

death, and concern for the child's future—are not fully appreciated by those caring for the family. Even when the child's condition is stabilized or corrected, the family may need to make adjustments in their lifestyle. Introducing them to other families with similarly affected children can help them adjust to the daily stresses.

Educate the Family About the Disorder

When parents are ready to hear about the heart condition, they require a clear explanation based on their level of understanding. A review of the basic structure and function of the heart is helpful before describing the defect. A simple diagram, pictures, or a model of the heart can help parents visualize the heart and the congenital defect. Parents appreciate receiving written information about the specific condition.* Health care professionals should take advantage of subsequent encounters to assess parental understanding of the condition and clarify information as needed.

Increasingly, families are using the Internet as a source of information about heart disease in children. They are also finding support through contacts with other parents and parent groups.† It is important for parents to realize that not all websites offer medically accurate information and that information from other parents might not be applicable to their own situation. Some children with rare, complex heart defects require individualized treatment plans, and general information on the Internet or in books may not apply to their child. Parents should use their health care team, in particular their cardiologist, to discuss information they have received from other sources.

Information given to the child must be tailored to the child's developmental age. As the child matures, the level of information is revised to meet the child's new cognitive level. Preschoolers need basic information about what they will experience more than what is actually occurring physiologically. School-age children benefit from a concrete explanation of the defect. Including the child at this age early in their own health care and education about their condition will improve self-care and their own accountability (Mickley, Burkhart, and Sigler, 2013). Preadolescents and adolescents often appreciate a more detailed description of how the defect affects their heart. Children of all ages need to express their