

# Family Education Sheet

## Getting and asking for help while helping a child with medical complexities



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This sheet gives you information about finding help while you are caring for a child with complex medical needs.

### Key points

- Caring for a child with complex medical needs can be exhausting.
- It's more than OK to ask for help — it can be necessary.
- Organizing tasks in order of importance and according to your own abilities can help you figure out how and who to ask for the help you need.

### Why might I need help?

Caring for a child with complex medical needs can feel overwhelming, especially as their medical requirements change and grow. As a parent or caregiver, you may find yourself juggling the demands of caregiving alongside your own personal life. While it can be challenging to ask for help, it's important to remember that you don't have to do everything alone. Getting support can make you a better caregiver and help manage the stress of your caregiver role.

### Why do some parents hesitate to ask for help?

Research shows that many parents don't seek help when they need it. This can lead to stress and burnout. Common reasons for not looking for help include:

- Fear of being seen as selfish or not good enough by family or friends
- A sense that they should be able to handle everything on their own
- Resistance from the child, who may not want help from others
- Guilt about needing or wanting personal time
- A lack of offers or help from others in their social circle
- Worries about the cost of hiring outside help
- Feeling like they're burdening others by asking for help
- Not knowing where to turn for support or how to ask
- Being too busy to think about asking for help

Overcoming these barriers is important for both your well-being and the well-being of your child. Asking for help and being open about your needs can take some pressure off you and improve your ability to care for your child.

## What are some options for managing tasks?

As the main organizer of support, you have 3 options for managing tasks:

### 1 Do the job yourself:

Consider these tips if you choose to handle caregiving responsibilities alone:

- **Prioritize tasks:** Figure out what needs attention right away and what can wait. This can help you focus on the most important tasks.
- **Use your benefits:** Check to see if your employer offers paid or unpaid leave for family caregiving. Also, see if your child qualifies for assistance programs that can help with services.
- **Learn caregiving skills:** Many organizations offer trainings to help parents learn specialized caregiving skills. This can make some things easier for you as you deal with your child's complex medical needs.

### 2 Coordinate family or volunteer assistance:

Try these strategies if you'd like to coordinate help from family or volunteers:

- **Define clear roles:** Break down the tasks you need help with and communicate them clearly to the people you're asking for help.
- **Reach out to support networks:** Approach family members, friends or community groups. You may also want to explore church groups, school organizations or social clubs that could be helpful.
- **Keep a master calendar:** If you have several helpers for your child, consider keeping a master schedule to make sure everyone knows when and where they're needed.

### 3 Hire outside help:

Hiring outside help can offer relief, especially for specialized caregiving tasks. Here are some options:

- **Home health agencies:** Reach out to local healthcare agencies that provide nurses or aides who are trained in caring for children with complex medical needs.
- **Community resources:** Many organizations offer free or low-cost services like transportation, daycare or personal care assistance.

Choosing the most suitable option depends on your circumstances and preferences. It's important to think about what resources and support are available to help you be the most effective caregiver for your child.

## How do I decide which tasks to manage by myself and when to look for help?

Balancing caregiving duties can be tough, especially when you're trying to manage your own life. Consider these 4 main caregiving areas:

1. **Personal care:** Tasks like feeding, bathing, dressing and hygiene
2. **Household care:** Cooking, cleaning, shopping and maintaining the home
3. **Health care:** Giving medication, managing symptoms, going to medical appointments and overseeing treatments
4. **Emotional support and companionship:** Spending quality time with your child, engaging in activities and providing comfort



Think about these questions as you decide which tasks to handle personally and which to delegate:

- **How crucial is this task to my child's quality of life?**

These are things that directly impact your child's well-being and are the most important.

- **Which tasks can I let go of?**

Some responsibilities can be handed off to others to ease your workload.

- **Do I get personal satisfaction from doing this?**

Think about how fulfilling certain tasks are for you. Does it make you feel good to do this? Or is it simply something necessary to get done?

- **Could someone else take over?**

If there's someone in your network who can handle certain tasks, let them step in.

By giving these questions serious thought, you can make decisions on which tasks to manage and which to delegate. This will help you create a solid balance between caregiving and self-care.