

ashen skin color, growth retardation, and lack of sexual maturation) are stress provoking. Dietary restrictions are particularly burdensome for both children and parents. Children feel deprived when they are unable to eat foods previously enjoyed and that are unrestricted for other family members. Consequently, they may fail to cooperate. Diet restrictions may be interpreted as punishment. Some children, unable to understand fully the purpose of restrictions, will sneak forbidden food items at every opportunity. Allowing children, especially adolescents, maximum participation in and responsibility for their own treatment program is helpful.

After months or years of dialysis, the parents and child feel anxiety associated with the prognosis and continued pressures of the treatment. The continuous need for treatment interferes with family plans. The time spent in transportation to and from the dialysis unit and the time spent undergoing dialysis treatments cut into time for outside activities, including school. Graft and fistula problems, as well as peritoneal catheter exit site infections, may develop and present a common source of aggravation (see [Family-Centered Care](#) box).

Family-Centered Care

Family Priorities

Families that have children with long-term chronic illnesses, such as end-stage renal disease (ESRD), spend much time in hospitals, outpatient clinics, and primary health care facilities. When they miss appointments or respond less quickly than anticipated, sometimes they are quickly labeled “noncompliant.” It is important to remember that families have to develop priorities for the unit as a whole. Sometimes the family may decide that it is more important for the parent to go to work or to attend a sibling's school performance than to attend an appointment scheduled for them by health care personnel. The chronically ill child cannot and should not always be the number one priority for the family. The professional staff who works with the family can help the parents prioritize the needs of the ill child within the needs of the family constellation.

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