

After the Diagnosis: Helping My Family Cope

Distress is common with the diagnosis of a child's serious illness. The whole family – the child, caregivers, sisters and brothers and other family members – may feel overwhelmed or unprepared. With time, understanding, and support, most children and families learn to adjust and cope with the experience. The information provided was developed to help your family cope with new medical demands and the uncertainty.

Things about the diagnosis and treatment that can be upsetting for some children and families:

- Being away from home
- Getting needles
- Pain
- Losing hair
- Being left alone
- Seeing other kids who are sick
- Not knowing what is going to happen
- Thinking you did something to cause it
- Being afraid of dying



Strong feelings are expected in the days and weeks after a diagnosis and can include:

- Feeling confused, upset, frustrated, numb, or worried
- Having trouble keeping your mind off of the diagnosis and what will happen in the future
- Wanting to avoid places (such as the clinic or hospital) and things that are reminders of the illness

Other common changes after diagnosis of a serious illness:

In younger children:

- Clinging to parents or other adults
- Crankiness and tantrums
- Bed wetting or thumb sucking
- Being afraid of the dark
- Trouble sleeping

In older children and teens:

- Wanting to be alone or with you all of the time
- Being irritable, more sensitive, or talking back
- Trouble eating
- Trouble sleeping, nightmares
- Being easily overwhelmed, jumpy, or irritable
- Missing friends, feeling left out, worrying about what others think



In parents and caregivers:

- Not wanting to be away from your child and worrying more about safety
- Getting upset seeing your child in pain or discomfort
- Feeling overwhelmed by your child's medical needs
- Being less patient and more easily frustrated
- Trouble eating or sleeping
- Worrying that your child will die

When and where to get extra help? Even though treatment can be difficult and overwhelming initially, most children and families learn to adjust. Be sure to talk with a member of your child's medical or psychosocial (social work, child life, etc.) team about changes in behavior. If your child's or family's reactions seem to get worse or get in the way of day-to-day activities, a team member can help. Also, for helpful hints on ways to cope after the diagnosis, read the tips on the other side of this handout or go to <http://www.curesearch.org> for more information.

10 Ways You Can Help Your Family Cope

After Being Diagnosed with a Serious Illness

- 1. Be patient and give everyone time to adjust.** Keep in mind that members of the same family can react in different ways. In children and teens, intense feelings and behaviors (e.g. temper tantrums, whining, talking back) are common but often temporary reactions. Most family members need time to adjust to and cope with the changes.
- 2. Help your child understand what is happening.** Diagnosis and treatment of a serious illness is usually new, confusing, and scary for children and siblings. Children have active imaginations; without accurate and appropriate information, they can get the wrong idea about what is happening. At the same time, parents often struggle with how to explain the illness and its treatment. Ask questions to figure out what your child knows and give information in clear, age-appropriate ways. If you would like some help, the team can be a resource for you.
- 3. Think of the medical team as helpers.** Remember that your relationship with the medical team influences how safe your child feels and how much your child trusts them to help. Remind your child that the staff has a lot of experience helping other children. Encourage your child to participate by asking the team questions.
- 4. Encourage your family to share feelings.** This can happen in different ways (talking, drawing, story-telling, hugging), at different times (dinnertime, bedtime), and in different places (in the car, in the hospital). Sometimes, sharing your feelings can show children that it is okay to do the same. When children or teens do talk, accept their feelings and be a good listener, even if what they say is hard to hear.
- 5. Keep as many everyday routines as possible.** Because illness and treatment can be unpredictable, regular routines help children and teens feel safer. Having everyday routines (e.g., meal and bed times, household chores) and activities give family members things to expect and look forward to. Decorating the hospital room with things that are familiar and comforting can create a comfortable environment for your child and family.
- 6. Set limits as usual.** You may want to relax family rules in order to help your child or teen feel special or to make up for hard times that your child is experiencing. However, in the hospital and at home, it is often better to keep most of your family rules and expectations the same.
- 7. Encourage your child do some things independently.** It is often tempting to do everything for a child who is ill. Doing things independently, as much as the illness allows, gives children a sense of accomplishment and control. For example, give your child the chance to do things like brushing teeth, dressing, cleaning up toys, and preparing snacks when possible.
- 8. Help family members stay connected with friends and family.** After the diagnosis of a serious illness, people can feel 'different' and alone. You and your children may wonder how others will react. Plan a few fun activities and encourage visitors. Talk ahead of time about how to explain the illness and respond to questions.
- 9. Take care of yourself.** You can care for your family better by taking care of your own needs and dealing with worries when they arise. Don't forget to pay attention to health habits that keep you strong and help you cope, like eating, sleeping, getting fresh air, and physical activity. Talk about your concerns with other adults, such as friends, family members, the psychosocial team, clergy, or medical staff.
- 10. Take breaks.** Time away from your child allows you to take care of yourself and other family members. It also gives your child the chance to feel safe without you and try more things independently. When you leave your child with a family member or familiar adult, be sure to let them know when you are leaving, when you will be back, and then follow through.