end, this journey will hopefully leave us all with a lasting legacy of better parenting, a solid outlook, powerful perspective, and a

healthy, strong family as a result of this lifesaving transplant procedure.

Everyone's situation and experience with transplant is unique—so some suggestions may be more applicable to you than others. When reviewing the following tips, use what works best for you.

## **1. Remember The Power of Choice**

*For You...*

As difficult as it is, the quicker we can snap ourselves into reality of “what is”—what we're dealing with—the better we can focus our energy, resources, and creativity to decide on the best course of action for our child and family. We can't choose the fact that this “event” has happened—that our child needs a transplant; that this is “happening to us”—yet we CAN choose how to respond. This is a powerful principle to help pull you and your child through the many difficult hours, days, and treatments ahead. So give yourself permission to choose, whenever possible. Choose to talk with friends about how you're feeling. Choose to take a break to collect your thoughts alone, and enjoy a cup of coffee. Choose to join a support group or listserve online. Choose to see a therapist. Choose to focus on the positive, versus the energy-draining “victim mentality” that can be so seductive. Choose to be an involved and informed parent through the transplant process. Choose to cry if you need to—then choose to “get up and keep going.” Choose to explore all available support options at work. Choose whatever works for you. This is where you do have control—in how to respond to this life-challenging event. We can each choose how to respond for ourselves in a way that will best meet our unique individual and family needs.

*For Children (Patient and Siblings)...*

The power of choice is just as strong for our children facing transplant—and their siblings. Sometimes, the options aren't as exciting as our kids would prefer, yet having choices in a situation that feels so totally out of their control can be helpful. Whenever possible, offer choices to your children. Let them be in the “driver's seat” with clear options such as: Would you like to leave now or in 10 minutes? Which leg should get the “poke” (shot)—right or left? Do you want a chocolate malted or a strawberry sundae? Would you like to help arrange the dressing change supplies or have me do that today? While in some situations there may seem to be no options available, try to creatively offer some choices. For example, it may be an absolute that your child must take Cyclosporine medication each day. Perhaps offering your child the option of taking it with chocolate milk or root beer soda will help him be a more willing participant. Even these seemingly small choices give some semblance of “control” in a world where so much seems to happen “to” your child. Choice is the ultimate freedom. Both you and your children may benefit greatly from this approach.

## **2. Take a Deep Breath and Seek Support...**

While many of our friends and neighbors may offer support on a one-time basis or even a few occasions, it often quickly becomes a harsh reality that most return to

their own daily lives. Therefore, it becomes vital to reach out for help. And yes, that means we need to ASK. Waiting for the right offers may be...well, a long wait! While we may feel alone in this journey, with few friends or committed helpers, ongoing support can be found through many sources. Check out religious and worship centers, religious groups' Caring Community Committees, your children's school parent organizations, their teachers and classmates' families, a special task force at work, not-for-profit organizations such as the National Marrow Donor Program, Office of Patient Advocacy, National Bone Marrow Transplant Link, The Marrow Foundation, Make-A-Wish Foundation, Ronald McDonald House Charities, and neighborhood outreach groups. Rely on the expertise of your hospital's transplant coordinator and social service team. And don't forget your own family members. Many extended family members have been known to say after transplant, "I didn't know how to help and didn't want to be in the way. I just wish they'd have asked." The key is to ask for help and enlist as many people as possible to share the support opportunities.

### **...And Then Accept This Support—Without Guilt!**

As parents, we have been thrust into this terrifying world with no warning and no preparation. We may be entrenched in the cultural norm of "I'd rather give support to others than accept it myself." Quickly, let go of that belief and accept the caring of others graciously and without guilt. Everyone needs help at some time or another. Now it's your turn. There's no question about it—no parent caregiver can muddle through this tremendous transplant challenge alone. So after you've asked for help, accept it. Save that energy for focusing on your task—bringing home a healthy child with you and your family intact, to life beyond transplant.

One way many caregivers clear the self-imposed barrier of accepting support is by making a personal commitment to provide help to others in the future—to continue the cycle of giving. This may be the key to giving yourself permission to ask for and then accept available support on an ongoing basis. As a wise person once bluntly said to me, "How dare you deprive us of the only thing we can do to help? PLEASE allow us to help you with meals, lawn mowing, pampering, carpooling, gifts, fundraising and public support. It's all we CAN do. It makes us feel good. And who knows? We may need your help one day, too. Please don't shut us out." With that understanding, it may become easier to accept support from friends, neighbors, and even strangers. Remember how good YOU feel when others accept your help? Offer that same gift to those around you. Accepting support helps others as much as it helps you—maybe even more

### **3. Focus On What's Important**

After transplant, many parent caregivers are greeted with awe and feedback from others as if they'd performed a superhuman feat. While it's a challenge to undergo transplant oneself, it's another thing entirely to manage the transplant process for a child who needs our undivided attention as well as a family that craves our participation, love, and care. One way to juggle this load of stress, strain, and pressure is to

peel away what's unimportant—at least for the immediate time. The most effective way to manage through transplant with and for our children is to use an ever-present filter of “Is this really important right now?” This “decision-making sieve” will allow you to preserve your attention and strength—and focus that energy where it's needed. Some things, like paying bills, must be attended to in a timely basis. Other chores can be prioritized as a back-burner task. We can only spread ourselves so thin without breaking—so why not spend our attention and energies on our most urgent short and long-term needs? Focus on what's really important and jettison the rest.

#### **4. This Is Important—You Come First!**

There's a very sensible reason why, in their safety briefings prior to takeoff, flight attendants tell parents, “In the case of a loss of pressure, oxygen masks will drop down. Put on YOUR mask first. THEN apply your child's mask and attend to their needs.” This principle applies to us—the transplant parent caregivers—as well. We certainly can't attend to our child's needs unless we've taken care of ourselves well enough to do so. What may seem like a luxury to you in the scheme of the transplant experience may actually be a necessity to ensure you will be as effective as possible in this role. Let go of the guilt. Here are some reminders of how this works:

- ***Just Say No***

Let go of the need to please others. If answering the phone's incessant ring is draining, unplug the phone during certain hours. If a procedure is scheduled for your child at a time when it's most difficult for you, ask if an alternative time is possible. Often, we accept what others impose upon us—at greater consequence to ourselves and our families. (If you've forgotten already, go back to the principle above—focus on what's important.) Right now, the health and survival of your child and family is job #1. Being a pleasant hostess, excellent committee member, or super work performer can wait until another day.

- ***Remember Your Identity***

Somehow, between the incessant pumps beeping in the hospital room, your three changes of clothes you rotate wearing in the hospital room, and the constant concern about your child's “counts,” it dawns on transplant parent caregivers that their name has become solely “Mom” or “Dad.” (With so many transplant families in and out of the units, most nurses and doctors refer to the generic parent name for everyone!) As strange as it sounds, after rotating night after night in a hospital room or nearby residence, we caregivers can begin to lose a sense of our own identity. Ask friends to remind you what it is that you do well. Ask them to regale you with stories “from the outside.” Read books or magazines that stimulate your special interests during the frequent five-minute quiet breaks. A little personal pampering can go a long way to stay grounded—whether it's a special soft music tape to take you “away” now and then or a special robe to wear in the hospital, find ways to honor yourself. Yes, you're an individual that needs to have nurturing, too.

- ***Preserve The Journey And Life Lessons***

Many parents find it a healthy catharsis to journal their thoughts, emotions and experiences during and after their child's transplant. Bring a laptop or write in a journal to preserve your experience—or use free communication web pages like [www.caringbridge.org](http://www.caringbridge.org) and [www.carepages.com](http://www.carepages.com) to help family and friends stay connected with you. While “chemo brain” seems to be a phrase used by transplant patients themselves, it's also common for parent caregivers to get so sleep deprived that all details get muddled. Many of these memories may be best left on pages unread by anyone other than you—but you won't know this until months or years later. So record this information now as a remembrance for yourself—and perhaps your child and others—in the years to come.

- ***Speak Up!***

Find ways to connect with your friends and loved ones that will squeeze within your child's busy hospital routine. Perhaps schedule a nightly online chat group for your closest buddies to catch up on the day's progress and some distracting cyber-laugh that they can bring. Then type like wildfire and enjoy the “company” during the dark and quiet hours between treatments. People want to know how things are going in the isolated world of transplant. While it's a tremendously personal experience for parent and child, often sharing these thoughts on a special Web site for your child, in a group “e-mail blast” or home voicemail message can be a wonderful way to help others feel engaged and for you to feel supported.

- ***You Deserve Better Than Table Scraps***

OK, be honest. How many peanut butter and jelly sandwich crusts have you ingested by the time you've read this paragraph? How many of your child's unconsumed hospital food tray choices have you polished off “because it's there and it saves a trip to the cafeteria.” Healthy food for you means more energy. Get rest when you can. Even squeeze in a brisk walk or run now and then. And eat from the healthy food groups—now, more than ever!

- ***Go With A Pro***

It's OK to seek support from a professional counselor or therapist. For those of you who need to read this twice, yes, it's OK! Many parent caregivers mistakenly feel that choosing to seek outside support is a sign of weakness. On the contrary, it takes a strong individual to know when outside help can be valuable. Your caregiving style may be vastly different than that of your spouse. You may now be facing strains on your marriage that seemed inconceivable before stepping into the “transplant world.” You may not understand your own reactions, moods, behaviors, fears or decisions. You may be stumped by the mood and energy swings coming from “the child you knew so well” who is undergoing transplant and feeling the effects of steroids, chemo and radiation. You may experience issues with your other children or family members that are difficult to manage, on top of all the

other strains you're experiencing. All these issues are legitimate—and they are vital to acknowledge and work through. Search for a professional that has experience in dealing with childhood illness and/or family/marriage therapy. Or better yet, ask a trusted friend or workplace Employee Assistance Program (a confidential service often a part of your employee benefits program) professional to do homework for you to select the right counselor(s). Having a skilled and caring professional to listen to your thoughts can provide release, peace, and clarity that will reap rewards for years to come.

### **5. Do Your Homework, Trust Your Gut, and Don't Look Back**

Take advantage of the many resources available to you. Ask questions of your child's medical team, social worker, nutritionist, and child-life specialists. Read research studies on transplant procedures. View support tapes, such as nbmtLINK's award-winning video *The New Normal*, addressing life after transplant. Choose your transplant team and hospital according to criteria that's most important to your child's diagnosis and your family's particular needs. Use Internet search engines such as Yahoo or Google to find support group links, specialty organizations, listserves, Web sites for your child's diagnosis, and even other families who have traveled this journey. Because not all information is credible, be discriminating with what you learn and discard that which doesn't add value. And as you make each decision, trust your intent that you've made the best possible decision, with information available at the time—then go with your gut decisions, and don't waste precious emotional energy on "Why did I do this?" questioning. You will face many decisions along the transplant journey with your child—and multiple course corrections along the way. Give yourself credit for doing the best you can, each step of the way.

### **6. Bring Out the Child In YOU**

During the long, challenging, frightening and often boring hours—before, during and after the actual transplant—your creativity may be tested to its limits. Sometimes, our own playfulness can be the best healing therapy for our children as well as ourselves. So why not allow your child to "tie you up with the Velcro straps" on the empty gurney while you wait for a delayed MRI? Why not bring a book of jokes to prompt silly giggles while you try not to think about the bone marrow aspiration yet to come? Why not invent a treasure hunt in your child's hospital room or use approved window "paints" to decorate your surroundings together? Why not learn a new craft with your teenaged patient during these focused hours? Whatever works for you, your child, or your family—try out new alternatives. Pull out all the stops, and don't be embarrassed at your need to bring laughter, joy, fun, and creativity into this scary world. You'll be amazed at some of the beautiful moments to treasure as you and your child look back at "those days during transplant."

### **7. Look for Beauty**

It's a bold statement to suggest that beauty can be found anywhere near your child's transplant procedure. Yet, many transplant parent caregivers have expressed the

feelings that even amidst the biggest nightmare of their lives, moments of rare beauty have pulled them through. Take a moment to appreciate the cocoon of support that's been blanketed around you, your child, and family. Send thoughts of support or prayers in honor of your child's amazing donor—for the miracle of life this person has provided your child and family. Think about the advances in medicine, and consider the professional support team that has made this day possible. Appreciate the uninterrupted moments of cuddling in your child's hospital bed, giggling over a story together. Be aware that this journey has brought you a rare glimpse of what's really important in life—an insight that many people never get. At times, these beautiful moments may be all that pulls you through one more medicine pump beep in the middle of the night. Seek and acknowledge these treasures.

### **8. Be Your Child's Advocate**

On a very practical level, be aware that you are the best advocate for your child. Don't be shy about asking question after question of the medical team. You are a part of that team—for and with your child. Don't be afraid to challenge decisions that you don't quite understand or agree with—and then do calmly work out an amicable solution together with the medical team and your child. Document everything! One would think that the medical pros will have it all handled, but we're all human and everyone makes mistakes. Also, your child's team (including perhaps you and your family) operates in shifts, so effective transfer of information is critical. You may never need to re-read all these details, yet from time to time, the notes you've kept will be the vital information necessary to determine next steps. Attend the "rounds" meetings each day regarding your child. Typically, the physician and team will gather together in or outside your child's room to discuss clinical progress, challenges, and courses of action. It is in your child's best interest to listen, learn, and participate in these briefings. Don't be shy about being present. And lastly, remember to solicit your child's input and feedback. Many transplant children feel tremendous frustration that they're constantly being talked "around," rather than being invited to share a comment. YOU can be that advocate to ensure that your child's voice and needs are heard.

### **9. See Through A Child's Eyes**

Look for ways to enhance your child's surroundings during the transplant experience (possibly months long). Bring her softest slippers or his favorite boxer shorts to wear in bed. Stick glow-in-the-dark stars on her hospital room ceiling. Bring a treasured picture to place on the wall near the radiation equipment, so he might be transported to his own happy world during those long moments of standing still through noise, nausea, and fear. Choose and rotate posters in her room. Hang letters and cards on a wall-to-wall string in the room. Write for your teen's favorite idols to send autographed pictures to display. Arrange for videotaped messages from friends, neighbors, and classmates to be made for your child. Borrow a laptop computer to go online and enjoy the many children's Web sites together. Bring decorations at eye level for your child. Make paper chains together to string throughout the room and add color

and cheer for you both. Bring soft and special blankets to comfort you AND your child. As sterile and scary as the room and hospital surroundings may seem to you, remember how your son or daughter perceives them—and then take steps to add delight to those surroundings.

## **10. Create Opportunities to Honor Siblings**

The unfortunate reality is that the transplant process affects siblings in very profound ways. Carve out precious moments for private time with you and your other children, one at a time. Finding time and energy isn't easy. Yet it is so important to be extra-vigilant attending to sibling's fears, questions, self-esteem, and needs. Take a daily 15-minute walk together. Somehow, being out of doors brings freedom to sharing thoughts, questions, and feelings. Perhaps schedule a nightly phone call to read a bedtime story together, or sing bedtime lullabies. Or choose a special recurring "date night" with an older child to have coffee and hot chocolate in the cafeteria. Ask questions like, "What's the hardest part of this experience for you?" "How can we help you feel special through all this?" And then listen to those feelings your child expresses. Just letting them know that you hear them—and honor their thoughts as valid—is sometimes enough to help siblings through their part of the transplant challenge. Create special moments to carve and strengthen a special relationship—and even lifelong memories—together.

### **• *Sibling Support From The Pro's***

Just as it's helpful for you to have professional support at times, so too can this be a lifeline for the siblings of your child undergoing transplant. Try to arrange for your child to visit with an experienced therapist (or "feelings doctor," as we called her) or hospital social worker on an occasional basis. Siblings need to know that their concerns and feelings are valid—and that it's safe to share their thoughts with someone who cares just about them and won't tell others about these private issues. Sometimes the child may feel guilt or anger about what's happening to their brother or sister—or tremendous frustration about how you have been consumed with the transplant process and their sibling. The best gift you can provide to this child is the safe, confidential, and caring environment to help him process through these conflicting and confusing feelings.

### **• *Encourage Happy Reminders***

Ask neighbors, friends, synagogue, church members, or schoolmates to send "happy cards" to your other children. While your child undergoing transplant may receive daily cards and gifts, it is difficult to watch their siblings race to the mailbox every day and return knowing that nothing is for them. Caring cards and letters can reinforce the feelings that these children are valued and special as well.

### **• *Siblings As Special Heroes***

Bestow a hero's title on these special siblings. While many people will praise the transplant child for being so brave and heroic—or fawn over a sibling

marrow/stem cell donor as being a special hero—often, the other siblings feel left by the wayside, having no special “role” or “value.” You can create a special designation for your other children: “Champion Hero” or “Life Hero.” We call them SuperSibs! Reinforce that this title holds important meaning as well—that the child is special just for being who she is. As well, these sibling heroes add true healing value—by their energy, support, sense of humor, reminders of stories, and “real” life outside the transplant world. Look this child in the eye and tell them sincerely and directly what makes them so very treasured and special to you. Do this often.

- ***Choose Your Words Carefully***

Many parents and professionals unfortunately use language that can become a lifelong wound for siblings whose marrow is not a perfect match for the brother or sister in need of a transplant. When parents and others say, “Steven didn’t match,” this can become a very challenging and negative imprint for that well sibling. This negative language is an inappropriate and far too heavy burden for siblings to carry the feeling that “I wasn’t a match.” Many siblings then feel like they weren’t good enough; they didn’t do enough; or that they failed in a life-threatening situation. Instead, parents (and transplant professionals) can use this more appropriate language:

**“When no one in the family was a close enough match...”**

This slight change in language can mean the world of difference for the self-esteem and emotional healing for siblings and even impact their lives going forward in a profoundly more positive way. It’s important to reinforce the concept: that the whole family is in this together—that “No one in our family was a match,” rather than the sense that “It was all up to you, and you didn’t match.”

**“And if there is a sibling match...”**

Remember that a sibling can feel a tremendous amount of pressure and responsibility if he’s called upon to donate marrow or stem cells for his brother or sister. Do make sure he’s informed about the process, in age-appropriate language and in ongoing conversations. Encourage him to ask questions and talk about how he feels to be a donor. If positioned that the survival of their sibling “depends on your stem cells or marrow,” this can feel overwhelming for a child. Rather, parents can position the sibling’s donation as a wonderful opportunity to help in a way that gives his brother or sister an even better chance for full health and recovery.

- ***Engage The Siblings***

Help siblings understand what’s going on around them, as appropriate to their level of maturity. Rather than shut the siblings out of appointments or hospital visits, help engage them in the healing process. Talk to the hospital transplant team about encouraging sibling visits as part of the healing process. Teach siblings the full hand-washing and anti-microbial cleaning procedures. Enlist their help in being vigilant—and even as the official reminders of others to do so. Older

siblings can take the lead on helping to flush lines or other procedures. Engage all your children in the hopes of life beyond transplant. If you are working with an organization to fulfill a special wish for your transplant child, include all of the siblings. The power of that wish for the future can be as strong for the siblings at home as it is for the child in the hospital.

• ***Recognize Sibling Uniqueness***

Just as you are more than “Mom” or “Dad,” so too is the sibling more than the transplant child’s “little/big brother/sister.” Encourage friends, family, neighbors, medical staff, school personnel, and others to refer to these siblings by THEIR names—not always in the context of the transplant child. Their identity is so important. While engaging the sibling in the transplant process is important, it should not be imposed or all-consuming, either. Plan for a flow of involvement, mixed with special interest and conversation about the sibling’s interests, hobbies and school performance. Whatever you and others can do to honor each sibling’s unique and non-transplant-related activities will be a strong foundation to support their “recovery” from this process.

**11. Fasten Your Seatbelt—Before, During, AND After**

A harsh reality that sets in for all transplant parent caregivers is that this is one, loooooooooooooooooooooooooooooong roller coaster ride. “Don’t get too excited during the highs, and don’t get too discouraged during the lows. Try to somehow manage in the middle.” Whatever that means, right? While many people (undergoing transplant or just observing from the “outside”) believe that after transplant and homecoming you’re “finally done,” it’s just not that simple. Particularly as parents of children who have undergone transplant, the job of caregiving can increase in intensity once the child is discharged from the hospital. Suddenly all that round-the-clock care that was provided in the hospital (sometimes to you, too!) is now all on your shoulders. Ordering supplies, changing dressings, administering meds, preparing food, transporting back and forth to clinic check-ups, dealing with setbacks, and managing household and family logistics is a huge undertaking. Being aware of this phase of the journey in advance may help as you wonder “Why isn’t this easier now that we’re home?”

***And AFTER Transplant?***

After the return home from months away during our son’s transplant, I recall heaving a sigh of relief, as if I’d held off a huge freight train with my arms locked in front of me. At that point, I apparently “let my arms down,” thinking the “train” was now gone. Somehow, I thought it disappeared after we’d left the hospital. Much to my surprise, the “freight train” ran me over—body and soul. I’d not realized or acknowledged how deeply the transplant process had drained my every source of strength, mentally and physically. In fact, some parent caregivers are officially diagnosed with Post-Traumatic Stress Syndrome as a result of this life challenge. This was true in my case. Through rest, proper nutrition, and excellent counseling, I was able to work through

this latest development. Another lesson I personally learned was that it became too difficult to be a primary caregiver for my children during the transplant process AND a working professional all at the same time. Some parents negotiate with their employers for a paid leave of absence (ideally, in a dream world) or vacation (sometimes with days donated by other colleagues), unpaid days off, or changed performance expectations to manage through the most difficult months. In my case, I qualified for Short Term Disability leave of absence, due to the official medical diagnosis of Post-Traumatic Stress Syndrome. While this would have never crossed my mind (I figured I would just have to quit), it became clear that the benefits coverage to which I was entitled did in fact apply. This may not be an option for many working parent caregivers, but the lesson learned is to consider all the options available and acknowledge the tremendous responsibility you have been shouldering. Use your support resources—and reframe your thinking from “When is this over?” to “Life after transplant” with greater insight and wisdom and commitment to self care.

### **12. Think Positive**

While there are moments during the transplant journey when we as parent caregivers feel “positively negative”—more often than not, a positive attitude can make a significant difference to pull our child and ourselves through the darkest moments. Find others who have successfully moved through and beyond transplant. These people can be powerful beacons of hope. One phrase that helped our family focus on the positive during even the most awful and blunt medical conversations was, “Even if the odds were 99:1, someone would have to be that ‘one.’ THAT’S going to be our child.” Another helpful thought: As a wise transplant patient once said, “I may have cancer, but cancer doesn’t have me.” This phrase applies to us as parents of children going through transplants as well. One thing I know for sure is that a positive attitude might help—and it surely won’t hurt. Envision life beyond transplant with something exciting to wish for and come true. Picture graduation or a special family trip together. Use that vision as a powerful draw to guide you through difficult moments and mood swings together. Then, when this day comes true for you, include your closest friends and family to celebrate the miracle of life together.

### **13. Give Forward**

One unexpected outcome of having experienced the transplant process with one’s child is the tremendous knowledge and experience you now carry. This insight can be of immense value to others not yet as far on this path as you, your child, and your family. Sharing these stories, information and lessons learned with school classes, public groups, news media, friends, and other patient families can help further the research support for marrow and stem cell transplantation. You may interest others to enter the National Marrow Donor Program Registry as a potential donor. You may help other families cope with challenging situations. Be available as a resource to parents, children, or organizations that may benefit from your unofficial “Transplant Graduate Degree.” Become involved in the organizations that helped save your child’s

life (and your sanity). Contribute to a special service at your house of worship—to celebrate life and honor those that are still facing the challenge of survival and cure. Bring your child back to visit the transplant wing of the hospital to thank the medical team for their hard work and caring—and to bring hope to them and others who are experiencing the transplant intensity. You can remind them that there is hope—that there is “life beyond transplant.” You can make a difference in the lives of others, and serve as a role model for your own children, by giving forward to others who may be in need—just as you and your family once were. Honor this gift of life with your caring and insights to enrich the lives of others.

≈  
*Another Way to Say  
I Love You*

*A Wife's Perspective*



by Kay Forsht



*Kay Forsht is a graduate of the University of Maryland who has been married to her husband, Woody, for 37 years. As the parents of a son and a daughter, they spent many years involved in school, church, and community activities. Being an only child, Kay first served in the role of advocate and secondary caregiver for her father for the 14 years after he suffered a stroke. However, none of this prepared her for Woody's diagnosis of AML and the responsibility of being the caregiver for a*

*bone marrow transplant patient. With their commitment to each other—and a lot of hope and optimism—they knew they could face this challenge together. Now, more than five years since Woody's successful transplant, Kay volunteers with the NMDP Office of Patient Advocacy, using her experiences to benefit other transplant patients and their families.*

**W**hen my husband, Woody, was diagnosed with acute myelogenous leukemia (AML) in late 1999, he was no stranger to life-threatening illness. In 1986, he had battled Hodgkin's Disease, which was successfully treated with extensive radiation therapy. With the leukemia diagnosis thirteen years later, it seemed like the past was once again colliding with an uncertain future.

Upon his leukemia diagnosis, Woody entered Johns Hopkins Hospital to begin induction chemotherapy. After one month, he was discharged. Following a six week rest at home, we again returned to the hospital for the second round—a month of consolidation chemo. Following this aggressive treatment regimen, my husband went into remission; sadly he relapsed six months later. When Woody's disease recurred, his doctors concluded that a bone marrow transplant was his best chance at long-term survival, and the search for a donor began.

Because Woody's sister was being treated for breast cancer and his brother was not a match, the doctors decided to conduct a search for a matching unrelated donor through the National Marrow Donor Program. While the search was underway, several of our friends organized and underwrote the expense of a community bone marrow drive. Over 150 people turned out to be tested and had their names added to the Registry. Though none of them were a match for Woody, a few have been contacted as potential donors for other patients. In raising awareness for our own plight, hopefully Woody and I have been able to help other patients who are struggling to find a donor.

A matching unrelated donor was eventually found, and Woody began preparing for a non-myeloablative (also known as a "reduced intensity") transplant. The reduced intensity regimen leaves some of the patient's immune cells intact so that the patient is not as susceptible to infection immediately after transplant. Also, since the chemotherapy isn't as intense, there is less chance that a patient undergoing a "reduced intensity" transplant will experience chemo-related toxicity.

Woody's transplant occurred at the Seattle Cancer Care Alliance on an outpatient basis, meaning that I, as his caregiver, had even more responsibilities throughout his recovery. When doctors told me that I would be playing this critical role in my husband's treatment, I initially felt overwhelmed and wasn't sure that I would be able to handle all that comes with caring for a transplant patient. As an only child and as a mother of two, I've had a lot of practice caring for others, but I had never administered an injection or cleaned a catheter. The hospital staff provided excellent educational materials to the families and friends of transplant patients to help us feel confident in our new role as caregivers. I feel strongly that by educating caregivers, the hospital staff empowers us and helps to create a sense of being in control of a chaotic situation.

I was also so thankful that I was not on my own in facing the challenges of being a caregiver. Our son was able to visit from California, and our daughter, now a licensed clinical social worker, was able to take three months off from graduate school to help care for her father. Kimberly stayed with us in Seattle and very willingly took on the responsibilities of being a second caregiver. Words cannot express what an incredible support both emotionally and physically this was to us. (Needless to say, I thoroughly enjoyed her companionship on our therapeutic shopping outings too!)

To adhere to a routine, Kim and I awoke each morning and got ready for the day just as though it were any other morning under less stressful circumstances. We found that dressing and putting on our make-up as if we were going out had a positive psychological effect on us as well as on Woody. Maintaining any small semblance of normalcy had a measurable impact on helping us feel more "like ourselves."

Woody was strictly monitored especially during those first 100 days. Almost daily there were doctors' visits or lab draws, multiple monitoring and charting of his tem-

perature, hooking up a two liter IV, giving two injections (Woody much preferred Kim's technique to mine!!!), and dispensing and recording of up to 45 pills which were very time sensitive (I frequently had a portable three function kitchen timer set and in my pocket).

After five months, Woody was discharged, and we were finally able to return home to the East Coast. This was wonderful news, but I was a bit anxious. We were no longer going to have around the clock access to an incredible transplant team who had "seen it all." However, we were returning to Woody's former oncologist at Hopkins who greeted us with open arms. Her compassion and commitment to treating Woody guided him to a milestone—the one year transplant anniversary.

After transplant, you define "normal" very differently. Woody has returned to his job, but has modified his schedule so that he can work from home two days a week. He still has to be very mindful of germs and take many precautions to avoid contracting infections. As a very friendly and extroverted professional, it has been hard for Woody not to shake hands with colleagues and acquaintances—a precaution he must take to avoid the spread of germs. To prevent possible infection, we now sit in the back pew at church, and Woody jokes that I have become quite the gentleman—always opening doors for him whenever we are out.

We frequently enjoy parties, weddings and dining out. I use a trick I learned from the hospital staff in determining whether a restaurant seems like a good choice for a transplant patient: I check the restrooms for cleanliness because a restaurant with clean bathrooms is likely to have a spotless kitchen! Woody participates in most activities and events that he enjoyed before his transplant; it just requires a bit of scheduling. He gets fatigued easily, so he is careful to pace himself and plan ahead for what he really wants to do so that he'll have sufficient stamina.

Even though he's again able to drive to work and appointments, I still accompany him to each doctor's visit because four ears are better than two. Throughout Woody's recovery, our relationship has remained strong, though not untested. He got frustrated at times and wanted to break the rules, but I refused to let him. Woody also occasionally felt irritated that I never felt comfortable leaving him by himself; I learned the hard way that things can happen very quickly. So initially, I insisted on waiting until our daughter could be there before going off to run errands. Looking back, Woody says that Kimberly and I probably had a harder time throughout his transplant experience than he did. We remember it all; medication blurred his memory! We were quite fortunate to have incredible support. Our family and friends kept in daily contact and even flew to Seattle to see us and lend a hand when Kimberly returned to school. My other "ace in the hole" was an old friend who had recently moved to the West Coast and became our guardian angel. Caring for Woody was really a team effort!

Since returning home, we've enjoyed some downtime and adapting to our new definition of "normal." Of course, there are many more doctor appointments than any of

our friends experience, but that is a small price to pay. Throughout everything, we've always been the best of friends. As my husband approaches his sixty-second birthday, we're looking forward to retirement and preparing for the future. While we still have many ups and downs, we view any challenge as the small cost of doing business.

Twenty-five years ago if this had been in my horoscope, I would have said I couldn't do it. Of course, I wish this had never happened to the person I love most, but I've been privileged to have the opportunity to witness Woody's strength, his hope, his faith, his courage, and his determination. Being his caregiver is really just another way to say to him, "I love you!"

---

≈

# Emotional Aspects of Caregiving

## *An Oncology Social Worker's Perspective*



by Linda Diaz



*Linda Diaz, LMSW, ACSW, is a national leader and lecturer in the field of oncology social work. For the past 23 years her primary focus has been on providing psychological counseling to cancer patients and their significant others. Linda has developed numerous support, education and complementary programs, which have been integrated into traditional medical care settings. She currently has a psychotherapy practice at the Birmingham Maple Clinic in Troy, Michigan.*

It is normal to have strong feelings when someone you love has been diagnosed with cancer, especially when their treatment includes a bone marrow transplant. Emotions, including sadness, anger, depression, and feeling generally overwhelmed, are common for caregivers going through this experience. Do not be critical of yourself when you feel strong emotions. Caring for a person who is seriously ill may challenge you in ways that are completely new.

Normal emotional reactions of caregivers vary dramatically from day to day. Patients embarking on the transplant process often describe their experience as an “emotional roller coaster.” This roller coaster has many passengers including caregivers. The ride can be intense, and you may find yourself wondering if it will ever be over.

### **Managing Feelings of Anger and Guilt**

Mary underwent a transplant in January, and her family was thrilled when she was finally discharged in February. Her husband, Paul was relieved that her blood counts were high enough to allow her to be home and that he no longer had to run between the hospital and his responsibilities with work, the children, and maintaining the house. The first week home Mary and Paul received lots of support from friends who brought in

meals and helped with the children. However, by week three, Mary was still resting for the majority of the day. Paul began to feel resentful and angry that all of his efforts to keep the ship afloat over the last several months were less often acknowledged by his wife. He was more than ready to have his normal life back. He was exhausted and began feeling trapped and angry.

Then Paul began feeling guilty about having such feelings; after all HIS WIFE WAS FIGHTING FOR HER LIFE! By judging his feelings as “right or wrong,” he was adding guilt to his long list of stresses. This self-criticism put an even greater burden on him and eventually on his family. One strategy is to acknowledge these uncomfortable feelings, perhaps to a trusted friend. This would enable him to receive support and perhaps gain perspective. Talking about these feelings may defuse his anger and sense of powerlessness. Emotional exhaustion for caregivers is a reality. Managing negative feelings becomes easier once they are acknowledged.

Caregivers often describe feeling overwhelmed with medical tasks. Caregivers must become familiar with medical terminology, such as the implications of lab results and blood counts. This is a lot of responsibility for a non-medical person. Try to organize your tasks by writing things down as they are explained to you.

People experiencing serious illness can sometimes become irrational with demands, ungrateful and irritable. Feeling anger is a normal response. Any two people spending a lot of time together may become agitated with one another. Getting a break, even for ten minutes is critical for both the patient and caregiver. It can be constructive to talk about the source of your tension. Such conversations are most productive if you enter into them when you are both reasonably rested and have had some cooling off time. Express your feeling in the least destructive way possible. Avoid statements like “You made me feel...” Rather, begin the discussion with a statement like, “Yesterday when you yelled at me I felt...” If you take responsibility for what you feel, it stands to reason that you can also assume responsibility for feeling better. You can choose not to take negative comments from others personally. Blaming someone else for your feelings gives you the false impression that you have no control over how you respond.

Try to see the situation from the patient's perspective. This might increase your tolerance and understanding. Talking to a third party about your feelings can also be a constructive way to keep your personal bias in check. Putting energy into regret, anger, and resentments from the past robs you of energy needed to manage the job in front of you. Sadness, worry and fear are particularly difficult emotions for the caregiver to manage.

Caregivers have the role of “cheerleader,” reassuring their loved ones that they can get through this. Encouraging the patient is the best strategy when he or she is feeling particularly vulnerable. However, caregivers need to have an outlet of their own for expression of worry and fear. It may be helpful to join a support group of other

caregivers people with similar experiences that can offer advice and support. Other caregivers understand your situation but are not personally involved with your family and can be objective. Caregivers do not need to take on that “cheerleader” attitude with other caregivers. Your medical center can provide information about available support groups.

Is it ever appropriate for the caregiver to discuss his or her worries and fears with the patient? The answer is “sometimes.” Patients need to know that their caregivers are on the same page as they are, and that they acknowledge the seriousness of the situation. Patients can experience feelings of abandonment when everyone takes the “Don’t worry about a thing” approach. The truth is that a transplant is frightening and honest dialogue about that reality can help patients and caregivers feel connected and less isolated.

### **Enhancing Communication**

A patient’s need for conversation may change from day to day. Many patients express the need to discuss normal every day things like the weather or politics. They may get bored and agitated with the constant question “How are you?” Alternatively, there may be days when patients are coping with some difficult feelings or decisions and feel that their caregivers are being insensitive to bring up the weather when they are experiencing depression or fear. A statement such as “I’m here to listen if you wish to talk about your feelings, treatment...” can take the guesswork out of cancer-related communication from day to day. Accept that no two people approach the transplant process in the same way.

Communication around sensitive issues like sexuality or finances can present an additional challenge. Choose a time for such discussions when both parties are rested. In the heat of an argument it is unlikely that a conversation will result in creative problem-solving or increased understanding. The goal is to SOLVE PROBLEMS. This is different than “talking about issues.” Talking about issues implies that underlying obstacles exist that will never go away. Solving problems implies that solutions can be found. Professional help can really make a difference. Fortunately most medical institutions have names of social workers, psychiatrists, or health care workers who have experience facilitating effective communication.

### **Delegating Responsibilities**

Caregivers frequently take on multiple roles and responsibilities. Delegating tasks is a skill which requires conscious effort. Delegating tasks to others means giving up some control over the specific details of how things are accomplished. For example, if you allow a neighbor to bring in dinner for your family, you have to accept what your neighbor chooses to cook and how they choose to prepare it. Many people find giving up this control difficult. When caregivers fail to share responsibilities, they may exhaust themselves, leaving them depleted for the more urgent tasks. Delegating is also a challenge for people who define themselves by the tasks that they accomplish.

Delegating causes one to confront their sense of identity. If I'm not the cook, breadwinner, driver, who am I? Appreciate that your new job, Caregiver, is more than accomplishing tasks. Lots of people can make a meal; no one else can sit at the hospital and be you.

Delegation of responsibilities can be especially delicate when children are involved. Children may need to take on additional chores that were previously handled by their parents. While some of this is appropriate, it is important that children not be pressured into a level of responsibility that is beyond their capacity or maturity level. Statements like "you'll have to be the lady of the house now" can feel overwhelming to a young child.

Well-meaning friends and family members may ask caregivers what they can do to help. Prepare a list of tasks that others could do. This avoids duplication of effort, particularly around meal preparation. A prepared list of tasks allows other helpers to select jobs that fit their abilities.

### **Managing Family Conflicts**

Getting along in a family can be demanding even in the best of circumstances. Individual personality traits frequently conflict, creating tension and resentment. Many people have the fantasy that when cancer strikes a family, all the pre-existing anger, jealousies and other emotional baggage will go away. "I thought our family would become closer due to this crisis," is a common idea. Many people do grow closer in a crisis but not because anyone changes their pre-existing personality.

The bad news is that negative personality traits tend to be accentuated when people are under stress. For example, the person who tends to be controlling will become more controlling when under pressure. The critical person will become more judgmental. The person with an addiction will rely on their substance more heavily. Caregivers and patients have their share of unflattering personality problems. Professional counseling may provide specific practical strategies for moderating conflicts during the transplant process. Patients and caregivers who have a history of anxiety, depression or addictions are at higher risk for distress during the treatment period. In these situations counseling can be a real lifeline through the most difficult months. Caregivers who are assisting patients with psychiatric disorders need to remember that they are not responsible or capable of "fixing" the emotional distress of their loved ones.

Criticism from extended family can be difficult to take. Sometimes extended family members or friends are critical of the way you are caring for the patient. It is common for caregivers to feel frustrated with the advice of others to "do more" or "do less." Remember that you are not helping your loved one through the transplant process to win popularity points with the well wishers. Surround yourself with people whom you respect and who are invested in the well-being of both you and the patient.

## **Post-Transplant Concerns**

Patients and caregivers often become frustrated with the chronic symptoms that persist after a transplant. For caregivers there is a natural sense of relief when the acute period of treatment ends. However, it is helpful to understand that for the patient the transplant experience is not over, physically or mentally, and the long hoped for feeling of being “finished” is still elusive.

Spouses are obviously affected by the side effects that extend beyond treatment. It is helpful to understand that the physical and emotional symptoms patients are still experiencing are not always obvious. During follow-up visits with the transplant team, the physician may well say, “You are doing great!” Caregivers need to understand that statement may not translate into patients FEELING great in the initial months post-transplant. As caregivers, we can be most helpful by acknowledging the reality of these side effects, which may include fatigue and loss of strength, especially in the post-transplant period when these symptoms can be particularly discouraging.

Helping your loved one cope with fears about recurrence of cancer requires lots of patience and listening. Patients frequently say, “Everyone has moved on, and I’m still back here worrying about my health.” Caregivers may become frustrated with patients who need constant reassurance about their wellness. Encouraging the patient to attend a support group or see a counselor who specializes in medical counseling issues could assist the patient in managing these fears.

Returning to former roles is also an ongoing concern. Roles may include that of cook, financial advisor, lover and more. Stepping back into daily activities of life varies tremendously from patient to patient. There is no prescribed time frame for “readiness” to enter into specific activities. Open dialogue about expectations and feelings can help with this gradual transition from illness back to normalcy.

## **Caring for Yourself as a Caregiver**

Do not expect yourself to be perfect. You are only human and most likely dealing with many things that you have never been confronted with before. It is natural to make mistakes along the way. Forgive yourself when mistakes do happen. The sooner you shift your thinking to the positive aspects of what you are doing right, the better for you and the patient.

Recognize your physical and emotional limits. Seek help from others before you reach the end of your energy reserves, (see delegating responsibilities.) Understand that you will be a much more effective caregiver if you focus on non-cancer activities periodically. For example, go out with friends; watch a funny movie; and have non-cancer related telephone conversations with others.

Be aware of thoughts along the lines of “I can do it all because I’m not the one who is sick.” While it is true that you are not the patient, that does not mean your energy is limitless. When confronted with your tasks for the day, ask yourself, “How am I going

to accomplish this in a way that promotes energy and health for both of us?" Needless to say, the patient facing transplant needs a caregiver who will remain healthy.

Take in the appreciation that your loved ones send your way. Accept their compliments and gratitude graciously. Focus on your accomplishments. The ability to simply be there is a greater gift than you can imagine.

≈

# Relying On a Family of Strangers

*A Patient's Perspective*



by Jim Myers



*Jim Myers was diagnosed at age 31 with Chronic Myelogenous Leukemia in 1995 after a routine eye exam. He underwent a bone marrow transplant in September the same year and has been in remission ever since. His wife and three children played an important role in his recovery. Jim is a heating and air-conditioning service technician. In his view, caregivers often share some of the same emotions and physical fatigue experienced by the patients themselves. He recommends that caregivers take a break now and then from their responsibilities and hopes they will receive ongoing support and encouragement from others.*

**M**y name is Jim Myers. I was diagnosed with Chronic Myelogenous Leukemia in the summer of 1995. My bone marrow transplant was in the fall of that same year. My wife Kelly and I have three children, oldest to youngest, Zachery, Jeremiah, and Elizabeth. We live in Cheboygan, Michigan.

With the diagnosis of cancer, there are many questions and concerns that arise. Once you have decided on a course of treatment, additional questions and concerns arise.

One of these questions for Kelly and me was that of caregiving after I was discharged from the hospital. We live approximately four hours from the hospital where my transplant was to occur. When I finally went home, Kelly was to be my caregiver. The problem was with the period of time between the hospital discharge and when I could go home. We considered all sorts of options, including relocating closer to the hospital, but Elizabeth was just starting kindergarten the same month as my transplant.

Jeremiah was to have a tonsillectomy on the day of my transplant. The solution to our problem came from an unexpected source—a church.

We were helped in so many ways by our families, individuals, churches, schools, my employer, and the institutions that help those facing cancer, its treatment, and specifically bone marrow transplant. But one particular church and what they did for my family and me is one of the fondest memories of my treatment.

### **Our Family of Strangers**

There were times that Kelly and other members of my family were able to be in Ann Arbor to stay in the apartment with me and take me to my appointments. But I was not permitted to be alone at any time and thus needed someone to be with me 24 hours a day. The Church of Christ in Ann Arbor, Michigan and its members were about to become family in a whole new way. This is how they did it.

We gave the church all of the dates and times that my family was to be with me. They created a schedule divided into three shifts during the day and a nine-hour shift at night. Then they posted that schedule and asked for people to fill in the times when they would sit with me and if necessary prepare my meals, take me to the emergency room, or to doctor appointments. Basically, they were my babysitters, for after all, I was in a sense given a rebirth. They were my providers and companions when my own family could not be present.

I met a very diverse group of individuals who came together to care for someone that they did not know and would not meet until that first time they came to take their shift. Each one of these people made sacrifices for my family and me and never asked a thing in return.

This group of volunteers saw my need and provided for it. With some, I enjoyed only conversation. With others, I enjoyed conversation and games, a stroll around the complex, or a ride in the countryside. We talked about jobs, families, politics, the past, the future, the Scriptures. Some I barely met at all; they would come in for the night shift just as I was going to bed exhausted; then they would be gone before I awoke, but they were there for me just the same.

These people were indeed, as someone said, a “family of strangers.” I have lost contact with most of them, at least physically but not in my heart. There is one woman that we see and hear from often. We even met the family of some others, family that did not live in the area.

When I was well enough, it was my privilege and honor to preach during an evening service for the Church. It was also my privilege to be able to express to them my family's gratitude for their sacrifices and their care.

### **How about Community?**

I believe that a “family of strangers” can be found very close to home. I have never

given much thought to the word “community,” but it seems to me that, in this context, the word is a combination of two other words: “Common” and “unity”—a group of people united by a common purpose, goal, or cause.

In addition to focusing on my medical treatment, we had real financial concerns while waiting for disability benefits. Some friends organized a sock-hop for our benefit. It drew people not only from our town, but as far away as 30 miles. That’s community!

I know of a man in Wisconsin whose co-workers gave him enough of their own paid vacation to ensure him a continuous paycheck while he could not work. That’s community!

May I suggest that if people are willing to promote a “family of strangers” campaign in their community, they could find volunteers to supply the caregiving needs of the bone marrow/stem cell transplant patient. One of the nice things about drawing from your own community is the fact that not all of your caregivers would be total strangers.

I believe that this can be very good for a community—a shared purpose in order to achieve a common goal. I believe that this is one way in which to develop a strong sense of trust and appreciation for one’s community.

### **Caring for the Caregiver**

It was not necessary that this “family of strangers” be the primary caregivers. Sometimes this family of strangers could be the relief for the primary caregiver. So often people focus all of their attention and energies on the patient and forget about the family. Kelly and the kids all went through the transplant and recovery. They are survivors too. There were times when Kelly really needed a break from the responsibilities of caregiving. She needed to be able to get out of the house and away from everything, just to keep her sanity. There were times when she just needed to rest.

Caring for the caregiver—this is a variation on caregiving that deserves more attention. Not all people who are willing to help can do so in the same way, but every effort should be made to accommodate their talents and their desire to help. For example, the bone marrow transplant patient is on a strict diet with many restrictions and food preparation requirements. This often made it necessary for Kelly to prepare one meal for me and a separate meal for the rest of the family. There were many times when people would stop by the house and drop off dinner for the family, already prepared, only needing to be heated. What a relief this was for Kelly!

Your family of strangers may include those who perform service on behalf of the caregiver and the rest of the family. Here are a few things that can help the primary caregiver, but incorporate your own ideas into this “family of strangers” concept:

- Have a regular schedule of people to prepare meals, do laundry, go shopping, or help with house cleaning.

- Have someone scheduled to sit with the patient while the caregiver naps, takes a walk, visits a friend, or runs an errand.
- If there are children, have people take them out for ice cream, to the park, or help them with their homework.

### **Child Caregivers**

When I had my bone marrow transplant, our children were five, seven, and nine. Kelly and I got them involved. There was not a lot that they could do, but I think that it is important that children are made to feel a part of things.

We taught the children to wash their hands just like a surgeon does before performing surgery. Then they were allowed to push the heparin into my catheter. Three children—three tubes. It worked out perfectly for us. Your family is like a community in miniature.

### **The Patient's Role in Caregiving**

The patient has some responsibility. When strangers showed up at my apartment in Ann Arbor, they were often full of questions like, "How should I prepare the food if a meal is required during my shift?" They wanted to know the warning signs, in case something serious happened. They were afraid that they would do something to cause me harm. The patient can dispel, or at least calm, these fears. First, it is important that the patient understand what is required for his or her own care. The patient, along with the health care team, can pass on caregiving information.

In conclusion, I suggest that patients be open to receiving help from others. Don't be too proud to accept it. Think of the times when you were able to assist someone else and the way it made you feel. Accept the help that people are willing to give, and give them the joy that comes with caregiving.

≈

# Symptom Management for Caregivers

*An Oncology Nurse's Perspective*

≈

by Maria Thompson



*Maria Thompson, ARNP-c, is an Advanced Registered Nurse Practitioner Certified. She worked at Duke University Medical Center BMT Program for six years and currently works at the Cleveland Clinic Florida, Hematology/Oncology Department. She spends most of her free time chasing after her 14 month old twins.*

A large part of the caregiver role is often associated with symptom management. After chemotherapy and bone marrow/stem cell transplant, your loved one may experience a wide variety of side effects and symptoms secondary to their treatment. The purpose of reviewing a variety of different symptoms is to equip caregivers with the knowledge of possible situations and encourage successful problem-solving. As intimidating as this chapter might seem, it was written so that caregivers understand that each patient will experience transplant in a very unique way, and the medical team will support caregivers in any event that may occur.

## **Nausea and Vomiting**

Most patients will experience some nausea and vomiting after receiving chemotherapy. Often, anti-nausea medications will be prescribed to help lessen the severity of the nausea. However, there are some other techniques that can aid in decreasing the risk of nausea. If the patient is nauseous, have them avoid heavy foods or milk products. Try a clear liquid diet at first until the patient is feeling better, then advance to a bland diet with easy to digest foods, including noodles, rice, clear soups, toast, or eggs. Try to avoid taking medications on an empty stomach unless instructed specifically to do so. It is often helpful to eat a small amount of food prior to taking pills to help prevent

nausea associated with medications. Sometimes, taking an anti-nausea pill prior to taking other oral medications can help prevent nausea and keep the oral medications down. It may also be helpful to have the patient take oral medications 15-30 minutes apart. Certain smells can induce nausea, so avoid cooking strong smelling foods near the patient. Give the patient his anti-nausea medications as prescribed by your institution because every person responds differently. Let your medical professional know how the prescribed anti-nausea medication is working. Often medications can be changed or doses adjusted to provide better relief.

### **Diarrhea**

Diarrhea is another symptom that is often associated with chemotherapy regimens. Your health care providers will usually prescribe an anti-diarrhea medication after a stool sample has been sent to check for a bowel infection called *Clostridium Difficile*. If the patient is found to have *Clostridium Difficile*, he will be started on an oral antibiotic and advised to avoid anti-diarrhea medications so that the infection can be cleared from his intestinal system through bowel movements. Use the anti-diarrhea medications only as instructed because these medications can cause constipation if used incorrectly. It is important to have your loved one drink as much fluid as possible (preferably fluids like sports drinks or fruit juices) when he has diarrhea to avoid severe dehydration. It is recommended that patients avoid milk products and supplement drinks because they may further loosen the stool due to lactose intolerance. It is recommended that you keep your medical professional updated on how much diarrhea the patient has daily and how much fluid he is able to consume. This information, the intake and output, is very important in helping your medical staff treat the patient.

### **Pain**

Pain is a symptom that can occur for many reasons. ALWAYS notify your medical professional about any pain that the patient may be experiencing, no matter how minor. Your health care provider will then treat the pain according to type, severity, and location and may order certain tests to find out the cause of the pain. Narcotics are often prescribed and are very effective in treating pain, but they also have side effects, including nausea, lethargy (sleepiness), constipation, and slowed breathing. Take narcotics with food to avoid the nausea associated with taking pills on an empty stomach. It is recommended that pain medications be used only as instructed by your medical professional. Taking pain medications more frequently or at higher doses than prescribed can lead to sleepiness and slowed breathing. If the patient becomes too sleepy or has a severe reaction to the medication, stop the narcotics and call your medical professional immediately! Understand that each patient will react to narcotics differently based on past exposure to pain medications and other medications that the patient may be taking at that time. Let your medical professional know how the pain medication is working. There are often changes in the medication or dose that can be made to improve pain relief and decrease side effects.

## **Fevers**

Fevers can be related to certain chemotherapy agents but are most often related to neutropenia (decrease in white blood cells) or infections. After chemotherapy, the patient will become neutropenic and will have no immune system to protect him or her from infections. During this neutropenic phase, fevers are fairly common. It is essential to treat fevers quickly to avoid the possibility of developing serious infections. Notify the medical provider of any fever >101.0 degrees Fahrenheit so that intravenous antibiotics can be started as soon as possible. The patient should use Tylenol only when instructed because taking Tylenol can hide a fever that may be present. A fever is a sign to your medical provider of a possible infection.

## **Neutropenia (Low White Blood Cell Count)**

High-dose chemotherapy will cause the patient to lose his white blood cells (neutropenia). The patient will remain neutropenic for approximately 2-3 weeks. When a patient has no white blood cells, he has no immune system to protect him from infection. When the patient is neutropenic, avoid public places and sick people that may expose the patient to infection. If the patient has to visit the hospital for any reason, have him wear a TB or surgical mask that can be obtained from your medical institution. It is recommended to avoid all fresh fruits, vegetables, or any uncooked foods that can expose the patient to bacteria and fungal organisms. Good hand washing is the most important thing that patients and caregivers can do to prevent infection. When neutropenic, the patient should have minimal contact with small children. Children often transmit viral infections that they contract from other children in schools or day care facilities. However, the emotional benefit of maintaining these contacts must be considered. With adequate precautions such as avoiding children that are ill and all parties practicing good handwashing, the benefits may well outweigh the risks.

## **Bleeding related to Thrombocytopenia**

Bleeding is related to the low platelet count (thrombocytopenia) that occurs after high dose chemotherapy. When platelets are low, the blood becomes thin and has a decreased ability to clot. Platelet transfusions will be necessary when platelet counts fall below 10,000-20,000, depending on your hospital's guidelines. During this time, the risk for bleeding is higher and certain measures can be taken to avoid bleeding. Instruct the patient to avoid vigorous nose blowing, shaving, and not to participate in any vigorous sports, strenuous exercise, or heavy lifting during this time. Soft bristle toothbrushes are necessary, and patients should not use dental floss to avoid gingival bleeding. Do not use any rectal suppositories, and avoid using any over-the-counter medications that can cause bleeding, including aspirin, ibuprofen or naproxen. Before beginning sexual activity, consult with a member of your transplant team. Platelets will recover a few days after the patient's white blood count recovers. Notify your health care professional immediately if you notice any bleeding in the stool or the urine or should the patient experience a sudden onset of a severe, debilitating headache.

## **Fatigue**

Fatigue is an often debilitating symptom that has many contributing factors, including chemotherapy, malnutrition, insomnia and anemia (low red blood cell count). Immediately after transplant, REST is the most important component in combating fatigue. Appropriate sleep and eating patterns can add to the overall well-being of the patient and can help lessen the fatigue. Inform health care providers if insomnia is a problem so that sleeping aids can be prescribed. Blood transfusions can provide a short-term energy boost if the patient's hemoglobin is low. Exercising post-transplant is recommended to strengthen muscle and boost energy levels once the patient has returned home. Always begin with light exercise, advancing as the patient tolerates. Energy levels generally improve with time but sometimes can take up to 3-6 months to fully recover. Everyone recovers at a different pace. Do not be discouraged if recovery takes longer than the patient expected.

## **Mouth Pain and Mucositis**

Certain chemotherapy agents can cause mucositis (an inflammation of the tissue in the mouth and esophagus) that can be very painful. Good oral hygiene and mouth rinses with oral solutions as prescribed by the health care provider will help with the pain and prevent infection. Let your health care provider know when the patient first experiences a sore throat or mouth pain so that pain medication can be started. Sometimes, the pain can become severe enough that the patient is unable to swallow fluids or medications. During this time, intravenous narcotics and fluids are often needed to control the pain and to keep the patient hydrated. Pain medications only help alleviate the pain, not cure the mucositis. Fortunately, mucositis is temporary and typically resolves when the patient's white blood cell count recovers.

## **Anorexia or Loss of Appetite**

Patients, post-transplant, will often experience a loss of appetite due to chemotherapy and nausea. During this time, prepare small meals and encourage the patient to eat frequent, small snacks throughout the day. Appetite stimulants can be prescribed but usually are reserved for patients who lose large amounts of weight. Diets high in protein are recommended to help keep the patient nourished despite poor oral intake. Supplement drinks once or twice a day can provide caloric and nutritional boosts essential for malnourished patients.

## **Skin Rash**

Skin rashes, post-transplant, are usually associated with a reaction to a medication or to viral and fungal infections. Your medical professional should be alerted to any new skin rashes and should evaluate the rash daily to determine type and effectiveness of treatment strategies. As a caregiver, it is essential to help keep the patient bathed, avoiding any new lotions, soaps or laundry detergents that can contain ingredients that can lead to allergic rashes. Use only medications prescribed by your medical professional because over the counter creams or lotions can exacerbate many skin rash-

es. Let your medical professional know if itching occurs because medications can be prescribed to alleviate an irritating itch.

### **Pulmonary Symptoms**

Shortness of breath and cough are the most common pulmonary symptoms that occur during bone marrow transplant. Shortness of breath and cough can be related to many different things after chemotherapy including fluid overload, lung abnormalities and infection. Notify your health care professional immediately if these symptoms occur so that appropriate medications can be given. A chest x-ray will often be performed to examine the lungs if shortness of breath or cough persists.

### **Graft Versus Host Disease (GVHD)**

Graft versus host disease is a condition that is experienced by allogeneic (stem cells from a donor other than the patient) stem cell recipients only. Graft versus host disease is a reaction of the donor cells to the patient. Acute GVHD can affect the skin, the gut, and/or the liver. GVHD of the skin presents as a redden skin rash over 25-50% of the body that is often very itchy. GVHD of the gut presents as sudden onset of severe nausea, vomiting and large amounts of diarrhea. The nausea and vomiting usually do not respond to typical anti-nausea medications. The diarrhea is often very watery, dark in color and is associated with abdominal cramping. Sometimes the diarrhea and vomiting prevent adequate nutritional intake, making it necessary to start intravenous nutritional support. GVHD of the liver occurs with elevated liver enzymes, which can lead to jaundice (yellow tinge to the skin and eyes), itching, fluid retention in the abdomen, and right abdominal pain. If any of these symptoms occur, notify your medical provider immediately so that treatment can be initiated quickly. Delay in treatment can worsen the GVHD and its symptoms, making it more difficult to control.

### **Safety Issues**

Patient safety, after transplant, is a very important caregiver task. Hand washing is an essential step in preventing the spread of infection to the patient.

There are other safety concerns that need to be considered in post-transplant patients. These include any respiratory difficulties, chest pain or neurological changes (confusion, severe headaches, sleepiness or black-outs). Notify your health care provider of any unusual symptoms or changes in the patient, no matter how trivial. Rapid notification leads to a quicker response, often saving the patient from dangerous situations. Safety of the patient is of the utmost importance. If safety is maintained, it can increase the chances of a successful transplant course.

### **Post-Transplant Expectations**

Once a patient has successfully engrafted (recovered his white blood cell counts) after transplant, it is usually time for him to return home. The caregiver and the patient will realize that though they have returned home, they will still need assistance for a few weeks after transplant. Profound fatigue can often linger for many

weeks after transplant and generalized fatigue can remain for up to 5-6 months after transplant. A daily exercise regimen and appropriate nutritional intake is essential in optimizing the patient's recovery once he has returned home. Exercise should be increased gradually and only as the patient tolerates. Post-transplant complications may sometimes occur after the patient has left the hospital. Therefore, it is very important that the patient notify his local physician and his bone marrow transplant team immediately, if any changes or problems should occur.

Upon discharge, the patient will be scheduled for follow-up visits with the bone marrow transplant team. Each institution will have different post-transplant schedules that will be individualized to the patient's specific needs. It is essential that the patient keeps these appointments and has a caregiver present during these visits in case the patient needs assistance getting to specific tests or when recovering from certain procedures (bone marrow biopsy, catheter removal, etc.).

Psychological stress is another common factor for the caregiver. The demands placed on caregivers may be overwhelming at times. The medical team will be a great resource for you to discuss any concerns and questions you may have. There will be a social worker, psychologist or other mental health care professional to help you or the patient cope with issues that arise during the transplant process. Rely on them for support and to validate your caregiver role. Caregivers really are partners-in-care along with the transplant team and are an essential part of the overall transplant experience. Many find it helpful to talk with previous caregivers who may be able to provide first-hand knowledge and helpful tips during this difficult period.

≈

# How to Be a Successful Family Caregiver

## *An Advocate's Perspective*



by Suzanne Geffen Mintz



*Suzanne Geffen Mintz is President/Co-founder of the National Family Caregivers Association, the only organization comprised of and reaching out to all family caregivers. In September 2006, Mintz was named a winner for the first-ever national Purpose Prize, a major new initiative to invest in Americans 60 and above who are leading a new age of social innovation sponsored by Civic Ventures. She is author of "Love, Honor, & Value - A Family Caregiver Speaks Out About the Choices and Challenges of Caregiving," (Capital Books 2002) and regularly writes for numerous publications on the issues related to family caregiving.*

*This chapter has been excerpted and edited from a series of agency brochures available from the National Family Caregivers Association.*

### ***Defining the Help You Need and Figuring Out How to Get It***

**A**sking for and accepting help is a complex issue. Obviously you first need to admit that having someone help will make a real difference in your loved one's quality of life, and therefore yours as well. Then you need to define what help you need. Which tasks or chores would be easier to ask others to do? Which do you really want to do yourself? Here are six steps to getting help:

- Recognize that caregiving, like any job, is made up of lots of individual tasks. Not all tasks are of the same importance. The challenge is to know the difference.
- Recognize that asking for help is a sign of strength and not of weakness. It means you truly have a grasp on your situation and have come up with a proactive, problem-solving approach to making things better.

- Create a list of tasks that need to get done in any given week. When you see how long the list is you'll quickly understand why you are so tired.
- Group your tasks into categories such as personal care tasks, transportation and household chores.
- Write down your caregiving worries. Seeing them in black-and-white helps diffuse some of their emotion. It also allows you to think more rationally and understand how getting help might lessen the stress.
- Share your lists with someone you trust before you reach out for help—a friend, therapist or clergy, perhaps. Then take a deep breath and ask for help or guidance in resolving your worry. Don't get discouraged if you are rejected at first. It takes perseverance. The goal is better care for your loved one and yourself.

### ***Tips for Family Caregivers from Doctors***

- Write down questions so you won't forget.
- Be clear about what you want to say to the doctor.
- If you have lots of things to talk about, make a consultation appointment.
- Educate yourself about the disease.
- Learn the routine at your hospital.
- Separate your anger and sense of impotence about not being able to help your loved one as much as you'd like from your feelings about the doctor.
- Appreciate what the doctor is doing to help, and say thank you from time to time.

### ***Tips for Doctors from Family Caregivers***

- Be open and forthright.
- When you prescribe medications, be sure caregivers understand potential side effects so they know what to expect.
- Be accessible—especially when a caregiver is opening his or her heart.
- Be sensitive about where you talk to caregivers about difficult subjects—waiting rooms and corridors are not appropriate.
- Now and then ask the caregiver, “How are you?” Let them know you understand that illness is a family affair.

## ***Share the Caring, Helpful Hints for Caregivers and Those That Care about Them***

If you're a caregiver who needs help or if you're a friend who wants to provide it, use these handy checklists to help create an action plan:

### ***Checklist...Help I need:***

- A night out with friends
- A ride to doctor's appointments
- Mow the lawn or shovel snow
- Dinners prepared
- House cleaned
- Shopping done
- A shoulder to cry on
- A handyman
- Pick up prescriptions
- More information on available resources
- Some quiet time alone at home
- A sitter at home
- Someone to ask how I am

### ***Checklist...Help I can Offer:***

- Dinner and a movie on me
- A ride at pre-assigned time
- A lawn mowed/driveway shoveled
- A meal prepared ...times a week
- A maid brigade once a ...
- Grocery shopping every ...
- A shoulder to cry on
- A couple of hours of my tools/time
- Run errands
- Resource research
- Taking ... out for a few hours
- Some of my time to stay with ...
- A weekly phone call

## Resource Listing

*Note:* This Resource Listing includes organizations that provide support and information for caregivers. You may find additional resources in the following two booklets and video available from the nbmtLINK:

***Resource Guide for Stem Cell Transplant, Including Bone Marrow, Peripheral Blood, and Cord Blood, Friends Helping Friends***

***Survivors' Guide for Bone Marrow/Stem Cell Transplant, What to Expect and How to Get Through It, by Keren Stronach***

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

### Organizations

#### **Aplastic Anemia & MDS International Foundation, Inc.**

PO Box 310  
Churchton, MD 20733  
800-747-2820 or 410-867-0242  
help@aamds.org  
www.aamds.org

#### **BMT Infonet**

2310 Skokie Valley Rd., #104  
Highland Park, IL 60035  
888-597-7674 or 847-433-3313  
help@bmtinfonet.org  
www.bmtinfonet.org

#### **CancerCare National Office**

275 Seventh Ave., Floor 22  
New York, NY 10001  
800-813-HOPE or 212-712-8400  
info@cancercare.org  
www.cancercare.org

#### **Family Caregiver Alliance**

180 Montgomery, #1100  
San Francisco, CA 94104  
800-445-8106 or 415-434-3388  
info@caregiver.org  
www.caregiver.org

#### **Family Voices**

2340 Alamo SE, #102  
Albuquerque, NM 87106  
888-835-5669 or 505-872-4774  
kidshealth@familyvoices.org  
www.familyvoices.org

#### **Friends' Health Connection**

P.O. Box 114  
New Brunswick, NJ 08903  
800-483-7436 or 732-418-1811  
info@friendshealthconnection.org  
www.friendshealthconnection.org

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

800 Yamato Rd., #101  
Boca Raton, FL 33431  
800-9MARROW or 561-988-0140  
info@giftoflife.org  
www.giftoflife.org

#### **Gilda's Club Worldwide**

322 Eighth Ave., #1402  
New York, NY 10001  
888-445-3248 or 917-305-1200  
info@gildasclub.org  
www.gildasclub.org

## Organizations

---

### **Lance Armstrong Foundation**

PO Box 161150  
Austin, TX 78716  
866-235-7205 or 512-236-8820  
livestrong@laf.org  
www.laf.org

### **The Leukemia & Lymphoma Society**

1311 Mamaroneck Ave.  
White Plains, NY 10605  
800-955-4572  
infocenter@lls.org  
www.lls.org

### **National Alliance for Caregiving**

4720 Montgomery Lane, 5th Floor  
Bethesda, MD 20814  
301-718-8444  
info@caregiving.org  
www.caregiving.org

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

20411 W. 12 Mile Rd., #108  
Southfield, MI 48076  
800-LINK-BMT (800-546-5268) or  
248-358-1886  
info@nbmtlink.org  
www.nbmtlink.org

### **National Family Caregivers Association**

10400 Connecticut Ave., #500  
Kensington, MD 20895  
800-896-3650 or 301-942-6430  
info@thefamilycaregiver.org  
www.thefamilycaregiver.org

### **National Marrow Donor Program (NMDP)**

3001 Broadway NE, #500  
Minneapolis, MN 55413  
800-MARROW-2 (800-627-7692)  
888-999-6743 (Office of Patient Advocacy)  
www.marrow.org

### **Patient Advocate Foundation**

700 Thimble Shoals Blvd., #200  
Newport News, VA 23606  
800-532-5274  
help@patientadvocate.org  
www.patientadvocate.org

### **Rosalynn Carter Institute for Caregiving**

Georgia Southwestern State University  
800 GSW Drive  
Americus, GA 31709  
229-928-1234  
rci@canes.gsw.edu  
www.rosalynncarter.org

### **Well Spouse Foundation**

63 W. Main Street, #H  
Freehold, NJ 07728  
800-838-0879  
info@wellspouse.org  
www.wellspouse.org

## Books

**Across the Chasm, A Caregiver's Story**

by Naomi Zigmund-Fisher, BMT Infonet, 2002

**After the Diagnosis: How to Look Out for Yourself or a Loved One**

by Donna L. Pikula, DDS, MS, 2006

**And Thou Shalt Honor: The Caregiver's Companion**

edited by Beth W. McLeod, 2002

**Being a Cancer Patient's Carer: A Guide**

by Wesley C. Finegan, 2005

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

by Rosanne Kalick, 2005

**Cancer as a Turning Point: A Handbook for People with Cancer, Their Families, and Health Professionals**

by Lawrence LeShan, 1990

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

National Bone Marrow Transplant Link, 2007

**Caring and Competent Caregivers**

by R. Moroney, P. Docecki, J. Gates, K. Haynes, N. Noshier, 1998

**Caring for You, Caring for Me: Education and Support for Caregivers**

by D. Haigler, K. Mims, and J. Nottingham, 1998

**The Caregiver's Companion**

by Theola Jones, 2000

**The Caregiver Helpbook**

by V. Schmall, M. Cleveland, M. Sturdevant, 2000

**Caregiver's Reprieve: A Guide to Emotional Survival When You're Caring for Someone You Love**

by Avrene Brandt, 1997

**Caregiving: A Step-by-Step Resource for Caring for the Person with Cancer at Home**

by Peter Houts and Julia Bucher, 2000

**Caregiving for Yourself While Caring for Others**

by Lawrence Brammer, PhD, 1999

**Caregiving Sourcebook**

by Joyce Brennfleck Shannon, 2001

**Caregiving: The Spiritual Journey of Love, Loss and Renewal**

by Beth McLeod, 2000

**Childhood Leukemia: A Guide for Families, Friends and Caregivers**

by Nancy Keene, 3rd ed. 2002

**Daily Comforts for Caregivers**

by Pat Samples, 1999

**Everyone's Guide to Cancer Supportive Care: A Comprehensive Handbook for Patients and their Families**

by Ernest H. Rosenbaum and Isadora Rosenbaum, 2005

**Gifts of Caregiving**

by Connie Goldman, 2002

**Helping Yourself Help Others: A Book for Caregivers**

by Rosalynn Carter, 1995

**Help Me Live: 20 Things People with Cancer Want You to Know**

by Lori Hope, 2005

## Books

---

**Homecare Management of the Blood Cell Transplant Patient**

by Cathy H. Kelley, Susan Randolph, Linda McBride, 1998

**Living with Childhood Cancer: A Practical Guide to Help Families Cope**

by Leigh Woznick, 2001

**Love, Honor and Value—A Family Caregiver Speaks Out About the Choices and Challenges of Caregiving**

by Suzanne Mintz, 2002

**100 Questions and Answers about Caring for Family or Friends with Cancer**

by Susannah L. Rose and Richard Hara, 2005

**Pebbling the Walk: Surviving Cancer Caregiving**

by Steve Reed, 2000

**Resource Guide for Stem Cell Transplant, Including Bone Marrow, Peripheral Blood, and Cord Blood**

National Bone Marrow Transplant Link, 2006

**Share Care—How to Organize a Group to Care for Someone who is Seriously Ill**

by Cappy Capossela and Sheila Warnock, 2004

**Supportive Cancer Care: The Complete Guide for Patients and Families**

by Ernest H. Rosenbaum, MD, et al, 2001

**Surviving your Spouse's Chronic Illness: A Compassionate Guide**

by Chris McGonigle, 1999

**The Professional and Family Caregiver—Dilemmas, Rewards and New Directions**

by Jack and Joanne Nottingham, 1990

**When Life Becomes Precious: A Guide for Loved Ones and Friends of Cancer Patients**

by Elise NeeDell Babcock, 1997

## Videos/DVD's

---

**Educated Caregiver**

by Nancy Van Camp (3 tape series), Life View Resources, Inc., 1998

**The Grit and Grace of Being a Caregiver: Maintaining Your Balance as You Care for Others**

Willowgreen Productions, 1997

**Home Nursing Care: A Practical Guide for Family Caregivers**

by G. Timpane and M. Wholey, AYA, Inc., 1998

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

National Bone Marrow Transplant Link, 2001

## *Information on the Internet*

The Internet is a valuable tool.

It offers a wealth of information, some helpful, some misleading.

Rely on credible sources for information, such as hospitals or medical associations.

Proceed with caution when searching the Internet. Evaluate material by asking:

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

When evaluating the Internet sites, check the address (URL).

The final segment of the address offers a general idea of who is sponsoring the web site.

Examples include:

- .edu... site sponsored by an educational institution
- .gov... site sponsored by a government agency
- .org... site sponsored by a non-profit organization
- .com...site sponsored by a commercial company

## *Internet Resources for Caregivers:*

- American Association for Retired Persons . . . . . [www.aarp.org/families/caregiving](http://www.aarp.org/families/caregiving)
- Association of Cancer Online Resources . . . . . [www.acor.org](http://www.acor.org)
- Caregiver’s Marketplace . . . . . [www.caregiversmarketplace.com](http://www.caregiversmarketplace.com)
- Caregiving.com . . . . . [www.caregiving.com](http://www.caregiving.com)
- CaringBridge . . . . . [www.caringbridge.org](http://www.caringbridge.org)
- Kids Konnected. . . . . [www.kidskonnected.org](http://www.kidskonnected.org)
- Lotsa Helping Hands. . . . . [www.lotsahelpinghands.com](http://www.lotsahelpinghands.com)
- MedlinePlus . . . . . [www.medlineplus.gov/caregivers](http://www.medlineplus.gov/caregivers)
- National Bone Marrow Transplant Link . . . . . [www.nbmtlink.org](http://www.nbmtlink.org)
- National Respite Locator Service . . . . . [www.archrespite.org](http://www.archrespite.org)
- Strength for Caring. . . . . [www.strengthforcaring.com](http://www.strengthforcaring.com)
- The Healing Project . . . . . [www.thehealingproject.org](http://www.thehealingproject.org)
- The Never-Ending Squirrel Tale . . . . . [www.squirreltales.com](http://www.squirreltales.com)
- Today’s Caregiver Magazine . . . . . [www.caregiver.com](http://www.caregiver.com)



National Bone Marrow Transplant Link

## **Resources and Reassurance When You Need Them Most**

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

Founded in 1992, the nbmtLINK is an independent, non-profit organization funded entirely through the generosity of individuals, corporations and foundations. Tax-deductible contributions are welcomed and vital to ongoing programs and services.

National Bone Marrow Transplant Link  
20411 W. 12 Mile Road, Suite 108  
Southfield, Michigan 48076

248-358-1886

Fax: 248-358-1889

Toll Free: 800-546-5268

E-mail: [info@nbmtlink.org](mailto:info@nbmtlink.org)

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

*“A Second Chance at Life Is Our First Priority”*



# CAREGIVERS' GUIDE FOR BONE MARROW/STEM CELL TRANSPLANT



*Practical Perspectives*

**NATIONAL  
MARROW  
DONOR  
PROGRAM®**

***nbmt*LINK**  
National Bone Marrow Transplant Link

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