

Rarely are families prepared to cope with the numerous decisions that must be made when a child is dying. When the death is unexpected, as in the case of an accident or trauma, the confusion of emergency services and possibly an intensive care setting presents challenges to parents as they are asked to make difficult choices. If the child has either experienced a life-threatening illness (such as cancer) or lived with a chronic illness that has now reached its terminal phase, parents are often unprepared for the reality of their child's impending death (see [Family-Centered Care](#) box).

Numerous studies have found that families facing the impending death of a child depend on information provided to them by the health care team, particularly an honest appraisal of the child's prognosis, to make difficult decisions regarding care options for their children ([Lipstein, Brinkman, and Britto, 2012](#); [Hinds, Oakes, Furman, et al, 2001](#); [James and Johnson, 1997](#); [Wolfe, Friebert, and Hilden, 2002](#)).

## **Family-Centered Care**

### **Family of the Dying Child**

As the group of health professionals that is most involved with families, nurses are in an excellent position to ensure that families are presented with the options available to them. The nurse's first responsibility is to explore the family's wishes. This is best done in concert with the physician but at times may need to be initiated by the nurse. Statements (such as, "Tell me about your thoughts for the type of care you want your child to receive when he is dying" or "Have you considered the types of interventions you would like us to use when your child is near death?") can begin discussion of this sensitive but critical aspect of terminal care.

### **The Dying Child**

Children need honest and accurate information about their illness, treatments, and prognosis. This information needs to be given in clear, simple language. In most situations, this best occurs as a gradual process over time that is characterized by increasingly open dialogue among parents, professionals, and the child ([Barnes,](#)