

The diagnosis of a genetic disorder in a child can be a life-altering experience for families. They may have to reassess their perception of “self” and the loss of the dream of the perfect infant. Parents may change educational, employment, and reproductive plans after the diagnosis of a genetic disorder in their child.

Families may need to have the genetic information repeated several times. Families may also encounter ethical or moral dilemmas regarding genetic evaluation and testing options, as well as potential involvement of other family members. Nurses are pivotal caregivers in assessing the family's understanding of the genetic disorder, psychological responses, and coping mechanisms. Nurses may help families by providing support and attempting to alleviate possible feelings of guilt and by helping the family make the best possible adjustment to the disorder.

It is important to stress that there is nothing shameful about an inherited or congenital defect and to emphasize any appropriate remedy. The thought of a hereditary disorder often creates intrafamily strife, hostility, and marital disharmony, sometimes to the point of family disintegration. Relatives may change their reproductive plans after the diagnosis of a genetic disorder in a member, or the decision to reproduce may be postponed indefinitely on the basis of a disorder in a relative, even a remote one. Although people may understand the information on an intellectual level, they may still harbor fears on an emotional level. Nurses can help the family identify their personal strengths and offer them information about local and national support groups. (The Genetic Alliance\* is a nonprofit organization that has a database of support groups for genetic conditions.) Finally, it is important to keep in mind that the infant or child has the same basic needs after the diagnosis of a genetic disorder as he or she had before the diagnosis.

## **NCLEX Review Questions**

1. Identify the anatomic changes that occur shortly after birth that affect the newborn's adaptation to extrauterine existence. Select all that apply.
  - a. Closure of the foramen ovale