Parenting a Child with a Chronic Medical Condition

Parents of a chronically ill child face many challenges, which affect the whole family. This handout includes tips and advice shared from other parents and families. We are here to support you, your child and your family. Please feel free to contact your team, including chaplains, child life specialists, psychologists, and social workers, at any time.

Parent to Parent Communication:

Communication between parents is important. All of your child’s caregivers (even if they don’t live in the same home) need to understand what is shared by the medical team.

Ask the care team for support and explanations. Parents do not always agree. It is important not to argue in front of your child.

Using “I” statements can be an important tool. For example, “Help me understand, I heard you saying” OR “I read from your e-mail/text…and this is what I understand for our child. Is that correct?” Come to a common agreement about what is being said.

We all learn and understand differently. Some of us learn best by hearing, others by reading. Find a system that works for both of you to share information (e.g., a journal in your child’s hospital room if he is inpatient or somewhere at home). Taking a walk together is another way to share information, thoughts or feelings without distraction.

Parent, Child, Family Interactions:

Talk with your child about how her illness makes her feel. She may think the illness is her fault and feel guilty. If so, reassure her that it is not her fault that she is sick. She does not need to feel guilty or responsible. Help her understand bad things happen without it being anyone’s fault. You can say it is unlucky that she got sick and it is okay to be sad or angry. Let her talk about her feelings.

Let your child know you will try to answer questions honestly. The goal is trust and assurance. If he asks a question and you don’t know the answer, it is okay to say so. If he asks a question which is emotionally hard to answer, explain that you will talk some more when you can.

When your child is present, try not to talk or argue about things that might make her feel guilty or worried. These are some topics that often cause worry or guilt:

- Money
- Time away from work
- Relationships
- Worries about siblings
Help your child be honest and open about his feelings. Be a role model by talking about your own feelings. Let him know you will be honest, and you want him to be honest with you.

Sometimes your child may say ‘I hate you’ or even hit you. This can be a way of letting you know she is hurting and scared. Acknowledge her anger and hurt. While you may feel guilty for not being able to protect her from her illness, you also deserve respect. Help your child to find healthier ways to show anger. Some ideas are:

- Squeezing a stress ball
- Punching a pillow
- Drawing what makes her angry
- Talking with someone from your health care team

Even though your child is ill, keep setting limits with him. If the rules change too much, he may be confused, sad or worried about why you changed them. Practical and fair rules can and should continue. Our health psychologists have a handout on discipline for children with chronic illness and can talk more with you if you would like.

Go out of your way to give your child extra praise and reassurance.

There are books you can read with your child to help her feel proud and strong. Ask your health care team for suggestions.

Reassure your child that when hard things happen, families work together and support each other. Give him examples. Let him know he does not need to take care of the family or protect you. Here are some ways you can support him:

- Parents provide their own self-care so child can focus on what they need rather than what a parent needs.
- When conflicts arise the family members take the discussion to a private area and let the child know as adults you are reaching a resolution.

A child’s medical needs often affect sibling and family relationships. If your sick child has brothers and sisters, they will have many feelings. They may feel:

- Jealous or angry that their sibling is getting attention
- Lonely when their parents are at the hospital
- Guilty or worried they did something to cause the illness

The changes in their lives may make them act differently. You can help by working to understand rather than just reacting to the behavior. Try to fit in quality time with siblings. Your treatment team can help with ideas about responding to your children’s feelings and behaviors. Additional resources are listed below.
Resources:

1. **Caring for a Seriously Ill Child**  
   This online article includes information on explaining long-term illness, tackling tough emotions, behavioral issues, dealing with siblings and lightening the load.

2. **The Chronically Ill Child, A Guide for Parents & Professionals.**  
   *Audrey T. McCollum, Yale University Press, 1981*  
   This guide offers a sensitive look at both the physical and emotional troubles children face at each stage of development. It also addresses the pressures facing their families and focuses on ways to give meaning to the ill child’s quality of life.

3. **Sharing Difficult Information with Children**  
   *Health Facts for You, ID #7280 - available on uwhealth.org*  
   This article has many tips and ideas about sharing difficult information with children. It includes developmental considerations, reactions to expect, ways to encourage support, and warning signs.

4. **Children with Chronic Conditions. Your Child Development & Behavior Resources.**  
   *University of Michigan Health System. [http://www.med.umich.edu/yourchild/topics/chronic.htm](http://www.med.umich.edu/yourchild/topics/chronic.htm)*  
   This guide explains how kids adjust to chronic medical conditions at different stages, the impact on the family, family coping, camps, sibling issues, and resources including books (for children and parents), organizations and websites.

5. **A Different Dream for My Child – Meditations for Parents of Critically or Chronically Ill Children.**  
   *Jolene Philo, Discovery House Publishers, 2009*  
   The author offers guidance through biblical insights and her own personal experiences. Parents can find spiritual wisdom, practical resources and tools.

6. **How to Be Sick, A Buddhist-Inspired Guide for the Chronically Ill and their Caregivers.**  
   *Toni Bernhard, Wisdom Publications, 2010*  
   Although Buddhist is in the title, the author leads meditation for any spiritual practice. She combines her own experience with guidance, encouragement for the chronically ill, their family, friends, and loved ones.

7. **Imaginations: Fun Relaxation Stories and Meditations for Kids.**  
   *Carolyn Clarke, 2011*  
   This book provides stories to help children learn to calm their bodies and relax their minds. Parents of chronically ill children can teach mindful ways through fun for their child’s body and mind to feel good.

8. **The Challenge of Parenting When a Child is Ill**  
   *Stephanie Farrell - #13132 available at uwhealth.org*  
   This article discusses picking your battles, knowing your own triggers, and caring for siblings.

Your health care team may have given you this information as part of your care. If so, please use it and call if you have any questions. If this information was not given to you as part of your care, please check with your doctor. This is not medical advice. This is not to be used for diagnosis or treatment of any medical condition. Because each person’s health needs are different, you should talk with your doctor or others on your health care team when using this information. If you have an emergency, please call 911. Copyright © 2015. University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing. HF#7419.