

The Caregiver's Companion
to Emotions:

Coping with your
**feelings and
expectations
of caregiving**



“I wasn’t really interested in any of the things I used to do. I was so busy trying to make it through each day that I never noticed that I had changed. My doctor explained that I was depressed and overwhelmed – and he prescribed anti-depression medication (which helped). Both my daughters said they were happy to hear me laugh again. — **Jeanette, caregiver** (with her daughters)

A roller coaster of emotions

In many ways, illness and recovery can be as hard on you as it is on the transplant recipient. It is common to experience worry, stress and fatigue during this time. It can be hard to know how to cope with the emotions and the expectations you have for yourself. Taking the time to know and understand your feelings can help you cope.

This chapter will focus on how to listen to the signals your emotions are sending you and help you find coping strategies that work for you.



Joscelyn, caregiver to son Nick

The purpose of *The Caregiver's Companion: Coping with Your Emotions* is to help you find healthy and effective ways to cope with emotions commonly experienced by caregivers. In this chapter:

How do you know when you're not coping as well as you could be?

- Understand common thoughts and feelings
- Use your emotions as a signal

What to do when you're not coping as well as you could be

- Use different coping strategies for different kinds of problems
- Watch out for “stinkin’ thinkin’”

Channel your emotions

- Write about them—Get emotions out of your mind and down on paper
- Read about others’ experiences—Learn about others’ experiences and get validation for your own
- Express them—Find a creative outlet that works for you
- Cope with them—Try out suggestions from an emotional care checklist

How are you doing **right now**?

Before you read on, take a minute to answer a few questions about how you are doing in these areas:

When you are overly tired or stressed, do you like the way you are coping? Yes No

If you recognize more serious signs of depression and anxiety in yourself, do you know where to seek help? Yes No

Do you allow yourself to say “no” when you are feeling overwhelmed or tired? Yes No

Do you have a creative outlet that you are using now? Yes No

Do you have someone to talk to openly about your feelings? Yes No

Do you get at least 10 minutes of fresh air a day? Yes No

Do you take time to take care of yourself every day? Yes No

If you’ve checked at least one “No”, you may benefit from trying the suggestions in this chapter to help you find healthy and effective ways to cope with your emotions.

How do you know when you're **not coping** as well as you could be?

Usually our bodies and minds are very good at letting us know when we are not coping as well as we would like. Intense reactions—like being unexpectedly tearful or impatient—jumbled thoughts, poor concentration, headaches, stomach aches, or trouble sleeping can be some of the physical and emotional signs that you may not be coping as well as you could be.

On the other hand, positive emotions and healthy physical signs may be telling you that you are coping well! Experts say it's important to listen to both positive and negative emotional and physical signs.

You name it, I've felt it. Angry—that my husband had this disease; guilty—that I wasn't being a good enough mom/wife/employee; panic—there were many ups and downs and many moments that felt very scary; stretched thin—I felt like I was being pulled in every direction; gratitude—for all the help that we were given.”
— **Allison, caregiver**

Use your emotions as a signal

What are your emotions telling you?
Your emotions may be telling you to:

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

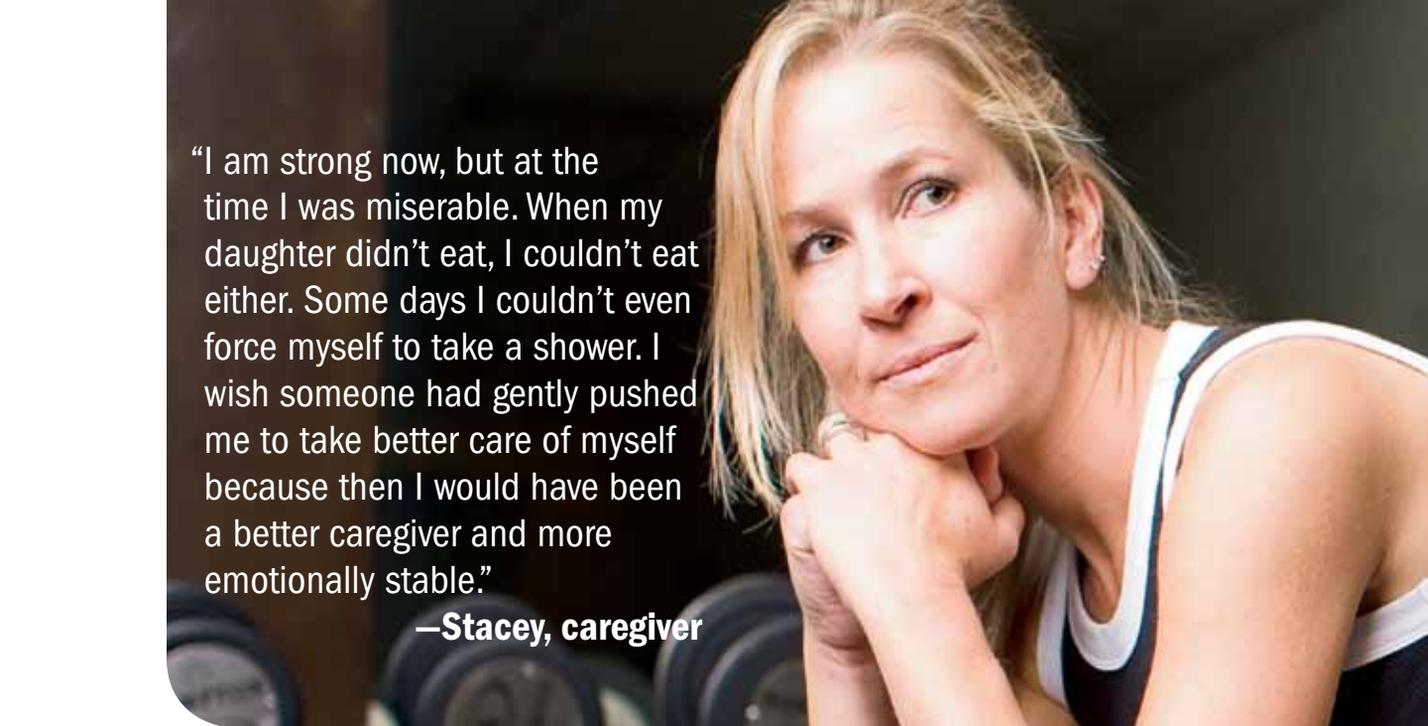
Other emotions may be telling you:

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

Pay attention to your emotions

They can be signals that tell you how well you are coping.





“I am strong now, but at the time I was miserable. When my daughter didn’t eat, I couldn’t eat either. Some days I couldn’t even force myself to take a shower. I wish someone had gently pushed me to take better care of myself because then I would have been a better caregiver and more emotionally stable.”

—Stacey, caregiver

Common thoughts and feelings

If you have felt or are feeling 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 at 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.”

You may feel a mixture of these thoughts and feelings at the same time, or at different times, throughout the same day. Each one is okay, and being in touch with your feelings, both positive and negative, is important to your mental and physical health.

Remember that these feelings are not only normal, but can actually be useful.

Recognize if you need to seek additional help

Many of the symptoms described on the next page are normal for short periods of time. However, when symptoms last for several days or weeks, and interfere with your ability to carry out your normal activities, they can be a sign that you need to seek additional help.

If you have any of these signs **for more than two weeks**, let your health care provider

know. Anxiety and depression can create both physical and emotional symptoms.*

If you think you may be experiencing anxiety or depression, contact your doctor. Tell him or her about any symptoms you are experiencing and ask about treatment options. You may want to talk with the doctor, social worker or psychologist on the BMT team about getting professional support.

*Modified from the National Cancer Institute's guide: "Support for Caregivers: When Someone You Know is Being Treated for Cancer"



Jody, caregiver

Changes in your feelings

- Feelings of being worried, anxious, “blue,” or depressed that don’t go away
- Not being interested or finding pleasure in hobbies and activities that you once enjoyed
- Feeling guilty or worthless
- Feeling overwhelmed, out of control, or shaky
- Feeling helpless or hopeless
- Feeling irritable, grouchy and moody
- Crying a lot
- Thoughts of hurting or killing yourself
- Focusing on worries or problems
- Not being able to get a thought out of your mind
- Avoiding situations or things that you know are really harmless
- Having trouble concentrating or feeling scatterbrained
- Feeling that you are “losing it”
- Body changes
- Unexplained weight loss or gain
- Trouble sleeping or needing more sleep
- Racing heartbeat
- Dry mouth
- Sweating a lot
- Upset stomach
- Diarrhea (loose, watery stools)
- Slowing down physically
- Fatigue that won’t go away
- Headaches or other aches and pains

“For you, as the primary caregiver to be most effective, you’ll need to indulge yourself once in a while—whether it’s a walk outside, a relaxing massage, an hour with a good book, or simply coffee with a friend. You must take care of yourself.” — **Kay, caregiver**

When you feel like you are struggling with your emotions

Coping is finding ways to deal with and overcome difficulties. It is important to understand the coping process and identify ways to cope. Everyone has different coping styles, and although there are no right or wrong ways to cope, some ways of coping are healthier than others.

Here are some strategies that may help

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

Emotion-focused coping—Try this when faced with a situation you cannot change. For example, while you cannot change the fact that your loved one is ill, it may be helpful for you to cope by letting out your thoughts and feelings.

Problem-solving coping—Figure out what's needed and make a plan. Used best when there is an aspect of a situation that is changeable. 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 delegating some tasks to others.

Thought-focused coping—Regain your sense of control by changing your expectations and attitude. Much of the stress we experience often has more to do with the way we think about an event—and react to it—rather than the event itself.

In some situations, you could benefit from using all three coping strategies, one after another. But it's also likely that you would want to focus on applying one strategy that best fits the situation.

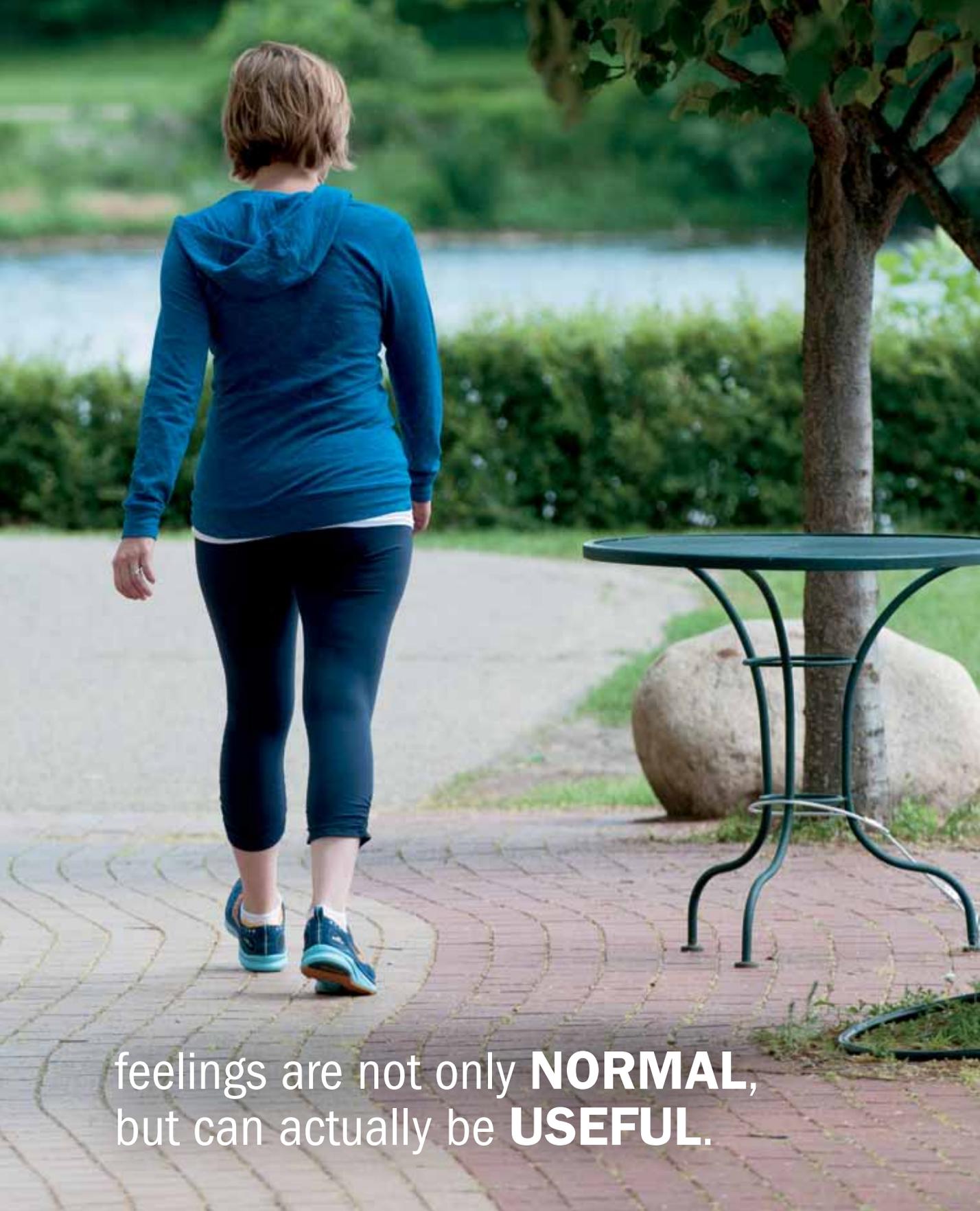
Do you feel like hiding your feelings?

You may feel like you need to keep your feelings to yourself so that you don't burden your family or others. However, not expressing your feelings can lead to loneliness and feelings of isolation and can actually increase the stress on your body and mind.

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 that it is not okay to experience or acknowledge negative feelings.

At other times, you may feel guilty for feeling positive emotions. Maybe you say to yourself that it's wrong to feel happy when your loved one is struggling with his or her 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.



feelings are not only **NORMAL**,
but can actually be **USEFUL**.

Using problem-focused coping

For situations involving something you can change or control, a problem-solving approach works best. To use a problem-solving strategy, you:

- Figure out what is needed to change the situation
- Make a plan to do what is needed
- Execute the plan
- Reassess the situation to see if your plan worked

For example, are you feeling overwhelmed with all that you have to do as a caregiver? Fortunately, this is a changeable situation, and problem-solving coping would be the best type of coping to use. To problem-solve, get more information if you need it. Write down all the individual tasks you need to do. Prioritize those that are most important. Give some of the tasks to others to do.* Decide which things can be left until later. Focus on those tasks that you have designated for yourself to do. Reassess the situation and see if you feel less overwhelmed.

*See the chapter on *Social Support* for tips on how to do this.

Using emotion-focused coping

For situations that involve something you cannot change or control, an emotion-focused approach works best. Let's say you are feeling sad and angry about your loved one's life-threatening illness. Unfortunately, you can't change the fact that your loved-one has the illness, but you can find ways to cope with your emotions.

First, tell yourself that it is reasonable and understandable to feel sad and angry. How-

ever, keeping that sadness and anger inside can make it difficult to think clearly or to feel positive. Engaging in emotion-focused coping can help lessen the feelings of sadness and anger. Examples of this could be:

- Talking to a friend
- Taking time to cry or scream
- Writing down your thoughts and feelings

By letting out and processing those thoughts and feelings, they will become less overwhelming, allowing you to focus more on the things on which you want to focus. You also may find that by allowing those feelings out you are able to make room for feelings such as hope and gratitude.



Jody, caregiver

Using thought-focused coping

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

For example, if another car cuts in front of you, while you are driving you might think, “What a jerk! That driver almost crashed into my car!” But you also might choose to think, “Wow! That driver sure is in a hurry! I’m so glad there wasn’t a crash!” The first way of looking at it would cause you to feel angry,

the second would result in a feeling of relief. That’s because how we think about things, situations, and ourselves directly affects how we feel.

The great news is that we have the power to change those thoughts and perceptions, which in turn changes our emotions. 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.

Watch out for “stinkin’ thinkin’”

How we think about things can affect how we feel about them. Negative thinking is easy to do without even realizing it. Have you ever found yourself doing the following:

1

All-or-nothing thinking We think things are either all bad or all good. We lose sight of the fact that most of life is experienced in the “gray zone” and is neither black nor white. We just need to remind ourselves of this. 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

Over-generalization We see or hear about a single negative event and immediately think everything is bad. We might find ourselves using words such as “always” and “never” which makes us feel there is little hope. You can remind yourself that both positives and negatives are almost always present and we can try to think in terms of “sometimes” rather than “always.”

3

“Shoulding” on yourself Sometimes we talk to our self in absolute terms. We feel we should do this, we must do that. This doesn’t leave much room for being human! It also can lead to feelings of guilt and anger. Instead, try saying to ourselves, “I would like to, if I can.”

Channel your emotions



Allison, caregiver, with her daughter

Studies have shown that holding in emotions can create stress on the body. This doesn't mean you should blurt out your feelings every chance you get, but it does mean that talking, writing, and reading about thoughts, feelings, and experiences is an important part of coping.

Here are three ways to take care of yourself emotionally:

1 Reading and sharing

Reading may not seem like an obvious way to deal with emotions, but it can help validate your feelings and help you feel less alone and uncertain about what you

are experiencing. Several caregivers have written books that openly share their challenges. One well-regarded book about BMT caregivers is:

“Caregivers’ Guide for Bone Marrow/Stem Cell Transplant”, by nbmtLINK.

Reading about other’s experiences or sharing your own story with others, whether online or in person, can have a big impact on both you and others. We hope some of the quotes included in these booklets have been validating, too!

2 Find a creative outlet

Many people find that a creative outlet can be helpful. Painting, gardening, drawing, sewing, and sculpting can be invaluable ways to channel and work through your thoughts and emotions.

You don't have to be an artist or use

expensive materials. For example, making a collage, by cutting out words or pictures from a magazine that represent your thoughts and feelings, and pasting them on paper, can produce a fascinating picture of your experience. Remember, most often it is the process of doing the creative work that is more important than the end product. You might be surprised by what comes out!

3 Empty your mind out on paper

Writing can help empty and free the mind of the numerous things you have to do or remember. Writing can:

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

Expressive writing, sometimes known as "journaling," is a good way to get in touch with your thoughts and feelings, and can be an important first step to improve your ability to cope with stress. It can bring awareness of thoughts and feelings that you did not realize you had. Your journal is a great tool to help you get your thoughts down on paper. Journaling is easy because there is no right or wrong way to do it. It's just a way to record what you are feeling at the time.

Things to think about before you grab your pen:

- You don't have to spend all afternoon – **keep it short**. You only need to spend about 15-20 minutes at a time.

- **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.
- Writing down your thoughts and feelings **more than once** can be helpful. Feelings can become less intense or you may find your thoughts get clearer writing over time.



It is possible that writing will bring up emotions. It is okay to experience those, of course. However, if you find yourself feeling very upset, it is best to stop writing, or to change writing topics. The point of the exercise is to express and process thoughts and emotions, but not to lose yourself in the process.

Emotional care checklist

Finally, here's a checklist of activities and strategies you can use to cope with some emotions commonly experienced by caregivers.

if you feel

Sad

- Include pleasant activities in your daily schedule
- Listen to your favorite music
- Spend a few moments in a space you enjoy, such as a garden
- Talk on the phone with a supportive friend

Discouraged

- Take one day at a time
- Imagine that tomorrow will be better

Afraid

- Talk to someone about the worst thing that could happen
- Make a plan to handle this worst-case scenario

Angry

- Take a break and leave the situation, if possible
- If you can't leave, stop and take a few deep, deliberate breaths
- Focus your anger on the situation and not on another person
- Avoid difficult people, or those who are overly critical

Guilty

- Give yourself credit for what you do well

Down/Serious

- Read a humorous book or watch a funny TV show or movie
- Tell yourself that it's okay to laugh

Overwhelmed

- Know that it's okay to say "no" to things
- Determine which chores can be put on the back burner
- Focus on what's really important to you and let go of the rest
- Let others help you

try this

The Serenity Prayer

This brief prayer holds much coping wisdom and may be helpful for you.

*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.*

Chapter Recap:

- *Use your emotions as signals that tell you how well you're coping*
- *Talk to your doctors if excessive feelings of sadness or worry interfere with your daily life; they could be symptoms that require medical attention*
- *How we think about things can affect how we feel about them; watch out for "stinkin' thinkin'"*
- *Try writing your thoughts down on paper; this can help you sort through problems and process feelings*

Visit **BeTheMatch.org/companion** for a list of resources and tips to help you cope with your emotions

