

# Family Education Sheet

## Managing stress while caring for a medically complex child



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This sheet gives you information about the stress that can come with caring for a child with complex medical needs.

### Key points

- Finding yourself stressed as you care for your child is completely normal.
- There are ways to manage your stress so that it doesn't add to the challenges you're already dealing with.
- It's not selfish to take time to care for yourself while you're caring for your child.

### What can I do about stress?

Caring for a child with medical complexities can be deeply rewarding but also incredibly stressful. While your focus is on providing the best care for your child, it's just as important to manage your own stress for your own physical and emotional well-being.

This handout offers practical strategies to help you cope with stress while dealing with the challenges of caregiving.

### Why am I feeling more stress than usual?

Stress happens when we feel overwhelmed by the demands of life, especially when caring for a child with special medical needs. It can happen when we're faced with unexpected challenges or when we feel a lack of control over the situation. Everyone handles stress differently. The amount and kinds of stress you may feel depends on things like genetics, past experiences, your personality and life circumstances.

### What effect does stress have on me?

Stress triggers a physical response in the body. It makes the body release hormones that prepare us to react quickly. This is called the "fight or flight" response.

This response can be helpful in short bursts. But long-term stress can be bad for your health and lead to anxiety, exhaustion and burnout. Ongoing stress over a long period of time can also hurt your ability to provide the care your child needs. This means that it's very important to manage stress effectively.

### How does stress work?

Understanding how stress affects your body can help you manage it. Stress triggers systems in the body that can lead to a higher heart rate, muscle tension and other symptoms. These reactions can be helpful in short term, high-stress situations. But long-term stress can lead to chronic health problems like sleep issues, fatigue and weakened immune function (making you more at risk for getting sick).



#### Stress

Stress operates through a series of stages. It begins with a **stressor** (something that creates or triggers stress).

The first trigger could be anything from:

- Balancing your job and home life
- Making sure you don't miss any doctor's appointments
- Feeling worried about your child's sickness
- Seeing your child struggle with symptoms



#### Thoughts and feelings

After something stressful happens, you start **thinking about it and having feelings**. Here are some things you might think:

- "I can't handle this."
- "I wish this would just disappear."
- "How will we pay for all this?"
- "Why did this have to happen?"

You might also feel worried, nervous, sad, mad, guilty, frustrated or scared.



#### Behaviors and habits

Thoughts and feelings like this often lead to certain **behaviors and habits** as they grow stronger and happen more often. These can come out in many ways, like:

- Forgetting things
- Struggling to finish tasks
- Ignoring or avoiding problems
- Getting really mad easily
- Drinking or smoking more than usual
- Not wanting to eat or eating too much



#### Physical symptoms

These behaviors and habits can take a toll on your **physical health**. This can lead to seeing a range of symptoms, such as:

- Always feeling tired
- Having trouble sleeping
- Getting headaches
- Feeling pain
- Having a stomachache
- Getting skin rashes
- Not feeling interested in sex
- Having trouble focusing

## How can the STOP method help me manage my stress?

The STOP method (Stop, Think, Observe, Proceed) is a simple and effective tool for managing stress.

Here's how it works:

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**STOP unnecessary stress:** Don't simply ignore stressful situations. See if you can get rid of some of them.

- **Learn to say "no":** Recognize your limits and avoid taking on more than you can handle. Saying "no" when you have too many things to do can help you avoid feeling overwhelmed.
- **Avoid stressful people:** Spend less time with people who make you feel stressed out.
- **Take control of your environment:** Change things in your surroundings to help you feel less stressed. For example, you can turn off the TV if watching the news makes you feel worried.
- **Shorten your to-do list:** Look at your schedule and the things you have to do. If you have too many things to do, try to focus on the most important ones. You can leave out the ones that aren't as necessary.

**T**

**THINK about the situation:** If you can't avoid a stressful situation, try to change how you deal with it.

- **Express your feelings:** Talk about your feelings instead of keeping them inside. It's important to share how you feel with others. This will help you not to feel upset, angry or resentful toward them.
- **Create a balanced schedule:** Try to build balance into your day. Make time for taking care of your loved one as well as work, family and time for yourself.

**O**

**OBSERVE the stressor:** Notice what's causing stress and try to change how you think about it.

- **Reframe problems:** Try to see stressful situations in a different way. Try to see them as chances to learn or grow instead of seeing them as bad.
- **Adjust your standards:** Don't try to be perfect. It's OK to do things that are "good enough" instead of trying to do everything perfectly.
- **Practice gratitude:** Think about the good things in your life when you are feeling sad or upset. Take time to reflect on your family, your friends, a hobby, a vacation or simply things you enjoy doing.

**P**

**PROCEED with what you can't change:** Accept what you can't change and focus on what you can control.

- **Don't try to control the uncontrollable:** Focus on how you can control your own reactions instead of trying to control things you can't change.
- **Look for opportunities:** Try to see challenges as chances to learn new things or become stronger.
- **Learn to forgive:** Let go of anger or bad feelings towards others. Forgiving people for their mistakes can help you feel better.
- **Share your feelings:** Talk with someone you trust about how you're feeling. Talking can help you feel better about a situation even if you can't change it.

**Remember:** Managing stress is an important part of taking care of yourself and your child. It's an ongoing process. You should always feel able to ask for help when you need it.

## Is it OK to take care of myself while I'm caring for my child?

Caring for a child with complex medical needs is a serious responsibility that can often feel overwhelming. It's important to remember that you have rights as a parent in this role. The "Caregiver's Bill of Rights" reminds you that taking care of yourself is **not selfish**. It's **necessary** in order to provide the best care for your child. The Bill highlights key rights that parents of children with medical complexities should keep in mind. This includes the right to ask for help, to set personal boundaries, to express your emotions and to prioritize your own well-being.

By acknowledging and respecting these rights, you strengthen your ability to care for your child. You also make sure that you are maintaining your own health and resilience.

## What is the "Caregiver's Bill of Rights"?

Caring for yourself is a very important part of being able to care for your child. Reading and thinking about the "Caregiver's Bill of Rights" can help remind you of the importance of your own well-being and give you some tools to find your way through the challenges of caregiving. It's a daily reminder that your health matters and that taking time to care for yourself will benefit both you and your child.

*I have the right to take care of myself. This is not an act of selfishness. It will give me the ability to take better care of my loved one.*

*I have the right to seek help from others even though my loved one may object. I know the limits of my own endurance and strength.*

*I have the right to maintain parts of my own life that do not include the person I care for, just as I would if they were healthy. I know that I do everything that I reasonably can do for this person. I have the right to do some things just for myself.*

*I have the right to get angry, be depressed and express difficult feelings once in a while.*

*I have the right to reject any attempt by my loved one to make me do things out of guilt or anger. (It doesn't matter if they know that they're doing it or not.)*

*I have the right to get consideration, affection, forgiveness and acceptance for what I do for my loved one, as I offer these in return.*

*I have the right to take pride in what I'm doing. And I have the right to applaud the courage it has taken to meet the needs of my loved one.*

*I have the right to protect my individuality. I also have the right to a life that will sustain me in times when my loved one no longer needs my full-time help.*

*(Author unknown)*