



Forming Your Support Team

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When your child has a life-altering diagnosis, support becomes more than a comfort - it is a lifeline and a necessity. The right people can help you carry both the emotional and practical load, allowing you to direct your energy where it matters most: your child and family. In the last section, we focused on how to ask for help. This section focuses on who can support you, based on your needs, timing, and circumstances.

Forming a Support Team means surrounding your family with people, both personal and professional, who can step in to do what will best serve you and your unique situation. We will use the results of your Needs Assessment coupled with the consideration of your pre-existing relationships, offers from those who have expressed care and concern, and logistics such as proximity, to set up a solid framework for your family's individual team.

Some of you will come to this reality with the helpful structure of a natural, built-in network. For others it may require a little more thought or effort to piece together. There is no right or wrong way.

This module will help to provide ideas for building meaningful connection and support in other ways.



BRAINSTORMING

1). Start with who you already trust.

Think of the people who have shown up for you in the past - friends, relatives, neighbors, faith community members or coworkers. Long-standing friends or family may already understand your rhythms, boundaries, and communication style. **These people are your foundation or the core of your team.**

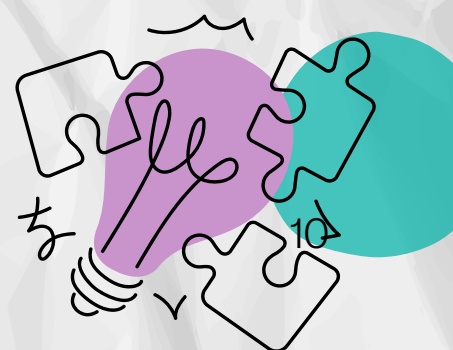
Questions to consider-

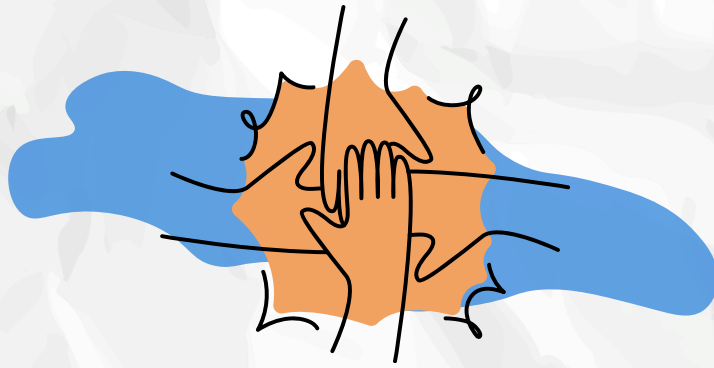
- Who could and would come to for help if you needed it, today?
- Who listens well and respects your boundaries?
- Who makes life feel easier, not heavier?

2) Recall offers for help and/or begin to intentionally notice who reaches out consistently, even if they are not close.

Most people who offer to help are genuinely willing and want to help. As we work through this building process, it's okay to be very particular with who you allow to help as well as how you want them to help. **You are the expert on your child and your family.** You will always be the one to decide:

- Who is part of your core team?
- What information to share with whom?
- What boundaries protect your family's peace?





3) Include your professional support system.

Your child's various teams are a core part of your care network. It's okay to ask them for emotional resources and recommendations for logistical help. If you have not already accessed the PPCC's [Care Plan Book](#), we encourage you to do so to help with this step. **Ask your care team: "Who else can I add to help us manage this phase?"** They often know resources you may have not yet discovered.

Everyone's team will look different, so include those who meet the needs of your family. Some suggestions include:

- Doctors, Nurses
- Social Workers, Case Managers, and Chaplains
- School Counselors and Teachers
- Local Non-Profits and Faith-Based Volunteers
- Hospice and Respite Professionals
- Child Life Specialists

Important Considerations

Proximity

Support can come from many places, in many ways. Some will come through local connections and some from across the country (or even the world). Each type of proximity brings its own strengths and challenges.

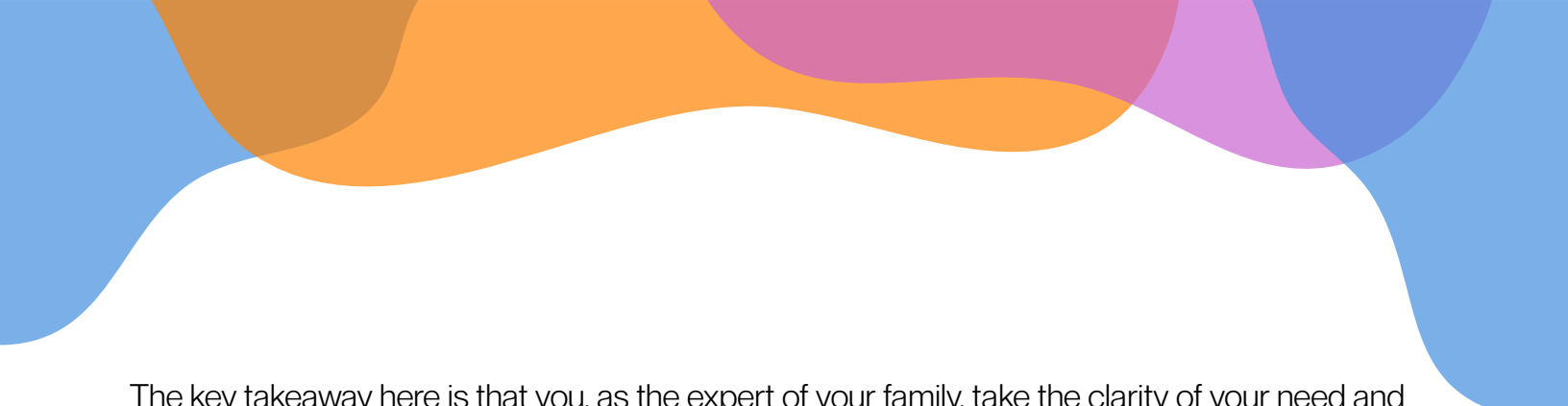
In many cases, it is most practical for nearby help to step in for daily tasks - but, distant help can still play an important role in supporting you and your family by alleviating burdens in other ways. In fact, you may be surprised by how much strength comes from people you cannot see every day, and how deeply nearby helpers appreciate being given clear, specific ways to help.

It can be helpful to consider people who live out of town but travel often, work remotely or can step in during key times. Some examples include a sibling who visits monthly, a grandparent who stays during treatment weeks or a friend who helps remotely but flies in when needed.

Clarity

Getting clear on *what* you actually need and being clear in communicating that will be a game changer when it comes to logistics and the load you are carrying. We maintain that people want to help, but need direction to do it well. Likewise, remember that needs change over time — and so do people’s capacities to help. Some people shine in the early crisis stages, while others are better for the long haul.

As you already know, living a life accompanied by medical complexity means that much of the “plan” is fluid and requires flexibility. So does the team. In many cases families find that new people may enter their lives through care connections or through school systems. Always remember, you can gently rotate roles or take breaks from certain supports when needed. You may even consider revisiting the makeup of your team at regular intervals (every 3-6 months, for instance).



The key takeaway here is that you, as the expert of your family, take the clarity of your need and the offers for help and make the most of what's at hand. In the next section we will help you identify the specifics of what you need in your own individual situation, but once you have that outlined, you can match your helpers with their strengths.

Maximization

When you complete the upcoming Needs Assessment, it might be helpful to think of things in terms of reverse engineering. If your goal and hopeful outcome is a smooth and healthy life for everyone involved, then it will be beneficial to consider all the possible ways people can help.

For instance, those who are local can help with transportation (school drop-offs, appointments, errands), sibling care or playdates, and household tasks (meals, cleaning, laundry, groceries). Additionally they can help by sitting with your child while you nap, shower or take a short break and even providing in-person emotional presence — hugs, coffee chats, and companionship.

Likewise, those at a distance can help by managing online updates or a care page (so you don't have to repeat news); sending encouragement — letters, cards, voice notes, video messages - contributing with gift cards, meal deliveries, or transportation funds; doing research: local respite programs, grants, or equipment options; and, maybe most importantly, planning visits that give you something positive to anticipate.

Tips for maximizing local support:

- Having someone identified as your “lead” can be a great advantage in many ways – even if nothing more than serving as the communicator of your needs to your extended circles. Likewise, having an old-school, emergency phone chain can alleviate the demand on you.
- Consider identifying two or three people you can text for urgent, “I need someone now”, moments. When something pops up, you know they are reliable and will do all they can to show up quickly. Communicating this need and expectation to them will set you up for success.

Tips for maximizing support from a distance:

- Consider designating a “remote coordinator” — someone who can rally faraway supporters and organize logistics (meals, donations, communication).
- When possible, schedule visits intentionally (for key appointments or respite needs) to avoid overwhelming your calendar.