One important aspect of promoting normal development is to encourage the child's self-care abilities in both activities of daily living and the medical regimen. An assessment of the child's age and physical, emotional, and mental capacities, as well as the support and structure provided by the family, should be considered in determining the appropriate level of self-care in the medical regimen. Even toddlers can be involved in their own care by holding supplies for the parent during a procedure. Over time, children should be encouraged toward greater autonomy in the self-care arena.

Early Childhood

During infancy, the child is achieving basic trust through a satisfying, intimate, consistent relationship with his or her parents. However, affected children's early existence may be stressful, chaotic, and unsatisfying. Consequently, they may need more parental support and expressions of affection to achieve trust. Likewise, the parents require assistance in finding ways to meet the infant's needs, such as how to hold a rigid or flaccid infant, how to feed a child with tongue thrust or episodes of dyspnea, and how to stimulate a child who seems incapable of achieving any skills. If hospitalizations are frequent or prolonged, every effort is made to preserve the parent–child relationship (see also Chapter 19).

During early childhood, the goal is to adapt to periods of separation from parents, autonomy, and initiative. However, the natural parental response to having a sick child is overprotection (Box 17-7). Parents need help in realizing the importance of brief separations of the child from them and from others involved in the child's care and of providing social experiences outside the home whenever possible. Respite care, which provides temporary relief for family members, can be essential in allowing caregivers time away from the daily burdens.

Box 17-7

Characteristics of Parental Overprotection

Sacrifices self and rest of family for the child