

After the Diagnosis: Helping My Family Cope

Feeling distressed or having strong emotional reactions is common with the diagnosis of a serious illness. Even though it is your child who is ill, your whole family – parents, brothers, sisters, or other relatives – can feel overwhelmed or unprepared to cope with the new demands and uncertainty that illness brings.

What should I expect in the days and weeks after being diagnosed with a serious illness?

It is common for children (and other family members) to feel confused, upset, frustrated, numb, or worried. Most need extra time to adjust to the illness and to treatment. After the diagnosis, some children and parents may act or feel differently – they may have trouble keeping their mind off of the diagnosis and what may happen in the future. They may try to avoid places (such as the clinic or hospital) and things that remind or upset them about the diagnosis and treatment. For most families, these reactions get better with time, understanding, and support.

It is often helpful to know aspects of diagnosis and treatment that can be upsetting for some children and families. These may include: being away from home, getting needles, hair loss, seeing other kids who look sick, or not knowing what is going to happen. These are certainly not true for all children and families, but they are a concern for some.



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

- Having trouble keeping your mind off of the diagnosis and what will happen in the future
- Feeling confused, upset, frustrated, numb, or worried
- 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
- Bed wetting or thumb sucking
- Trouble sleeping
- Crankiness and tantrums
- Being afraid of the dark

In older children and teens:

- Wanting to be alone or with you all of the time
- Trouble eating
- Being easily overwhelmed, jumpy, or irritable
- Being irritable, more sensitive, or talking back
- Trouble sleeping, nightmares
- 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
- Feeling overwhelmed by your child's medical needs
- Worrying that your child will die
- Getting upset seeing your child in pain or discomfort
- Being less patient and more easily frustrated
- Trouble eating or sleeping



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 www.healthcaretoolbox.org for more information.

Ten Ways You Can Help Your Family Cope With 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. Siblings and other children can feel upset and may have questions. Most family members need time to adjust to and cope with the changes. It can be helpful to talk as a family about how the illness affects everyone.
- 2 Help your family understand what is happening.** Diagnosis and treatment of a serious illness can be new, confusing, and scary for children and adults. 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 can influence 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 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, at home, in the hospital). Help your children name their feelings, such as being sad, scared, or angry. Sometimes sharing your feelings can show children that it's okay to do the same. When children or other family members 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 so many aspects of illness and treatment can be unpredictable, regular routines help children and teens feel safer. Having regular 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 can create a comforting 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 other children feel special or to make up for hard times they are experiencing. However, in the hospital and at home, it is often better if you set limits and keep most of your family rules and expectations the same.
- 7 Encourage your child to do some things independently.** It is often tempting to do everything for your 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. If possible, 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.** Feeling worried or upset are common reactions in parents and caregivers. You can more easily care for your family 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 another 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.