



The **Caregiver's** Companion



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This book is dedicated to all those caregivers who have helped a loved one through a transplant, showing strength and humility, and to those who have yet to begin their journey.

As a caregiver, I have the right:

- To take care of myself, to rest when I am tired, to eat well, and to take breaks from caregiving when I need them
- To recognize the limits of my own endurance and strength
- To seek help from family, involved parties, and the community at large
- To socialize, to maintain my interests, and to do the things I enjoy
- To acknowledge my feelings, whether positive or negative, including frustration, anger, and depression, and to express them constructively
- To take pride in the valuable work that I do, and to applaud the courage and inventiveness it takes to meet the needs of my care recipient

From Ilardo and Rothman, *I'll Take Care of You: A Practical Guide for Family Caregivers*

Welcome to the Caregiver's Companion for caregivers of BMT patients

The caregiving journey is more like a marathon than a sprint

This book is designed to help you build upon your already existing strengths and help you develop new ones as you take on the role of caregiver.

This book was developed with the specific needs of BMT caregivers in mind. The road to, through, and beyond BMT can be challenging for both the patient and caregiver. Caregivers are critical to the recovery and well-being of the BMT patient, but the impact of BMT on the caregiver has not always been fully acknowledged. Caregivers may struggle with taking on multiple new roles, adjusting to changes in old roles, all while trying to cope with watching their loved one manage their illness and treatment.

“For us, transplant was a long, winding path with some unexpected bumps and turns but with the marvelous guidance of the medical team and the loving support of family and friends, we did very well indeed. **So remember**, there is light at the end of this long and meandering tunnel you too are about to enter.” – Kay, caregiver

Taking care of you

As a caregiver, you may be thinking about all you have to do, but may not be thinking about yourself and your own needs along the way. You may be surprised to learn that the most important thing you can do as a caregiver is to take care of yourself! It is the only way that you will be able to have the strength and stamina to take care of your loved one. In this book, you will find tips to help you understand and cope with the challenges and feelings that come with being a caregiver. You will also hear from actual caregivers who share their insights, having cared for a loved one through the transplant process.

The BMT journey can be both stressful and rewarding, full of intense emotions, both negative and positive. In these chapters, you will find tips to help you understand and cope with the challenges and feelings that come with being a caregiver:

Coping with Emotions: How to cope when you are feeling so many different emotions

Communication: How to communicate better with your healthcare team, loved one, family

Social Support: How to accept support from others and stay connected

Physical Health: How to keep yourself healthy and feeling good

Relax and Recharge: How to lower your stress, relax and recharge

Peace and Positives: How to find calm, peace, meaning and appreciate the positive aspects of caregiving

You can also visit [BeTheMatch.org/companion](https://www.bethematch.org/companion) for additional tips and resources to help you along your caregiving journey

Who is a caregiver?

A BMT caregiver is anyone who provides direct support or care to someone who has received a marrow or cord blood transplant. This can include spouses or partners, children, siblings, parents, friends, or even co-workers. If someone you love had or will have a transplant, you may be a caregiver, even if you don't think of yourself as a "caregiver". While you might see the care you provide as an expected part of your relationship and not anything special, your new role as caregiver is an important one and is vital to your loved one's treatment and recovery.

Remember:

No two people are alike. Some chapters of this guide may apply to you while others may not. It is possible that you will find some sections helpful to you now and others more useful to you later. The key is to keep checking in and keep taking care of yourself as you go along.

Insights from caregivers

Here are just some of the caregivers who share their story



“Looking back, I wish I would’ve let others help more. I didn’t realize how much I was holding back until I finally let them in. They wanted to help us so deeply but didn’t know how.” — **Kate, caregiver to her mom, Dixie**

“It was hard for me to deal with uncertainty and helplessness. I tried to be there for my wife, to do whatever I could to help her through the difficult times, but at the end of the day I had to recognize that I could only do so much. I had to accept that there were many things I just could not control.” — **Brian, caregiver to his wife, Betsy**



“Talking helped. Admitting things like anger, asking for help, asking to be reminded that I can’t do it all, asking questions when I didn’t understand.” — **Allison, caregiver to her husband, Sean**

“I learned to enjoy the simple things in life; the first time my husband was able to go out without wearing a mask, or the day his port was removed. Going out for a meal was a big milestone. I learned to be grateful for each precious day we have. What matters is concentrating on positive thoughts that will help your loved one get better.” — **Jody, caregiver to her husband, Steve**



It's not only okay to take care of yourself, it's **extremely** **important**

Many caregivers have said that they felt guilty thinking about and taking care of themselves when a loved one was dealing with the stress of a transplant. But the stress of the transplant affects you too. And if you become physically exhausted or emotionally overwhelmed, you won't be able to provide the care you want to give your loved one, and both of you will suffer. Your own health and well-being is critical to the health, adjustment, and quality of life of your loved one.

Do you ever find yourself thinking some of these thoughts? If so, the advice in this guide can help you.

“I've always been able to take care of things by myself, and this is no different.”

Trying to take on every task that goes with being a caregiver can lead to burnout.

Use the tips in the **Social Support** chapter to let go of things that aren't essential for you to do, so you have energy for what's important.

“My focus has to be on my loved one. I don't have time to worry about my own health.”

As a caregiver, your focus is on your loved one's health and well-being. But you need to be healthy yourself in order to be an effective caregiver.

Follow the quick and simple tips provided in the **Physical Health** chapter to see how easy it can be to incorporate healthy habits into your life today.

“I shouldn't need to take a break. I'm strong.”

You ARE strong and CAN do a lot, but you will only remain strong by pacing yourself and taking breaks.

Follow the advice in the **Relax and Recharge** chapter to get you going down the road to relaxation.

“I'm doing okay, although I do feel sad and lonely a lot of the time.”

Both positive and negative emotions can be helpful signals to tell you how well you are coping.

The **Coping with Emotions** chapter will teach you how to listen to the signals your emotions are telling you, and help you find coping strategies that work for you.

“I'm a capable person; I don't need help talking with doctors.”

Coordinating care isn't easy, and miscommunication is common, especially when dealing with multiple health professionals from different medical specialties.

Learn how to communicate effectively in a wide range of situations in the **Communication** chapter.

“If I ever laugh, people will think I'm not taking my loved one's illness seriously.”

Laughing at something funny doesn't mean you are making light of your loved one's situation. It simply means that you are not allowing it to get the better of you!

Learn about the power of acceptance and other meaningful thoughts in the **Peace and Positives** chapter.

Give yourself permission

Many caregivers are so focused on their loved one that they hardly notice how the experience is affecting them. Caring for someone undergoing a transplant requires a lot of energy. You might feel like you have to do everything—for the patient and your family. Give yourself permission to take care of “you,” so you’ll have more energy in the long run.

It might help to remember:

- You are doing the **best you can**
- No one is **perfect**
- Your feelings are **normal**
- You don’t have to **pretend** to be cheerful all the time
- Put **first things first** and let the little things go
- It’s okay to take some **time alone**
- There are people who can **help**
- It might help to talk with your **family or friends**
- You do many things **very well**



Susan, caregiver

This book is your companion. Let the tools and stories from others help you along your caregiving journey.

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About Be The Match®

Be The Match helps patients with leukemia, lymphoma and other diseases who need a marrow or umbilical cord blood transplant. People can join the Be The Match registry—the largest listing of potential marrow donors and donated cord blood units—contribute financially and volunteer.

Patients and their families can also turn to Be The Match for support and resources before, during and after transplant. Be The Match is operated by the National Marrow Donor Program® (NMDP), a nonprofit organization that matches patients with donors, educates health care professionals and conducts research so more lives can be saved.

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Email: patientinfo@nmdp.org

Call: 1 (888) 999-6743

Every individual's medical situation, transplant experience, and recovery is unique. You should always consult with your own transplant team or family doctor regarding your situation. The information is not intended to replace, and should not replace, a physician's medical judgment or advice.



Patient Services, National Marrow Donor Program
3001 Broadway St. N.E., Minneapolis, MN 55413-1753
1 (888) 999-6743 | BeTheMatch.org/patient