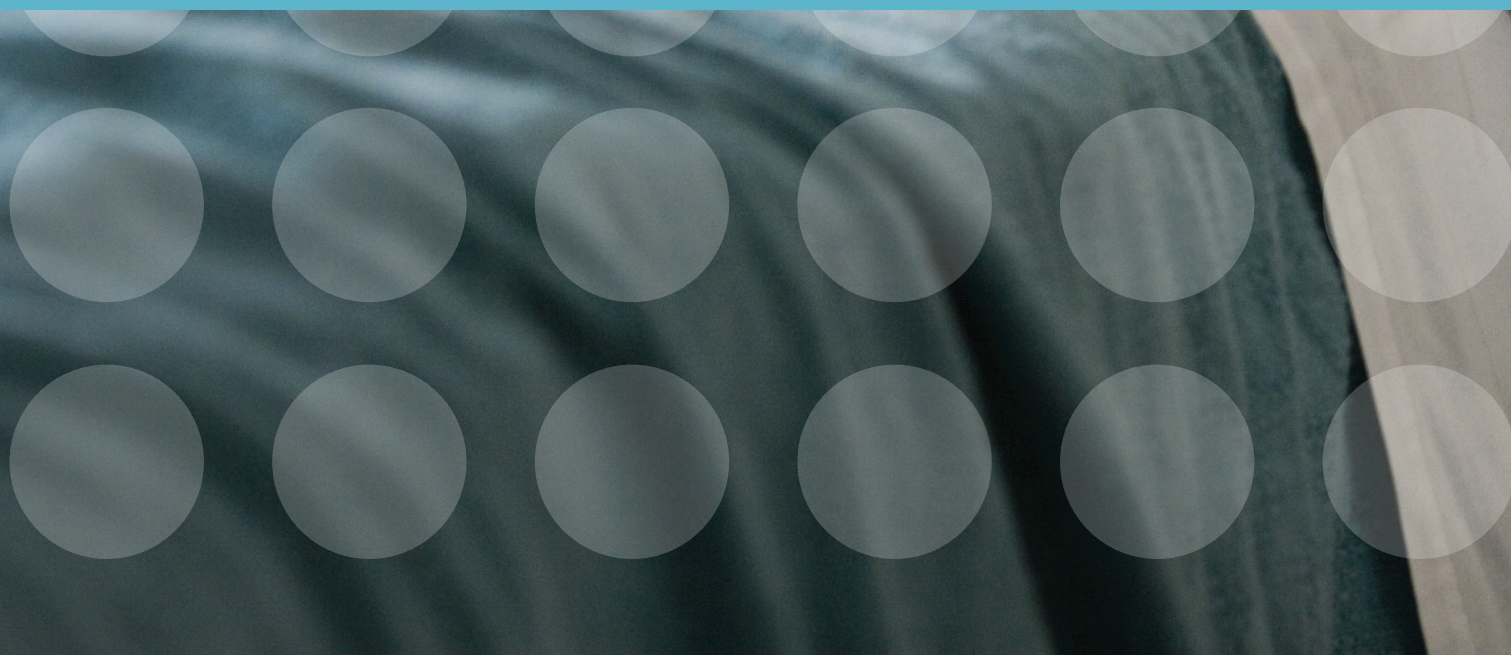




## A CAREGIVER'S GUIDE

Taking Care of Yourself  
While Your Child Is in the Hospital



“As the parent of a seriously injured child, I learned that it’s not helpful to try to do it all on your own. Parents of sick and injured children feel responsible for everything. We feel like it’s our job to soothe everybody’s feelings, to comfort, to encourage, and to make sure everyone knows it’s going to be all right.

But there is a downside to that — and it can be draining. I was so focused on everyone’s well-being that I forgot to take care of myself.

I think the best advice I can give other parents in the same situation is that when help like this is offered, take it. It will help you and your child cope better.”

– Kathy, mother of Stephen



## A message for caregivers:

No one expects serious illness or injury to happen. When it happens to your child, it is common to feel upset, worried, and alone. You have an important job in the hospital: to be your child's source of strength. In order to be strong for your child however, you will need to take care of yourself.

We understand that this is a stressful time for you. We created this guide to help you feel more in control of the situation — your child's as well as your own. The activities and worksheets will help you communicate more clearly with the medical team and cope better with your feelings and reactions, and will give you ideas on how to take care of yourself — and your child — in the hospital and after you return home.

You are not alone. Just as the medical team surrounds your child with care and support, there are people surrounding you — family, friends, and professionals in the hospital. Many times, people want to help but just don't know how, until you tell them. Take the advice of other caregivers who have been in your shoes: by taking better care of yourself while in the hospital, you will definitely be taking better care of your child.

# Serious medical events can be traumatic.

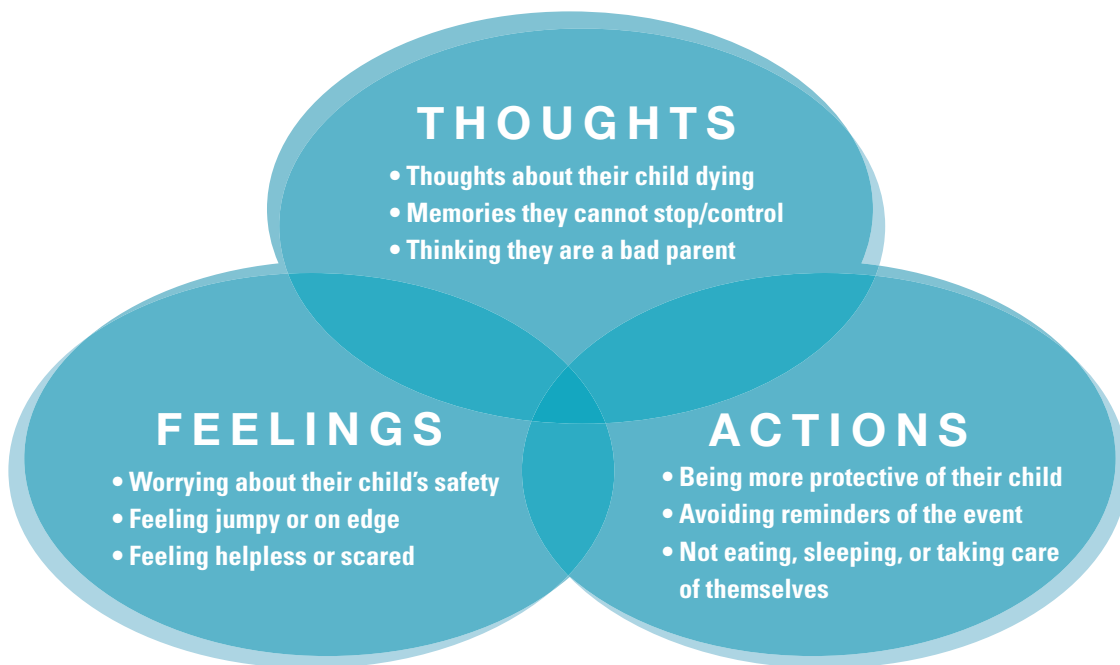
## **No one expects a serious illness or injury to happen to their child.**

Acute medical events like these are called “medical traumas.” When they occur, it is common for children and parents to feel upset, scared, or worried at first.

The sudden nature of the illness or injury, the possible life-threat, and seeing your child go through difficult or painful treatment can cause even more distress to parents and caregivers.

Caregivers and family members react to medical trauma in different ways. These reactions often include thoughts, feelings, and actions that can be upsetting or get in the way of work, school, or life at home.

- ▶ Listed below are common reactions that parents may have right after a child’s medical trauma:



**Write down  
your thoughts.**

- ▶ What are some of your thoughts about your child's medical trauma?
- ▶ How do these thoughts make you feel?
- ▶ If you feel upset or worried, how does that make you act?



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# It's important to take care of yourself.

**This workbook can help you take care of yourself during your child's medical trauma.** In order to be emotionally available for your child and family, it's important to manage your stress and take care of yourself.

Try a few of these tips to help stay strong and focused while your child is in the hospital.

► Check off (✓) what you are doing already. Keep in mind other things you can try:

- Ask for support.** Make sure a family member or friend is with you at the hospital early on. Don't be afraid to ask others to help take care of things at home.
- Remember to eat.** You may be tempted to skip meals, but make sure to eat so that you have energy to care for yourself and your child.
- Get rest.** Try to rest when your child is sleeping. If you cannot sleep at the hospital, ask a family member or friend to stay with your child while you go home and rest.
- Take breaks.** A few minutes away from your child will calm you and renew your energy. Take a walk or get fresh air while your child is sleeping or getting treatment.
- Take time to deal with your own feelings.** Your child can tell when you are worried or upset. Sharing your worries with another adult, like a friend, family member, clergy, or counselor, will help you feel better, think clearly, and make good decisions.

**Write down  
your thoughts.**

- ▶ How are you caring for yourself?
- ▶ Whom can you turn to for support?



# The hospital can be a scary place, even for adults.

**The hospital can be a strange and scary place for children and adults.** You may not know where to find things or who to ask for help. The medical staff is here to help, so don't be afraid to ask them questions.

**Here are some helpful things to ask about:**

- When are visiting hours?
- Who is allowed to visit?
- When does the nurse change shifts?
- Can you show me where things are on the floor?

There may be a lot of strange equipment in your child's room. These machines may make many types of noises and alarms.

**Ask your child's doctor or nurse:**

- How does each machine help my child?
- What noises should I expect?
- What should I do if a machine is alarming?

Most caregivers feel sad, upset, or guilty the first few times they see their child in a hospital bed, hooked up to machines, or feeling sick. It is common for parents to feel this way.

It is helpful to meet and talk with other parents on the floor about how they have coped. It is also helpful to focus on what you can do to help your child feel more comfortable. If you are unsure, ask your nurse to show you what you can do.



Write down  
your thoughts.



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# Get to know your child's healthcare team.

**There are a lot of people on the medical staff caring for your child right now.** Each person has a different role. It's OK to ask their name and role in your child's care.

- ▶ Use the boxes to write down information about your child's medical team:

**Name & title:**

**Role in my child's care:**

**Contact info:**

**My notes:**

**Name & title:**

**Role in my child's care:**

**Contact info:**

**My notes:**

**Name & title:**

**Role in my child's care:**

**Contact info:**

**My notes:**

**Name & title:**

**Role in my child's care:**

**Contact info:**

**My notes:**

**Name & title:**

**Role in my child's care:**

**Contact info:**

**My notes:**

# Ask questions and write down answers.

**When your child is ill or injured, you have to deal with a lot of information and medical terms.**

Don't be afraid to talk to the doctors, nurses, or other staff if you are confused or need more details. Make sure your child's condition or treatment has been explained in a way that you understand.

► Below are questions that parents often ask. These might help get you started.

**Can you tell me in simple terms what is going on with my child?**

**Is my child in pain? What is being done to ease his/her pain?**

**What is my child's treatment plan right now?**

**What changes should I expect in my child over the next few days?**

**Will my child heal/get well?**

**What medicine is my child on, and what is each one for?**

# A caregiver's role changes in the hospital.

**It can be upsetting to watch others care for your child.** Even when you are able to care for your child, you may feel scared or worried that you will do something wrong. But you have a very important role in your child's care.

▶ Here are some things to keep in mind right now:

- **You are the expert on your child.** Let the staff know how to comfort and put your child at ease. Tell them about your child's strengths, skills, and personality.
- **Ask the staff to show you how to help care for your child.** Your nurse can show you things you can do, such as feeding, bathing, or helping your child stay active.
- **You are your child's source of strength and a role model.** Your child depends on you to stay calm and to answer his or her questions. Be honest about what is happening, but reassure your child that the staff is doing everything they can to help.
- **Create a home-like setting.** Both you and your child will feel better if you bring some things from home into the hospital room. Pictures and other favorite items can help comfort both of you, even if the stay is just a few days.



► List some other things you can do to help care for your child at the hospital:



- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10
- 11
- 12



# It's hard to be in two places at one time.

**When a child is in the hospital, most parents want to spend as much time with their ill or injured child as they can.** Sometimes they feel guilty for not being at home with their other children, or they try to be in two places at one time.

It is helpful to lean on family members and friends during this stressful time, rather than trying to do everything on your own.

- ▶ Here are some tips from other parents who have been in the same situation.
- **Ask for help.** Family and friends often want to help but don't know what to offer. Ask them for help with meals and errands.
- **Check in with your other children.** Siblings can feel quietly upset or worried but may not want to tell you. Spend a little time with them each day — even if it's just by phone. Ask them how they are feeling and what they need. Ask friends to help with their school or after-school activities, if you cannot be at home.
- **Check in with your other children's teachers.** Teachers can keep an eye on your children and get others at school to provide support. Give them quick updates on what is happening. Ask them to let you know if they see any changes in your child.
- **Keep track of household bills.** Ask someone to help if you cannot. Keeping track of bills now will prevent more stress later for you and your family.





**Make a list.**

► List some ways you can manage things at home while you are away:



1

2

3

4

5

6

7

8

9

10

11

12



**My self-care reminders**

# Prepare yourself when leaving the hospital.

**Caregivers often feel relieved yet worried when their child leaves the hospital.** Sometimes, they may not feel ready to give their child the medical care he or she needs at home.

Before going home, talk to the doctor or nurse about what you need to know, what you need to do, and what to expect.

- ▶ Use the next two pages to write everything down. This will help make going home easier.

- **What medicines will my child need to take at home?**

- **How often does my child need to take the medicine? For how long?**

- **Is there anything my child is not allowed to do? For how long?**

- **Are there any foods my child should not eat? For how long?**

- **What medical care do I have to give to my child at home? How often?**

- **What follow-up appointments do I need to make?**

# Write down important phone numbers.

## **There may be medical staff who will continue to care for your child after going home.**

Before leaving the hospital, it's a good idea to have the phone numbers of staff you may need to contact in case of emergency or for follow-up questions and appointments in one place.

- ▶ Use the boxes to write down the information on staff that you may need to contact for follow-up.

### Who do I call to schedule a follow-up appointment?

**Name:**

**Department:**

**Phone number:**

### Who do I call in an emergency?

**Name:**

**Department:**

**Phone number:**

### Who do I call if I just have a few questions or concerns?

**Name:**

**Department:**

**Phone number:**

# Get back to a routine.

**After returning home, it is helpful to get back to as many daily routines as possible.** Routines help children and parents feel safe, organized, and in control.

Routines also help you set normal limits with your child. It may be tempting to relax the rules, but it is better to keep house rules the same as before.

► Here are some ideas for daily routines. Check off (✓) those that will help you and your family:

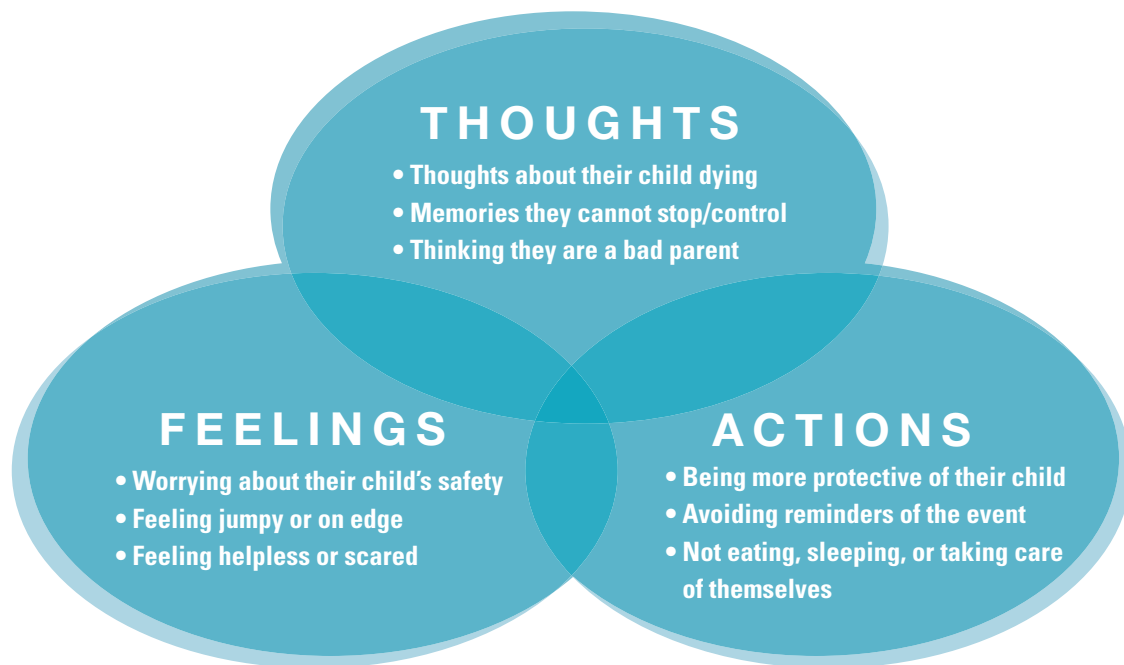
- A morning routine.** Keep the same wake-up and breakfast time each morning. This can make it easier to start the day.
  
- Family check-in routines.** A quick check-in each morning gives parents and children a set time to talk and to plan the day.
  
- A playtime routine.** Set aside time for your children to have fun. This can include playing games, drawing pictures, watching movies, or playing sports with friends or family.
  
- A dinner routine.** Eating together most nights allows families to talk about their day and helps them feel closer.
  
- A bedtime routine.** Keep the same routine at night — everyone will sleep better. Do something relaxing before bedtime, like take a bath or read a story.
  
- A “me time” routine.** Set aside a brief time to check in with yourself every day. Relax and breathe. Think about what is going well in your life at the moment.

# Everyone needs time to adjust after a medical trauma.

**After returning home, be patient and give everyone time to adjust. Remember that family members cope in different ways.** It may be easy for your children to get back to school, be with friends, and do things they used to do.

Often, parents have a harder time. You might feel happy and relieved, but may also feel guilty, angry, or worried. Take time to talk about your feelings to help you cope with them.

- ▶ Which of the reactions (below) are you still having?



**Write down  
your thoughts.**

- ▶ Having these thoughts, feelings, or actions are common early on.
- ▶ But, if these reactions get in the way of your daily life or last more than one month, it might be a sign that you need extra help.
- ▶ Talk to your doctor, a clergy member, or a counselor for more help in coping with your child's medical trauma.



# Renew relationships.

## **Having an ill or injured child can put a strain on your relationships.**

Family and friends can have different reactions: some may be openly upset while others may become quiet and keep their distance.

Brothers and sisters can feel worried but also jealous, and may not want to talk about their feelings. Friends may think everything is fine once your child has come home.

You can help by being patient and by getting back in touch with family, friends, and other important people in your life. Here are some ideas to renew your relationships:

- **Share.** Talk about your thoughts and feelings. Let others know what worries you and what you need from them.
- **Listen.** Be open to what others in your family are thinking and feeling. Be aware that their feelings may be different from yours, but they may also need your support.
- **Be patient.** During times of stress, conflicts and fights may happen more often. Let people cool off, and then discuss the issues in a calm and helpful way.
- **Reach out to others.** If you feel alone, reach out to someone you trust, even just to say “hello.” Arrange to spend time with a close friend or family member.
- **Make an effort to stay in touch.** If someone in your life has become quiet or distant, reach out to him or her, and try to reconnect.
- **Relax and take your mind off things.** Set aside some time to get together with family and friends to do fun or relaxing activities.



**Write down  
your thoughts.**

- ▶ Keep your own record of your child's time in the hospital, with dates, treatments, what you were told, and who was involved.
- ▶ This will help you make sense of what has happened and keep track of your questions.



# For more information...

## Books for caregivers after a child's trauma:

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- **Children and Trauma: A Guide for Parents and Professionals.** Cynthia Monahan, Jossey-Bass Publishers; San Francisco; 1997
- **Freeing Your Child from Anxiety: Powerful, Practical Solutions to Overcome Your Child's Fears, Worries and Phobias.** Tamar Chansky, Broadway Books; New York; 2004
- **A Parent's Guide to Building Resilience in Children and Teens: Giving Your Child Roots and Wings.** Kenneth R. Ginsburg & Martha M. Jablow. Published by the American Academy of Pediatrics; 2006

## Websites for caregivers after a child's trauma:

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- **HealthcareToolbox.org** is a website of the Center for Pediatric Traumatic Stress (CPTS) offering downloadable handouts for families after a child's medical trauma.
- **NCTSN.org** is the website of The National Child Traumatic Stress Network (NCTSN) offering information and resources for caregivers after a child's trauma.
- **AftertheInjury.org** is a website dedicated to helping caregivers understand their child's reactions to injury and learn what they can do to help their child.
- **BeyondtheCure.org** offers multiple readings and resources for survivors of childhood cancer and their families.
- **KidsHealth.org** offers information about child health, behavior, and development.



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CENTER FOR PEDIATRIC  
TRAUMATIC STRESS



A PARTNER IN  
NCTSN

The National Child  
Traumatic Stress Network