

Working closely with other team members, nurses assist the family in developing the child's self-help skills to give the child the satisfaction of being as independent as possible for as long as possible. This requires continual evaluation of the child's capabilities, which are often difficult to assess. Fortunately, most children with MD instinctively recognize the need to become as independent as possible and strive to do so.

Practical difficulties faced by families are physical limitations of housing, transportation, and mobility. Some families live in houses or apartments that are unsuited to wheelchairs. Transportation may also be a barrier for families of children with MD. Assisting with these challenges requires team problem solving. Diet, nutritional needs, and nutrition modification are discussed according to the needs of the individual child and family.

Children with MD tend to become socially isolated as their physical condition deteriorates to the point that they can no longer keep up with their friends and classmates. Their physical capabilities diminish, and their dependency increases at the age at which most children are expanding their range of interests and relationships. To gain peer associations, they often learn and use behaviors that bring them the rewards of other children's company. These friends are often children who have been rejected by more able-bodied classmates.

The parents' social activities are also restricted, and the family's activities must be continually modified to accommodate the needs of the affected child. When the child becomes increasingly incapacitated, the family may consider home-based care, an assisted living facility, or respite care. Unless the child is severely incapacitated, he should also be involved in the decisions regarding such care. Nurses can assist with decision making by exploring all available options and resources and support the child and family in the decision. Older boys with MD may also need psychiatric or psychological counseling to deal with issues such as depression, anger, and quality of life. Parents need encouragement to become involved in support groups because there is evidence that adequate social support from family, community, and other parents is crucial to appropriate coping in families with children with chronic illness.

Regardless of how successful the program or how well the family adapts to the disorder, superimposed on the physical and