

pediatric endocrinologist is recommended.

Children and adolescents with CF should receive routine primary care with special attention to diet, growth and development, and immunizations. Care providers should be alert to any weight loss or flattening in the growth curve associated with loss of appetite, which could indicate a pulmonary exacerbation in children with CF ([Hazle, 2010](#)). Anticipatory guidance concerning issues of discipline, how to incorporate aspects of the treatment regimen into the school environment, and delayed pubertal development are also important considerations for the primary care provider.

Home palliative care for the child or adolescent with CF who is in the terminal stages may be carried out with the assistance of palliative care or hospice as appropriate (see [Chapter 17](#)).

The nurse can assist the family in contacting resources that provide help to families with affected children. Various special child health services, many local clinics, private agencies, service clubs, and other community groups often offer equipment and medications either free or at reduced rates. The Cystic Fibrosis Foundation\* has chapters throughout the United States that provide education and services to families and professionals.

## **Family Support**

One of the most challenging aspects of providing care for the family of a child or adolescent with CF is meeting the emotional needs of the child and family. The diagnosis, treatment, and prognosis for CF are often associated with many problems and frustrations and may evoke feelings of guilt and self-recrimination in parents.

The long-range problems for an infant, child, or adolescent with CF are those encountered in any chronic illness (see [Chapter 17](#)). Both the child and the family must make many adjustments, the success of which depends on their ability to cope and on the quality and quantity of support they receive from outside sources. It is often the nurse who assesses the home situation, organizes and coordinates these services, and collects the data needed to evaluate the effectiveness of the services.

The persistent need for treatment several times a day places tremendous strain on the family. When the child is young, a family member must perform postural drainage and other ACTs. Children often balk at these treatments, and the parents are placed in the