The Parent’s Companion to Peace and Positives:

Finding the positives along your journey
“For me, the unanticipated reward was inner strength. I feel like I can handle anything life throws my way after dealing with this crisis.”

— Janet, Ava’s mom
You are on a difficult journey that can be demanding and full of unexpected twists and turns.

But that doesn’t mean you can’t experience positive things along the way. In fact, many parents say that they found positives on the transplant journey, such as moments of love or gratitude that helped them at just the right time. Some parents have said they experienced changes in their outlook on life, or became stronger in their faith.
The purpose of *The Parent’s Companion to Peace and Positives* is to help you find some positives during this time. In this chapter:

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**Finding peace**
- Remembering your identity
- Search for meaning

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**Finding joy and beauty**
- Create positive memories
- Humor, smiles, and laughter

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**Exploring spirituality**
- Find what works for you

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**Expressing gratitude**
- Ways to give back

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“My son decided to color all over himself and the walls. I look back on all that he’s been through and realize how grateful I am to have a child who can color on the walls. It’s amazing to see how much stronger and healthier he gets every day.” — *Sarah, Alex’s mom*
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:

- Have you discovered a strength you didn’t know you had? ☐ Yes ☐ No
- Are you able to find small things for which you are grateful? ☐ Yes ☐ No
- Are you able to find moments of joy and beauty in your life? ☐ Yes ☐ No
- Do you feel closer to your child, or to others? ☐ Yes ☐ No
- Are you still able to find something to make you smile each day? ☐ Yes ☐ No

If you’ve checked “No” more times than “Yes,” you’re not alone. You may benefit from trying the suggestions in this chapter to help you find positive things during your family’s journey.
Finding peace through acceptance

One key to finding peace with all the changes in your life is to first acknowledge them. You may need to yell, cry, laugh, or express in other ways your fear, anger, frustration, and other emotions. Acknowledging that your life has changed, in ways that you wish it hadn’t, is the first step toward acceptance. Not recognizing the changes in your life allows the strong feelings about those changes to hang over you like a dark cloud.

Letting go of negative feelings about those changes can help you be more effective in caring for your child.

Acceptance can be as simple as saying to yourself, “Okay, this is our life at this moment. Now, what am I going to do about it? How can I make the best of it?”

Express your negative feelings.

Write them down in your journal.

Remember that acceptance does not mean giving up hope. Acceptance will actually help you to move forward, which can’t happen if you continue to go around in circles wishing things were different.
Helping your child is perhaps your biggest role right now, and it may even seem like it has defined you. It is part of you, but it is not all of you. It’s important to keep in touch with aspects of your own identity. Here are 4 easy ways to do that:

1. **Keep activities** that you enjoy and mean the most to you. For example, something related to your hobbies and interests, your friends, your job, your community, or your place of worship.

2. **Spend some time** going through old photos.

3. **Look through letters**, cards, or emails you have received.

4. **Share a fond memory** with a friend. Maybe it’s a story from your childhood or a special family vacation.

**Search for meaning**

Making sense of the experience your family is going through and finding meaning is a very personal journey.

Know that it’s normal to mourn the things in your life that have changed, such as your daily routine, your job, your child’s health, your finances, and your family plans and activities. Doing so will allow you to begin to realize that there may be things you have gained, perhaps things that are surprising. Such as learning that you are stronger than you thought.

Forming relationships with other families you’ve met along the way. Feeling closer to your child, or to your partner. Or you may feel that you are making different choices in your life — living more simply or spending more time with your family.

Here are some ways to explore meaning:

- Write your thoughts and feelings in your journal. First focus on your feelings and then begin to look for positives or meaningful changes that have occurred.

- Participate in your faith community. Talk to your pastor, clergy, rabbi, or other spiritual leader.

- Talk over your feelings with a counselor, social worker, or psychologist.

- Talk with others who have gone through similar experiences.

- Read a book about finding meaning through challenges.

- Teach others about what you’ve learned through your experience.

- Refer to resources on **BeTheMatch.org/companion**.
Find moments of joy and beauty

Lizette and her daughter, Amanda
Look for moments of joy and beauty in your life. They are there, if you keep your eyes and ears open. They can spring up in unexpected places — an especially kind nurse who goes out of the way to help or a special moment with your child.

Be ready to grab those moments and hang on to them. Relish them, write them down, put them in your memory, so that you can bring them out again and again, especially when you are feeling down or discouraged. You might write these things in your journal so that you can look back at them any time.

“One of my fondest memories during transplant was when Alex learned it was Nana’s birthday. He wanted to have a party and make a cake. He was very weak, but he really wanted to make it special so he made her flowers and helped make decorations.”
— Sarah, Alex’s mom

Create positive moments and memories

Because of the many changes that come during your child’s transplant journey, some of the family activities you once did may no longer be possible, at least temporarily. However, it is still possible to keep up some family traditions or find new activities and make new memories together.

Here are some things to try:

• Start or continue a family game night
• Read stories to your children
• Buy a webcam or exchange photos, so you can still see family and friends who are far away
• Take a picnic lunch to a park or picnic in your backyard
• Celebrate a small accomplishment or milestone with a fancy cake

Parents have said that starting a new tradition was very helpful, such as:

After everyone sits down at the table for dinner, and before eating, each person says what was the best thing that happened that day, no matter how small. It’s amazing how realizing there were many positive moments in the day and sharing them with others can make everyone feel better!
Questions about the meaning of life and death may come up as you travel the path you are on. Spirituality is very personal and means different things to different people. For some people, feeling close to a higher power is an incredible source of strength and support.

Try some of these ways to explore and add something spiritual to your daily life:

- 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
Reflection

Take time to reflect back on how far you have come. You have made it through some tough times and you can be proud of that. So often we quickly forget how we got through those other difficult times, and don’t realize how far we have really come.

“You learn to appreciate the little things in life. You become grateful for what you do have and learn that some of the things you worried about before this all began become less important.” — Dan, Grace’s dad
Ways you can express your gratitude

Even in the most challenging times, it is possible to find things for which we are grateful. Some parents have said they were grateful that the recovery process has gone well, that their child is alive, that they have received wonderful support from others, and that they have experienced positive moments along the way.

Keep a gratitude diary

Some people keep a “gratitude diary” and have found that it shifts their mindset from taking things for granted or feeling powerless to feeling empowered and glad.

To start, you simply take a moment to write down the things in your life or things that happened during the day for which you are grateful. These can include simple everyday things (for example, enjoying the sunshine, having a hot shower, sleeping in a comfortable bed) as well as big things we can be grateful for (like a good test result or progress in recovery).

If you make a commitment to yourself to write at least 3 things down for which you are grateful or thankful on that day, you will find:

• On the first day it may be hard to come up with things
• On the second day it will be easier
• Soon, you will begin to recognize things to be grateful for as they happen

With a gratitude diary, you may experience an overall shift to more positive well-being. And since it can’t hurt, it might be worth a try!

“I have learned to let go of whatever happened yesterday. Today is a gift; it’s a new day.”

— Sarah, Alex’s mom
Ways to give back:

- **Participate in a support group** or online discussion and share your experiences with others.

- **Share your story**, whether one-on-one with others or through social media or blogs. Your experience can touch other people’s lives in meaningful ways.

- **Get involved with a national or local organization.** You could attend a survivorship conference and make sure challenges for parents and other issues are discussed and heard.

(Modified from the NCI publication, *When Someone You Love has Advanced Cancer: Support for Caregivers*)

“We’re on the donor registry now. Perhaps someday we can do the same thing for someone else that our son’s donor did for us.”

— Lisa, Kameron’s mom
“As much as we wish we could have protected our son from cancer, we would never have had the ability to show him first-hand all of the amazing people who are in this world. We met so many incredible people along this journey ... the ultimate being our son’s donor and ‘blood brother,’ Nick.” — Tracy, Cameron’s mom
Humor, smiles and laughter

It can be hard to find humor in difficult circumstances. To laugh can feel strange, as if you are not taking the situation seriously. Humor is not only okay, it’s good medicine for you. Laughing releases hormones (called endorphins) in your body that may actually help you stay healthier.

Laughing doesn’t mean that you are making light of the situation, it means that you are making the best of it. If you feel guilty for laughing, think of it as letting your child see that joy is still possible!

“I made it a point to appreciate the little things in life, like a beautiful day, a time alone to read, a small sign that our daughter was doing better that day, and finally, making people laugh. I did my best to keep my sense of humor during the entire treatment.”

— Pete, Megan’s dad

Chapter Recap:

- Choose a way to find peace that helps you feel good about yourself
- Remember to hold onto moments of joy and love, and keep them in your memory
- Take time to feel and show gratitude to yourself and others during difficult times

Visit BeTheMatch.org/companion for a list of resources to help you find positives along your caregiving journey