

After the Diagnosis: Helping My Family Cope

What Families Can Do

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, or worried. Most need extra time to adjust to the illness and to treatment. After the diagnosis, some children and parents may act differently – they may keep thinking about the illness and get upset when they do. Sometimes, they try to avoid places (such as the clinic or hospital) and things that remind or upset them. These reactions usually get better with time, understanding, and support.

Other common (but usually temporary) changes after being diagnosed with a serious illness:

In younger children:

- Clinging to parents or other adults
- Bed-wetting or thumb-sucking
- Being afraid of the dark
- Trouble sleeping or having nightmares
- Being cranky or having tantrums

In older children and teens:

- Changes in sleeping and eating
- Wanting to be alone or with you all the time
- Being irritable, more sensitive, or talking back
- Feeling empty or numb
- Being overly self-conscious or worrying about what others will think
- Feeling left out; not able to do usual activities with friends or family



In parents and caregivers:

- Being overprotective or “on guard”
- Getting upset at seeing their child in pain or discomfort
- Feeling overwhelmed about caring for their child’s medical needs
- Having a short fuse, having trouble sleeping or eating
- Worrying in private that their child might die, but not wanting to share their worries with anyone

Signs that your child may need extra help:

- Watching out for danger all the time
- Having new fears not related to the illness
- Not wanting to go to school, or doing a lot worse in school
- Not wanting to be with friends or go back to usual activities
- Arguing more than usual with friends or family

When and where should I get extra help for my child or family? Even though the illness and treatment can be overwhelming at first, most children and families learn to adjust. If your child’s reactions get worse or get in the way of regular activities, or if other family members continue to be upset or worried, talk with your doctor or a mental health counselor about getting additional help. Some illnesses have associated behavior changes, so keep your child’s doctor up-to-date. Also, read the tips on the other side of this handout.

Nine Ways You Can Help Your Family Cope With Serious Illness

1 Be patient and give everyone time to adjust. Members of the same family can react in different ways. Siblings and other children can feel upset or worried 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. The diagnosis of a serious illness can be new, confusing, and scary for children and adults. Children have active imaginations; without all of the facts, they may get the wrong idea. Ask questions to figure out what your children know and what they are imagining. Share the facts honestly, using simple words and examples they can understand. Allow your children to ask questions and to share their worries – big and small.

3 Encourage your family to share their 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). Help your children name their feelings, such as being sad, scared, or angry. Sometimes sharing your own feelings can show your children that it's okay to do the same. When your children or other family members do share, accept their feelings and be a good listener, even if what they say is hard to hear.

4 Keep as many everyday routines as possible. Because so many aspects of illness are unpredictable, normal routines help children feel safe. Having regular routines (meal and bed times, household chores) and activities give children and adults things to expect and look forward to.

5 Set normal limits. You may want to relax the rules in order to help your child or other children feel special. However, it is better if you set normal limits on behavior and keep most of your family rules and expectations the same. Plan fun activities as family rewards.

6 Help your child do some things on his or her own. It is often tempting to do things for your child when he or she is ill. Doing things on his/her own, as much as the illness allows, gives a child a sense of accomplishment and control, including: getting dressed, cleaning up room, and getting things for him/herself whenever possible.

7 Encourage your child to spend time with friends. With a serious illness, some children feel a little “different” or alone. They may also wonder how their friends will react. Talk ahead of time about how to explain the illness and answer questions (*Is it contagious? How long will you be sick?*) If possible, invite your child's friends to visit, and plan a few fun activities.

8 Take time to deal with your own feelings. Feeling worried or upset are common reactions in parents and caregivers. However, it will be harder to help your child if you feel overwhelmed or unable to cope. Talk about your feelings with another adult, such as a friend, a counselor, or a member of the clergy.

9 Follow up with the doctor. Even if your child is getting better, the doctor needs to know how he or she is coping, especially since some illnesses have behavior changes associated with them. For children and families who need extra help (*see front side*), don't hesitate to contact your doctor or a counselor.

