

# Caring for a Chronically Ill Child

When children suffer from diabetes, cancer, asthma, cystic fibrosis and other illnesses, their medical needs may vary from those of adults. But some needs and the ways to meet them are the same no matter what the illness.

## THE NEED FOR NORMALCY

Children cling to the familiar. It's their way of coping with stress. When illness takes away the normalcy of childhood, try to make your child's life as normal as possible.

- If a full day of school is not possible, consider an adapted schedule, such as school in the morning, home study in the afternoon.
- Encourage a normal social life.
- An ID bracelet or a pager may give an older child the means to be more independent.

Normalcy means staying with rules of behavior that were in place before your child got sick. You naturally want to make things as easy as possible for your child and you may need to make some allowances. But your child will benefit in the long run if you set clear, familiar boundaries and maintain them. Children feel protected by boundaries they know and can count on.

## COMMUNICATION IS YOUR ALLY

Keep the lines of communication open with your child's healthcare team, school staff and family members. Encourage them to communicate with each other. Ask questions and keep them up-to-date on your child's progress.

## EDUCATE YOURSELF AND YOUR FAMILY

Learn as much as you can about your child's illness. This way you can make smart decisions about care and treatment.

- Ask your child's healthcare team for books and pamphlets.
- Share your knowledge with your family and especially with your ill child.
- Ask your healthcare team's advice on talking to your child about his or her illness.



## CHANGING FAMILY ROLES

One of the most stressful aspects of a childhood illness is the way the whole family has to change roles. A working parent or older child may have to become a caregiver. Siblings may get less attention than they're used to. It's good to talk about these changing roles and how to adapt to them. Pay special attention to the needs of siblings. If possible, arrange to spend time with each. Enlist the help of a favorite relative or friend from church or the neighborhood to spend time with them.

Illness can put a strain on your family and marriage. It's true that sometimes marriages fail, but others seem to emerge stronger from the challenge.

## FEELINGS ARE IMPORTANT

It's normal to feel a roller-coaster mix of grief, anger, guilt, fear and hope. Share these feelings with someone you trust. And remember that your child's illness is not your fault.

## REACH OUT FOR SUPPORT

Parenting a child with a chronic illness can be a lonely task—until parents reach out to others in the same situation. Ask about parent support groups in your area. If there isn't one, ask your healthcare team for help in forming one. Many parents say that knowing others who have gone through the same thing has saved their sanity. And support groups are an invaluable source of information on the daily challenges of the illness.

Reach out to the wider community of church, friends and health organizations for help with child care, meals and emotional support.