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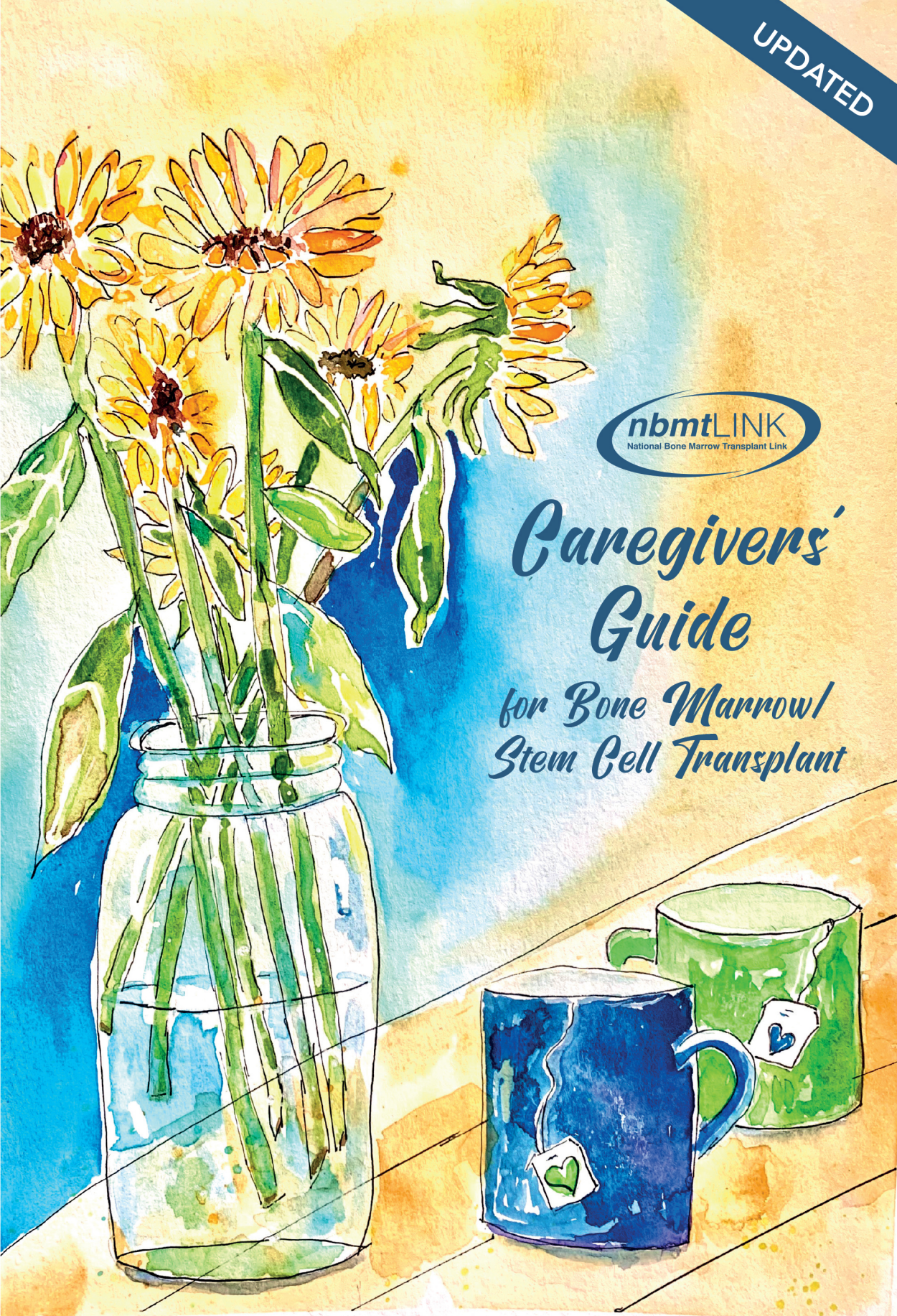

nbmtLINK
National Bone Marrow Transplant Link

Caregivers' Guide

for Bone Marrow/ Stem Cell Transplant

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

- Rosalyn Carter, Helping Yourself to Help Others

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

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

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

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

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Marrow Masters podcasts cover topics sure to help you throughout your transplant experience.

With multiple seasons on topics such as caregiving and chronic Graft Versus Host Disease (cGVHD), our podcasts will help you and your loved ones feel more supported and less alone, better educated, and equipped to advocate.

Survivors and caregivers have downloaded our podcasts more than 46,000 times to date.

Get comfy and tune in by visiting marrowmasters.simplecast.com.

We gratefully acknowledge our current Link Partners for all they do to support our efforts, including the updating of books such as this one.

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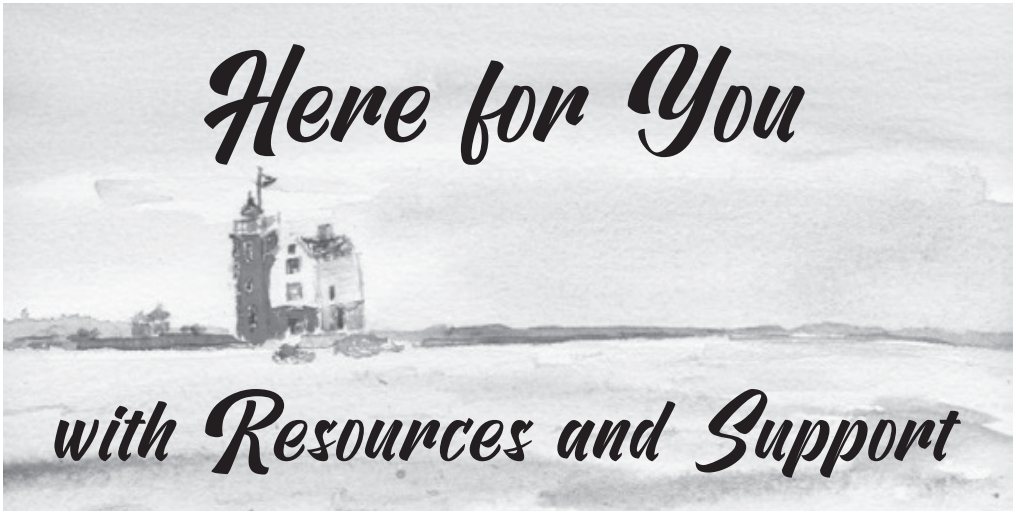

The National Bone Marrow Transplant Link (nbmtLINK), established in 1992, strives to help patients, caregivers and families cope with the psychosocial challenges of bone marrow/stem cell transplants from diagnosis through survivorship.

We offer patients, caregivers, and health care professionals the following free of charge:

- Lunch & Learn Monthly Free Call-In Programs
- Marrow Masters Podcast Series
- Survivors Thrive Book Club
- Informative Annual Webinars
- Peer Support Mentoring Program
  (Be A Peer or Request A Peer)
- Information and Referrals through our Licensed
  Staff Social Worker
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Our award-winning books are modestly priced and available online. Visit www.nbmtlink.org for more information, call 800-LINK-BMT (800-546-5268) or email, info@nbmtlink.org. Be sure to like us on Facebook, www.facebook.com/nbmtlink or X (formerly known as Twitter), nbmtlink.

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Introduction

The Importance of a Book Just for BMT Caregivers

by Michelle M. Bishop, PhD

Family caregivers are the unsung heroes of the blood and marrow transplant (BMT) process; most transplants will not go forward without them. They are critical members of the care team and are instrumental to the health, adjustment, and quality of life of the patient.

However, providing care and support to someone going through transplant is no simple task. It is physically and emotionally intense and involves multiple, often new and unfamiliar roles. The caregiver serves as nurse, medical manager, patient advocate, provider of information to friends and family, cook, driver and cheerleader—all while continuing the roles of spouse, parent, or sibling! Many family members don't see themselves as "caregivers," yet in the context of BMT they certainly are...look at all the extra things they are doing!

Unlike professional caregivers, who go home at the end of the day, family caregivers are on the transplant "journey" themselves. They not only serve as a resource to the patient and part of the care team, but they also are navigator and co-pilot on a shared path. They are "co-survivors" impacted both directly and indirectly by the experience. Their world, too, is turned upside down—work/career, family life, an imagined future—while they witness their loved one's illness and transplant, often worrying and wishing they could do more to help.

In this way, we might think of the BMT experience—from diagnosis to treatment through recovery and survivorship—as a long road trip that the patient and caregiver have embarked on together. Although sometimes this trip is relatively short and smooth, more often it is longer than expected, rife with twists and turns, detours and roadblocks, potholes and pitfalls.

So how do you prepare for an extended road trip when you don't know how long it will be or exactly where you are going? First, it can be helpful to sketch out a rough road map, gathering general information about what lies ahead, the kinds of challenges you may face, and where some of the tricky turns and twists are likely to be. The stories in this book will help highlight some of the experiences you may face on your journey. In particular, it is important to develop realistic expectations for this trip, so that you are not caught off-guard on the road, scrambling to adjust and make changes while in motion.

The transplant team is a great source of information and support, as are books like this one. The National Bone Marrow Transplant Link, and other BMT patient/family-centered organizations (such as BMT InfoNet, Blood Cancer United and NMDP), have specialized materials on what you need to know, what you can expect, and what resources are available to help. You can read about, listen to, and connect with others who have traveled this road before you.

There is no substitute for talking to another patient or caregiver, through a peer-to-peer program or a support group, who "just gets it" because they have been there. It can help you feel you are not alone and part of an incredibly supportive community. One of the authors in this book, Stephanie Scoletti, likens this to finding your herd: "Finding your herd provides a sense of relief and the support you need because it's a place where everyone genuinely understands what you are going through."

The key to coping with an uncertain path is to build up external and internal resources to help buffer the bumps in the road and increase coping flexibility. You can do this by gathering support and engaging in proactive self-care. Since caregivers are both the "vehicle" that carries and supports the patient, as well as the "driver" on this transplant road trip, support and self-care is what allows you to go the distance and not break down. It is often said, transplant is "more of a marathon, than a sprint." It's not a road trip you can just "power through." It will require frequent refueling and recharging stops along the way. In this way, self-care is not a selfish act, but rather the means and method to maintain your strength and stamina to go the distance.

Support can come in many forms—practical, emotional, social, spiritual, financial—and from many sources—friends, family, co-workers, neighbors, spiritual community members, and professionals. Communication is key, since family and friends often don't understand all that you are experiencing. In particular, they may not realize that the journey isn't over when the patient comes home from the transplant center; in fact, this is the beginning of a new phase of the trip where the burden of care shifts

more squarely onto your shoulders as the family caregiver. Using your support system is a key way to care for both yourself and your loved one. When you prioritize what you personally need to do and allow others to take over other tasks, you increase your bandwidth by lightening the physical load, so you can recharge your emotional batteries. Remember, you help others when you let them help you, as well!

Although self-care helps to ensure a successful trip, it can be extremely difficult to do. You may feel you don't have the time or space for self-care and put your own needs at the bottom of the pile. You might feel guilty or selfish for acknowledging your own fatigue or stress, particularly in the face of your loved one's illness and recovery. However, maintaining your own health and well-being really is one of the best ways you can care for your loved one.

Self-care is an ongoing process of refueling and recharging physically, emotionally, socially, and spiritually. It can range from small moments of respite to scheduled time for your own medical care and personal needs, as well as doing things that help you to remember who you are outside of the caregiving role. Jennifer Gillette, LMSW, notes in her essay: "You need to discover what keeps you strong... what ways you can be kind to yourself. Sometimes it is the littlest gestures that can fuel you for another day."

Not only does proactive self-care help with stamina, but is instrumental in being able to successfully and more easily maneuver any unexpected hazards or turns in the road. Remember, if your "tires" are low on air, you may struggle to stay on the road through unanticipated sharp turns. If you prioritize keeping your tires pumped, battery charged, and tank topped off, you will have an easier time successfully switching gears and rerouting as needed. As Jim Bulger, caregiver to his wife Nancy, points out in his essay: "We kept a "go bag" in the car with clothes and toiletries in case there was a need for an urgent run to the hospital... you simply build "flex" into every activity in case things change (and they will)."

Checking in with yourself regularly also is an important part of self-care. Your body and mind have a "dashboard" of warning lights to indicate "low fuel" or an "overheated engine." Symptoms of fatigue, headaches, irritability, and tearfulness are indicators that attention to your mental and physical health is needed. If you ignore that "oil light" or "gas gauge," eventually your mind/body will break down, and it will be more difficult and disruptive to have to stop for "repairs." Keep in mind, even professional counseling can be a form of self-care—a place of your own to share, process, and problem-solve without worrying about burdening others. For Juanita Brooks-Fultz, who was caregiver to her adult daughter Sharde, self-care was playing a video game,

praying and showering. She heeded her warning light by taking long showers when she had the time: "I could have a good cry. That was my soothing and relaxing time."

The amazing thing about road trips is that no matter how many stops and starts, twists and turns, detours and roadblocks along the way, there can be an equal number of pleasant surprises, beautiful moments, and opportunities for growth. Often through adversity, we come to recognize our own strengths and realize what is really important in life. The caregivers in this book talk about "knowing miracles happen every day," about relationships growing stronger, and about using laughter as an antidote for constant medical discussions.

Families frequently mention ways they felt deeply moved by the kindness of others or experienced a sense of gratitude toward the medical team. Caregivers find their inner strength renewed by a sense of purpose and meaning. Couples describe becoming more closely bonded as they creatively find new ways of doing old things. The resiliency of the human spirit is boundless and these special moments along the way can help to buoy one's mind, body, and soul when the road gets rough.

With this book, we hope to acknowledge and validate your experience as a family caregiver and help you see how incredibly valuable you are. The stories from caregivers who have traveled this road before may help outline a rough roadmap of the journey to come. Chapters by medical professionals and social workers offer guidance and suggestions for ways to make the trip more successful. We encourage you to remember that caring for yourself, as you care for others, is an unselfish act that will help prevent you from burning out.

We hope this resource book shows you that you are not alone. You are part of a larger community of BMT survivors, families, health care professionals, and support organizations that are here to support you. We wish you well and hope to make your caregiver journey an easier one.

Advocating for a Loved One

by Sharon Minton

At the end of 2011, my husband Rob accepted a job transfer across the country. It was a welcome move, as we were happy to be leaving the cold winters of Michigan for sunny Florida. By that spring, Rob started to complain of an itchy rash that broke out around his waist. We thought it might be a heat rash, but it kept getting worse no matter what we did. He visited many doctors over the course of the next year who were unable to figure out his worsening symptoms. Rob's body began to swell from head to toe, his skin itched like crazy and turned a reddish/purple color and would flake off until he was raw. He was unable to perspire, and constantly felt cold even when it was 95° F outside. We finally decided to set up an appointment with the dermatology department at Mayo Clinic/Jacksonville; a 2½ hour drive from our home. There, he had dozens of skin biopsies that proved inconclusive.

Meanwhile, I spent almost every waking moment researching each of Rob's symptoms by reading every medical publication available to me. Without medical training, I looked up each term or word that I didn't understand. I ended up finding a very scary diagnosis that seemed to tick off exactly every symptom that he had. It was an extraordinarily rare form of Cutaneous T-Cell Lymphoma called Sezary Syndrome. I printed out everything that I could find and brought it with us to his next appointment at Mayo Clinic. We were told that the chances of Rob having this rare cancer was extremely slim since only one in one million people ever actually get this type of cancer. In my research, I read that this Sezary Syndrome is very difficult to diagnose and the most reliable test is a flow cytometry. I asked if they would please run this test so we could rule it out. Several flow cytometry tests were performed over the next nine months.

Rob's symptoms were now becoming life threatening. He had several bouts of MRSA and staph infections, and his kidneys were not able to flush all of the fluid buildup in his body. His lymph nodes were swollen so he had an inguinal lymph node biopsy. A week later, in early November of 2013 we received the results of both the lymph node biopsy and the latest flow cytometry; Rob was diagnosed with stage 4 Cutaneous T-Cell Lymphoma/Sezary Syndrome. We were informed that he had a 25% chance of living up to five years. Our family was devastated.

If it were not for my strong faith, I believe that I would have fallen apart. I had to trust that God had a plan for us, and I was going to accept whatever it was. I prayed for guidance. I am absolutely sure that each doctor we saw, website I found, and people that we came into contact with along the way were answers to my prayers.

I knew that I could have never gone this through my own abilities. I sought out and joined every online cancer group that related to Rob's cancer from email groups, CTCL Listserv, to Facebook groups. I also found that the Cutaneous Lymphoma Foundation website (clfoundation.org) had patient stories, so I contacted a gentleman whose medical story sounded exactly like Rob's. This man had been diagnosed with Sezary Syndrome in 2005 and had an Allogeneic Stem Cell Transplant in 2009. Rob and I both ended up speaking with him via telephone and he was tremendously helpful. His suggestion for us: get onto the bone marrow recipient registry while doctors try to get Rob into a remission.

Since there is no cure for Sezary Syndrome and remissions from chemotherapy treatments had shown to be temporary, an Allogeneic Stem Cell Transplant was Rob's best hope for long-term survival. We let the doctors know that was the path we wanted to follow. We consulted with specialists from around the country. They all agreed a transplant was Rob's best option as his disease proved to be refractory. As much as we had come to trust and love the doctors at Mayo Clinic, we decided to switch to a medical team closer to home in Orlando since treatments would be several days a week.

Rob's only brother was tested to see if he was a human leukocyte antigen (HLA) tissue match, but he was not. Rob was put on the bone marrow registry in January of 2014. At the same time, his oncologist started him on a chemotherapy drug to clear the cancer cells in his blood. We had trouble obtaining approval from our health insurance company to cover this treatment. After going back and forth with them several times and finally getting Rob's oncologist to step in for us, they approved it.

Rob finished his chemotherapy treatments that May and was pronounced "in blood remission." In early July of 2014, we got a call letting us know that an eight out of ten HLA match was found for Rob. Again, our prayers were answered!

Rob was almost ready for his allogeneic transplant, but he had to have one more treatment to get rid of any remaining cancer cells in his skin. He had 30 grays of Total Skin Electron Beam Radiation Therapy over a 1½ month period (a gray is a measure of radiation). It caused him to lose all of his hair, but cleared his skin of any remaining cancer cells. Two weeks later, we went up to the University of Florida in Gainesville (where his transplant would take place) so Rob could go through several days of extensive physical, dental and psychological exams to make sure that he was able to go through the procedure. He had been working out as much as he could during his treatments to stay in the best physical shape possible. In hindsight, that was the best thing that he did to be ready for the transplant. We also had to make arrangements for where we would live after he was released from the hospital. We couldn't be more than 30 minutes away for emergency purposes. We found a fully furnished apartment to rent up the street from the hospital.

On October 2, 2014, we both moved into Rob's room as he was admitted to the seventh floor Bone Marrow Unit of Shands Cancer Hospital. He had a small surgery to have the Hickman (Tri-fusion catheter) placed in his chest. This device would be the means in which he'd receive all of the chemotherapies, fluids, blood transfusions, platelets, and even the new stem cells. He was hooked up to this huge IV pole that would become his constant companion until he left the hospital. We even gave it a name: Medusa.

Rob began his first round of the chemo and drugs that would be given over the next several days to wipe out his own immune system in preparation to accept the new donor stem cells. Some of these drugs made him quite sick. As awful as he felt, we would make sure that he would get up out of bed and walk laps around the unit. Getting exercise is necessary both physically and psychologically. He would also get up each morning and shower and get fully dressed. We felt that was important to help him feel more like a normal day and not a day to be sick in bed.

October 7 was day zero—transplant day! We had a "new birthday" party for Rob in his room, complete with presents that friends and family sent along with special letters of encouragement, balloons, and his favorite German Chocolate cake. Two of our four children, my sister, and Rob's brother were able to be there with me to help

celebrate and watch as the new donor stem cells were infused through Rob's tri-fusion catheter into his body. These healthy new donor cells would give Rob and our whole family a renewed life together.

The days ahead would not be easy. Rob had to be monitored carefully. We were grateful for his incredible team of doctors and nurses. They closely watched all of his counts, blood pressure and temperature. He would get blood transfusions and platelets. When he'd get a fever, he'd be taken for an x-ray to check for pneumonia. This happened at all hours of the day or night.

Since Rob didn't have much of an appetite and found the hospital food repulsive, I'd run out to the store to pick up whatever sounded appealing to him, just so he would eat. His diet was pretty restricted, so finding something he could eat that sounded appetizing to him was a tricky task.

Seventeen days after Rob was admitted into the hospital, his medical team released him. This was much earlier than we had expected. I believe that Rob's positive attitude and daily physical activity helped a lot. We were able to move into the apartment that we had secured just up the street. I went over to the apartment a day ahead of Rob arriving to completely clean and disinfect everything. I wiped every surface down with a bleach solution, vacuumed all the carpeting, furniture and air vents and made sure that there was a clean filter in the air conditioner/ furnace. Being in Florida, we have to be aware of molds and fungus that are common.

It was crucial for Rob to be in a clean environment since his new immune system was very delicate. I was really glad to be able to sleep in an environment where we weren't disturbed by sounds of medical monitors or nurses coming in throughout the night to check Rob's vitals, but I was nervous at the same time. Now it was completely my responsibility for caring for him, for keeping him safe, checking his temperature throughout the day and keeping him relatively germ free! I was taught to administer Rob's intravenous medication twice a day and to sterilize and flush his tri-fusion catheter. We would take our daily walks to the hospital where we still spent hours almost every day in the outpatient clinic of the Bone Marrow Unit. There Rob had to get IV fluids, medications and blood work regularly.

Forty-six days had passed since Rob's transplant and his doctor gave him a weekend pass allowing us to travel the 2½ hour drive to go home! It was wonderful to see family again. My sisters, my parents, our daughter and a couple of friends had been

taking shifts to stay with our 14-year-old son so he would be able to carry on with school and everyday life while I was with Rob in Gainesville. We were very blessed to have that help so I was able to completely concentrate on Rob and his recovery. His health continued to progress over the next weeks. We would take short day trips to interesting places around Gainesville. This was very therapeutic and helped us appreciate the new lease on life together that both of us had been given. Rob would still get very fatigued quite easily so I was careful not to push him to do too much.

On day 70, just over a week before Christmas, we were given the "all clear" to move home. We were overjoyed. It was the BEST Christmas gift ever! Rob continued to improve over the next several months. We celebrated milestones together as a family. Day +100 is a turning point in the recovery process. This is when the greatest risk for critical side effects has passed and engraftment is complete, so new blood cells are being made. Rob had fully transformed from his former blood type of O+ to his donor's blood type of A+. I continued to keep him somewhat secluded from crowds and especially anyone that had a sniffle or a cough. I made sure that he didn't do anything in the yard that involved touching the soil (a lot of germs and microbes live there!) and limited his sun exposure. He continued his exercise routine every day by working out at our clubhouse gym or walking. Patience, perseverance, and positivity were all key factors in my husband's recovery.

At seven months post-transplant, Rob had a very scary set back. He came down with a sore throat, cough and fever. He was admitted to the hospital, but progressively became worse and was transferred to the ICU with sepsis and pneumonia. I asked if they would do a bronchoscopy to biopsy his lungs to check for GVHD. Fortunately, there was a pulmonologist on staff that was familiar with bone marrow transplant patients and agreed to do this. After being treated with several different antibiotics and steroids, his condition still wasn't improving so he was transported by ambulance up to Gainesville to be readmitted to the Bone Marrow Unit.

The results of the bronchoscopy proved that Rob did not have GVHD, but instead he had a fungal pneumonia called Aspergillosis. Aspergillus is a common mold or fungus found indoors and out, and a mild breeze can cause it to become air borne. Generally, a healthy person is unaffected by it, but it can cause serious illnesses when someone with a weakened immune system inhales the fungal spores. Rob was treated with IV antifungal meds and released after 18 days of hospitalization. He would have to stay on oral antifungal meds for another six months.

At the beginning of our journey for Rob's bone marrow transplant and recovery, I created a private Facebook page to keep all of our family and friends up to date, almost daily, on Rob's status. I documented each day with pictures and videos. It became a diary of sort. The many prayers and messages from everyone were such a source of encouragement for both of us.

Today, we can look back at that Facebook page and know how incredibly blessed we are to have been granted the experience for a renewed life that we have together. Rob is almost seven years post-transplant and is in the best health of his life. He's working, running four miles a day, bikes, plays pickleball several times a week and goes fishing almost every day. Rob was very fortunate to never have any issues with GVHD. We are grateful every day to his wonderful donor and all of his doctors and the staff at Shands Cancer Hospital.

One of the most important things that I did leading up to my husband's transplant was to line up help at home with tasks like child care, pet care, yard maintenance, and getting my mail to me. This way, I was completely able to focus on Rob. It was also important to have someone to be able and ready to step into my position as caregiver temporarily so that I could take breaks for myself, too. I would go get my hair cut or attend to some other business that needed to be taken care of outside of my caregiving duties for my husband. I made lists of everything that I needed and schedules of who was able to help and when. We were so grateful for everyone that helped things go so smoothly.

I must admit that taking care of myself was not a priority during this time and in hindsight, I should have made more time to do that. The most important thing for me was reading my devotionals daily. Philippians 4 was my go-to chapter in the New Testament throughout our journey. Philippians 4:8 says:

"Finally, brothers and sisters, whatever is true, whatever is noble, whatever is right, whatever is pure, whatever is lovely, whatever is admirable, if anything is excellent or praiseworthy, think about these things."

Staying in God's word and trusting that He was with us every moment was so comforting and important in helping keep a positive mindset. I had no doubt that He had guided us through it all.

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