Examples of Handouts for the Chronic Illness Toolbox
Stress Management for Parents of a Child with a Chronic Illness

What Are Common Stressors for Parents?

- Worry about your child’s illness and treatments
- Feeling guilty about your child’s illness
- Disruption of family routines
- Balancing the demands of work, medical appointments, hospitalizations
- Attending to the needs of all of your children when your child who is ill requires much of your time
- Having less time to spend with a partner
- Challenges finding time for recreational and social activities
- Challenges in looking after your own health and well-being
- Family concerns: financial, health, separation of family members

What are Common Responses to Stress?

- Sleep problems (trouble falling asleep, waking up at night, not getting enough sleep)
- Feeling tired, low energy
- Stomachaches, headaches, and other physical symptoms
- Changes in appetite
- Increased worries and feeling nervous
- Irritability, moodiness
- Getting into arguments more often
- Feeling distracted, difficulties paying attention

What Can Parents Do To Manage Stress?

- Identify your responses to stress. We feel stressed whenever we face challenges that appear beyond our ability to cope. Our bodies have a specific way of responding to stress called the "fight or flight" response which can include the following:
  - Physical: increased muscle tightness, fast heart rate, shallow and fast breathing, sweating, cold hands
  - Mental: attention narrows, increased worry

(Bubble) Identifying how your body responds to stress can help you become more aware of when you are starting to feel stressed. This awareness can help you to develop ways to notice stress early on when it may be easier to manage. The following exercise can help with body awareness, including noticing and letting go of tension in your body.
1. Focus your attention on your environment. Start with noticing things you hear and see (I am aware of cars going by outside, the breeze blowing in the trees, the TV in the background).
2. Shift the focus of your attention to your body and your physical sensations (I am aware of tension in my back, the sensation of the back of my thighs against the chair).
3. Shift your attention back and forth between your environment and your body (I am aware of tension in my shoulders, the sounds of others talking).
4. Practice this exercise in free moments during the day to help become more aware of your body responses and to help yourself attend to what is happening in the “here and now.”

- Engage in stress-reducing habits:
  - Healthy eating: eating breakfast, regular meals, and healthy snacks
  - Regular sleep: aim for 7-9 hours per night, try to keep a consistent schedule on weekdays and weekends
  - Exercise: 3-5x per week for 30 minutes; walking is good exercise

- Spend time doing activities you enjoy (reading, movies, hobbies, talking to a friend)

- Identify the difference between controllable and uncontrollable stressors. Each requires a different response.
  - Controllable stressors are those that we know about and can plan for. Oftentimes we know what situations are the most stressful for us. Thinking ahead about these situations and planning ways to manage them may help reduce stress. An "information seeking" approach to controllable stressors allows us to plan ways to manage our response and we may feel less distress when dealing with the actual stressor. This strategy can also help increase our self-confidence for facing future stressors.
  - Uncontrollable Stressors are those over which we have no control. Become aware of your stress response and ways you can manage it both mentally and physically (the way we think about it, deep breaths, or other ways to relax the body).

- Pay special attention to negative thinking ("I can’t handle this") or thinking the worst ("This is just going to get worse and worse"). When we think the worst we often feel overwhelmed and our stress increases. Consider other ways to view the situation, such as “I need to take a deep breath and figure out the steps I can take to manage this situation.” Changing the way we think about a stressful situation can go a long way toward reducing our distress.

- Use simple problem-solving strategies:
  - State the problem
Brainstorm solutions
Choose a strategy
Try it out
Change strategy based on results

- Learn stress reduction techniques:
  - Deep breathing (sometimes a few deep breaths can really help!)
  - Muscle relaxation (tense and relax muscles throughout your body)
  - Imagery (imagining yourself in a favorite place doing something you really like to do.)
  - Yoga
  - Meditation
  - Talk to someone you trust about your situation.

**Resources**


**Free Apps:**

Breathe2relax (free) Abdominal breathing and stress management
I-CBT: help with sleep
Calm: relaxation techniques
Meditationoasis.com: free apps you can use on your computer or phone with meditations for a range of problems (sleep, anxiety)

Find other helpful handouts on the Children’s Hospital Colorado’s home page: [www.childrenshospitalcolorado](http://www.childrenshospitalcolorado), under “Chronic Illness Tool Box”.

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Helping Your Child Cope with Medical Procedures

Introduction
Children show a wide range of reactions in medical situations. These reactions are shaped by many factors, including their personality, developmental age, style of handling stress in other situations, and experiences with past medical procedures. It is impossible to take away all of the stressful, painful, or scary parts of many medical experiences. Fortunately, there are many ways to help children and parents cope with them in the best possible way.

What can I do to help prepare my child for medical procedures?

- It is important to remember that no parent handles all situations perfectly, and that there is not a right or wrong way of doing things to help your child. You are the expert on your child and you should trust your instincts, while also being open to suggestions from others. Most parents are able to do their best to help their child cope, even under stressful or scary circumstances.

- **Prepare yourself**
  - Children’s responses tend to be influenced by the responses of their parents.
  - When you can control your worries and be as relaxed as possible about the upcoming procedure, you send helpful messages of comfort and confidence to your child.
  - Parents often have many questions about how the medical experience will affect their child. It is helpful to write down all your questions to discuss with the medical team prior to the procedure. It can be hard to remember everything when meeting with the doctors and it can add stress if you are trying to remember all your concerns.
  - You can ask for psychological support or consultation with a Child Life Specialist to help offer suggestions and interventions to help your child cope.

- **Help prepare your child**
  - **When to Tell.**
    - Again, you are the expert on your child. How has your child coped with stressful situations in the past? Some children do better when provided with detailed information in advance, whereas others might best tolerate having less time to know about the procedure.
    - Think about your child’s developmental age when deciding WHEN to talk about the procedure:
      - Young children: Because they do not understand time the way older children do, it can be best to talk with them on the same day of the procedure
      - Preschool children: 1-2 days before is appropriate
      - School-aged children: 1 week ahead of time
• Teenagers: Usually do best when involved in planning and scheduling as it happens

  **How to tell.**
  
  - Be honest and use simple explanations.
  - Some children do better when this information is presented in multiple discussions versus one discussion.
  - Use clear and simple language. Sometimes books can help to keep things simple and to explain things in a way that makes sense to even the youngest child.
  - Choose more neutral words: “the doctor will make a small opening” vs. “cut a hole.” “the nurse will slide the needle into your arm” vs. “stick” or “poke”
  - Focus on what your child will directly experience (feel, see, hear, smell). It is not necessary to talk too much about what will happen while your child is sedated.
  - Include things that your child can do if they start to feel scared or stressed about the procedure (hugging your bear, holding a parent’s hand, asking the doctor to slow down during preparation).

  **How to prepare.**
  
  - Rehearsal: Have your child practice a procedure on dolls and on you, coach your child and empower them to use their strategies.
  - Try to make particularly distressing parts of the procedure time limited by counting or quantifying how long that part will last. Dependent on developmental level, work with your child on identifying tools to distract during particularly distressing moments.

**How can I help my child cope with their worries about the procedure?**

• **Tips for helping your child before or during a procedure**
  
  - Things children can do:
    
    - *Breathe deeply:* Breathing can actively divert a child’s attention from a painful or frightening experience. Active breathing may be elicited by having your child count while breathing, imagine a familiar experience, or by having the child take slow and deep breaths, imagining they are blowing up a balloon in their belly as they breathe in and the balloon goes back down as they exhale.
    
    - *Distraction:* Engaging your child in games or activities, such as blowing bubbles, interactive books, music, counting objects in the room, I-Spy, thinking about a favorite thing or a favorite place and imagining it, telling funny stories or singing songs out loud,
counting backwards, holding and squeezing your hand, or looking at a distracting toy or book.

- **Guided imagery:** A strategy used to encourage your child to cope effectively with the pain or anxiety associated with the procedure instead of avoiding their fear or discomfort. Have your child imagine a relaxing scene and describe all the elements and sensations of that scene to promote calmness and reduce anxiety.

  - **Things parents can do:**
    - Bring a few things from home. This can help your child feel more comfortable and can also be used for distraction and coping.
    - Stay near your child’s face. This helps comfort and distract him/her. Hold your child’s hand, stroke your child's face or arm.
    - Help the child choose a position that will comfort him/her. For example, having your child sit on your lap facing you during a blood draw or IV. Remember, being held feels different than being held down.
    - Tell your child what to expect. Use a calm and soothing voice. Give encouragement.
    - Distract your child (see above).
    - Show that you trust the doctors and nurses by staying calm and sharing any concerns with the medical team out of your child’s earshot.

- [BUBBLE GRAPHIC] Sometimes children do not experience distress related to the actual procedure, but might be worried about something else. Because their fears might be related to something you are not aware of, it is important to talk with your child about what they are most concerned about, and what questions they have related to the procedure.

- Have your child share with you what their understanding is of the procedure. This can also help show any potential fears that they have or misunderstandings that they may have.

**Other Resources**

- If you feel that you or your child might need additional help or support in coping with their hospitalization or medical experience, you should ask your doctor or nurse to request a consultation with a psychologist on the Psychiatry Consultation/Liaison Service or Child Life (7-6979).

- “It Doesn’t Have to Hurt” YouTube Video: Strategies for Helping Children with Shots and Needles
  - [https://www.youtube.com/watch?v=KgBwVSYqfps](https://www.youtube.com/watch?v=KgBwVSYqfps)

- Relaxation Resources for Children
  - [http://kidshealth.org/parent/_cancer_center/feelings/relaxation.html](http://kidshealth.org/parent/_cancer_center/feelings/relaxation.html)
• Therapeutic Recreation/Child Life
  o Specialists who help patients and families adjust and cope with the hospital setting, illness or injury, and medical procedures
  o 720-777-6979
  o www.thechildrenshospital.org/visit/familyservices/trcl/index.aspx

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Hoping for the Best, Preparing for the Worst

Sometimes in the course of a medical illness the treatments for curing an illness may no longer be working, or may be causing more harm than help to the body. When this happens, the medical team may talk to you about changing focus from curing or managing an illness to preparing for what is called “end-of-life care.” This can look different depending on the situation, and can mean facing days or years of life left for your child. In this situation, we always want to hope for the best outcome for your child, while preparing for the worst. There is no greater fear for most parents than the loss of their child. Below are common challenges and strategies for managing this very difficult situation.

What are challenges that I may face when medical treatments are no longer working to cure my child’s illness?

- **Communication**
  - How do I talk about this with my child? My other children? My partner and other family members?
  - Misunderstandings with the medical team around our family’s goals for this part of my child’s care.

- **Decision-Making**
  - Making decisions about treatments related to my child’s comfort.
  - Answering questions about end-of-life decisions, such as whether to have a DNR order (Do Not Resuscitate).

- **Emotions**
  - Worries that the medical team will no longer do ANY treatments, even ones that will help my child be more comfortable. It might feel like they are giving up on us.
  - My own feelings: shock, grief, hope, confusion, frustration . . .

What parenting strategies could I use to best support my child and manage all of these challenges?

- **Talk about it.** The first instinct of most parents is to protect their child by not talking about sad and scary topics. Kids usually know when things have changed and their parents are upset, and it can make them feel worse to feel that they can’t talk about it. Children often want to protect their parents as well. Asking your ill child for their thoughts and ideas about their medical care can help you know what to do, and helps your child feel important and included. Let your other children know you are there to answer whatever questions they may have. If it feels too overwhelming to start these conversations, ask for help from a psychologist, social worker, or child life specialist.

- **Be clear and honest with the medical team.** Tell your team if you fear that they may treat your child differently if the focus is no longer on a cure. This
will help the medical team know how to communicate with you. It helps them to know what your goals are for your child and family in this difficult time. If you need a break from meetings, you can tell them. If you need more information, ask. If you have questions bothering you, tell your team you need time to ask your questions. If you change your mind about a medical decision, explain this to the team so everybody stays on the same page.

- **Sharing decisions.** When medical treatments are not curing an illness anymore, this might mean starting to think about end-of-life care. It is a lot of pressure to make such big decisions about when and how to stay alive, or when and how to die. It’s okay to ask your child how much they want to know, and how much they want to decide. Some kids want to be a big part of making decisions, and other kids feel too overwhelmed by this and want their parents to make decisions. Every child and family is different and nobody has prepared for this situation, so you need to figure out what works best for your family.

- **Find support.** You are not alone. Think about your community and how it can support you – friends, faith, and other family. What do you need from the hospital? Ask about palliative care services and/or other supportive services such as social work, chaplaincy, and psychology. If you feel more supported, you are able to give more support to your child.

- **Focus on comfort and quality of life.** Think about what is most important to your child and family. What would make your child’s day today even just a little better? Is your child having pain or other symptoms causing distress? Pain can make anxiety, fear, and sadness even worse. Comfort is not just physical, it is also emotional. If your child needs to be in the hospital, are there favorite items from home to bring to the hospital room? Is it possible to be at home instead of the hospital? Quality of life means focusing on what is important to us every day and making the most of our relationships and what brings us happiness.

- **Take care of yourself.** When facing the possible death of your child, it is common to forget to eat and drink, and it can feel impossible to sleep. Not sleeping, eating, and drinking can make all the stress even more overwhelming, and you will have less to offer your child. If you are taking care of your basic needs, you can be more present to give comfort and spend quality time with your child and family.

- **Hope.** Hope helps us get through every day. Think about what you hope for each day, and talk to your child about their hope. Hope is a powerful way of thinking that can give us great comfort. It does not mean you do not understand your child’s situation or what the medical team is telling you, but it can help you face each day.
• **Prepare.** If you are able to plan for your child’s possible death by making decisions before the dying process starts or the death happens, you can be more focused on you and your child when you need to be. It is easier to make these decisions before the crisis or the intense emotions make it more difficult to think clearly. It can also be helpful to pick a trusted person in your family to be available to the medical team at the time of death to share your decisions, so you can have privacy and time to grieve.

**Where can I find additional information or support about end-of-life care for my child?**

• If your team has not talked to you about the hospital’s palliative care service, ask for a consultation to find out more about its range of services to support communication among medical teams, decision-making, and symptom management.

• Additional resources include:
  o **My Wishes:** a booklet to help children share how they want to be cared for if they become seriously ill; this can help begin important conversations
  o **Grief Books for Kids:** childrenswishingwell.org
  o **Grief Support:** www.griefhaven.org for resources and an online network of support

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