## FACTS for FAMILIES

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## The Child with a Long-Term Illness

The child who is diagnosed with a serious and chronic medical illness is at greater risk for developing emotional problems. Unlike a child who has a temporary medical condition such as the flu, the child with a chronic illness must cope with knowing that the disease is permanent, incurable and may even get worse with time.

The young child, unable to understand why the sickness has occurred, may assume it is a punishment for being "bad." He or she may become angry with parents and doctors for not being able to cure the illness. The youngster may react strongly against pampering, teasing, or other attention because they highlight his or her differences from other healthy children. Uncomfortable medical treatments and restrictions in diet and activity may make the child unhappy and withdrawn. Parents often wish to be supportive of their children and withhold information because they don't want their children to worry unnecessarily. However, it is important for parents to understand that they can best help by providing age appropriate information about the disease, prognosis and the importance of compliance to treatments to minimize advancement of the disease or to control the symptoms.

A teenager with a long-term illness may feel pulled in opposite directions. On the one hand, he or she must take care of the physical problem, requiring dependence on parents and doctors. On the other hand, the adolescent wants to become independent and join his or her friends in various activities. When a teenager with a long-term illness tries to decrease or stop taking the prescribed medication without consulting his or her physician, this may reflect a normal adolescent desire to control one's own body.

Chronic illness entails frequent physician visits and medical leaves requiring the child or adolescent to miss classes and school activities. The lack of continuity in school attendance may cause problems, including avoidance or refusal to attend school. This can increase the child's loneliness and feeling of being different from other youngsters. It is important for parents to help a child maintain as normal a routine as possible. They should respond not only to the child's illness, but to the child's strengths. Child and adolescent psychiatrists know that if isolated or overprotected, the child may not learn to socialize or may have difficulty separating from parents when it is time to be involved in school or other activities outside the home. How can parents help? The following is a list of suggestions to consider for the child struggling with chronic physical illness:

 Help your child to be in contact with others who have successfully adjusted to living with a chronic illness.

- In their prolonged periods of hospitalization and/or rest at home, children may develop excellence in a hobby or a special talent such as art, model airplanes, or a foreign language.
- Help your child learn as much about their illness as possible. Such activities are emotionally healthy and should be encouraged.

Children with long-term illnesses are often treated by a team of medical specialists. This team often includes a child and adolescent psychiatrist, who can help the child and family identify and overcome problems resulting from the burden of chronic medical illness. The psychiatrist can help families and their children understand the impact on the family of coping with multiple life changes imposed by the illness and develop emotionally healthy ways of living with the disease and its effects.

For additional information see *Facts for Families*: #8 Children and Grief

#7 Children Who Won't Go to School #30 Children and AIDS

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