

BE  THE MATCH<sup>®</sup>

# The **Caregiver's** Companion



*Dena, wife and caregiver to David*

This book is for all caregivers who help a loved one through a blood or marrow transplant (BMT).

## CAREGIVER BILL OF RIGHTS

### As a caregiver, I have the right to:

- Take care of myself, rest when I am tired, eat well, and take breaks from caregiving when I need them
- Recognize the limits of my own endurance and strength
- Seek help from family, friends and my community
- Socialize, maintain my interests, and do the things I enjoy
- Acknowledge my feelings, whether positive or negative, including frustration, anger, and depression, and express them constructively
- Take pride in the valuable work that I do, and applaud the courage and inventiveness it takes to meet the needs of my loved one

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

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#### Find tips to help you:

- Make meaning out of challenging experiences
- Create positive memories

**Remember, no two people are alike.** Some chapters in this book may be helpful now and others may be more helpful later. Consider reading a few pages every week to help you take time for yourself and cope with new challenges.



***Caregivers have to be able to take care of themselves in order to help take care of the patient. And sometimes that means being willing and able to say, 'I need some help.'"***

—Amelia Langston, MD  
transplant doctor

## **THIS BOOK WILL HELP YOU:**

- Build on your strengths and develop new ones
- Cope with the challenges that come with caring for a loved one during the transplant journey

## **WHO IS A CAREGIVER?**

A caregiver can be anyone who provides direct support or care to a loved one during and after BMT. This support may be medical, financial or emotional.

### **A caregiver may be:**

- A spouse or partner
- Adult children
- Brothers or sisters
- Parents
- Friends or co-workers

***We didn't sign up for this. All of a sudden, we were there. That's just part of being married and making that commitment years ago."***

—Steve, husband and caregiver

## Take care of yourself

The BMT journey can feel stressful and rewarding. You may feel strong positive and negative emotions. Many caregivers have said they felt guilty thinking of themselves. Give yourself permission to take care of you.

### Remember:

- You do many things very well.
- No one is perfect.
- You are doing the best you can.
- 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 OK to take some time alone.
- There are people who can help.

*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.”*

—Jody, wife and caregiver

*It was hard for me to deal with uncertainty and feeling helpless. 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, husband and caregiver to Betsy







Chapter 1:

# Coping with Your **Emotions**

*Deborah, mom and caregiver to Jack*



Audrey, wife and caregiver

It's common to feel worried, stressed and tired during this time. This chapter will help you:

- Listen to the signals your emotions are sending you
- Find coping strategies that work for you

## HOW ARE YOU DOING RIGHT NOW?

Take a minute to see how you're doing:

	YES	NO
When you feel tired or stressed, do you find ways to cope that help you get through?		
If you notice signs of anxiety or depression in yourself, do you know where to get help?		
Do you allow yourself to say "no" when you feel overwhelmed or tired?		
Do you have a creative outlet that you use now?		
Do you have someone to talk to openly about your feelings?		

If you checked "No" more times than "Yes" this chapter may help you find healthy and effective ways to cope with your emotions.

If you've checked "Yes," more times than "No," you're doing great! This chapter includes tips that may help you keep up the good work.



# What your emotions are telling you

## COMMON THOUGHTS AND FEELINGS

If you've felt any or all of these emotions, you are not alone.

- "I'm sad for what we can't do. We had so many plans."
- "I feel overwhelmed. I just can't do it all."
- "I'm scared about what might come next."
- "I feel like the doctors aren't listening to me."
- "I am all alone."

### Positive emotions are possible too!

- "I feel that I am a good caregiver!"
- "I am thankful for all the support we received."
- "There is so much love in our family. My heart is filled with joy."

All of your feelings are OK. Listen to them and they can tell you how you're coping.

Coping is finding ways to deal with and overcome difficulties. Everyone has different styles. While there are many different ways to cope, some ways are better for some situations than others.

## HOW WELL IS YOUR COPING STYLE WORKING?

Our bodies and minds tell us when we're not coping as well as we would like. Here are some signs that you may not be coping as well as you could be:

- Headaches
- Stomach aches
- Feeling unexpectedly tearful or impatient
- Having jumbled thoughts
- Having trouble focusing
- Having trouble sleeping

### Your body may be telling you to:

- Slow down
- Problem-solve
- Ask someone for help
- Take a break and take care of yourself

### These may be signs that you're coping well:

- Feeling alert and focused
- Eating and sleeping well
- Feeling confident in your ability to meet the challenges of the day

### Your body may be telling you:

- Your coping strategies are working.
- You've taken time to care for yourself.
- You have confidence in your abilities as a caregiver.

## SIGNS THAT YOU NEED TO ASK FOR MORE HELP

Anxiety and depression can cause physical and emotional symptoms.

If you've had any of these symptoms most days for 2 weeks or more, tell your doctor.

### Changes in Your Feelings

- Crying a lot
- Feeling guilty or worthless
- Feeling helpless or hopeless
- Feeling irritable, grouchy and moody
- Feeling overwhelmed, out of control, or shaky
- Feeling that you are “losing it”
- Feeling worried, anxious, “blue,” or sad
- Focusing on worries or problems
- Having trouble concentrating or feeling scatterbrained
- Not being able to get a thought out of your mind
- Not being interested or finding pleasure in hobbies and activities that you once enjoyed
- Thoughts of hurting or killing yourself or someone else

### Body Changes

- Diarrhea (loose, watery stools)
- Dry mouth
- Fatigue that won't go away
- Headaches or other aches and pains
- Racing heartbeat
- Slowing down physically
- Sweating a lot
- Trouble sleeping or needing more sleep
- Unexplained weight loss or gain
- Upset stomach

## THE BE THE MATCH® PATIENT SUPPORT CENTER CAN HELP

We offer free counseling services for BMT caregivers. You'll talk with a licensed clinical social worker who can help you:

- Adjust to the BMT process and survivorship
- Develop coping strategies
- Manage emotions, such as anxiety or sadness
- Improve communication with the health care team and family members
- Identify and cope with family role changes that have happened because of transplant
- Find reliable mental health-related information and community resources
- Manage financial challenges

Counseling is available over the telephone, no matter where you live in the U.S., or in person at our office in Minneapolis, MN.

**CALL: 1 (888) 999-6743**, option 3  
Monday through Friday,  
8:00 a.m.–5:00 p.m. Central Time

**EMAIL: [patientinfo@nmdp.org](mailto:patientinfo@nmdp.org)**

**IF YOU'RE HAVING  
THOUGHTS OF HURTING  
YOURSELF OR OTHERS,  
GET HELP IMMEDIATELY.**

Call the National Suicide Prevention Lifeline at **1 (800) 273-TALK (8255)** any time—24 hours a day, 7 days a week to talk with someone who can help. You can also dial **911** or go to your local hospital emergency department.



## DO YOU HIDE YOUR FEELINGS?

You may feel like you need to keep your feelings to yourself so that you don't burden your family or others. But, not expressing your feelings can lead to loneliness and feeling isolated. This could make you feel even more stressed.

Sometimes, well-meaning friends and family members may tell you to “be positive” or “be strong” all the time. These messages may make you feel like it's not okay to have negative feelings.

Other times, you may feel guilty for having positive emotions. Maybe you say to yourself that it's wrong to feel happy when your loved one is struggling with an illness.

Research tells us that it's important to accept and deal with *all* emotions, both positive *and* negative. And acknowledge and release those feelings in ways that are safe, comfortable and helpful.

# What to do when you're struggling

If emotions are so strong that they interfere with your daily life, try these coping strategies to help you through.

## A situation you can't change

It may be helpful to let out your thoughts and feelings. Keeping them inside can make it hard to think clearly or to feel positive. When you express your thoughts and feelings they may be less overwhelming and you may have more room for other feelings, such as hope.

First, tell yourself that your feelings are OK. Then, find a way to express them. You may want to:

- Talk to a trusted family member or friend.
- Take time to cry or scream.
- Write your thoughts and feelings down on paper.

## A situation you can change

Figure out what's needed and make a plan. For example, if you're feeling overwhelmed with all you have to do as a caregiver, you may consider making a list, prioritizing tasks and giving some tasks to others. The chapter on *Social Support: Getting the Help You Need* has tips on how to do this.

## Feeling out of control

Some stress has more to do with the way we think about and react to an event, rather than the event itself. Have you noticed that it is possible to have different interpretations about the same event?

We have the power to change thoughts and perceptions, which can change how we feel. For example, if you are kept waiting in the doctor's office, try not to think that the doctor doesn't care about you, which may make you feel angry. Instead, try thinking that the doctor may have had an emergency, or another patient may have needed some extra time. This may help you to feel less angry.

Regain your sense of control by changing your expectations and attitude.

# Watch out for stinkin' thinkin'

**Negative thinking is easy to do without even realizing it.** Have you ever found yourself thinking like this:

- 1. All-or-nothing** – Think things are either all bad or all good. It's easy to forget that much of life is in the “gray zone” and neither black nor white. For example, instead of saying, “I’m a terrible caregiver!” You could say, “I wish I had the energy to cook a nice meal, but I am feeling very tired today. Getting take-out tonight is okay and doesn’t make me a terrible caregiver.”
- 2. Jump to conclusions** – See or hear about one bad event and immediately think everything is bad. For example, you might think that a close friend is ignoring you because they haven’t called. Don’t let this assumption keep you from reaching out. Maybe they don’t know what to say, or are afraid of bothering you.
- 3. “Should-ing”** – Talking about what should be done. Thinking about what someone should or must do doesn’t leave much room for being human. It also can lead to feeling guilty and angry. Instead, say to yourself, “I would like to, if I can.”

## CHANNEL YOUR EMOTIONS

Holding in emotions can create stress on the body. Talking, writing, and reading about thoughts, feelings, and experiences is an important part of coping.

**Here are 3 ways to express your emotions:**

### 1. Reading and sharing

Reading may help you feel less alone and uncertain about your experience. Sharing your own story can have a big impact on you and others.

### 2. Find a creative outlet

Find a project you’ve been wanting to do. This could be gardening, a woodworking project, or a craft project. Give yourself permission to spend time on it. Even if it’s just 10 or 15 minutes it can help release stress.

### 3. Empty your mind out on paper

Writing is a way to empty and free the mind of all the things you have to do or remember. Writing can:

- Help you sort through problems
- Process thoughts and feelings
- Make sense of your experiences

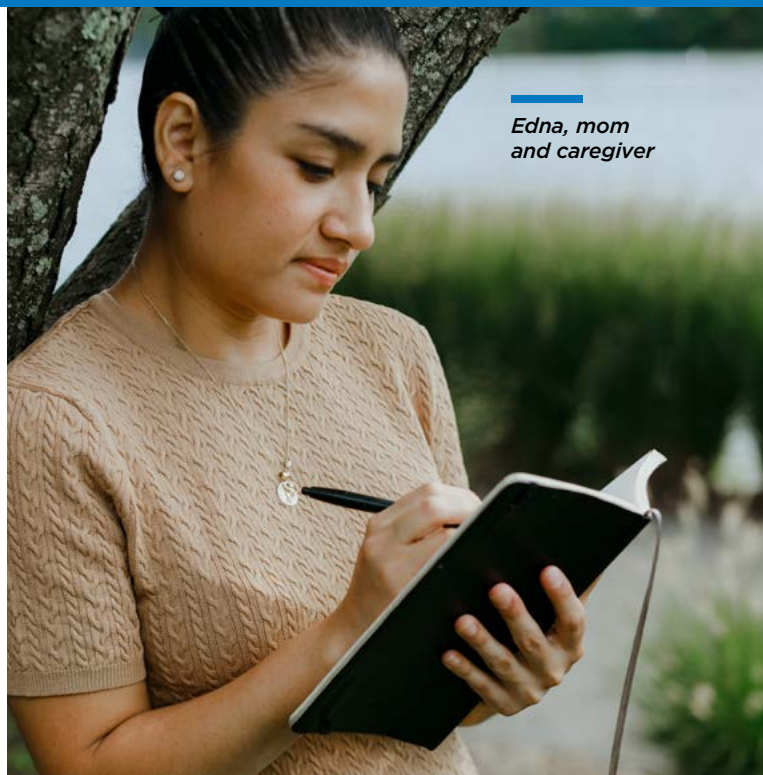
### Keep in mind:

- **There is no right or wrong way to write.** It's a way to record what you are feeling at the time.
- **Keep it short.** You may only need a few minutes to get started.
- **Forget about grammar.** Don't let punctuation or sentence structure get in the way of putting your thoughts down on paper. Just keep writing. Write whatever comes to mind.
- **Write down your thoughts and feelings a few times.** Feelings may become less intense or thoughts may get clearer when you write them out a few times.

To help you get started, use one of these writing prompts. Then write for just 2-3 minutes.

- Right now I feel...
- I am grateful for...
- I'd like to thank...

Writing can bring up emotions. It is okay to experience those. But, if you find yourself feeling very upset, stop writing, or change writing topics. The goal is to express thoughts and emotions, but not to lose yourself in the process.



*Edna, mom  
and caregiver*



### Resources to help you connect with others and express your feelings:

- Talk with someone who's been a BMT caregiver: [BeTheMatch.org/PeerConnect](https://www.bethematch.org/PeerConnect)
- For stories from other caregivers, and tips on how to write your own story, visit: [BeTheMatch.org/BMTJourneys](https://www.bethematch.org/BMTJourneys)

# Emotional care checklist

Use these activities and strategies to help you cope with some emotions you may have.

IF YOU FEEL	THIS MAY HELP
<b>SAD</b>	<ul style="list-style-type: none"><li>• Do something you enjoy each day</li><li>• Listen to your favorite music</li><li>• Spend a few moments enjoying the garden</li><li>• Talk on the phone with a supportive friend</li></ul>
<b>DISCOURAGED</b>	<ul style="list-style-type: none"><li>• Take one day at a time</li><li>• Imagine that tomorrow will be better</li></ul>
<b>AFRAID</b>	<ul style="list-style-type: none"><li>• Talk to someone about the worst thing that could happen</li><li>• Make a plan to handle this worst-case scenario</li></ul>
<b>ANGRY</b>	<ul style="list-style-type: none"><li>• Take a break and leave the situation, if possible</li><li>• If you can't leave, stop and take a few deep, slow breaths</li><li>• Focus your anger on the situation and not on another person</li><li>• Avoid difficult people, or those who are overly critical</li></ul>
<b>GUILTY</b>	<ul style="list-style-type: none"><li>• Give yourself credit for what you do well</li><li>• Remind yourself that nobody is perfect</li></ul>
<b>DOWN/SERIOUS</b>	<ul style="list-style-type: none"><li>• Read a funny book or watch a funny TV show or movie</li><li>• Tell yourself that it's OK to laugh</li></ul>
<b>OVERWHELMED</b>	<ul style="list-style-type: none"><li>• Remind yourself that it's OK to say "no" to things</li><li>• Decide which chores can be done later</li><li>• Focus on what's really important to you and let go of the rest</li><li>• Let others help you</li></ul>

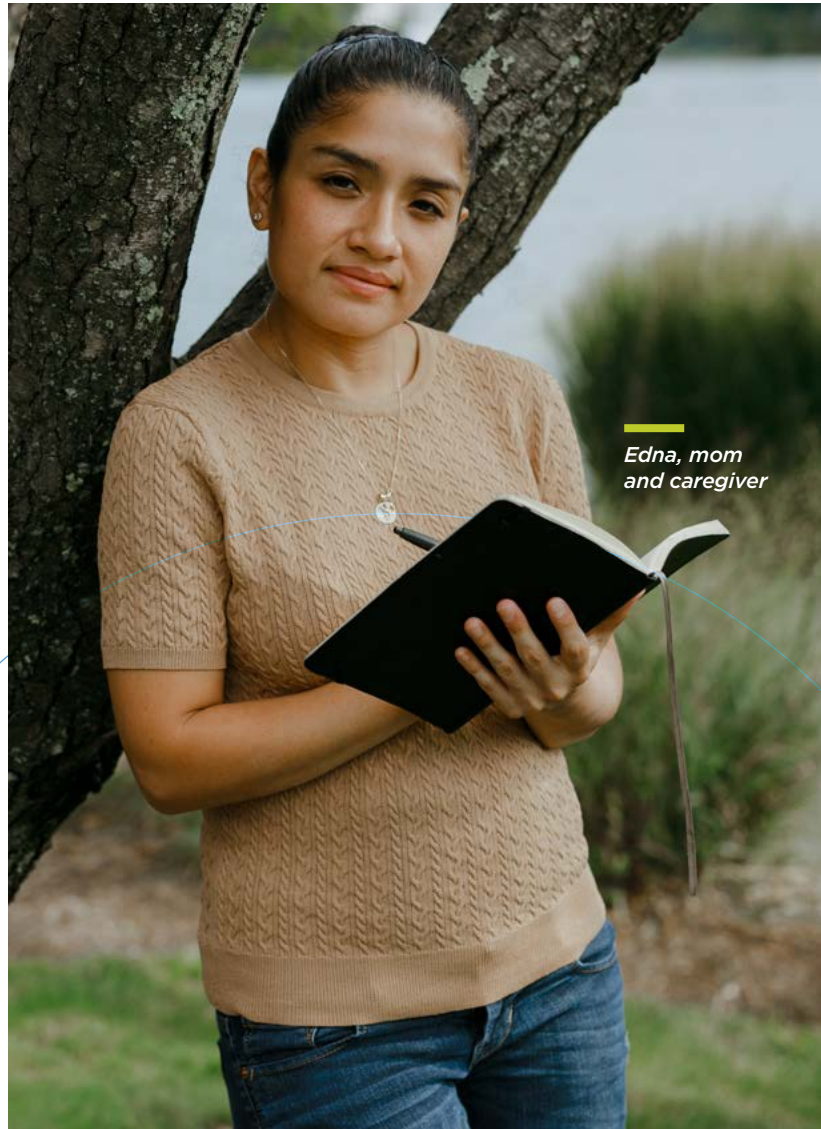


## Chapter summary

- Use your emotions as signals that tell you how well you're coping.
- Tell your doctor if strong feelings of sadness or worry affect your daily life. They could be symptoms that need treatment.
- Keep in mind that how you think about things can affect how you feel. Watch out for stinkin' thinkin'.
- Try writing your thoughts down on paper. This can help you sort through problems and process feelings.

### THE SERENITY PRAYER

*Grant me the serenity  
to accept the things  
I cannot change,  
the courage to change  
the things I can,  
and the wisdom to know  
the difference.*



Edna, mom  
and caregiver



Chapter 2:

# Improving Your **Communication Skills**



*Francis (left) and Johnnie (right),  
parents and caregivers*



## Your Communication Skills

Communication is a key part of being a caregiver. Simple and direct communication will help you get what you need and avoid misunderstanding. This chapter provides some tips on how to communicate clearly.

### HOW ARE YOU DOING RIGHT NOW?

Take a minute to see how you're doing:

	YES	NO
Do you take notes during doctor's appointments?		
Do you make a list of questions to ask when you see the doctor?		
Are you prepared to communicate effectively in an emergency?		
Do you have a notebook to keep you organized?		
Do you feel comfortable talking with your friends and family?		

**Q** *I found the more questions I asked, the more at ease I felt because it armed me with information instead of uncertainty."*

—Jana, wife and caregiver

If you've checked "No" more times than "Yes," you're not alone. This chapter includes tips to help you express yourself with the health care team, your family and friends.

If you've checked "Yes" more times than "No," you're doing great! This chapter includes tips that may help you keep up the good work.

# It's not what you say, it's how you say it

## BE CLEAR—AND BE UNDERSTOOD!

First, think about what you need or want before you communicate with others. If it's not clear to others what you need or want, they may not respond as you expect. This can leave you feeling frustrated. When people talk, they generally want 1 of 4 things:

1. Information
2. Advice
3. Understanding
4. Reassurance

If you know what you're looking for, be clear about what you need.

For example, if your loved one feels dizzy and you're concerned, do you need information, advice, understanding, or reassurance? If you want information, say this when you talk to the doctor:

*“My partner has been having dizzy spells at home. He hasn't had this before. I'd like to know what could be causing these and if there is anything we can do to stop them.”*

One way to make sure your thoughts are organized before you meet with a doctor is to complete these phrases:

“What is happening is \_\_\_\_\_”

“My concern is \_\_\_\_\_”

“What I need is \_\_\_\_\_”



*Tami, mom and caregiver*



**You have to be an advocate for your loved one. Advocate with love, but strength. Know what's going on so you can feel comfortable during the process. There wasn't anything that I didn't know about."**

—Scherika, mom and caregiver to Rhiannon

## CHOOSE THE BEST WORDS TO GET THE BEST RESULTS

It's good to be assertive—that is, say what you need in a respectful way. Here are some ways to speak assertively:

### Use “I” statements

Statements that start with “you” can put people on the defensive.

**Instead of saying:** “Why aren’t you doing anything about my husband’s pain?”

**Say:** “I am concerned that my husband is in so much pain. Is there anything you can do for him?”

### Start with a positive instead of a negative

Nobody likes to be talked to in a negative way, because it feels like an attack.

**Instead of saying:** “You don’t explain things well. We don’t know what to expect.”

**Say:** “We appreciate you taking time to talk through this with us. Can you please give us more information on what we can expect for side effects?”

### Describe your feelings, don’t display them

Say what you are feeling without displaying anger, frustration, or fear.

**Instead of:** Yelling or pounding your fist on the table

**Say:** “I feel very angry and frustrated that we have been waiting so long.”

# Plain and simple communication with your health care team

## HELP YOUR HEALTH CARE TEAM HELP YOU

### Ask questions and ask for clarification

- If your health care team doesn't explain things clearly to you, speak up! It's OK to ask for clarification. They want to communicate well with you, but they may not know when they're not being clear.
- If your doctor can't spend more time with you, ask if another staff member, such as a nurse or physician assistant, can talk with you.

### Take notes and write down your questions

- Use a notebook to write down any questions that come up between doctor's appointments. This helps you to remember all the things you want to talk about when you're with the doctor. List your most important questions first.
- Write down any instructions about caring for your loved one.
- Ask for print handouts or other resources that may help you care for your loved one.



*Patsy, transplant recipient,  
with Steve, her husband and caregiver,  
with Patsy's doctor*

***It's very overwhelming to keep track of all of the medications. Don't be afraid to ask a lot of questions."***

—Tiana, mom and caregiver

## **WHAT TO ASK WHEN A NEW MEDICINE IS PRESCRIBED**

If your loved one starts a new medicine, here is a list of questions to ask the doctor or pharmacist. Write down the answers, put a date on it and keep it with your medicine list.

- What is the medication for?
- What side effects can we expect? And which are signs of an emergency?
- Will the medicine interact with other drugs taken?
- How much should be taken? And how often?
- Should the medicine be taken with food? Or on an empty stomach?
- Are there special instructions, like avoiding alcohol, sunlight, or certain foods?
- What should we do if a dose is missed?





## SKILLS TO HELP YOU IN AN EMERGENCY

### When to call the doctor

It may be hard to know when to call the doctor and when to wait for the next appointment.

- Ask your doctor and health care team what is considered an emergency and how you should reach them.
- Save the emergency phone numbers in your phone and write them down in your notebook. Make sure you have numbers for both weekday emergencies and weekend or nighttime emergencies.
- Post the emergency contact information on the refrigerator at home and share it with your close family or friends.

Don't hesitate to call 911 if you think it may be an emergency.

### Before you call

Be ready to answer these questions:

- When did the problem start?
- What do you think brought it on?
- What makes it better?
- What makes it worse?
- What is your loved one's temperature?

Also, have a list of current medicines, doses and the most recent time each one was taken.

### DURING THE CALL

**Be sure to say that it might be an emergency.** For example, you might say,

**“I am very concerned about my loved one. I think it may be an emergency. Can you help me?”**

# Communicating with your family and friends

## CONNECTING WITH YOUR LOVED ONE

You may have noticed a change in your relationship with your loved one. It can be hard for caregivers to know when to encourage and nudge their loved one and when to just support them. It can also be hard to let go of new patient-caregiver roles when your loved one gets better. The most important thing you can do is to talk openly and let each other know what you are feeling.

### Here are some tips to help you support your loved one:

#### DO:

- ✓ Let your loved one express their feelings.
- ✓ Encourage them to say what could be causing their feelings.
- ✓ Listen carefully and try to understand their feelings.
- ✓ Offer support and encouragement.
- ✓ Let them know that the feelings are normal.
- ✓ Encourage them to talk to friends, other survivors, or a counselor.

#### DON'T:

- ✗ Force your loved one to talk if they're not ready.
- ✗ Tell your loved one how they "should" feel.
- ✗ Assume that it's your fault if they're feeling down or depressed.
- ✗ Feel that you must cheer them up in order to be helpful—sometimes just listening is the best way to help.
- ✗ Try to talk them out of how they're feeling.

Sometimes, it can be hard to find the "right" words to help a loved one. There may not be anything that we can say to make them feel better. But you can still show love, support and caring with a gentle touch, holding their hand, or just sitting with them for a while.

***If you aren't sure what to say, you can always say, "I'm not sure what to say. Can I just sit with you for a while?"***

## TALKING WITH FAMILY AND FRIENDS

Family members respond to transplant in many different ways. Some may feel that they need to talk about their feelings, while others may prefer to keep their feelings private. Some may look for information and others may not want too much information. There are different coping styles and none are “wrong.” Here are some tips for talking with your family:

- Have family meetings to talk about things as a group
- For those that aren't comfortable in a group, have one-on-one conversations
- Give everyone an opportunity to talk
- Don't set time limits on discussions
- Ask a BMT social worker or counselor to help you have difficult conversations



Visit [BeTheMatch.org/Caregiver](https://www.bethematch.org/caregiver) for more information and resources on communication.

[CaringBridge.org](https://www.caringbridge.org) can help you give updates to friends and family. Consider asking a trusted person to manage this for you.

## Chapter summary

- Speak assertively by using “I” statements.
- Organize your thoughts on paper before meeting with your health care team.
- Support your loved one by letting them express feelings when they're ready.
- Use resources, like websites or help from a friend, to organize how you keep family and friends updated.


## Chapter 3:

# Social Support: Getting the Help You Need



*Mitch, husband and caregiver*





Janice, wife and caregiver  
to Daryl

Many caregivers say that looking back, they took on too much themselves and wish they had asked for help sooner.

This chapter will help you use your social network to support you while you care for your loved one.

## HOW ARE YOU DOING RIGHT NOW?

Take a minute to see how you're doing:

	YES	NO
Do you feel you are able to handle all that you need to do?		
Are you ready with a list when friends volunteer their help?		
Do you have enough time to handle your essential tasks?		
Do you meet regularly with friends?		
Have you been able to delegate a task today?		
Did you say "yes" to an offer of help today?		

If you've checked "No" more times than "Yes," you are not alone. This chapter includes tips to help you share tasks so you can stay physically and mentally healthy.

If you've checked "Yes" more times than "No," you're doing great! This chapter includes tips that may help you keep up the good work.

# Social support helps everyone

Some people feel uncomfortable getting help, especially if they're used to doing things for themselves or for others.

Do you find it hard to ask others for help? Maybe you're worried about burdening others? Letting others help you is good for everyone.

1. Getting help keeps you healthy mentally and physically.
2. You're able to better care for your loved one when you get help.
3. Family and friends who offer help and support feel more useful and are happy to show you how much they care.

It may feel uncomfortable to ask for help, but in the end it's good for everyone.

There are people in your life who **want** to help. Likely, you'd want to help someone else who was in a similar situation. Keep that in mind if you feel reluctant to ask for help.

## IT'S NOT A SIGN OF WEAKNESS TO ASK FOR HELP.

Remember, most people will feel glad or useful when they help you. You may not be able to return the favor to each person. But you can offer a sincere thank you. Later, you may be inspired to give back to the community or others in need.

# Get the help you need most

## Here are tips to help you share the work:

- Take an honest look at what you **can** do and what you **want** to do.
- Name the things you're good at.
- Be realistic about how much time you have.
- Think about your friends' and family's strengths.
- List tasks you can give to or share with others.



## Contact the Be The Match Patient Support Center

**CALL OR TEXT: 1 (888) 999-6743**

Monday through Friday,  
8:00 a.m.–5:00 p.m. Central Time

**EMAIL: [patientinfo@nmdp.org](mailto:patientinfo@nmdp.org)**

All of our programs and resources are **FREE**.

As difficult as it may be, letting go of things that aren't essential frees up your energy for the things that are most important to you.

## Here are 5 steps you can take:

1. Make a list of the specific things that need to get done today or this week.
2. Circle the tasks that you need or want to do yourself. Avoid picking more than 5.
3. Make a second list of all the people in your life, such as your family, friends, coworkers and neighbors.
4. Think about their strengths and match each task with someone in your support network. For example, if you need help with meals, someone who loves to cook may be able to prepare and freeze meals for you.
5. Ask the people on your list to help you with the tasks you've listed.

If you're not getting enough support, consider reaching out to a church or a local community group. If you can't think of anybody to go to for support, call your BMT social worker or the Be The Match Patient Support Center.



## Online resources:

Use these online tools to help coordinate help from family, friends, coworkers, and neighbors.

- Lotsa Helping Hands: [LotsaHelpingHands.com](http://LotsaHelpingHands.com)



# Be ready when friends offer to help

## WHEN SOMEONE OFFERS TO HELP, BE READY AND BE SPECIFIC.

DO SAY:	DON'T SAY:
✓ Could you go the grocery store for me before this Friday? I can email you my list right now.	✗ Do you mind picking up a few groceries for me sometime?
✓ Next week we have several doctors' appointments. Could you watch the kids next Friday afternoon from 2 to 4 p.m.?	✗ Maybe you could watch the kids sometime.

Although it's best to be specific, it's also important to be flexible. So whenever possible, give your friends and family a few choices.

### HELP! THE HELP I'M GETTING ISN'T HELPFUL

Although people are well-meaning, support from others can sometimes fall short in meeting your needs or expectations.

If this happens, it's okay to say, "I really appreciate that you want to help, but right now, this isn't helping me. It would help me more if you would please..."

If people offer help that you don't need or want, thank them for their concern. Let them know you'll contact them if you need anything. You can tell them that it always helps to receive cards and letters.



**Words cannot begin to explain my gratitude. For 13 years, I never imagined a life without sickle cell anemia. I never dreamt that life could be so wonderful.”**

—Kari, mom and caregiver to Justin

## Prepare for the unexpected

Sometimes plans change or unexpected things happen. For example, a routine checkup could turn into a day of tests and appointments.

### Here are 3 ways you can prepare for unexpected events:

1. List the people you can call on at a moment's notice—including the middle of the night. Keep their contact information with you.
2. Give trusted friends and family copies of keys to your home so they can let out the dog or care for your children. Keep important contact information by the phone for them.
3. Make a phone tree or email list and put someone in charge of it so that if you need something unexpectedly, you only have to call 1 person and they can do the rest.

## Saying thank you

Thank you's don't have to be fancy or expensive. It can be as simple as sending an email or text.

Without that acknowledgement, they may wonder if what they did was helpful, or they may think you don't want or need their help any longer. Telling friends how much you enjoyed the meals they cooked for you, for example, can be all the thanks they need!

## Stay connected

With all that you are trying to do, it can be easy to lose touch with family and friends when you need the support and connection the most. Keeping your relationships with people who are important to you can help you feel better.

### Here are 6 simple ways to do that:

- 1. Walk it out.** Arrange a time with a friend to walk the neighborhood.
- 2. Talk it out.** Invite a friend over after dinner for a chat.
- 3. Schedule a phone date.** Arrange a regular time to connect. You'll get through the day better when you know that you will connect with a friend later.
- 4. Share what's bothering you.** Telling your concerns to someone can be the first step in finding solutions.
- 5. Declare a medical-free zone.** Agree not to talk about medical things. Give yourself a break!
- 6. Invite a friend over.** Ask a friend to keep you company while you do chores like weed the garden or do the laundry.

It's OK to be brief. Even if you only have 15 minutes to talk, still reach out. It can help you to relax, de-stress and recharge.



*Tiana, mom  
and caregiver*



*Maria, OPN-CG,  
Senior BMT Patient Navigator*

## Support for you

- Talk with someone who's been a BMT caregiver.  
Request a connection: [BeTheMatch.org/PeerConnect](https://www.bethematch.org/peerconnect)
- Connect with the local chapters of these organizations:
  - American Cancer Society: [Cancer.org](https://www.cancer.org)
  - The Leukemia and Lymphoma Society: [LLS.org](https://www.lls.org)
  - Sickle Cell Disease Association of America: [SickleCellDisease.org](https://www.sickledisease.org)
- Use online tools:
  - [CaringBridge.org](https://www.caringbridge.org)
  - [LotsaHelpingHands.com](https://www.lotsahelpinghands.com)

## Chapter summary

- Have a plan for when people offer help.
- Consider using online tools to coordinate help so you don't have to.
- Schedule a weekly phone date with the people closest to you to stay in touch.

*I would call my parents almost every day just to talk. It was extremely helpful to have that support from them.”*

—Tami, mom and caregiver



A photograph of a lush green park with several trees and a grassy area. A white arc graphic is overlaid on the image, curving across the top and right sides. The text is positioned in the lower-left quadrant of the image.

Chapter 4:

# Physical Health: Your Health Matters Too



*Tami, mom and caregiver to Sam*

Scherika, mom and caregiver



As a caregiver, you probably aren't thinking about your own health right now. When you're giving so much to your loved one, it's common to put aside your own health.

This chapter will help you learn and practice simple ways to boost your physical health.

## HOW ARE YOU DOING RIGHT NOW?

Take a minute to see how you're doing:

	YES	NO
Are your muscles relaxed and comfortable?		
Do you find time to walk—even 10 minutes—each day?		
Are you getting at least 7 hours of sleep each night?		
Do you eat healthy snacks and meals?		
Do you get at least 10 minutes of fresh air a day?		
Do you take time to take care of yourself every day?		

If you've checked "No" more times than "Yes," you're not alone. This chapter includes tips that may help you take better care of your body.

If you've checked "Yes" more times than "No," you're doing great! This chapter includes tips that may help you keep up the good work.



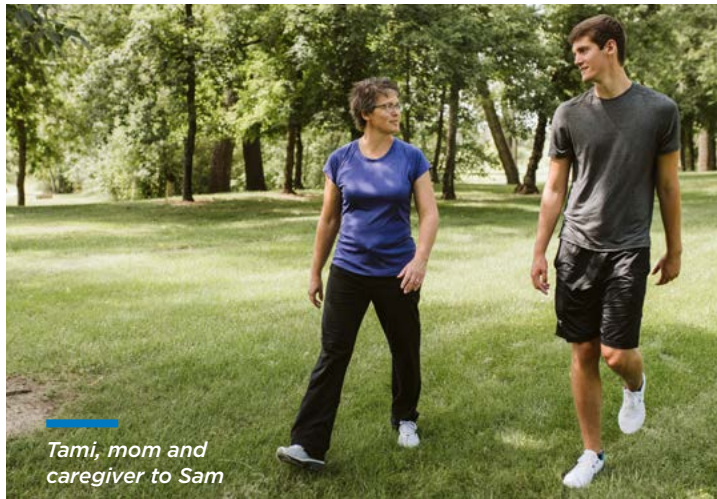
## Stretch and walk to burn off stress

One way you can lower stress is to “burn it off” by moving more each day. As a caregiver, you may spend a lot of time sitting—whether in the hospital, waiting for appointments, or talking with others.

### **Not only does moving feel good, but stretching and walking helps:**

- Relax tense and aching muscles
- Fight illness
- Give you more energy
- Improve your concentration
- Boost your mood

Write down a daily walking goal and then keep track of your progress.



*Tami, mom and caregiver to Sam*

Use the stretches and pictures on pages 40-42 to help you get started. Here are a few tips to get the most from your stretches:

- Set a goal to stretch at least 1 time each day.
- Stretch slowly and gently. Avoid “bouncing” to stretch more deeply because you could pull a muscle.
- Stretch only until you feel a mild pull—overstretching can cause damage—back off the stretch if you feel pain.
- Breathe slowly and naturally—don’t hold your breath while stretching.

## Simple stretches you can do anywhere



### SIDE OF NECK

1. Sit or stand with your arms hanging loosely at your sides
  2. Tilt your head sideways, first one side then the other
  3. Hold for 5 seconds
  4. Repeat 1-3 times
- 



### BACK OF NECK

1. Sit or stand with your arms hanging loosely at your sides
  2. Gently tilt your head forward to stretch the back of your neck
  3. Hold for 5 seconds
  4. Repeat 1-3 times
- 



### SIDE OF SHOULDER AND BACK OF UPPER ARM

1. Stand or sit and place your right hand on your left shoulder
  2. With your left hand, pull your right elbow across your chest toward your left shoulder
  3. Hold for 10-15 seconds
  4. Repeat on other side
- 



### SHOULDER, MIDDLE BACK, ARMS, HANDS, FINGERS, WRIST

1. Interlace your fingers and turn your palms out
  2. Extend your arms in front of you at shoulder height
  3. Hold for 10-20 seconds
  4. Repeat 1-3 times
-



### BACK OF UPPER ARM (TRICEPS)

1. Stand or sit with your arms overhead
2. Hold your elbow with the hand of your opposite arm
3. Gently pull your elbow behind your head as you slowly lean to the side until you feel a mild stretch
4. Hold for 10-15 seconds
5. Repeat on other side



### MIDDLE BACK

1. Stand with your hands on your hips
2. Bend your knees slightly
3. Gently twist your torso at your waist until you feel a stretch
4. Hold for 10-15 seconds
5. Repeat on other side



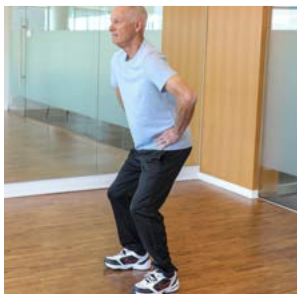
### ANKLES

1. Sit, or stand and hold onto something for balance
2. Lift your right leg and rotate your foot and ankle 8-10 times in one direction, then 8-10 times in the other direction
3. Repeat using your left leg



### CALF

1. Stand near a wall and lean on it with your hands
2. Place your right foot in front of you and bend your right leg
3. Keep your left leg straight behind you
4. Slowly move your hips forward until you feel your left calf stretch
5. Keep your left heel flat and your toes pointed straight ahead
6. Hold for 10-20 seconds
7. Repeat on other side



### **BACK OF THIGH (HAMSTRINGS)**

1. Stand with your feet shoulder-width apart
  2. Keep your heels flat and your toes pointed straight ahead
  3. Bend your knees slightly to do a squat
  4. Hold for 30 seconds
  5. Repeat on other side
- 



### **FRONT OF THIGH (QUADRICEPS)**

1. Stand near a wall and place your right hand on the wall for support
  2. Standing straight, reach behind you with your left hand to grab the top of your left foot
  3. Pull your heel toward your bottom
  4. Hold for 10-20 seconds
  5. Repeat on other side
- 



### **INNER THIGH, GROIN**

1. Stand with your feet pointed straight ahead, a little more than shoulder-width apart. Hold on to something for balance.
  2. Bend your right knee slightly
  3. Move your left hip downward toward your right knee
  4. Hold for 10-15 seconds
  5. Repeat on other side
-

## Easy ways to walk more each day



Every step counts, but do you know how many steps you take in a day? You may not know how little you move, until you feel stiff or sore.

An activity tracker or pedometer can help you see how many steps you take now, and set goals to walk more. Many of these are free and available through your smartphone or smartwatch. You can also keep track of how many minutes you walk. Then, each day add a few more.



### MAKING THE MOST OF AN ACTIVITY TRACKER OR PEDOMETER

- **Set a goal.** See how many steps you take on an average day, and set a goal to add more. Gradually work up to 10,000 steps each day.
- **Check your progress.** If it's mid-afternoon and you're only halfway to your goal, take a few minutes to walk more.
- **Write it down.** Use a diary or daily log to keep track of your progress. Celebrate your success!



*Alison, wife and caregiver*

## Ways to add more steps to your day

### WHILE AT THE HOSPITAL:

- Walk with your loved one or other caregivers up and down the halls.
- Ask if there's a treadmill or walking track at the hospital that you can use.
- Ask if someone could fill in for you while you take a short walk—even 10 or 20 minutes.
- Take the stairs instead of an elevator.
- Take a long way to the cafeteria.
- Ask a physical therapist about walking, workout, or yoga classes in the hospital or in the community.

### WHILE AT HOME:

- Walk the dog an extra 5 or 10 minutes.
- Instead of meeting a friend for coffee, suggest a walk as an alternative.
- Walk around your home during TV commercials.
- If it's OK with the doctor, take short walks outside with your loved one.

*Karen, wife and caregiver to Bob*



# Turn off stress to get the rest you need

For many caregivers, it's hard to get 7 to 8 hours of restful sleep each night. If you aren't sleeping well, you may have less energy, a harder time coping with stress and trouble thinking clearly.

## 7 THINGS TO HELP YOU SLEEP BETTER AT NIGHT

- 1. Wake up and go to bed at about the same time every day.**
- 2. Spend some time each day outside.**
- 3. Walk, stretch or do other exercises in the morning or afternoon.** Avoid strenuous exercise close to bedtime because it may make it harder to fall asleep.
- 4. Don't have caffeine at least 4 to 6 hours before bedtime.** This includes coffee, tea, soft drinks and chocolate. Some people need to limit caffeine even earlier in the day to sleep well.
- 5. Avoid alcohol near bedtime.** Although it may help you fall asleep faster, it may also cause you to wake up during the night, leaving you less rested.
- 6. Limit heavy meals near bedtime.** Eat a light snack before bed if you're hungry.
- 7. Try not to smoke near bedtime** or in the middle of the night. If you're on the nicotine patch, put a new one on in the morning, not at night.

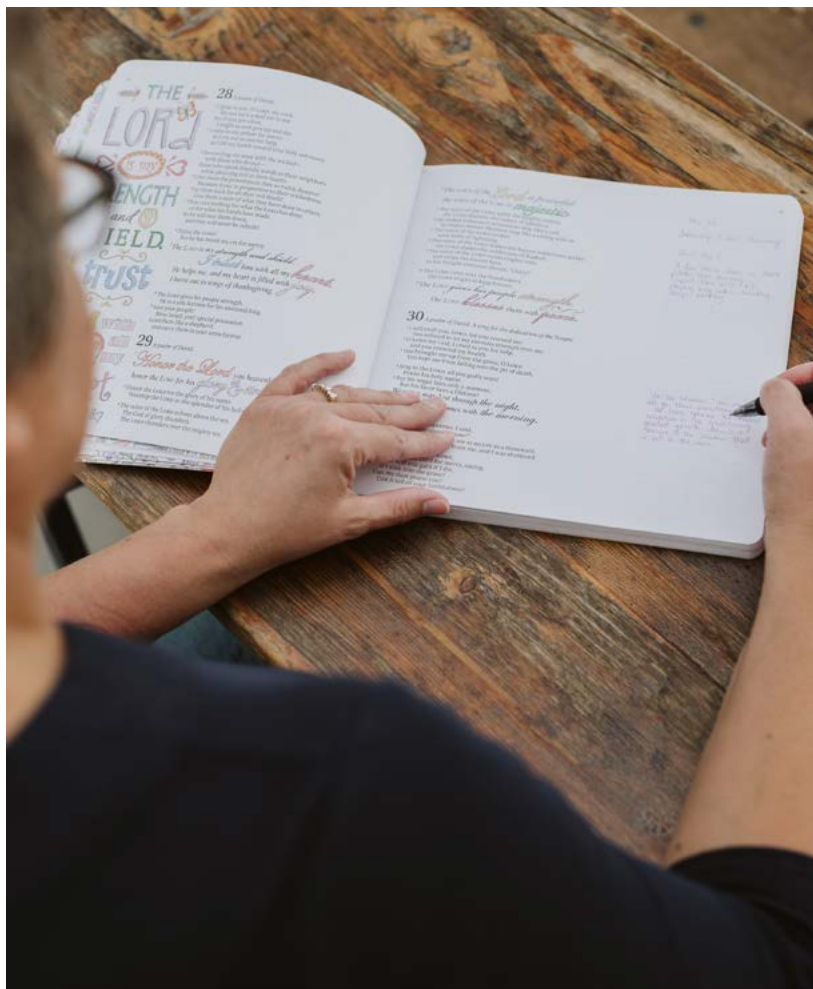
## 5 THINGS TO HELP YOU FALL ASLEEP EASIER

- 1. Use the bedroom only for sleep.** Don't eat or watch TV. Avoid looking at your phone, tablet or laptop at least 30 minutes before bed.
- 2. Keep your bedroom dark, a comfortable temperature and quiet.** If noise wakes you up, use a fan for background noise or wear soft earplugs.
- 3. Use relaxation techniques before bed,** such as deep breathing or meditation exercises to slow your thoughts.
- 4. If your loved one is awake or restless at night, sleep in a separate room.** A baby monitor may help if you're worried that you won't hear a call for help.
- 5. Talk to your doctor about your sleep problems.** There may be things they can do to help. Keep a diary of your sleep habits for 1 to 2 weeks before your appointment and share it with your doctor.



### 3 THINGS TO DO WHEN YOUR THOUGHTS KEEP YOU AWAKE

1. **Read a book or magazine** for distraction.
2. **If you don't fall asleep within 20 minutes, get out of bed and do something relaxing.** Drink a warm glass of milk, do a deep breathing exercise, take a warm bath, or do some gentle stretching. Then go back to bed.
3. **Write down your thoughts on paper** to get them out of your mind. Then, take a deep breath and tell yourself, “There is nothing I can do about this now. I have put them down on paper and will come back to them in the morning with a fresh start.”



## Eating on the go: Eat this, not that

Stress can affect how you eat. It may be easy to eat too much or too little, or choose what is quick or comforting, but not nutritious. Healthier eating can help you have more energy and feel better during the day.

**When you don't have time to cook, or are at a hospital, there are some things you can do:**

EAT THIS:	NOT THAT:
✓ Raisins, nuts, cereal, dried fruit or pretzels	✗ Vending machine candy, chips, or going hungry
✓ Yogurt, string cheese and crackers, bananas, grapes	✗ Cookies, candy bars, or high-sugar cereals
✓ Water, sparkling water, iced tea or juice	✗ Cola or sports drink
✓ Baked potato and side salad at a fast-food restaurant	✗ Cheeseburger and French fries
✓ Pre-washed and cut vegetables like celery, carrot sticks and peapods	✗ Skipping vegetables
✓ Several small meals and snacks a day	✗ Skipping meals and then eating a lot before bed
✓ Foods higher in Vitamins B and C, to fight illness, such as: sweet potato chips, whole wheat toast, oranges	✗ Foods lower in nutrition: Fried potato chips white toast, orange candy slices



*Scherika, mom and caregiver to Rhiannon (center),  
with Reyna, Rhiannon's sister*

*Staying hydrated can help you  
feel more focused and energetic  
so you can better care for your  
loved one.”*

—Bilan, MSW, OPN-CG,  
BMT Patient Navigator

#### **These tips could help you stay hydrated:**

- Carry a water bottle with you during the day.
- Use a freezer-safe water bottle to have ice-cold water all day long.
- Add lime or lemon to your water to improve the taste.
- Snack on foods with a lot of water in them, like grapes, watermelon or popsicles.

## “Stress relievers” that may add stress

Sometimes people drink alcohol or smoke to relax. But, the relaxing effects don't last long and can even cause other problems.



### ALCOHOL

Alcohol may not be helping you relax if:

- You're not sleeping well
- You feel hungover in the morning

**If you drink alcohol, it's best to drink in moderation.**

**This means:**

- **For women:** No more than 1 drink each day
- **For men:** No more than 2 drinks each day



### Resources:

If you're worried that you may have a drinking problem, visit [FindTreatment.SAMHSA.gov](https://www.samhsa.gov) or call **1-800-662-HELP (4357)** for free and confidential support and resources.

## SMOKING

It can be hard to quit smoking when you're feeling very stressed. But tobacco can affect your sleep, cause heart and lung disease and put your loved one at higher risk for infection.

As much as you can, limit your smoking and only smoke outside. To cut back, swap cigarettes for nicotine gum or lozenges. You can also ask another caregiver or friend who doesn't smoke to go for a walk with you if you're feeling an urge to smoke.

If you're ready to quit smoking, call *QuitLine Services* at **1 (800) QUIT-NOW (784-8669)** for free telephone support and resources.



*You don't need to change your entire lifestyle. Instead, choose one thing to focus on (eating well, walking more, or cutting back on alcohol or cigarettes). Ask your family and friends to support you in making this change."*

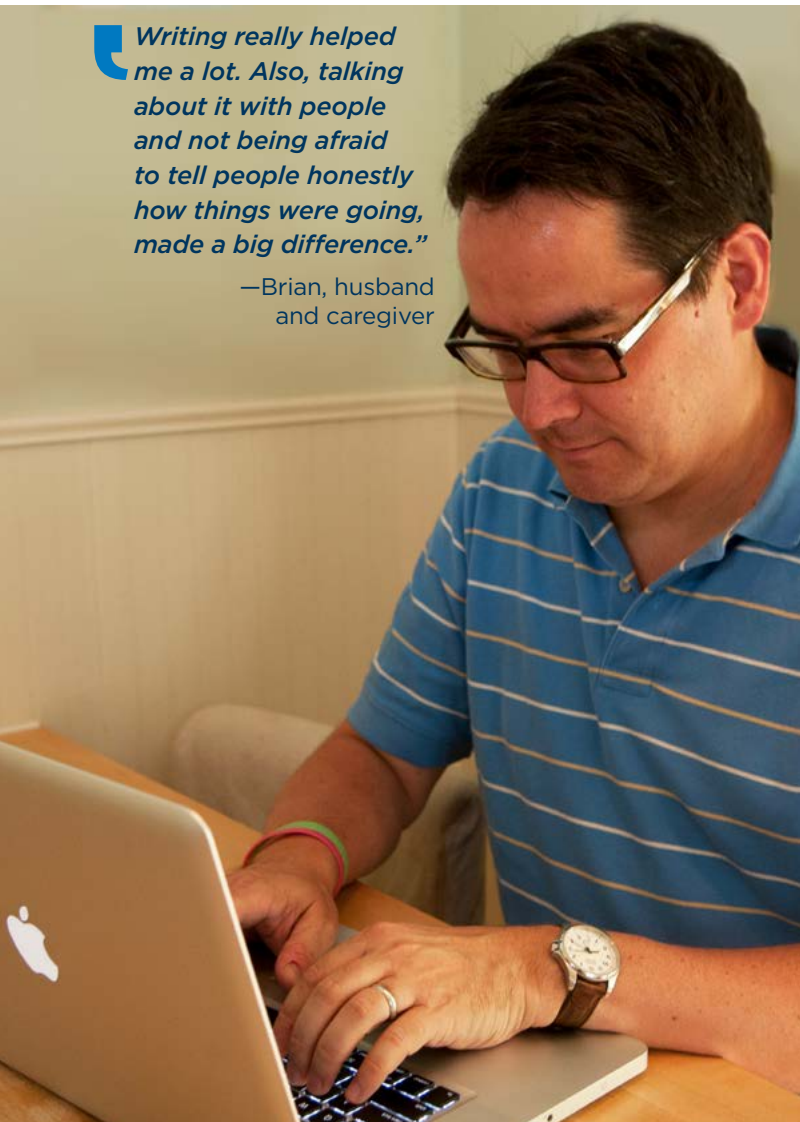
—Brenna, MPH, RN, ONN-CG,  
BMT Patient Navigator

## Treat yourself well

With everything going on around you, it's very common to ignore what your body is telling you. Take some time to write down how YOU are feeling—what do you need today?

*Writing really helped me a lot. Also, talking about it with people and not being afraid to tell people honestly how things were going, made a big difference."*

—Brian, husband and caregiver



- **Be gentle with yourself**  
Listen to when your body says it's tired and needs a rest. It's OK to take a break.
- **Keep your appointments**  
Keep your own doctor's appointments as much as possible. And don't forget to refill your own prescriptions. If you're far from home, talk to the BMT social worker for help finding local health care resources.
- **Take time for a massage**  
For a low cost massage, ask if a massage therapist donates time to patients and families at medical centers. Or, check for a massage school in your area.
- **Take time to laugh and play**  
Take 5 minutes to watch a funny video on YouTube or find a good book of jokes.
- **Treat yourself as you would treat a friend**  
If you find that you're being hard on yourself or talking to yourself in a negative way, think about how you might talk to a friend. You probably would be kind and understanding with your friend. Talk to yourself the same way.

## Chapter summary

To stay physically healthy and reduce stress:

- Stretch a little each day—anytime, anywhere.
- Set a daily walking goal, either by counting steps or minutes.
- Get rest by following the tips for good sleep.
- Make healthy food choices.
- Treat yourself well.

*In the hospital, my daughter and I had the best times. We had dance parties, we decorated the room and we laughed. But I never really found time for myself. Looking back, I wish I had taken better care of myself physically.”*

—Scherika, mom and caregiver



*Scherika mom and caregiver to Rhiannon*



*Audrey, wife and caregiver*



The background is a soft-focus photograph of a lush green forest with a waterfall. In the lower-left foreground, an open book is visible, with its pages slightly curled. The book's cover has a green and brown design with the title 'THEY' and 'FAMILY' visible. The overall mood is peaceful and natural.

Chapter 5:

# Relax and Recharge:

## Find Ways to Lower Stress



*Edna, mom  
and caregiver*

If you feel tense and stressed, use the relaxation exercises in this chapter to release tension and ease stress. Many of these exercises don't take long. Just spending a few minutes here and there throughout your day can help you feel relaxed and recharged.

This chapter will help you learn and practice simple ways to relieve stress.

### HOW ARE YOU DOING RIGHT NOW?

Take a minute to see how you're doing:

	YES	NO
Do you know what triggers your stress?		
Do you find time to rest and relax each day?		
Can you easily let go of negative emotions?		
When stress builds up, are you able to quickly respond?		
When you try to let go of stress, does it work?		
Are you able to do at least one thing you enjoy every day?		

If you've checked "No" more times than "Yes," you're not alone. This chapter includes tips that may help you reduce your stress.

If you've checked "Yes" more times than "No," you're doing great! This chapter includes tips that may help you keep up the good work.

# Figure out what causes your stress

Everyone has different triggers that lead to stress and ways to calm down. If you see signs of stress in yourself, a relaxation exercise could help you feel better.

When you feel stressed, keep track of what happened. Write down:

- What caused the stress?
- Where did you feel it? Your back? Your neck? Or, maybe your shoulders?
- How did you feel physically and emotionally?
- How did you respond?
- What helped you feel better?

## SIMPLE RELAXATION

Relaxation exercises are skills—the more you practice, the more they help. When you're relaxed, you'll have:

- A lower heart rate
- Lower blood pressure
- Better concentration
- Less discomfort

## 5 EASY WAYS TO RECHARGE NOW

1. Take 5-10 minutes every day to be quiet and breathe. You could stretch, gaze out the window, or do a 5-minute meditation.
2. While you're stopped at a stoplight, take your hands off the wheel for one moment and put them in your lap. Take 1 deep breath in and out and then be on your way.
3. Take time to appreciate the water as you shower.
4. Hold and pet your cat for a few minutes or play outside with your dog.
5. Watch a few funny online videos to get your funny bone working again. If you have more time, have a movie night with your loved one.



**AT THE END OF THE DAY**, think about everything you've accomplished and celebrate. If you need to, make a "to do" list for tomorrow. You've done enough for today.

Edna, mom  
and caregiver



**TAKE A BREAK EACH DAY.** You may need to actually schedule it in. Make it a priority. Set aside 10-20 minutes a day as YOUR time.

## Breathe your way to a peaceful state

Deep belly breathing is a simple activity that you can do almost anywhere. It quickly gives you energy and oxygen to reduce stress and body tension.

### DEEP BREATHING STEPS:

1. Sit or stand with good posture
2. Place your hand gently on your stomach
3. Breathe in through your nose
4. Fill your lower lungs and feel your stomach push your hand out
5. Hold your breath for 1-2 seconds
6. Exhale slowly, and visualize pushing out stressful thoughts or worries
7. Do this for 5-10 minutes, twice a day

**Optional:** With each deep breath, tell yourself something to help you feel calm. For example, you might say to yourself “I am calm and relaxed” or “I am the best caregiver I can be.”

## LET PICTURES IN YOUR MIND TAKE YOU AWAY

Imagery is using your imagination to form a mental picture of something that helps you feel positive or relaxed.

### Here are some examples of mental images you can form:

- **A favorite place,** somewhere you go with your family or by yourself. What sounds do you hear? What do you smell in the air?
- **A forest with mountains and a lake.** See the sunlight or moonlight reflecting off the water. Hear the birds singing. Smell the pine trees.
- **A tropical beach.** Feel a cool breeze on your body. Hear the ocean waves. Smell the tropical flowers. Taste the tropical fruit.

### Let yourself be guided into relaxation

If you have trouble coming up with your own images, you might prefer guided imagery, which uses a narrator. Here are some of the different types of guided imagery:

**Deep breathing:** Encourages deep breaths to help you relax your mind and body.

**Progressive relaxation:** Helps you relax tense muscles from your head to your toes.

**Sonic meditation:** Uses sound to help you feel relaxed.

**Scanning:** Helps you find places in your body where you hold tension and then relax them.

Search “guided imagery” or “guided meditation” on YouTube to find a variety of short video clips.



*Tiana, mom and caregiver  
to Demier*



*Tami, mom and caregiver*

## LET MUSIC TAKE YOU AWAY

Listen to music while you:

- Do the gentle stretching exercises described in the *Physical Health* chapter
- Fall asleep
- Write in your wellness journal
- Deep breathe
- Tap your toes or dance

**If you can't take the time today,  
make it a priority for tomorrow.**

## CARVE OUT SOME “ME” TIME

Here are **5 EASY WAYS** to carve out some personal time:

1. Give yourself permission to rest and to do things for yourself.
2. Let others know that your “me” time is off limits.
3. Make it a priority for yourself and for your loved one.
4. Schedule the time and commit to it.
5. Figure out what helps you most. Is it sitting in your garden? Walking? Spending a few minutes on a hobby? Or reading a book?

## Chapter summary

### MORE WAYS TO LOWER STRESS

- 1. Keep some of your usual activities.** This could be your hobbies, sports and exercise programs, spending time with friends and other family members and work projects. These routines may help to give you balance.
- 2. Add breaks to your routine.** Set aside 15-30 minutes a day as your time. Put it in your calendar. Use the time to:
  - Lie down and close your eyes
  - Listen to music
  - Sit outside
  - Take a walk
  - Read a chapter of a book
  - Look through a newspaper or magazine
  - Call a friend
- 3. “Medical-Free Zone.”** Take breaks from talking about transplant and other medical things by creating a “medical-free zone.” Set aside an hour or a whole evening when you’ll talk about everything, except transplant and recovery.
- 4. Find places to take a mental break.** Sing along to upbeat music in your car. Or, while waiting in line somewhere, think of 3 things that you’re thankful for today.
- 5. Get away for a night if you can.** Take a brief vacation, even if only for 1 night. It could be a night alone, with your loved-one, or with friends. A night away may help you get a fresh start or new perspective.

If you feel like your stress is growing, figure out what’s causing it and then use the exercises in this chapter to relax and recharge.

You can get started right away by adding these to your daily routine:

- Listen to music.
- Take deep breaths.
- Do guided imagery.
- Imagine yourself somewhere relaxing.
- Schedule some “me” time.







Chapter 6:

# Ways to Find Peace and Positives

*Scherika (right), mom and caregiver to Rhiannon (center),  
with Reyna, Rhiannon's sister*



Terri, mom and caregiver to Jodi

## Ways to find peace and positives

Many caregivers say that they found positives in their journey, such as moments of love or gratitude that helped them at just the right time. Some caregivers have even had deep changes in their faith or philosophy towards life.

This chapter will help you find positives along your caregiving journey.

### HOW ARE YOU DOING RIGHT NOW?

Take a minute to see how you're doing:

	YES	NO
Have you discovered a strength you didn't know you had?	<input type="checkbox"/>	<input type="checkbox"/>
Are you able to find small things that you're grateful for?	<input type="checkbox"/>	<input type="checkbox"/>
Are you able to find moments of joy and beauty in your life?	<input type="checkbox"/>	<input type="checkbox"/>
Do you find that you feel closer to your loved one, or to others?	<input type="checkbox"/>	<input type="checkbox"/>
Are you able to find something to make you smile each day?	<input type="checkbox"/>	<input type="checkbox"/>

If you've checked "No" more times than "Yes," you're not alone. This chapter includes suggestions that may help you find positive things during your caregiving journey.

If you've checked "Yes" more times than "No," you're doing great! This chapter includes tips that may help you keep up the good work.

# Remembering your identity

Being a caregiver is perhaps your biggest role right now. It's part of you, but it's not all of you. Here are 4 ways to stay in touch with other parts of your identity:

1. Keep doing activities that mean the most to you—for example, something related to your hobbies or your friends.
2. Spend time looking at old photos.
3. Read old letters, cards or emails.
4. Share a fond memory with a friend, such as a story from your childhood.

## Finding peace by acknowledging change

Acknowledge that your life has changed in ways that you wish it hadn't. This is the first step towards acceptance and peace. Then, express the emotions you feel. You may need to yell, cry, laugh, or write.

## Practice acceptance

Keep in mind that acceptance and peace does **not** mean giving up hope. Acceptance will help you to move forward. It can be as simple as saying to yourself, "This is my life at this moment. Now, what am I going to do about it? How can I make the best of it?"


## SEARCH FOR MEANING

It's normal to mourn the changes in your life, such as your career, health, finances and your life with your loved one. It's OK to feel sad for the changes and losses. But also watch for things you may have gained. For example, you may:

- Learn that you're stronger than you thought.
- Feel closer to your loved one, family or friends.
- Make different choices in your life, such as living more simply or spending more time with your family.

## Here are some ways to explore meaning:

- Write down your thoughts and feelings in a journal.
- Talk to your religious or spiritual leader.
- Talk with a counselor, social worker, or psychologist.
- Talk with others who have gone through similar experiences.
- Tell others what you've learned through your experience.



*Tiana, mom and caregiver to Demier*

## **FIND MOMENTS OF JOY AND BEAUTY**

If you keep your eyes and ears open, you can find moments of joy and beauty. They can spring up in unexpected places—kind nurses who go out of their way to help, a special moment of affection with your loved one, a new or stronger friendship.

Be ready for these moments and hang on to them. Enjoy them, write them down and keep them in your memory. They can help you when you're feeling down or discouraged.

## **CREATE POSITIVE MOMENTS AND MEMORIES**

It's still possible to find new activities and make new memories together. Some caregivers have said that starting a new tradition was very helpful.

### **Here are some ideas:**

- Start a family or friend game night.
- Read a story to a child.
- Use social media to stay connected to family and friends who are far away.
- Eat a picnic lunch in a park or your backyard.
- Celebrate small accomplishments or milestones.
- Before a meal, ask everyone to share the best thing that happened to them that day, no matter how small.

Sharing positive moments with others can make everyone feel better.

## REFLECTION

Take time to reflect back on how far you have come. It may feel bad now. Was there a time in the past that was worse? You have made it through some tough times and you can be proud of that. You are strong and resilient.

## SPIRITUALITY

Questions about the meaning of life and death may come up as you travel down the caregiver path. Spirituality is very personal and means different things to different people. For some people, feeling close to a higher power is a source of strength and support.

### Here are ideas to help you explore your spirituality each day:

- Read an inspiring book.
- Listen to spiritual music.
- Keep an uplifting or meaningful quote handy.
- Pray or meditate.
- Talk with a member of your faith community or someone else with a similar spiritual nature.
- Visit a place of worship or a special place of contemplation.

## WAYS TO EXPRESS GRATITUDE

Even in the most challenging times, it is possible to find things to be grateful for. To help you feel thankful during your loved one's transplant recovery, keep a gratitude diary:

1. Write down the things in your life that you're grateful for. Think of simple things, such as sunshine, having a hot shower, sleeping in a comfortable bed.
2. Each day, add something new that happened that you're grateful for. For example, it may be a good test result, progress in recovery or a call from a good friend.

If you commit to write down at least 3 things you're grateful for each day, you'll find:

- On the 1st day it may be hard to make a list.
- On the 2nd day it will be easier.
- Soon, you'll begin to recognize things to be grateful for as they happen.

# When you're ready, consider helping others who are in your shoes

**I have always set personal boundaries of what is funny and what is not. I have been quoted as saying 'there are just some things you don't poke fun at.' I was wrong. Laughter rises out of tragedy when you need it the most and rewards you for your courage."**

—Erma Bombeck  
writer and cancer survivor

Giving back may be a way to create something meaningful and positive from a very challenging and difficult experience.

## Ways to give back:

- Share your experiences in a support group or online discussion. Your experience can provide hope and motivation to others.
- Get involved with a national or local organization you believe in.
- Advocate for caregiver support and resources at your clinic.

## HUMOR, SMILES AND LAUGHTER

It can be hard to find humor in difficult circumstances. Laughing can feel strange when the situation is serious. But humor is OK and good for you. It helps you release stress and cope with challenges.

When you laugh it doesn't mean you're making light of the situation. Instead, it means you're making the best of it. Think of it as your way of not letting transplant and recovery get the better of you.

## Chapter summary

- Caregiving can be demanding and full of unexpected twists and turns.
- Whether or not you find any positives along your caregiving journey, be open to the possibility.
- Look for small expressions of love, peace or gratitude each day.

*Tiana, mom and caregiver to Demier*



## About Be The Match®

For people with life-threatening blood cancers—like leukemia and lymphoma—or other diseases, a cure exists. Be The Match connects patients with their donor match for a life-saving blood or marrow transplant. People can be someone's cure as a member of the Be The Match Registry®, financial contributor or volunteer. Be The Match provides patients and their families one-on-one support, education, and guidance 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.

**LEARN MORE** at [BeTheMatch.org/Patient](https://www.BeTheMatch.org/Patient)



## SUPPORT FOR BMT CAREGIVERS

**We're here for you.**

In addition to resources for patients, Be The Match® Patient Support Center offers information and support programs for BMT caregivers.

We can help you cope with the challenges that come with caring for your loved one during the transplant journey.

**CALL OR TEXT: 1 (888) 999-6743**

**EMAIL: [PatientInfo@nmdp.org](mailto:PatientInfo@nmdp.org)**

**VISIT: [BeTheMatch.org/Caregiver](https://www.BeTheMatch.org/Caregiver)**

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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. This information is not intended to replace, and should not replace, a doctor's medical judgment or advice.

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