

feelings concerning the diagnosis.

Help the Family Manage the Illness at Home

Parents are the child's principal caregivers and need to develop a positive, supportive working relationship with the health care team. Because most children spend the majority of their time at home with episodic trips to the hospital, parents manage their child's illness on a daily basis. They monitor for signs of illness, give medications and treatments, bring their child to appointments, work with a variety of caregivers, and alert the team about problems. Successful relationships are partnerships between parents and caregivers that are built on mutual trust and respect. Good communication among the family, the cardiology specialists, and the primary care practitioner is essential. As children reach adolescence, they begin to take a larger role in managing their illness and making decisions about their care.

Parents should be aware of the symptoms of their child's cardiac condition and signs of worsening clinical status. Parents of children who may develop HF should be familiar with the symptoms (see [Box 23-5](#)) and know when to contact the practitioner. Parents of children with cyanosis should be informed about fluid management and hypercyanotic spells (see earlier in this chapter). Parents should have an information sheet with their child's diagnosis, significant treatments such as surgical procedures, allergies, other health care problems, current medications, and health care providers' contact numbers available in case of emergencies and to share with other caregivers such as teachers, babysitters, and daycare providers.

The family also needs to be knowledgeable regarding the therapeutic management of the disorder and the role that surgery, other procedures, medications, and a healthy lifestyle play in maintaining good health. Medications play a critical role in managing some cardiac conditions, such as dysrhythmias, severe HF, anticoagulation for artificial valves, and antirejection medications after heart transplantation. Some patients must take multiple medications daily for their lifetime. Many medications can be dangerous if taken incorrectly and require close monitoring. Parents are taught the correct procedure for giving medications and cautioned to keep them in a safe area to prevent accidental