

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 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.**

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.

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The nbmtLink gratefully acknowledges the *practical perspectives* shared by each writer and the vision and generosity of Dr. Jeffrey Chell and the National Marrow Donor Program.

We would like to acknowledge the following individuals who helped make the *Caregivers' Guide* a reality:

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

Sustaining Partners

David Wortman Fund

J.P. McCarthy Foundation



Josephine Ford Cancer Center



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Lula C. Wilson Trust

National Marrow Donor Program



Metro Health Foundation



Pietrasiuk Family Foundation

St. Joseph's Mercy of Macomb Cancer Care Center



The Jewish Fund



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William G. and Myrtle E. Hess Charitable Trust

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Siteman Cancer Center, Barnes Jewish Hospital, Washington University School of Medicine



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The NMDP Office of Patient Advocacy

is a valuable resource for blood stem cell transplant patients and their families. We help patients:

- Understand the donor search and transplant process
- Learn about treatment options for their disease
- Overcome financial and other barriers to transplantation
- Access good information and resources
- Advocate for their own health care needs

The Office of Patient Advocacy's services are free and confidential. For more information, please contact us at 1-888-999-6743, or visit our Web site at www.marrow.org.



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Bone Marrow/Stem Cell Transplant**
Practical Perspectives

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Foreword

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by Dr. Mary Horowitz

As a transplant physician for the past 15 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—that I feel much more comfortable discharging a patient when I know he or she has a strong support system upon which to lean. 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 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. More importantly, it hopefully lets you know that you are not alone, that it is worth the struggle and that your role is critically important and appreciated.

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*Why a
Special Booklet
for BMT Caregivers?*

*From the Perspective of
nbmtLink Founder and
Executive Director*



by Myra Jacobs



***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 25 years. Through her many years of professional work, she was inspired by the plight and courage of bone marrow transplant patients and their families. Recognizing their need for information and support, she founded the nbmtLink in 1992. Since then Myra has successfully expanded the organization which is relied upon by the transplant community nationally as an important resource for educational materials and psychosocial support*

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 healthcare team actually relies upon the caregiver to provide services for the patient. 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 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, the hope for a positive treatment outcome. However, like the patient, the challenge of a BMT for the caregiver becomes life-changing as well. “How do the demands of a BMT caregiver differ from the demands of a non-BMT caregiver?” BMT caregiving, depending on the type of transplant, may consume one’s daily living for an extended time. It is not a casual responsibility. It is a serious and ongoing promise. BMT caregivers may at once “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 a year of duty. It can be a sobering challenge and responsibility but clearly one worth the effort. 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 healthcare team
- Encourage family members, friends, and the community to support the caregiver’s efforts and to 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
- 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.

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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. 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. When 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 demanding 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! We thought, "Wow, we must really be at the end of the road for the doctor to suggest such a radical treatment!" To our surprise, it was not that radical at all. BMT is a demanding treatment of choice, 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 but being organized; “in control” as much as is possible, and, ready to be a team player will serve you well.



*I Don't Know What to Say;
I Don't Know What to Do:
Cancer Etiquette*

*A 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 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*. Her research, her volunteer work, her five grandchildren keep her out of trouble.

The Words

Etiquette 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.

Every 25 seconds someone hears a doctor say, “It’s cancer.” Years ago, those words were often a death sentence. Then, a person who received the diagnosis had few options. Today, the opposite is true. Then 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.

Today, books about cancer, its treatment, alternative therapies, the psychological impact of the disease, etc. are in every bookstore and on every library shelf. Now that we speak openly about cancer, it is time to consider how we speak to the patient who has cancer. 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 a 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 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 doors 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 compared to yesterday.

Be careful, too, about commenting on how the patient looks. One woman whose husband has multiple myeloma heard her friend ask why her husband looked so bad when Geraldine Ferraro looked so good. 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.

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 ‘chemobrain.’ Obviously if she seems disoriented or excessively fatigued, postpone the question. When in doubt about what to say, don’t say it. Think before you speak.

There are two areas that are particularly sensitive. Hair loss is one. High dose chemotherapy causes the patient to lose his hair. Eyebrows, eyelashes, 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.

Equally personal is the God question. Again, if you’ve discussed God 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 views about God and you’re not sure of the patient’s, don’t speak about how God 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 possibilities for gifts. For practical purposes, 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, hot chocolate may stimulate a weak appetite. During the neutrapenic period, however, do not give gifts of flowers or certain fresh food.

The transplant patient's ability to concentrate won't be great at times. Bring books that are short and light. As he recovers, you can become more selective. Again, ask first. "I'm going to the bookstore. Do you want Steve Martin's new book, or do you prefer a CD?" A good gift is a subscription to a magazine. It can match the interest of the patient or it can be in an entirely new area. This gift delivered every week or month will serve as a reminder of the connection between you and the patient. Consider a subscription for the patient's children. They will feel included, and the magazine will serve as a positive distraction to children who may be getting less attention than they normally do.

A gift certificate is a good choice. It can be dinner for two at a local restaurant, for a manicure/pedicure, a day at the spa, a cleaning service for one day. This type of gift serves as a reminder that there will be life after the transplant; there will be a new normal.

The patient will be undergoing treatment for several months. One card or one casserole will not do the trick. Emails, notes, jokes, videotapes, computer games are all good possibilities. A gift to a cancer organization honoring the patient is appreciated. Remember the caregiver with small gifts. Plan for the long haul. Work in community. Your neighbors, church or synagogue, 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!

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Emotional Aspects of Caregiving

*An Oncology
Social Worker's Perspective*



by Linda Diaz



Linda Diaz, ACSW, is a national leader and lecturer in the field of oncology social work. For the past 19 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 is currently the Coordinator of the Cancer Support and Counseling Program, Radiation Oncology Division, of the Karmanos Cancer Institute and has a private psychotherapy practice in Birmingham, 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. Keep reassuring yourself, it does, in fact, end.

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 too felt exhausted and began feeling trapped and angry.

Paul began feeling guilty about having such feelings; after all *his wife is fighting for her life!* Focusing on guilt will add another negative emotion to his list of uncomfortable feelings (anger and exhaustion). Eventually this will put an even greater burden on himself and eventually his family. One strategy to employ is to acknowledge these uncomfortable feelings, perhaps to a trusted friend, which 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. Keep a pen and notebook handy to write down any questions that come up.

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, beginning 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. In many cases the caregiver’s primary support person is the patient they are taking care of. The caregiver is often the individual that patients talk with about *their* fears. 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 their worries and fears with the patient? The answer is sometimes. Patients need to know that their caregivers are on the same page as them, 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. Allow the patient to determine when they wish to talk about their feelings or illness. A statement such as “I’m here to listen if you wish to talk about your feelings, treatment, etc.” 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 as 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 independence and 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. Caregivers may come home to six casseroles on the kitchen

counter all in the same day! A prepared list of tasks allows other helpers to select jobs that fit their abilities.

For example:

Weekly Tasks:

- Drive Billy to his allergy appointment on Tuesday
- Dinner on chemotherapy day
- Weed the garden
- Read books with Joey

Daily Tasks:

- Walk the dog
- Water the garden

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, a 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 equal share of these 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 though 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 hard 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 extended well wishers. Surround yourself with people who you respect and who are invested in the well-being of both you and the patient.

Post-Transplant Concerns

It is common for patients and caregivers, to become frustrated with the chronic

symptoms that persist after a transplant. As caregivers, there is a natural sense of relief when the acute period of treatment ends. It is helpful to appreciate 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. A study published in 1994 asked 135 patients what aspects of their life they would rate most positively after their transplant. (The average amount of time post-transplant was 4 years.) Patients rated their quality of life highest in the areas of their ability to eat, overall perception of the BMT experience, and their relationships with relatives and friends. Negative ratings were noted in the arena of sexual satisfaction, physical appearance, control over personal circumstances, and relationships with spouse. (Baker, Wingard, Curbow, Zabora, et al. BMT 13:1994)

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 may not translate into patients *feeling* great in the initial months post-transplant.

A related study published in 1999 evaluated the perceptions of 84 patients one year after BMT. (Baker, Zabora, Polland, Wingard, Cancer Practice 7 (4):1999) The number one physical complaint was fatigue and loss of strength, which was listed as problematic by thirty-eight percent of patients. Post-transplant patients often report “feeling tired of feeling tired.” As caregivers, we can be most helpful by acknowledging the reality of the “fatigue factor” especially in the post-transplant period, when experiencing this symptom can be particularly frustrating.

Helping your loved one cope with post-transplant 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.” Twenty-seven percent of patients surveyed in the 1999 study reported significant fear about the future one year following transplant. 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.

Forty-eight percent of the post-transplant group noted that “returning to former roles” was an ongoing concern. “Roles” could include that of cook, financial advisor, lover and more. This finding is of particular interest to caregivers because they are the ones most often affected by the shifting of roles. 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. 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 the 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.

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*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 from their "hero" donor Marge. Melanie is also the Executive Director of SuperSibs!—a non-profit organization to honor, support and recognize siblings of children with cancer. Melanie is a former corporate change management business leader working with Fortune 500 companies. She serves as a Board Member of the National Marrow Donor Program and Advisory Board Member of The Marrow Foundation. Melanie is a three-time Leukemia-Lymphoma Society Team-In-Training marathoner. Her proudest role is as the mother of her two boys—transplant survivor Travis Yon, and SuperSib, Spencer Yon. Her family's personal journey is chronicled at www.keeptrying.com

As 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 their 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 good outcomes and shared their experiences so that we can all manage through with the best hope for positive results. 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 for 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 List Serve online. Choose to see a therapist. Choose to focus on the positive, versus the energy-draining “victim mentality” that can be so seductive (and yet, it doesn’t help us achieve the results we want, which is full recovery for our children). 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 with your 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 Child (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 them 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 lend support on a one-time basis or even a few occasions, it often quickly becomes a harsh reality that one’s support network returns to their own daily lives. Therefore, it becomes vital to reach out for support. And yes, that means we need to ASK. Waiting for the right offers for help 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’s Office of Patient Advocacy, nbmtLink, The Marrow Foundation, Make-A-Wish Foundation, Ronald McDonald Children’s 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 ongoing 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. One parent at the stage of utter exhaustion, expressed her dismay at returning from the hospital knowing she “had to” straighten out her home office and iron clothes. It became immediately apparent that something had to give. She came to realize, too, that not every blouse needed to be starched and ironed. The filing could be delegated to someone else. The garden could go an extra day without watering and a week or two more without weeding. Each friend and relative didn’t need a personal update or timely returned call. The gifts could go without thank you notes. All the dishes didn’t need to get washed immediately, and so on. 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 to 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 from the ceiling. 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. Yes, having a morning walk alone or a lunch outing with best friends may feel like time you can't afford away from your child. Or perhaps getting in a game of squash, a date with your spouse or a relaxing massage produces twinges of guilt that this pampering is inappropriate. On the contrary, managing through the transplant process with and for our children can feel like relentless torture to one's mind, body and spirit. 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 caring well-wishers bring you meals and manage to stand in your hallway asking loving questions and sharing their concerns and life stories — just when you need to grab a nap or eat in peace — be direct with your appreciation AND express your need to grab a moment for yourself. If a procedure is scheduled for your child at a time when it's most difficult for you, then 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!) One parent finally posted her name in her child's room, and kindly requested that all nurses and doctors call her by that first name — just to keep her own sense of self and sanity in a world where everything revolved around the transplant child. 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 5-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. While "chemobrain" 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-laughs 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 email 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 of 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. For the sake of your child undergoing transplant, your own close relationships and of course, your own sanity, don't be ashamed or

afraid to seek help. 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. Repeat this mantra: It's ok to accept professional help. The earlier on in the process, the better.

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, list serves, Web sites for your child's diagnosis, and even other families who have traveled this journey. While 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. The transplant journey is rife with unknowns, so just use whatever resources you can access to make the best informed decisions for your child, yourself and your family. Do your homework, trust your gut and go forward.

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? So what if the medical team gets greeted each day with a new pipe-cleaner spider swinging from the door? Why not learn a new craft with your teenaged patient during these focused hours? Try kit-building, beading, watercolor painting, memory-book making or story writing. You may even develop a new hobby together that you otherwise never would have discovered. (Ours was

Origami!) 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 those 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. As well, your child's team (including perhaps you and your family) operates in shifts, so effective transfer of information is critical. This documentation might include test results, times of medicine administration and reactions to each, your child's aches and complaints, foods that went down and stayed down, comments shared by the doctors about your child's progress, etc. 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 made for your child. Borrow a laptop computer, to go online and enjoy the many children's Web sites to play 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 them 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. The transplant journey produces ripples that are both obvious and unseen for you and all the children involved. These “super sibs” may benefit greatly from this outside and objective resource to help them navigate through the ripples (and sometimes tidal waves) of transplant.

- ***Encourage Happy Reminders***

Ask neighbors, friends, synagogue or 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. Perhaps during the long transplant healing days, you can create anonymous happy cards to go to your other children — for a quick lift to their day. For younger children, a trophy with their name and a message of how special they are could be just enough to help them feel joy and strength 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.” Reinforce that this title holds special meaning as well. These sibling heroes add true healing value — by their energy, support (sorting supplies, holding sibling’s hands, sharing a “don’t give up attitude,” etc.), 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.

- ***Engage The Siblings***

Help siblings understand what’s going on around them, as appropriate to their level of maturity. Rather than shut the sibling 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. Encourage siblings to ask questions of the doctors and nurses, so they can understand what is being done to help their brother or sister. Share your excitement at progress that’s been made — both with your transplant child as well as with accomplishments the sibling has had outside the hospital each day. Siblings pick up on much more than we imagine,

by watching our reactions, listening to our conversations, or overhearing bits and pieces from others. Rather than leaving it up to their imaginations of what is happening during this long challenge, offer up opportunities to help them understand. 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 their siblings. The power of that wish for the future can be as strong for the child in the hospital as it is for the sibling at home.

- ***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. This may be a perfect time to allow your other children to try something new that they’d always been wanting to learn. (In our case, Tae Kwon Do was a savior!) Sibling rivalry and independence is a challenge without the tremendous strain of separation and fear intruding on every thought. 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, loooooooooooooong 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?” Furthermore, your emotions have taken a toll from the relentless stress, worry and sleep deprivation, so it often becomes even more difficult to manage “events” that may have been routine in the past. Other issues arise at this point — such as whether or not your child will be able to attend any of the school year. Possibly, the school can arrange for home tutoring until such time as

your child has a strong enough immune system to attend classes. Meet with your child's doctors and teachers to discuss the best options — to be physically safe as well as emotionally and socially supported. You may find that your family's social life is somewhat compromised at this stage. You may have been advised to keep visitors to a minimum. Siblings may not be able to entertain friends at your home. Often, with very young children, nursery school becomes a thing of the past as you want to avoid bringing germs into the home from other small children. The best way to manage through these challenges is to again ask for and accept the support of others. Play dates may have to be at other people's homes, with fewer children or people you know very well. And cling to the fact that eventually your recovering child's immune system will develop strongly, like that of a newborn baby's — and you will be able to enjoy the company of others, both in public and in your 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. Whether your experience is this severe or not, the lesson learned is that the transplant process requires recovery for not only your child, but for you and your family. How you choose to treat your challenges and issues is a personal decision, but one that requires serious consideration. 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 join the National Marrow Donor Program Registry as a potential donor. You may help other families cope with challenging situations who follow your example. Be available as a resource to parents, children or organizations who 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.

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*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.

My 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 returned 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, Michigan 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 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 someone was willing to promote a “family of strangers” campaign in their community, he or she would find people willing to volunteer time 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.

- Having a regular schedule of people to prepare meals, do laundry, go shopping, or help with house cleaning.
- Having 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 5, 7, and 9. 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?” 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 try not to be a joy stealer. Don't be too proud to accept help. Think of the times when you were able to help 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.

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*The Caregiver
Journey*

*A Perspective on
Unrelated Donor Transplants*



by Kate Montgomery



Kate Montgomery, MSW, LICSW, is a Manager in the Office of Patient Advocacy, National Marrow Donor Program. She provided individual, family and group counseling while working for ten years as an oncology social worker at Fairview University Medical Center, first in the GYN Oncology Program and then for six years in the Blood and Marrow Transplant Program. In her current role at the Office of Patient Advocacy, she works to improve access to information and services for patients and families who may need an unrelated stem cell transplant. She is a member of the Association of Oncology Social Workers.

Imagine for a moment someone told you that for the next several months you were going to put your life on hold. You would leave your job, postpone all current activities and family responsibilities and move to a new address. If you have accepted the role of primary medical caregiver for someone in your family, you are probably making some of these changes right now. Being a caregiver for a family member receiving an unrelated donor stem cell transplant brings this unlikely scenario to life. This rigorous treatment doesn't happen without a caregiver standing by the patient, ready to help.

While an unrelated donor stem cell transplant is a source of hope for patients looking for a life-saving cure, it brings a unique set of issues and challenges. Compared to a related donor transplant, an unrelated donor transplant can mean added time locating a well-matched donor, additional risks, and sometimes, a longer and more difficult recovery. You may also have to go to a hospital that is farther from home, away from the familiar nurses and doctors, friends and family.

As a caregiver for someone who may be undergoing an unrelated donor transplant, you play a crucial role to the patient's survival and recovery. You will be challenged daily and, at times, will feel stressed by these challenges. Ultimately, you will find that you are not alone. You have people you can contact for help. An important resource is the National Marrow Donor Program® (NMDP) and its Office of Patient Advocacy.

The National Marrow Donor Program

The NMDP facilitates more than 2,000 unrelated bone marrow/stem cell transplants each year for patients with life-threatening diseases who do not have matching donors in their families. About 70% of patients needing a stem cell transplant will have to search for an unrelated volunteer donor. To aid these patients, Congress authorized the creation of a national registry of volunteer stem cell donors. The NMDP operates this registry.

Nearly 5 million people around the world are currently signed up to be volunteer donors through the NMDP Registry. These volunteers have been tested and had their tissue type entered on the Registry. They have agreed to be listed on the Registry until their 61st birthday, and are willing to donate to any patient, anywhere in the world.

From this willing pool of donors, more than 15,000 transplants have been performed to date. These transplants gave 15,000 people a second chance at life.

The Search for an Unrelated Donor

Compared to the process for related donor transplants, the unrelated donor transplant process usually takes more time, in part, because of the search for a suitable donor. Depending on the type of disease the patient has, there may be a very limited window

of opportunity to find a matched unrelated donor. This causes increased worry and tension for all the family members. You and the patient may feel sad one moment and angry the next. As a caregiver, you may feel a sense of urgency and want to make sure that everyone involved is doing everything within their power to find a donor. Your biggest role during this time is to provide support for the patient.

The wait can be frustrating. You may feel a need to start your own recruitment drive to find a donor. And while helping to increase the Registry through donor drives is one of the best ways to help the greatest number of patients over time, **it is extremely unlikely you will find a matched donor for the patient through your own efforts.** If there is going to be a match, the donor is most likely already on the Registry.

There are several reasons why the search for a donor takes time. When the doctor first checks the Registry for a match, he or she asks for a **preliminary search**—a summary review of how many potential donors may match the patient. The next step is a **formal search**. At this point, potential donors are actually contacted and further testing is done. During the formal search, the patient's insurance company or family agrees to pay for the testing required to find a matched donor and pay for the transplant itself. The family or patient usually signs a consent form with the transplant center to start this testing.

This is a good time to contact the NMDP's Office of Patient Advocacy, if you haven't already. There, trained staff can answer questions and help you understand the unrelated donor search process. The Office of Patient Advocacy can also help you answer questions about insurance or other patient-support resources.

When potential donors are identified through the NMDP, they are contacted to determine their willingness to donate and to request another blood sample for further testing. This higher level of testing is required to help minimize risks to the patient. Often several donors are tested to find the best possible match. As the caregiver, you share in the patient's struggle between hope, disappointment, patience and frustration throughout the search process. It helps to talk to people who understand this process and can explain it to you, such as the social workers and transplant coordinators at the medical center or case managers at the Office of Patient Advocacy.

A Donor is Found

It is a great relief when a matched donor is identified and agrees to donate. But this opens the way for a new set of concerns associated with the transplant and recovery. You may wonder how you can help the patient keep his or her spirits up. At times, you might find it tough to keep your own spirits up. There's no easy answer. It helps to share laughter, memories and even tears that help both you and the patient keep your hope for a life-saving cure alive. You may want to read about other people's transplant and

donation stories on the NMDP Web site at www.marlow.org.

Walking through the door of the hospital for the transplant stay is a profound moment, full of hope and fear, relief and anticipation. You may wonder, how will the patient's body respond to these cells? Will this be the cure, the end to this awful disease? Who donated these stem cells? Many of these questions may be in the minds of both you and the patient as you begin the transplant stay.

Risks After Unrelated Donor Transplants

After the transplant, many patients experience some degree of graft-versus-host disease (GVHD). GVHD means that graft, or the new stem cells (the cells from the donor) identify the patient (host) as foreign. This identification activates the new stem cells' immune response, similar to when your immune system fights and kills bacteria. For some patients who have a disease such as leukemia, some GVHD can be beneficial, because it kills leukemia cells. However, too much GVHD makes recovery from transplant more difficult. And until the patient's immune system recovers, there is an increased risk of life-threatening infections. The risk of GVHD is generally higher in an unrelated transplant than a related transplant with a perfect or nearly-perfect match.

The Recovery Process

After receiving the new stem cells, the days of waiting for the cells to grow and engraft begin. The recovery from unrelated donor stem cell transplant may be longer and more complicated than you expected.

While you're at the hospital, you may come in contact with other transplant patients and their families. Remember that each transplant experience is different. You may hear that a patient down the hall is recovering quickly and is ready to go home. You're happy for them, but it doesn't seem fair. Then you might share in the sadness of another family whose loved one is not doing well. It can be hard.

The changes you may see in the patient you are caring for might be dramatic. There may be hair loss and other appearance changes, as well as emotional swings from certain medications he or she may be taking. Since you see the patient every day, the changes are gradual and you'll have time to adjust. It's a good idea to prepare visitors for what to expect. This is especially true for children. Consider sending photos and videos back and forth between hospital and home to keep children connected and ready to deal with any temporary changes the patient has in appearance or functioning.

Leaving the Hospital

When the patient's cells start to grow and the white cell count increases — which shows that a fledgling immune system is developing — you can start planning to leave the hospital. You might be worried that it's too early and that you can't possibly handle the

caregiving responsibilities. It comes down to simply doing the best you can each day. You'll find that even when it seems impossible, the necessary tasks still get done.

Full recovery after an unrelated stem cell transplant may take a year or more. For the patient and his or her caregiver, this is a long journey. You may become exhausted with your caregiving responsibilities. That's to be expected. You will be eager to resume your old life — to pick up where you left off at work or school — but it's often hard to see beyond the day-to-day demands. Yet after this journey is finally done, you will have learned more about inner strength and the power of hope than you ever thought possible.

A Note About the Donor

Becoming a marrow donor can be a lot to ask. Donors must take time away from work and undergo a medical procedure that involves needles and some discomfort. In certain situations, donors are even asked to give a second donation for the same person. Yet donors are everyday heroes. Most donors are very committed, and they care about the unknown patient whom they may never hear from or meet.

The volunteer donor process is confidential to protect the donor and the patient. Sometimes the donor and the patient meet, and sometimes they don't. Some donors want to remain anonymous. Some countries have different philosophies and laws that must be followed in order to be able to exchange life-saving stem cells. In some countries, the donor and recipient of the stem cells are never allowed to meet. The patient may never learn the identity of his or her donor, or even where that person lives. If the donor and patient are both from the United States, NMDP policy allows them to meet after one year, if both parties want to do so.

Your life and the life of the patient will have been touched by a volunteer donor. This is a person who was willing to give the gift of hope — a second chance at life.

The Journey Completed

When you survive the journey of unrelated donor stem cell transplants as a patient or a caregiver, you'll be a changed person. You are a hero for this patient as you put your life on hold temporarily to help someone in need and to be by their side.

For more information about the National Marrow Donor Program's Office of Patient Advocacy, please call 888-999-6743. You can also visit our Web site at www.marrow.org.

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Symptom Management for Caregivers

An Oncology Nurse's Perspective



by Maria Thompson



Maria Thompson, ANP-c, is an Adult Nurse Practitioner Certified and Critical Care Registered Nurse who has worked at Duke University Medical Center since 1999. A native of Florida, she has lived in North Carolina for eight years. She and her husband enjoy traveling, running, and their cats.

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 information 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. It is often helpful to eat a small amount of food prior to taking pills. 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 their 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*, they will be started on an oral antibiotic and informed to avoid anti-diarrhea medications so that the infection can be cleared from their 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 they have 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 they are 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 trivial. Your health care provider will then treat the pain according to type, severity, and location and may obtain 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 dosage 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 them 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 to avoid developing serious infections. 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

High-dose chemotherapy will cause the patient to lose their white blood cells. The patient will remain neutropenic for approximately 2-3 weeks. When a patient has no white blood cells, they have no immune system to protect them 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 them 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 little or 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

Bleeding is related to the low platelet count 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 to not 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 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. It is recommended to always begin with light exercise and advance as the patient tolerates. Fatigue and energy levels generally improve with time. 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 the oral solutions as prescribed by their health care provider will help with the pain and help 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 rashes. 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 is a reaction of the donor cells to the patient. It can occur acutely in three different forms including: the skin, the gut and the liver. GVHD of the skin presents as a red 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 does 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 patients have successfully engrafted (have recovered their white blood cell counts) after transplant, it is usually time for the patient 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 they have returned home. Exercise should be increased gradually and only as the patient tolerates. Post-transplant complications may sometimes occur once the patient has returned home. Therefore, it is very important that the patient notify their local physician and their bone marrow transplant team immediately, if any changes or problems should occur.

Upon discharge, the patient will be scheduled for follow-up visits with their bone marrow transplant team. Each institution will have different post-transplant schedules that will be individualized to their specific patient needs. It is essential that patients keep these appointments and have 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. 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.

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*How to Be a
Successful Family
Caregiver*

An Advocate's Perspective



by Suzanne Mintz



Suzanne Mintz is the President and Co-founder of the National Family Caregivers Association, the nation's only caregiver grassroots organization that reaches across the boundaries of diagnosis, age and relationship to educate and speak up for all of America's family caregivers. She is the author of Love, Honor & Value—A Family Caregiver Speaks Out About the Choices and Challenges of Caregiving.

The following information has been excerpted and edited from a series of agency brochures available from the National Family Caregivers Association. For more information on family caregiving: www.nfcacares.org or call 800-896-3650.

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

Asking 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 feeling 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 a 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

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One Patient's Patient Caregiver

A Patient's Perspective



by Macklin Smith



Macklin Smith, PhD, teaches English literature and creative writing (poetry) at the University of Michigan. He is also an absurdly obsessed birder, who has traveled to the outer Aleutians, Newfoundland, and other North American hot spots in search of rarities. In order to maintain some semblance of spiritual fitness, he also practices yoga and meditation. Macklin's transplant, for Chronic Myelogenous Leukemia, took place at the University of Michigan Comprehensive Cancer Center on March 20th 1997, the day of the vernal equinox, and he remains grateful for life, good health, and the support of all involved. His caregiver Lynette and he have been married since 1987. They met in a yoga class. Macklin has recently published a book of poems, *Transplants*, available from Shaman Drum Books.

It's not easy to remember what it was like coming home from the hospital, settling into the chimerical routine of lethargy and sharp emotions, bad sleep and listlessness, anxiety and hope. Not only was my brain befuddled by the chemotherapy, but the anti-nausea drug Ativan, I later found out, was also an amnesiac. Trying to remember how I related at that time to my caregiver, my wife Lynette, is an iffy prospect. She remembers events and circumstances much better than I do, but of course only I can remember—or try to remember—what it was like being me as a patient.

I know I was grateful to have gotten out of the hospital and back home. I was hopeful that I might actually make it. I was dutifully obsessed with all the details of medication, sanitation, and gestation that were required if I were to continue on as a really slowly recovering cancer patient. I also know I was utterly relieved to be back with my wife in our own familiar environment. I remember being happy to see our dog Sadie again, even though I wasn't sure she recognized me right away, and even though I was worried about petting her. Our house, I remember, smelled very clean, almost antiseptic, no, actually antiseptic, and there were things missing—ah, all the plants were gone! I remember suddenly staring into space and needing to lie down on the nearby couch.

I couldn't do much on my own. Sometimes I felt I could do hardly anything on my own, and I resented the fact that Lynette, my dear wife and loving caregiver, was telling me what to do and why to do it. To eat, for example, because I had to eat to gain stamina, maintain my weight, and stay out of the hospital. Eat, eat, eat, eat, even though I wasn't hungry and the food proved, depending on the day, either unappetizing or nauseating. I wasn't much fun to be with. I was self-absorbed and indifferent to my surroundings. I was bored and boring. I felt guilty that I was so much trouble for her; at the same time, I felt grateful that she was doing so much for me. I also felt angry at being so helpless. All of these mixed feelings were probably quite intense, but my experience of them was dulled by drugs and fatigue.

For months after the transplant, I did what I could to get better, stronger, healthier, which for me also meant putting it behind me. I wanted to get on with life, get back to work, get out into the field, go to south Texas, Arizona, Alaska for some serious birding adventures. I did yoga and meditation to stay in the present moment, and I made plans for the future. I avoided the recent past. I think I wanted to avoid the past because it was, first of all, terrifying, and second, so terribly boring. Mine was the story of Lazarus, weakly paraphrased, but even for Lazarus the miracle seemed more bewildering than amazing.

I am among other things a writer, and all during the period from diagnosis to remission, people told me that I ought to be keeping a journal: this was an unusual

experience, I should be recording it. But I didn't want to write about it, I just wanted to live. After the transplant, I don't think I could have written anything about the process anyway, even had I wished. I took lots of books to the hospital and couldn't read any of them there. I couldn't read at home either. The only writing I could manage took the form of email messages. Like most other transplant patients, I was experiencing chemobrain.

Only much later, without actually intending to do so and almost against my will, did I start writing poems about the transplant experience. This began on my second anniversary. Collected now in a book called Transplant, these poems deal with everything from the shock of the leukemia diagnosis to the joys of remission. There are poems about the donor search, about Cytosin, about walking around with tubes and bottles, about mouth sores, and about hospital yoga. Here is a poem that deals with coming home:

Discharged

Since I had a lingering infection in my leg I got instructions
In how to flush and clean the various connections
For my home IV. Then we both got instructions and commiseration

On what would be possible, or rather not possible, with our sex life
In the coming period, from our favorite nurse Lea,
Who was very gracious and funny about it, and also quite sexy

Incidentally, I thought. We got instructions about diet
Too: no restaurant salads, no unwashed fruit, no sushi, microwave
All leftovers, wash hands, wash knives, wash cutting boards,

And then it was time to go. And believe it or not I felt nostalgia,
Nostalgia for Lea, Terry, Terri, Voravit, and even Dr. Adams,
And that young slight black man whose name I never heard, midnight

To eight, who would come in speaking his phrase in a voice
Like Nat King Cole's voice, and with sweet prophecy
Night after night would say, "Vital signs, vital signs."

It took two trips down the elevator to clear out all
My accumulated possessions. We left room 111, 8-A,
Behind for good, I earnestly hope, although we do return

At Christmastime with gifts and sentiments for the staff;
Last year it was clementines and some modest earrings for Lea
And a six-pack of Bell's Amber Ale for Terry,

I can't remember what else, but these people were great.
Lynette and Barbara went to get the car while I waited outside,
Smelling cigarettes for the first time in a month. Then home,

Where our friends and relatives had sanitized the house
Of dust and pollen and unruly plants, and where my dog Sadie
Barely recognized me, but where Lynette and I could sleep in bed.

As this poem suggests, the transition from hospital to home is a little disorienting. During the final days in the BMT ward, we patients become increasingly eager to leave. Antsy. My own departure was delayed by a leg infection, and when I first saw the red sepsis snaking up my vein I wanted to go home so badly that I considered (briefly) concealing this perilous fact from the nurses. However, no matter how eager we are to get out of the hospital, we come to feel safe there. We are cared for. We are cared for by fantastic, competent, wonderful professionals. I liked all my nurses and doctors, and I came to depend on them. I had turned my private room into a home away from home, stuffed with various possessions and knick-knacks. Would I be cared for well enough at home by my wife, however well-intentioned she was? I wasn't sure—even though she had already spent two full days with friends and relatives painting, cleaning, and otherwise creating a safe environment for me.

Several of our friends and colleagues cooked casseroles for us, ran errands, and did some household chores. But Lynette did most of the work. She drove me often to the hospital for clinic visits, she shopped, she cleaned vegetables and cutting boards and knives, she scrubbed surfaces, she vacuumed. Whereas we had previously split the household chores fifty-fifty, she now did all of them. She also kept on working, at a reduced load. This was the sort of generosity we could expect from each other if either of us was sick, but my sickness was lasting for weeks and weeks, and I wouldn't be functioning fully for months. Yet for the most part she received little acknowledgement for her caregiving. I was the center of attention. I was being given labels like “warrior,” “courageous,” “survivor.” Although everyone thought she was a real trooper in giving so much support, Lynette was getting very little support herself.

Even by me. Even though I recognized at the time the inequity in the situation, it seemed inevitable. What could I do about it? Even though I talked about and sometimes thanked her for all she was doing, nothing I could say could change the fact that she was going to be overworked and emotionally stressed. It was inevitable. It was built into the contract of patient and caregiver. It was in the job description. In other words, I was taking her love and care for granted. I am not proud of this attitude in retrospect, but I don't want to gloss over it. The following poem is indicative of my experience as patient:

Watching the Lilacs Grow

The first weeks home, flat on my back on the living room couch,
Short slow walks with Sadie,
Nausea, no appetite, almost force-feeding myself
To gain stamina, no weight loss allowed, doctors' orders,
Clinic visits twice a week, my face the color and consistency
Of beige naugahyde, bald as an ant.
When I wasn't sleeping I was complaining loud or silent,

And all this time the lilacs were coming into bloom
Then leafing out, so beautiful, something I'd never ever seen
Before, in that I don't usually spend days on the couch,
It was like a time-lapse movie in real time
Or a meditation retreat. Then the Mourning Doves
Started carrying nesting material into the highest lilac,
And things got a little more lively. Not much.

Note here my persona's historically accurate self-absorption. Note that the biweekly clinic visits are mentioned, but that there is no mention of the driver!

Lynette did get some much-needed emotional support at her job, where as a dental hygienist she works closely with colleagues and sees a steady procession of familiar patients. She would often be asked how I was doing, and occasionally she would be asked how she was doing. Although it may have seemed almost heretical, the idea emerged that she deserved a vacation. So once it became clear that I was probably out of the woods, that the clinical indices of this and that level of this and that had stabilized, she decided that it would be okay for her to travel a hundred miles from home and to stay away for two nights, to attend a yoga conference in Kalamazoo. For her at this point in time, going to Kalamazoo felt like going to the Bahamas. But it took planning. She couldn't just go. We had to make arrangements for this, as I couldn't be left alone. So I called an old friend, and he eagerly served as my substitute caregiver:

Michael

My best friend from high school visited so Lynette could go to a yoga workshop and take a break from all this. Michael, like the archangel, is an aggressive friend. It may be his personality, or it may have originated when we were in coastal Maine together for a month painting his Dad's house, eating illegal lobsters and playing cards. This was pre-beer. We drank Lapsang Suchong tea. Once we played cribbage all night, the agreement being that the loser at dawn would carry a designated large rock across the mudflat then and there. He lost, he squinted, he squished.

Michael, the zero-proof beverage expert, had me drinking twice as many Arizonas,

Vernors, ice waters, and herbal teas than I needed, called me “baldy” at every chance, snapped me up for walks I didn’t want to take, and made numerous unwanted appearances at all hours. We drove to Monroe to see the bronze Custer equestrian, which he needed to photograph because he is also the foremost expert on public sculpture in America, and because he needed to deduct this trip under his Schedule C travel tax shelter, which meant documenting a statue by the minor master Edward Clark Potter, on whose career I received a free lecture. My first long drive, and I felt like seaweed at low tide. What a pal.

As is probably clear here, I love Michael but I love Lynette more. Although grateful for Michael’s care—and grateful for his having enabled Lynette to get away for awhile, I was happy and more comfortable when she returned. Because she’s my wife and we know each other so well, and because she was my caregiver, and because maybe there can only be one primary caregiver, I wanted her with me. It was love, and it was dependency. For richer, for poorer, in sickness and in health....

However, the model of the caregiver is not a very good model for marriage, at least not for our marriage. We had struggled off and on with co-dependency issues in the past, but here was a case of structural co-dependency whose co-ness was almost entirely gone, whose dependency was almost entirely one-way. She could not go on giving like this and remain mentally healthy. Something had to give. Luckily it was my extreme neediness. Because my medical recovery was relatively uncomplicated, and because I myself felt discomfort at being constantly cared for, my neediness could diminish. As I got stronger and healthier, freer from risk, more able to fend for myself, her life could turn more normal. She could spend an evening with friends, or resume her yoga teaching, or work longer hours. I could feel more useful. Eventually I could focus on things I wanted to do besides just staying alive and getting healthier.

Meanwhile I could cultivate other friendships. With John, I could go on longer and longer dog walks, for example. I’m not sure that these were pure friendships, for just as my wife was doubling as my caregiver, my friends were doubling as specialized health providers. Thus John and I would walk Andy and Sadie because we liked hanging out together, but we would do this also because both of us agreed, implicitly, that John was going to be my stamina specialist.

Another friend became my chemobrain therapist:

Jonathan

Once a week he would take time out from his Spinoza
And come over here to activate my weak mind at chess.
Jonathan also plays with Rudi Arnheim, the pioneering
Film theoretician and art critic. It’s intellectual

Fun for them. They never play through their endgames;

They spar over space and pieces, then agree to a draw.

Chess is strictly spatial, schematic, and silent, true,

But the main idea is to outsmart your opponent and win.

The main verbs in Chess Life for this sort of activity

Are: smash, kill, trap, humiliate, wear down, and outfox,

And these are the more civilized verbs, not the verbs

In the actual minds of chess players, who sit violently

Imagining the deaths of their opponents, higher rated

Or lower rated. You can feel like an assassin,

Or you can feel like someone stomping a cockroach.

I've never actually played in a tournament, however,

And neither has Jonathan. We just play recreationally,

But we're pretty good players, we have some potential.

He plays his Chessmaster-6000, I work through Chess Life,

Both of us determined to smash and kill each other.

Jonathan is more of a trap and humiliate player,

Whereas I am more of a wear down and outfox player.

He initiates his power Judit Polgar opening, but I sit back

Like Karpov, serene, knowing I will wear down his useless

Attack and ultimately outfox him, a pawn up, in the endgame.

Just as chess sublimates warfare, this particular chess friendship sublimated my struggle against cancer. If I could learn to think again, get up off the couch and move, make good tactical moves with what I had available, maybe I could outfox my leukemia.

Or that was the idea. I'm still not sure how much my own play had to do with all this. To survive the ordeal, I needed not only my will to struggle "with a positive attitude," but the combined efforts of my medical providers, wife and caregiver, friends, colleagues, and even insurance company—as well as luck and, probably, grace. How many times did Lynette kill germs that might have killed me? How many times did she remind me to eat, the cumulative effect of which was that I kept eating, against my own volition? However isolated it can feel to be a transplant patient, I knew very well that my recovery depended largely on others.

It's hard to measure the value of caregiving in a life-and-death situation. The costs were evident enough, though, even to me in my debilitated state of mind. Lynette seemed tired, haggard, anxious, wistful, quiet. Although she never complained about such indignities as nighttime nausea or profuse sweating, I could tell that I had lost some of

my physical attraction.... Nor, of course, was I even minimally competent as a sexual partner for quite a long time.

But it was mainly the mental strain that took its toll. Here I refer not only to the precariousness of my health and the stress that that caused. My overall competence was vastly reduced, and so was my judgment about my competence. At times I willfully assumed that I could do something that I couldn't, or I did things that I shouldn't have done. During the first month home, our cat died suddenly, and just as suddenly I put on my facemask, grabbed a shovel, and began digging a grave for Nemo. This was a no-no: no garden work permitted, no handling of dirt. But I just charged out and did it; I was upset, and I didn't care what happened. Within this context of bad judgment, I exercised further bad judgment by forgetting to calculate the particular size of not-so-little dead Nemo, his limbs extended by rigor mortis. So I had to enlarge the grave. The day continued like that. For a couple of hours I had dropped my guard completely, and I didn't care. I was tired of being cautious. I was tired of being disabled.

On another occasion—a celebratory occasion, not a sad one—I also overextended myself:

Hockey

It's the night of the last game of the Stanley Cup sweep and we know
The Wings will win

So I go out and get the shrimp and octopus and bread and greens for
Our TV dinner

Even though I can barely drive and shouldn't be driving at all but
I need to shop early

The octopus being a sacred symbolic food from back when the playoffs
Took but eight games

If I don't get to Monahan's other fans will buy out all the octopi
To fling on the ice

Which must be done during the final minutes of the rare series when
We win the Cup

And shrimp because we all like to eat shrimp and even I feel like
Eating shrimp tonight

However I overcook the octopus so that it acquires the consistency
Of a warm puck

And I mistake the frozen raw shrimp for cooked and even sushi lovers
Won't eat raw shrimp

So I figure I should go cook the shrimp and then quit cooking and
Enjoy the game

So there I was, driving when ordered not to drive, and no longer the master chef I used to consider myself. I know it was hard for Lynette to see me fumbling around and doing foolish things. She didn't want to nag, and she wanted me to feel increasingly competent and confident, so at times she could only witness such behavior with wry detachment.

Looking back on the experience of recovery, I can see things in clearer perspective. Neither of us was adequately prepared for the huge burden—and huge privilege—that caregiving would entail. I have already mentioned the problem of no one adequately caring for the caregiver. Although I am not sure just what we could or should have done differently to prepare ourselves for this, I think it would have been a good idea to have somehow proactively set up some supports for Lynette. Perhaps this might have come from a hospital-sponsored support group. Perhaps it might also have come from a clearer plan drawn up with the help of a social worker. Perhaps we would have been well advised to concentrate not just on the disease process and the medical protocols for post-transplant care, but on our emotional and spiritual well-being.

One thing I certainly didn't understand was that caregiving begins immediately after the cancer diagnosis. My very first response, aside from shock, was to exclude Lynette: I thought that I should visit and consult with my physician alone. I am ashamed of my knee-jerk selfishness, but I mention it here to address what was a systemic problem for us: the relegation of the caregiver to secondary status. She of course protested my idea and accompanied me to all the office visits, for we both realized fairly soon that what was happening to me was going to affect her. It was her business too. However, our timing was off. I was very reluctant to tell friends and family immediately, which meant (we felt) that she couldn't talk about it either. This was very hard on Lynette, being forced, as it were, to keep this secret for my sake.

If I could do this over again—God forbid—I would insist that we take a vacation together to a destination of Lynette's choosing, not mine. I would also encourage her to take the opportunity to reward herself and pamper herself in every conceivable way—before things got hairy. And I would encourage her to continue doing so, as much as possible, during and after the ordeal of recovery.

I am guessing that the patient-caregiver dynamic has certain commonalities no matter who is involved. But different personalities are going to handle things somewhat differently. In our case, Lynette happens to be a Mediator. Like others of this type, she does a great job of helping and supporting others, and she often relies on others for her own sense of self; but she becomes very vulnerable to self-forgetting. I happen to be a Tragic Romantic, also known as Creative/Depressive. Like others of this type, I have

problems with envy and melancholy, and I experience a strong need to be special. So this whole episode was a terrific opportunity for both of us! I could be about as special as possible, undergoing a risky, heroic procedure, and Lynette could be, accordingly, about as supportive as possible.

This was not all bad. It worked. Indeed, I was a wonderful, special patient, and Lynette was a wonderful caregiver. Still, the extreme conditions surrounding bone marrow transplant were not easily sustainable. Each of us needed special healing after the healing. Each of us availed ourselves of individual and joint therapy in order to work out some of the lingering issues that arose from this extremely codependent experience.

In conclusion, I would like to offer a quiet ode to my caregiver. Here we can smile and laugh and make love again, and the plants are back in the house:

Lynette

The way she turns her mouth up squinting into her camera,
Her capacity
To see through things generously in herself and the world,
Even in me;
Usually has three dozen tropical plants and flower pots
In our house
And waters them on schedule before walking off to work
Monday mornings.
She has a whole desk drawer full of funny birthday cards
And postcards,
Yet she can solve and resolve any conceptual issue at hand
Just like that,
And when I keep shoving poems under her nose she is always
My best reader.
She can press paper, garden, bake apple pies, make pizza and
Belly-dance;
Makes love slowly, and she has hundreds of dental patients
Who love her
Too, and her yoga students, me one of them, who admire her
Good teachings
And her easy humor. Her smile in response to love. Her
Smile, playing,
And for me her inevitable laughter at her own jokes, always
Hilarious.

Resource Listing

Note: This Resource Listing includes organizations that provide support and information for caregivers. You may find the names of BMT patient service organizations in the following two booklets available from the nbmtLink:

A Resource Guide for Bone Marrow/Stem Cell Transplant, Friends Helping Friends

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

Organizations

National Respite Locator Service

800 Eastowne Dr., #105
Chapel Hill, NC 27514
800-773-5433
www.respitelocator.org

BMT Infonet

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

Family Caregivers Alliance

690 Market Street, #600
San Francisco, CA 94104
415-434-3388
Email: info@caregiver.org
www.caregiver.org

Family Voices

3411 Candelaria NE, #M
Albuquerque, NM 87107
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
732-418-1811
info@friendshealthconnection.org
www.friendshealthconnection.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

The Leukemia & Lymphoma Society

1311 Mamaroneck Ave.
White Plains, NY 10605
800-955-4572
Email: infocenter@leukemia-lymphoma.org
www.leukemia-lymphoma.org

National Alliance for Caregiving

4720 Montgomery Lane, 5th Floor
Bethesda, MD 20814
301-718-8444
Email: 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
Email: nbmtlink@aol.com
www.nbmtlink.org

National Family Caregivers Association

10400 Connecticut Ave, #500
Kensington, MD 20895
800-896-3650
Email: info@nfcacares.org
www.nfcacares.org

National Marrow Donor Program (NMDP)

3001 Broadway, NE, #500
Minneapolis, MN 55413
800-MARROW or 800-526-7809
888-999-6743 (Office of Patient Advocacy)

National Organization for Empowering Caregivers

425 W. 23rd Street, #9B
New York, New York 10011
212-807-1204
Email: info@nofec.org
www.nofec.org

Patient Advocate Foundation

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

Rosalyn Carter Institute

Georgia Southwestern State University
800 Wheatley Street
Americus, GA 31709
229-928-1234
www.rci.gsw.edu

Well Spouse Foundation

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

Books

- Across The Chasm, A Caregiver's Story** by Naomi Zigmund-Fisher (BMT Infonet)
- American College of Physicians Home Care Guide for Cancer: How to Care for Family and Friends at Home, 1994**
- A Resource Guide for Bone Marrow/Stem Cell Transplant** (nbmtLink)
- Cancer as a Turning Point: A Handbook for People with Cancer, Their Families, and Health Professionals** by Lawrence LeShan
- Caring and Competent Caregivers** by R. Moroney, P. Dokecki, J. Gates, K. Haynes, N. Noshier
- Caring for You, Caring for Me, Education and Support for Caregivers** by D. Haigler, K. Mims, and J. Nottingham
- The Caregiver's Companion** by Theola Jones
- The Caregiver Helpbook** by V. Schmall, M. Cleveland, M. Sturdevant
- Caregiver's Reprieve: A Guide to Emotional Survival When You're Caring for Someone You Love** by Avrene Brandt
- Caregiving: A Step-by-Step Resource for Caring for the Person with Cancer at Home** by Peter Houts and Julia Bucher
- Caregiving For Yourself While Caring For Others** by Lawrence Brammer, PhD
- Caregiving Sourcebook** by Joyce Brennfleck Shannon
- Caregiving: The Spiritual Journey of Love, Loss and Renewal** by Beth McLeod
- Childhood Leukemia: A Guide for Families, Friends and Caregivers** by Nancy Keene
- Daily Comforts for Caregivers** by Pat Samples
- Gifts of Caregiving** by Connie Goldman
- Helping Yourself Help Others: A Book for Caregivers** by Rosalyn Carter
- Homecare Management of the Blood Cell Transplant Patient** by Cathy H. Kelley, (editor) Susan Randolph, Linda McBride
- Living With Childhood Cancer: A Practical Guide to Help Families Cope** by Leigh Woznick
- Love, Honor and Value, A Family Caregiver Speaks Out about the Choices and Challenges of Caregiving** by Suzanne Mintz
- Share Care-How to Organize a Group to Care for Someone Who Is Seriously Ill** by Cappy Capossela and Sheila Warnock
- Supportive Cancer Care: The Complete Guide for Patients and the Families** by Ernest H.,M.D. Rosenbaum, et al
- Surviving Your Spouse's Chronic Illness: A Compassionate Guide** by Chris McGonigle
- The Professional and Family Caregiver-Dilemmas, Rewards and New Directions** by Jack and Joanne Nottingham
- When Life Becomes Precious: A Guide for Loved Ones and Friends of Cancer Patients** by Elise NeeDell Babcock

Videos

- The Caregiver's Journey** by Geila Barr-David (5 tape series), Aquarius Health Care Videos
- Educated Caregiver** by Nancy Van Camp (3 tape series) LifeView Resources, Inc.
- The Grit and Grace of Being a Caregiver: Maintaining Your Balance as You Care for Others,** Willowgreen Productions
- Home Nursing Care: A Practical Guild for Family Caregivers** by G. Timpane and M. Wholey, AYA, Inc.
- The New Normal: Life After Bone Marrow/Stem Cell Transplant** (nbmtLink)

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 like hospitals or medical associations. Proceed with caution when searching on the Internet and 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 Internet sites, check the address (URL). The final segment of the address offers a general idea of who is sponsoring the Web site. Examples include:

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

Some helpful Web sites for caregivers include the following:

American Association for Retired Persons
www.aarp.org/caregive

BMT Infonet
www.bmtinfonet.org

Cancer Care, Inc.
www.cancercares.org

Caregivers Listserv
www.acor.org

Caregiver's Marketplace
www.caregiversmarketplace.com

Caregiving.com
www.caregiving.com

Kids Konneted
www.kidskonneted.org

National Alliance for Caregiving
www.caregiving.org

National Bone Marrow Transplant Link
www.nbmtlink.org

National Family Caregivers Association
www.nfcacares.org

National Organization for Empowering Caregivers
www.nofec.org

Strength for Caring
www.strengthforcaring.com

The Never-Ending Squirrel Tale
www.squirreltales.com

Today's Caregiver Magazine
www.caregiver.com

Well Spouse Foundation
www.wellspouse.org



National Bone Marrow Transplant Link

Resources and Reassurance When You Need Them Most

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

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

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

248-358-1886

Fax: 248-358-1889

Toll Free: 800-546-5268

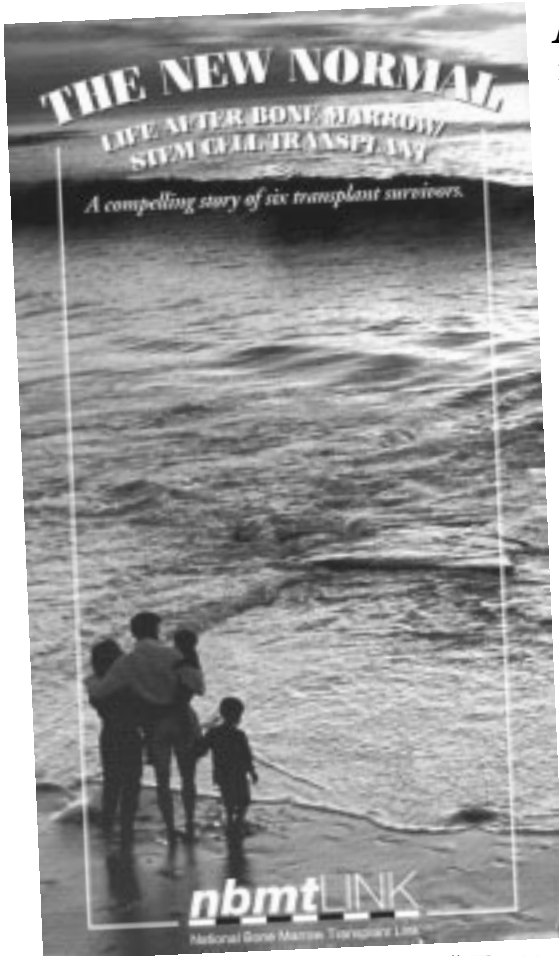
E-mail: nbmtlink@aol.com

www.nbmtlink.org

“A Second Chance at Life Is Our First Priority”

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

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



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

Some thoughts on The New Normal...

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

- Susan Vreeland, BMT survivor, author

“The New Normal is encouraging and inspiring.

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

- Richard P. McQuellon, Ph.D.

Director, Psychosocial Oncology

Wake Forest University/Baptist Medical Center

Please Contact:

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

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

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