

# Family Education Sheet

## Caring for your well-being while helping your child with medical complexities



Boston Children's Hospital

Where the world comes for answers

View more health education materials at  
[www.bostonchildrens.org/familyeducation](http://www.bostonchildrens.org/familyeducation)

This sheet gives you information about how to take care of your own needs while you're caring for a child with complex medical needs.

### Key points

- It's perfectly normal to feel frustrated or sad when your child is struggling with complex health issues.
- It's important to take care of your own health while caring for your child so that you don't burn yourself out.
- You can do this by finding support from others, exploring your spirituality, trying meditation and/or focusing on your emotional health.

## What does my own health have to do with my child's health?

Caring for a child with medical complexities is both a loving and challenging role. You're helping your child with their medical needs while also balancing your life responsibilities, like work, taking care of other family members and managing the household. It can feel like a lot to handle. But it's important to remember that you need to care for your well-being, too. Taking care of yourself helps you to be there for your child in the best way possible.

Here are some ideas to support your emotional, physical and spiritual health.

## How can I take care of my emotional well-being?

It's normal to feel lots of different emotions, like stress or sadness, uncertainty or hope when your child is struggling. As they go through emotional ups and downs, you may too.

- **Manage stress:** Make time for yourself to do something pleasurable every day, even if it's something small. Try activities like deep breathing, meditation, yoga or prayer to relax in moments when you feel overwhelmed.
- **Understand your emotions:** Special events, like doctor's appointments or hospital stays, can bring up worries or sadness. It's OK to feel this way. Talk to someone you trust about your feelings. Setting small, realistic goals for yourself can help you stay hopeful.
- **Talk to a professional:** You can always talk to a counselor if your emotions start to feel overwhelming. About 70% of caregivers go through tough times. It's normal to feel a bit down.
- **Allow yourself to laugh:** Humor is one of the healthiest and most powerful ways to find perspective on life's tough experiences. It's something we often share during tough times.

To find humor during a stressful time, think about what makes you laugh and try to bring that into your day. Laughter can help bring back your energy and change your perspective.

## How can I make sure I'm taking care of my physical health?

You need to be as healthy as possible to take care of your child. Caring for a child with complex medical needs can be more than a full-time job and can cause heavy and ongoing strain on your physical, mental and spiritual health. It's easy for families to put their own health needs aside. But this can lead to burnout. It's important to take care of yourself.

### Check with your doctor and think about these basic tips:

- **See your doctor:** Keep up with your own health checkups. Don't forget about your doctor's visits, screenings or medications.
- **Stay active:** Try to get at least 30 minutes of exercise each day. It's worth the time even though it can be hard to make the time. Even a short walk can make a big difference in how you feel.
- **Eat well:** Eating foods like fruits and vegetables helps keep your body strong. Drink plenty of water each day, too.
- **Get enough sleep:** It's important to rest. Try to get 6-8 hours of sleep each night. Your body needs sleep to recover and have the energy to care for your child.



## How can I build a support system?

Caring for a child with complex needs can make you feel like you're all alone. You might feel like nobody else could understand all the challenges you have to deal with. It's important to connect with other people.



### Here's how you can build a support system:

- **Talk to others:** Finding other parents who understand your situation can help. Look for support groups or online communities where you can share your experiences.
- **Ask for help:** It can be hard to ask for help, but you don't have to do everything alone. Asking for help can ease some of your stress. It could be anything: help with daily tasks, emotional support or even just a 1-time favor.
- **Join a support group:** Support groups are a great way to connect with other people who are going through similar experiences. These groups can provide emotional support and helpful advice.

- **Take quiet moments:** Sit quietly and focus on your breathing. This can calm your mind and reduce stress.

**Remember:** Caring for your child with medical complexities is a big responsibility. It can be emotionally and physically draining. But you can provide better support for your child by taking good care of yourself. It's OK to reach out for help when you need it.

*You're not alone on this journey. Reach out to others for support and remember to be kind to yourself along the way.*

## Can meditation help?

### Meditation for health and resilience

Meditation is a powerful tool that can help you relax, quiet the mind and to lower stress levels. It can support your physical and emotional well-being, offering a sense of calm and balance. If you're managing someone's ongoing health challenges, meditation provides a healthy coping mechanism, allowing you to navigate the ups and downs with greater ease and resilience.



### Helpful tools

If you're new to meditation or looking for additional support, there are several apps that can guide your practice:

- Headspace
- Calm
- Insight timer

## How can I explore my spirituality?

The journey of caring for a child with medical complexities may make you start to think about your purpose in life and what brings you peace. Spirituality is a very personal part of life that can help you feel balanced.

Here are some ideas to explore:

- **Reflect on your purpose:** Take a moment each day to think about what matters most to you. Whether it's prayer, meditation or spending time in nature, nurturing your spiritual side can bring comfort during tough times.
- **Practice mindfulness:** Mindfulness is a way to calm your mind and focus on the present. It can help reduce stress and bring clarity. Here are some simple ways to practice mindfulness:
  - **Write it down:** Keeping a journal can help you work through your emotions and thoughts and make some sense of them. Write about your day, your feelings or things that make you happy.
  - **Create a scrapbook:** You can make a scrapbook to capture memories of your caregiving journey. This can help you see things from a different perspective and celebrate your child's progress.
  - **Read something new:** Take a break from caregiving by reading something interesting or learning about a topic you enjoy.

### Gratitude meditation

Here's an example of a simple and calming gratitude meditation that you can use to help you connect with peace, relaxation and positive emotions.

*Welcome to this meditation space. I'm so glad you've chosen to take a moment for yourself. In the next few minutes, we'll focus on deep breathing, cultivating gratitude and connecting with the loving energy around us. This practice will help you recharge and fill your spirit with calm. Let's begin by creating a peaceful environment within.*

*Pause*

*Find a comfortable position, either sitting or lying down, with your arms resting gently. Close your eyes, and let's begin this journey toward inner peace, gratitude and love.*

*Start by taking a deep breath in through your nose, allowing your chest and belly to rise as you fill your lungs with air. Hold it for a moment... then exhale slowly*

*through your mouth. Let each exhale release tension. Continue breathing deeply, feeling the rhythm of your breath grounding you in the present moment.*

*In... and out. Good. Continue at your own pace, settling into a comfortable breathing rhythm.*

*Pause*

*As you relax into your breathing, bring to mind something you're truly grateful for. It could be a person, a place or a simple moment that brought you joy. Imagine this scene with all your senses—what do you see, hear and feel? As you hold this image in your mind, allow the feeling of gratitude to fill your heart with each breath in, and spread warmth throughout your body with each breath out.*

*Take a moment to breathe in this warm feeling of gratitude.*

*Now, think of someone you love deeply—a family member, a friend or even a beloved pet. Picture their face, their smile, the sound of their voice. As you breathe in, draw in love; as you breathe out, send love and gratitude toward them. Feel your heart expand with positive emotions, radiating outward.*

*Sit with this feeling of love and gratitude for a few more breaths.*

*When you're ready, slowly bring your awareness back to the present moment. Gently open your eyes. With practice, you'll be able to carry this sense of peace and love with you throughout your day.*

*Thank you for taking this moment for yourself. Remember, you can return to this state of calm and love whenever you need to. Namaste.*

## Introducing guided meditations

We invite you to explore these calming and healing meditations, designed to support your emotional and physical well-being. Each practice is intended to help you find peace, relaxation and healing, whether you're seeking rest, release or relief. Take a moment to focus on your breath, relax your mind and embrace the healing power of meditation.

- **Guided body scan meditation for sleep and relaxation:** This meditation gently guides you through a body scan, helping to release physical tension and promote deep relaxation, making it easier to unwind and fall asleep.
  - Listen: [youtu.be/T5QoAXGSI\\_k?si=lqSxkYPBNszqD-qC](https://youtu.be/T5QoAXGSI_k?si=lqSxkYPBNszqD-qC)
- **Meditation on letting go:** In this practice, you'll learn to be present in the moment, letting go of stress and worry. It's designed to help you navigate life's challenges with a calm and open heart.
  - Listen: [youtu.be/I6NFilvgObk?si=IDUr741TZNCEjUWO](https://youtu.be/I6NFilvgObk?si=IDUr741TZNCEjUWO)

- **Golden light guided imagery meditation for neuropathy:** This guided imagery meditation uses the energy of golden light to bring warmth and healing to your body, providing comfort and relaxation, especially for those with neuropathy.
  - Listen: [youtu.be/SfCCiyBaEko?si=TCyX1saxks-BkXt-](https://youtu.be/SfCCiyBaEko?si=TCyX1saxks-BkXt-)

We hope these meditations give you a sense of peace, healing and comfort. Take your time to explore and make these practices a part of your daily self-care routine.

## Should I try art or music therapy?

### Art and music therapy for those caring for people with medical complexity

Art and music therapy offer powerful ways to express yourself, especially when words might feel like they're not enough. These creative outlets allow you to connect with your emotions, develop inner strength and enhance your well-being. Both art and music can be soothing and provide a sense of relief from the challenges of dealing with medical complexity.



#### Art therapy prompts

- **Freestyle art:** Let your imagination flow! Create whatever comes to mind without worrying about the result. Focus on the process and let your creativity guide you.
- **Visualization art:** Close your eyes and take a few deep breaths. Imagine a place that makes you feel safe and happy. When you open your eyes, capture that peaceful place in your artwork.
- **Nature art:** Spend time outdoors or look at a photo of nature. Use it as inspiration to draw or paint the beauty of the natural world.

#### Music therapy prompts

- **Mindful listening:** Choose a song that speaks to you. Listen closely and check in with how it makes you feel. What emotions does the music stir? What parts of the song stand out to you and why?
- **Connecting to music:** Move, dance or sing along to music. Let the rhythm and melody uplift your spirits and release any tension. Don't worry about being perfect. Just enjoy the experience.
- **Explore new music:** Try using apps that offer relaxing playlists, like Spotify. Or try MusiCure, a scientifically backed music therapy app by Danish composer Niels Eje, designed to promote relaxation and well-being.

Both art and music therapy can help you connect with your feelings, find relaxation and foster resilience as you navigate your journey. These tools can be part of your self-care routine, bringing comfort, joy and a deeper sense of peace.

## What is journaling?

### Journaling for emotional well-being

Journaling is keeping a regular journal or diary. It's a safe, private space to express your emotions, thoughts and experiences. It's a way to release fears, frustrations and worries without fear of judgment. By putting pen to paper, you can better understand your feelings, reduce stress and increase self-awareness.

Journaling can also be a valuable tool to help you track your and/or your child's physical and emotional health, providing insights that can be shared with your medical provider during your next visit.

#### Journal prompts

- **How are you feeling physically and emotionally today?**

Take a moment to reflect on both your body and mind, noting any sensations or emotions that stand out.

- **Write about a moment of strength or resilience you experienced recently.**

Celebrate your inner strength by reflecting on a time you overcame a challenge.

- **What activities or practices help you feel calm and relaxed when dealing with symptoms or stress?**

Identify techniques or routines that bring you peace and comfort.

- **List 3 things you're grateful for today.**

Reflect on the small or big things in your life that bring you a sense of gratitude and joy.

- **Write a letter to your past self about how far you've come in your journey.**

Celebrate your growth and progress as you reflect on the changes you've experienced.

## Should I look into counseling?

### Counseling and support

Counseling offers a safe and confidential space where you can openly express emotions, concerns and fears. It provides an opportunity to discuss challenges, gain emotional support and develop coping strategies.

Whether you're dealing with the stress of managing a complex medical condition or simply need someone to talk to, counseling can be an invaluable resource for your well-being.

Journaling can be a powerful tool to process emotions, manage stress and create a deeper connection with yourself. It's a practice that allows you to be your own listener, offering support and understanding through your words.