

Pediatric Palliative Care



SUPPORT FOR CHILDREN WITH
SERIOUS ILLNESS & THEIR LOVED ONES

FULL-COLOR
LOGO HERE &
CHOOSE BORDER
SPOT COLOR

SAMPLE

© 2023 by Quality of Life Publishing Co.

All rights reserved. No part of this booklet may be reproduced without prior permission of the publisher. Printed in the United States of America.



Published by Quality of Life Publishing Co.
Naples, Florida

Quality of Life Publishing Co. is an independent, mission-driven firm specializing in branded publications that help ease the way for those with serious illnesses and their families.

Visit www.QOLpublishing.com.

HOW TO ORDER BRANDED COPIES: Call Quality of Life Publishing Co. during regular business hours (Eastern Time) toll free at 1-877-513-0099 or email info@QoLpublishing.com.

Introduction

When a child is seriously ill, the whole family can be overwhelmed with uncertainty and fear. Families must cope with hospital stays and treatments, learn how to manage care at home, and make big medical decisions. All this while balancing home, school, and work life.

This can lead to high stress, financial burdens, and strained relationships. Pediatric palliative care can help by providing support, reducing anxiety, and improving the quality of life for your child and your family.

This booklet explains pediatric palliative care and provides tips on how to support your child. An assessment at the back of the booklet encourages meaningful conversations and helps the care team learn more about your child.

You are not alone. We are honored to be part of your family's journey and are here to help during this difficult time.

Sometimes real superheroes live
in the hearts of small children
fighting big battles.

Table of Contents

Introduction	1
What Is Pediatric Palliative Care?	3
How Pediatric Palliative Care Works	5
The Pediatric Palliative Care Team	6
Improving Your Child’s Quality of Life	7
Physical needs	7
Emotional needs	9
Social needs	10
Spiritual needs	12
Communicating With Your Child	13
Developmental Levels	15
Siblings	17
Communicating With the Care Team	18
Pediatric Palliative Care Plan Assessment	19
Your Pediatric Palliative Care Team	25
Care for Parents and Caregivers	26

What Is Pediatric Palliative Care?

Pediatric palliative care (PPC) is specialized medical care focused on relieving pain and symptoms for children with severe or chronic conditions, such as cancer, genetic diseases, neurological disorders, and many others.

The PPC team works with your child's current providers, guided by you and your child's care goals, to help your child live as fully and comfortably as possible.

Pediatric palliative care is:

- **For any child with chronic symptoms** or serious illness from birth to young adulthood.
- **Provided at any point in the disease** and is based on your child's current needs, not their prognosis.
- **Whole-person care** that can be provided alongside curative care.
- **Support for the whole family** that addresses practical, financial, social, emotional, and spiritual needs.

Pediatric palliative care IS NOT hospice care:

It's a common misconception that palliative care is the same as hospice care. Some families refuse PPC because they don't want to "give up" on their child. While it is far from giving up, hospice care is only for patients expected to live six months or less.

Remember, PPC is for *all* children living with a serious illness at any point from diagnosis and beyond.

What makes palliative care different for children?

- **Young bodies and minds constantly grow**, respond differently to illness and treatment, and require unique approaches to support and communication at each stage.
- **Some illnesses affect children differently than adults.** Certain illnesses only affect children. Kids are also resilient to illness in ways adults are not.
- **Many patients must travel for specialized pediatric care that is unavailable locally.** Long hospital stays away from home may add extra emotional and financial strain.
- **Minors cannot make medical decisions for themselves.** It's common to have anxiety over making the “right choices” for your child (see communication tips, page 13).
- **Contact us at least six months before your child's 18th birthday** so we can provide extra information and support if needed. If your child is 18+ years old:
 - They are considered adults and can make their own medical decisions.
 - They must appoint a healthcare decision-maker if they want you (or someone else) to speak for them.
 - You may need to set up guardianship if your child cannot communicate their wishes.
 - Laws vary by state, but we can give you guidance.

“A sick child is much more than his or her sickness.”

— Fred Rogers

How Pediatric Palliative Care Works

Referral: Anyone—you, your child’s doctor, or a loved one—can suggest PPC as soon as your child is diagnosed or at any point during the illness. **The earlier the referral, the more your child and family can benefit from PPC.**

Eligibility: The PPC doctor determines if your child qualifies by assessing their illness, symptoms, and the level of treatment needed.

Payment: Insurance, Medicaid, or other benefit programs may cover all or part of PPC costs. Call your health insurance provider or contact us to explore your options.

Care plan: Once your child is enrolled, the PPC team partners with your current care teams to create a care plan based on your child’s needs, wishes, and family values.

You and your child are always in control of the care plan, and will make medical decisions with the PPC team’s guidance. Care plans often change with your child’s needs over time.

Providing care: After the care plan is discussed, the PPC team will contact you to talk about the next steps and schedule appointments.

PPC may be provided in a hospital, clinic, doctor’s office, or (in special cases) at home. Some care teams also offer 24/7 phone support for questions after hours.

The Pediatric Palliative Care Team

PPC is provided by healthcare professionals specializing in comfort care who work alongside your current care teams.

Your child, you, and your family are an essential part of the PPC team.

Members of the PPC team may include:

- **Doctors, nurse practitioners, and physician assistants** talk to you about the illness and treatment options, guide the care plan, and coordinate care with other care teams.
- **Registered nurses** track vital signs, manage medicines, and provide support. They may be assisted by licensed practical nurses or certified nursing assistants.
- **Social workers** provide emotional support, help fill out complex forms, navigate payment and insurance, and arrange for other financial, emotional, and social support.
- **Spiritual care professionals** provide emotional and spiritual support based on your family's values.
- **Child life specialists** help children cope with their illness and understand their experience through play and creativity while providing emotional support.
- **Counselors or psychiatrists** provide mental health support for your child and the whole family.
- **Physical, occupational, or speech therapists** teach your child exercises to help with movement, mobility, and daily activities such as eating, bathing, dressing, toileting, etc.
- **Other therapists** (massage, art, music, pet, etc.) may also be available.
- **Volunteers** from the PPC team or your family and friends can help with companionship, errands, and support.

Improving Your Child's Quality of Life

PPC improves your child's quality of life by addressing their physical, emotional, social, and spiritual needs. We can coordinate with your other care teams to make sure these needs are being met in other care settings.

Contact us if you believe your child's needs aren't being met so we can provide support. Our goal is to give your child a chance to learn, play, and grow—to just be a kid—even while fighting a serious illness.

Physical needs

A sick child's many physical needs include daily care (feeding, bathing, dressing, etc.) and managing symptoms such as pain, shortness of breath, fatigue, constipation, and many others. We provide caregiving advice and address physical symptoms with medication, therapy, and coping tips.

What you can do:

- **If you notice changes in your child, please share them with us.** Adjust activities, schedules, and care tasks as needed. You know your child best.
- **Avoid comparing your child's developmental milestones to others.** Choose milestones unique to your child (related to treatment progress, personal goals, or joyful moments) and celebrate with small rewards or meaningful activities.
- **Try small things to take your child's mind off their symptoms.** Gently rub their back or do calming activities like coloring, puzzles, or reading. Watch silly movies or tell jokes and funny stories. Humor can help lighten the mood and distract from pain and symptoms.

- **Contact us right away if your child’s pain or symptoms get worse.** Things to note:
 - Pain and symptoms can change daily (or hourly), so we may adjust the care plan often.
 - Follow the prescribed dose and schedule for your child’s medications. Contact your child’s doctor or us for guidance before making any changes or giving over-the-counter medicines or supplements.
 - We may suggest other symptom relief methods, such as hot/cold pads, simple exercises, or massage, art, music, or pet therapy.
 - Keep a daily log of symptoms to track changes. Note the time, intensity (on a scale of 0–10), and what makes the symptom better or worse.
- **Create a calm, comfortable space for your child.**
 - Keep the child’s room clean and free of clutter. Adjust the room temperature, noise, and lighting to levels your child prefers.
 - Having blankets, pillows, and favorite toys nearby can comfort children of all ages.
 - Having a family pet in the room can be comforting. Contact us to be sure it’s safe to have a pet near your child, especially if their immune system is weak.
 - If your child must stay in another room (for example, their hospital bed or other equipment may only fit in the living room), make sure they have privacy. Place furniture or hang sheets around their bed to give them their own space.
 - When your child is not home, decorate their hospital room with familiar items. Have your child choose blankets, pillows, pictures, or other things from home to place around the room.

Emotional needs

Kids with serious illness can suffer from fear, anxiety, depression, and other emotional symptoms just like adults but process their emotions in different ways. PPC can help you and your child manage these difficult emotions.

What you can do:

- **Contact us if you notice changes in your child's behavior.** This may be a sign they are struggling emotionally and need extra support.
- **Showing your emotions gives your child permission to do the same.** While more intense emotions are best shared with adults, there is strength in allowing yourself moments to cry and be vulnerable in front of your child.
- **Provide art supplies, toys, and plenty of chances to play** to help children express their feelings. What they draw or act out can reveal their thoughts and fears.
 - Older children can also benefit from creative outlets like playing games, making art, and journaling.
 - If your child cannot physically play, let them direct you in their play of choice. Using your hands/ movements to help your child act out their play provides the same benefits.
- **Though it may be hard, take time to give thanks.** Gratitude can improve mental health and build resilience. As often as you can, take turns naming one thing you're grateful for. Find gratitude in things outside the illness, like quiet time together or a visit from a friend.
- **See “Communicating With Your Child,”** pages 13–17.

Social needs

Children constantly learn about the world around them and how to interact with others. It is important that this social development continues, even through a serious illness.

What you can do:

- **Always treat your child with kindness and dignity.** Feeling respected, loved, safe, and secure are all important to a child, regardless of age.
- **Keep your child's routine as normal as possible.**
 - Wake up, brush, bathe, change, have meals, go to bed, etc., at the same times. Routine hygiene and changing into fresh clothes are important every day.
 - Don't be hard on yourself if you can't follow the routine. If there will be a change in plans, tell your child beforehand so they know what to expect.
- **If your child attends school, it's important they continue if they are able.** The PPC team can assist with a school plan or accommodations (like an aide, walker, or wheelchair). In some cases, children may qualify for a teacher to come to the home. Talk to your child's school and your PPC social worker about your child's options.
- **Continue to set limits and rules for your child,** even though they are seriously ill. Though they may not always appreciate rules, having guidance from parents helps kids feel safe and secure.
- **Watch for big changes in your child's social behavior,** which could be a sign they need more support from a counselor or therapist.

- **Join a support group** for firsthand advice you may not find elsewhere. Connecting with others having a similar experience can allow you and your child to share your thoughts, ease feelings of being alone, and provide hope for the future.
- **Sit with your child and read their favorite books.** This simple act can give kids the connection they need. Age-appropriate books about serious illness or how to handle big feelings can help kids of all ages. Ask us for recommendations.
- **Plan fun things between treatments and caregiving.**
 - Have a movie night, listen to music, make food or crafts to give to loved ones, or play board games.
 - Ask friends and family to visit, if possible, but within limits so you and your child aren't overwhelmed.
 - If visits aren't possible, set up virtual playdates. Older children can stay connected via text, social media, or online gaming.
 - Create positive memories as a family. Take photos, make videos, write letters, or spend quality time together cuddling or holding hands.
- **Contact a group that grants wishes to seriously ill children.** A big trip, letter from a celebrity, or shopping spree can boost morale. Contact us for recommendations.

“You don't have the power to make life 'fair,' but you do have the power to make life joyful.”

— Jonathan Lockwood Huie

Spiritual needs

For many families, asking “Why?” and seeking meaning are an important part of this journey. Practicing spirituality can help your family find a sense of peace and connection.

Spirituality is about finding out what gives our lives meaning. You can practice spirituality through religion, belief in a higher power, or appreciation for the joys and wonders of life.

What you can do:

- **Tell us about your family’s spiritual beliefs on pages 23–24.** Some beliefs may guide treatment decisions.
- **Try to accept that some questions may not have answers.** Some lean into their faith during hard times. Others turn away from their beliefs. Both are normal and valid ways to cope.
- **Meet with our spiritual care professional** for more emotional support based on your beliefs.
- **If your family is part of a religious or faith community:**
 - Attend services in person, attend remotely, or ask if members of your faith community can come to you.
 - Contact a trusted faith leader for support.
 - Set aside a special day or time to follow the rituals of your faith at home.
- **If you choose not to belong to a faith community:**
 - Practice new or old family traditions. Cook a family recipe, look through old photos, celebrate special holidays, etc.
 - Take time each day to practice mindfulness, reflection, and gratitude.

Communicating With Your Child

Adults avoid talking to children about serious illness because they don't want to scare them, think talking about it will make the illness worse, or they're not sure what to say. But kids understand more than adults think they do, and they need your support most right now.

The following tips apply to seriously ill children and siblings. Good communication lets you connect, express love, and know your child's wishes. **Contact us if you need help talking to your child(ren).**

What you can do:

- **Learn as much as you can about the illness.** Connect with organizations specific to your child's diagnosis and write down questions for your care teams.
- **Keep your child involved in decision-making as much as possible.** Update your child when there are changes in the illness or treatment.
- **Let your child lead conversations about their illness.** Pages 19–24 can help prompt talks about what they know, what to expect, how they feel, and their wishes.
- **Allow plenty of time for conversations.** Pick a quiet spot where your child feels safe. Sit close, hug or hold hands, make eye contact, and speak calmly and gently.
- **Start with basic facts using simple language.** Pause often to let your child ask questions and make sure they understand. Prepare to have many short talks over time.
- **Talk openly and honestly with your child** to prevent them from feeling lonely, helpless, or mistrustful. Let your child ask as many questions as they want. Children expect—and deserve—the truth.

- **Validate all your child's feelings.** Let them know it's normal to have all kinds of emotions.

☰ What you can say:

- *"It's okay to be angry. It's normal to feel that way."*
- *"I'm sorry you are sad. I'm sad, too."*
- *"I can see why you feel that way. Do you want to talk about it?"*

⊗ What to avoid: Telling your child how they should or shouldn't feel.

- *"Don't cry, we have to stay positive!"*
- *"Oh, I know exactly how you feel."*

- **Be prepared for questions you can't answer.** It's okay to admit that you don't know.

☰ What you can say:

- *"I don't know. Let's talk about it and figure it out together."*
- *"I'll write that question down so we can ask next time we see the doctor."*
- *"I'm not quite sure, but I think [say what you believe]. What do you think?"*

- **Ask your child open-ended questions.**

☰ What you can say: Start your questions with "How—" "What—," "Tell me about—," or "I wonder—."

- *"How are you feeling?"*
- *"What do you think about what the doctor said?"*
- *"I wonder if you might be worried about this?"*

⊗ What to avoid: Questions that can be answered with "yes" or "no," such as *"Are you mad/sad/scared?"*

Developmental Levels

This section provides insights into different age groups. If you have kids in separate groups, keep talks appropriate for the youngest, then have one-on-one time with older kids later.

Infants and toddlers (birth–2 years)

Things to know:	What you can do:
Infants and toddlers do not understand serious illness and treatment, yet may respond by being extra clingy and harder to soothe.	<i>Give this group extra love and snuggles to help them feel safe. Contact us if you need more help supporting your infant or toddler.</i>
They are affected by changes in their bodies, their daily routine, and the moods of the people around them.	<i>Create a new daily routine. Practice good communication with other adults (p 28) to help lessen tension around your child.</i>
This age group has the most fear and anxiety over changes in routine and with caregivers.	<i>Establish bonds with members of your care teams. Seeing familiar, friendly faces will help your child.</i>

Preschool (3–5 years)

Things to know:	What you can do:
Some preschoolers might know about serious illness through experience with a person or pet.	<i>Use open and honest communication when talking about serious illness.</i>
Preschoolers may have magical thinking about how illness is caused or cured.	<i>Explain things using simple language, pausing often to make sure your child understands.</i>
Preschoolers may ask the same questions over and over again to try to process the answer.	<i>Give the same answer each time. They're not looking for more answers or a deeper meaning.</i>
Stress can lead to temporary regression, which may present as thumb sucking, tantrums, bedwetting, etc.	<i>Give extra comfort and avoid punishment for regressive behavior. Contact us if the behavior causes issues or doesn't improve on its own.</i>

Elementary school (6–10 years)

Things to know:	<i>What you can do:</i>
This group may understand more about serious illness but, until now, may have thought it only happens to other people.	<i>Continue to use open and honest communication when talking about serious illness. Prepare to give this group more details.</i>
They may struggle with complex feelings like worry, anxiety, or guilt. They may have more questions you can't answer.	<i>Always validate your child's emotions. Check in often to give your child plenty of chances to talk and ask questions.</i>
Changes in school, friendships, and after-school activities may have a larger impact on older children.	<i>Set up and maintain a school plan for as long as possible and encourage your child to keep in touch with friends.</i>

Middle school & high school (11+ years)

Things to know:	<i>What you can do:</i>
This age group has a more adult awareness of serious illness but has a unique way of processing it. They may seek answers on their own from friends or on the internet.	<i>Let your teen guide conversations about their serious illness and medical decisions. Ask them to come to you with questions so you can help them find answers.</i>
Tweens and teens are seriously ill struggle the most with changing body image and depression.	<i>Check in often. Listen and avoid lectures or giving unwanted advice. Contact us if you notice big changes in behavior or loss of interest in things they enjoy.</i>
Tweens and teens may have more emotional symptoms and less control over mood swings.	<i>Try not to take outbursts or anger personally. Do not force your teen to talk if they need space.</i>
Loss of control during a time when they are seeking independence can also lead to depression in teens.	<i>Avoid being overly protective. Find a balance between giving your teen freedom and setting healthy limits.</i>
Tweens and teens may feel alone, alienated from peers, and afraid of being "different."	<i>Be aware of your teen's social needs (see pp 10–11) and encourage them to keep in touch with close friends.</i>

Other special needs & developmental disabilities

Things to know:	What you can do:
Some seriously ill children may need extra support for special needs unrelated to the illness.	<i>Use communication tips across different age groups, tailoring the approach to your child's needs.*</i>

* Consider working with a therapist specializing in your child's additional special needs. Contact us if you need help finding a referral.

Siblings

When a child is seriously ill, siblings may feel left out, lonely, helpless, guilty, jealous, or ashamed. Having other family members who need care can complicate an already stressful situation. It's normal to struggle balancing your sick child's needs with the needs of the rest of the family.

What you can do:

- **Let siblings know it's okay to feel however they feel and that you are there for them.** They may be afraid to share "negative" feelings or don't want to add to your stress.
- **Schedule dedicated one-on-one time with siblings when possible,** such as a lunch date or movie night.
- **Plan special outings or activities for siblings,** even if it's just for an hour or two. Ask friends and family to help.
- **Teach siblings about the illness in age-appropriate ways** to keep them from making up their own stories.
- **Involve siblings in the daily life of your sick child.** Make sure your children get regular quality time, like playing games or watching TV together. If siblings want to be helpful, give them simple tasks like tidying up or drawing pictures to decorate the sick child's room.

Communicating With the Care Team

Open, honest communication leads to better care, so we want you to be comfortable sharing your thoughts and feelings. Knowing what is important to your child and family will help guide the care plan and future healthcare decision-making.

What you can do:

- **Complete the assessment on the following pages with your child and share this with us.**
 - Older children may prefer to complete this on their own. Younger children will need your help.
 - If your child cannot communicate, do your best to answer the questions as your child would.
 - Skip questions that don't apply or are hard to answer.
 - Write answers on a separate sheet or make notes on a smartphone or computer if you need more space.
- **Feel free to ask us as many questions as you need to.** We are here to help you understand as much as possible about your child's illness and treatment.
- **Contact us right away if you have any concerns.** If something isn't working for you or your child, we will do our best to adjust the care plan so that it does.
- **It's helpful to learn the names and roles of the PPC team members working closely with your child.** Write their names and contact information on page 25 or save them on your phone to help you remember them.

Pediatric Palliative Care Plan Assessment for

Child's name

Parent/guardian helping complete

Date

- 1) List the names of close family members and how they are related to your child.** Include parents/guardians, siblings, aunts/uncles, cousins, grandparents, pets, etc.

- 2) List names of close friends** and other important people in your child's life.

- 3) What are the three most important things we should know about your child?**

4) What are things your child enjoys?

(Examples: Favorite foods, scents, music, hobbies, places, people, etc.)

5) What does your child dislike or fear?

(Examples: Dark, loud noises, bugs, certain animals, smells, textures, etc.)

6) Answer some (or all) of these questions to define what “quality of life” means to your child. This definition is unique for everyone.

- What values are most important to your family?
(Examples: Love, learning, spirituality, honesty, fairness, bravery, etc.)

- What are your hobbies and talents?
(Examples: Music, art, writing, sports, cooking, academics, gaming, etc.)

- What are some of your goals?
(Examples: Get good grades, go to a party, learn how to cook, etc.)

- What do you worry most about?
(Examples: Being in pain, missing family, missing out on things, feeling different from my friends, etc.)

- What are you most grateful for?
(Examples: My loved ones, my care team, my home, my favorite things, I feel loved, I feel safe, I can still do..., I still have..., etc.)

7) **Write your child's daily routine below** to help us build a care plan based on a schedule your family is used to.

List tasks and times you do them each day, such as wake/bed/nap times, meals/snacks, getting dressed, school, medication/caregiving times, etc.

TASKS	TIMES						
MORNING	M	T	W	T	F	S	S

AFTERNOON	M	T	W	T	F	S	S

EVENING	M	T	W	T	F	S	S

8) What are your and your child's goals for PPC? Number the goals below in order of importance (#1 is most important). Cross out goals that do not apply.

- _____ Relieve pain and symptoms
- _____ Help with moving, eating, bathing, dressing, etc.
- _____ Help staying engaged socially/with friends/in school
- _____ Emotional and spiritual support for my child
- _____ Emotional and spiritual support for our family
- _____ Help with financial, legal, or other complex matters
- _____ Other _____
- _____ Other _____
- _____ Other _____

9) How would you and your child like us to share information about the illness/treatment with you? Do you prefer details or general information? Do you want updates at each visit or only when there is a change? Is there anything you don't want us to tell you?

10) What physical symptoms is your child feeling now?

Check all that apply below. Circle/highlight the symptoms that bother you the most.

- | | |
|--|---|
| <input type="checkbox"/> Pain | <input type="checkbox"/> Spasms or seizures |
| <input type="checkbox"/> Shortness of breath | <input type="checkbox"/> Trouble standing/walking |
| <input type="checkbox"/> Fatigue | <input type="checkbox"/> Diarrhea |
| <input type="checkbox"/> Fever | <input type="checkbox"/> Constipation |
| <input type="checkbox"/> Loss of appetite | <input type="checkbox"/> Others: |
| <input type="checkbox"/> Weight loss | _____ |
| <input type="checkbox"/> Nausea or vomiting | _____ |
| <input type="checkbox"/> Trouble swallowing | _____ |

11) What emotional/social symptoms is your child feeling now? Check all that apply below. Circle/highlight the symptoms that bother you the most.

- Trouble sleeping
- Changes in personality
- Big mood swings
- Regression (thumb sucking, tantrums, bedwetting, etc.)
- Depression
- Anxiety
- Others: _____
- _____
- _____
- _____

12) List other emotional or spiritual concerns you or your child would like to discuss.

13) If your family is part of a religious faith community, name your place of worship:

Is there a member of your faith community you want involved in your child's spiritual care?

Name

Contact info

14) List religious or cultural beliefs that might affect healthcare decision-making for your child.

(Examples: We don't eat animal products, we can't receive blood or organs from others, etc.)

Your Pediatric Palliative Care Team

Doctor/nurse practitioner/physician assistant:

Name

Contact info

Nurse(s):

Name

Contact info

Name

Contact info

Social worker:

Name

Contact info

Spiritual care professional:

Name

Contact info

Child life specialist:

Name

Contact info

After-hours support:

Contact info

Other important names and contact info:

Care for Parents and Caregivers

A lot of time and energy goes into caring for a child with serious illness—and that is on top of all your other duties. Burnout is common among caregivers and can cause a variety of physical and mental health issues, including depression.

Trying to fit in time for self-care can seem overwhelming, but it's essential to avoid caregiver burnout. **Self-care is not selfish. It is a necessity that can help give you the strength to care for your child and your family.**

What you can do:

- **Reach out to your friends, family, and community for help.** Prepare a list of tasks to share with people who want to help but aren't sure how. You can add things like:
 - Grocery shopping or preparing meals
 - Cleaning (tidying, laundry, dishes, floors, kitchen, bathrooms)
 - Pick up mail, packages, prescriptions, etc.
 - Be a point of contact to share information and updates with family and friends
 - Drop off/pick up for school or after-school activities
 - Help kids with homework or school projects
 - Pet care (feeding, walking, cleaning, grooming, etc.)
 - Respite care (staying with my child so I can take a break; may involve training on some caregiving tasks)
 - Donation of money or items
 - Professional advice (legal, financial, insurance, etc.)
 - Others: _____

- **Create healthy habits that strengthen you emotionally and physically.** Choose one idea below that is easy for you to do. Once that becomes a habit, try another.
 - Stay connected. Schedule time to call or meet loved ones for a quick chat or hug. If you don't have time, keep in touch with a text or on social media.
 - If you have a partner, check in with each other often. Try keeping a standing appointment on the calendar to give yourselves time to talk and reconnect.
 - Focus on a simple creative project to bring you into the present. Create or enjoy music, journal, craft, create art, do a puzzle or a crossword, color, garden, cook, etc.
 - Allow yourself to feel your feelings. Cry to relieve stress, lower blood pressure, and promote emotional healing.
 - Avoid alcohol and drug abuse, overeating, or other unhealthy habits.
 - Get at least 7–8 hours of sleep per day. If that is not possible, take naps or rest whenever you can.
 - Stay hydrated. Drinking enough water (so that your urine is almost clear) has physical and mental benefits.
 - Eat healthy, balanced meals. Ask friends and family to help prepare nutritious meals that are easy to heat up.
 - Move your body. If you don't have time or energy for regular exercise, take quiet walks or do gentle stretches whenever possible.
 - Try meditation, yoga, deep breathing, or massage to quiet the mind and ease tension and anxiety.

“Rest and self-care are so important. When you take time to replenish your spirit, it allows you to serve others from the overflow. You cannot serve from an empty vessel.”

— Eleanor Brown

- **Practice good communication** with your care teams and other adults in your child's life to help ease tensions and avoid extra stress for you—and your child.
 - Speak honestly about your feelings and concerns. Ask for what you need, whether that's advice, validation, or just someone to listen.
 - Create a safe space for others to share their emotions and concerns. Recognize they may have different feelings and ways to cope than you do.
 - Try not to suppress difficult feelings such as anger and frustration. If it's impossible to communicate these feelings constructively, contact the PPC social worker or a counselor for support.
- **Take a break from caregiving.**
 - Ask family or friends to step in for a couple of hours so you can get away to recharge (check “respite care” on your list on page 26).
 - Try to schedule something for yourself during breaks instead of doing errands. Meet a friend for coffee, watch a movie, read a book, or have quiet time alone.
 - If friends or family aren't available, contact us. We may have resources available for respite care, or we can help you build a support network.
- **Remember no decision you make for your child is the wrong one**, and you are doing the very best with the information you have now.
- **Be kind to yourself and practice self-forgiveness.** It's okay not to feel strong all the time, and it's normal to be overwhelmed. Take each day one step at a time.



Questions and Notes:

SAMPLE


“Courage doesn’t always roar.
Sometimes courage is the little voice at
the end of the day that says,
‘I’ll try again tomorrow.’”

— Mary Anne Radmacher

PROVIDED BY

FULL-COLOR
LOGO HERE &
CHOOSE BORDER
SPOT COLOR

 (000) 000-0000

 (000) 000-0000

 info@domain.com

 www.website.com

 Street Address, City, State, Zip