

encourage parent membership on committees and advisory boards. They can keep parents informed of pending legislation on child health issues or take action when parents inform them.

The Child

Through ongoing contacts with the child, the nurse (1) observes the child's responses to the disorder, ability to function, and adaptive behaviors within the environment and with significant others; (2) explores the child's own understanding of his or her illness or condition; and (3) provides support while the child learns to cope with his or her feelings. Children are encouraged to express their concerns rather than allowing others to express them for them because open discussions may reduce anxiety (see [Nursing Care Guidelines](#) box).

Nursing Care Guidelines

Encouraging Expression of Emotion

Describe the behavior: "You seem angry at everyone."

Give evidence of understanding: "Being angry is only natural."

Give evidence of caring: "It must be difficult to endure so many painful procedures."

Help focus on feelings: "Maybe you wonder why this happened to you."

One of the most important interventions is alleviating the child's feeling of being different and normalizing his or her life as much as possible (see [Nursing Care Guidelines](#) box). Whenever possible, the nurse assists the family in assessing the child's daily routine for indications of a need for normalizing practices. For example, the child who remains in a bedroom all day requires a restructured daily routine to provide activities in different parts of the house, such as eating in the kitchen or dining room with the family. Such children may also be deprived of social, recreational, and academic activities that can be better accommodated by applying