

The Parent's Companion
to Emotions:

Coping with your **feelings**



“Early on in our journey, a friend told me, ‘No emotion is bad. All feelings are good. Just go with it.’ Through all the emotions, I always reminded myself of this.” — **Sherri, TJ’s mom**



A roller coaster of emotions

In many ways, your child's illness and recovery can be as hard on you and your family as it is on your child. Many parents describe their feelings as an emotional roller coaster with many ups, downs, twists, and turns. It's common to feel sadness, guilt, anger, loneliness, a desire to escape, a lack of control, and more. These feelings, and many more, are normal. But, it can be hard to know how to cope with the emotions and expectations you have for yourself, let alone the emotions your child may be experiencing. Taking the time to know and understand your feelings can help you cope.

This chapter will focus on how to recognize your emotional signals, help you find coping strategies that work for you, and offer insight on things you can do to help your child cope emotionally. Remember, different people have different coping styles. What works for you might not work for your child or others in your family.



Heather and her son, Owen, age 3 at transplant

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

How to 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'"

How to express 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 support for your own
- Express them — Find a creative outlet that works for you
- Cope with them — Try out suggestions from the emotional care checklist (page 14)

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

Do you know where to turn for help if you feel anxious or depressed most of the time? 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

Do you know how to tell if your child is feeling overwhelmed or stressed? Yes No

If you’ve checked “No” more times than “Yes,” you’re not alone. But that also means you may benefit from 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, you may also be experiencing emotions and physical signs that may be telling you that you are coping well. Listen to your body and the emotional and physical signs it's sending you.

“Early on, my emotions were more negative than positive. I was frustrated at the inability to get a definite diagnosis and develop a treatment protocol. I felt angry when things didn't work out like we had hoped. But, there were certainly positive emotions too. The littlest thing could give you hope to hang on.”

— **Lisa, Kameron's mom**

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 parent

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, mom of Kelsey, age 3 at transplant**



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 parent.”

“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 additional help

Changes in your emotional health can create both physical and emotional symptoms. 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 ask for help.

If you have any of the signs on the following page **for more than two weeks**, ask your

doctor about being screened for anxiety or depression.* Anxiety and depression can be treated. Your doctor can help you learn about resources and getting the help you need.

Your transplant team is there to help care for your child's emotional health, too. You know your child best. If you have any concerns about how your child is coping, talk to the transplant team.

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



Terry, dad of Ashley, age 19 at transplant

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 yourself
- Focusing on worries or problems
- Not being able to get a thought out of your mind
- Having trouble concentrating or feeling scatterbrained
- Feeling that you are “losing it”
- Trouble sleeping or needing more sleep
- Fatigue that won’t go away
- Experiencing physical symptoms that are not explained by a medical illness or condition

“Do your best to take the time to deal with your emotions. We did our best to find the silver lining in every situation. I would repeat this all the time, especially during the roughest parts of transplant: ‘Today is one day closer to a healthy immune system. It is going to get bad before it can get better.’” — **Dan, Grace’s dad**

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 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 — For situations you cannot change. For example, while you cannot change the fact that your child is ill, it may be helpful for you to cope by expressing your thoughts and feelings.

Problem-solving coping — Figure out what’s needed and make a plan. Use this strategy 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 parent, you may consider making a list, prioritizing tasks, and giving 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 can benefit from using all 3 coping strategies, one after another. But it’s also likely that you would want to focus on applying 1 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.” 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 child is suffering.

It’s important to learn how to accept and cope with all emotions, both positive and negative. And find ways to name your emotions and let go of those feelings in ways that are safe, comfortable, and helpful.

Helping your child **cope**

It's important that you take the time to recognize your emotions and learn coping strategies that work for you. But, it's natural that as a parent your emotions are also tied to how your child is feeling. If you sense that your child is having a hard time emotionally, there are things you can do to help. Depending on your child's age and developmental stage, the specific strategies can vary.

Encourage your child to talk about feelings, and answer your child's questions honestly.

Tell stories of how you have felt in similar situations, how you handled it (good or bad) and how it turned out.

Come up with options and problem solve together. You may want to try creative ways to express feelings, like drawing pictures, writing a story, acting out a play, or singing a song.

Give comfort by being with your child. Hold your child, give hugs, or offer a hand massage or back rub.

Express affection and encouragement. Say the words, "I love you," "I am proud of you," and "I am here for you."

Don't forget, you're not in this alone. Talk with your child's health care team for ideas on how to help your child learn healthy ways to cope with emotions.

My husband and I talked to and leaned on each other. We also pushed each other to get out for walks every other afternoon for a breath of fresh air, a change of scenery, and a little perspective."

— **Janet, mom of Ava,
age 1 at transplant**

"Prayer is a stable force in our lives. We are able to count our blessings every day—even if they are as simple as being given another day with our child, or that he was able to talk to us, or watching a funny movie together. There are many challenges each day, and looking for the good helps."

— **Mary Ellen, mom of Louis,
age 13 at transplant**

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? Fortunately, this is a changeable situation, and problem-solving coping would be the best approach to use. To problem-solve, get more information if you need it. Write down each task 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 child's life-threatening illness. Unfortunately, you can't change the fact that your child 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. However, 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
- 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.



Diane, mom of Matthew, age 6 at transplant, and Alexandra, age 9 at transplant

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 of the same event? 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 your child, 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 parent!” 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 parent.”

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 ourselves 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, “I would like to, if I can.”

Express your emotions



Sherri, TJ's mom

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 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 people have written books that openly share their challenges.

Reading about another person's experiences or sharing your own story with other parents, whether online, in person, or through a support group, can have a big impact on both you and others.

2 Find a creative outlet

Many people find that a creative outlet can be helpful. Painting, gardening, drawing, sewing, and playing a musical instrument 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 may even want to find a creative project that you can work on together with your child or other family members.

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 a lot of time — **keep it short**. Write for 15-20 minutes at a time — or sometimes even less!

- **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 over time.

It is possible that writing will bring up emotions. It is okay to experience those. 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.

“I used journaling, especially at the beginning and on down days. I tried to think of something positive each day. Later, I could look back on some days and think, ‘Okay, got through that ... on to the next!’”
— Sherri, TJ's mom

Emotional care checklist

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

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
- Do something fun with your child — play a game, read out-loud, laugh together

Discouraged

- Take one day at a time
- Imagine that tomorrow will be better
- Talk to other parents who have been through transplant

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
- Remind yourself that no parent is perfect — learn from mistakes and don't dwell on them

Down/Serious

- Read a humorous book or watch a funny TV show or movie
- Tell yourself that it's okay to laugh
- Have fun with your family and friends playing board games, video games, cards, etc.

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 feelings of sadness or worry interfere with your daily life or your child's 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'"*
- *Write your thoughts down on paper; this can help you sort through problems and process feelings*
- *Your child may be experiencing different emotions from you; help your child express their feelings*

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