

As soon as the parents are able to cope with the infant's condition, they are encouraged to become involved in care. They need to learn how to continue at home the care that has been initiated in the hospital, including positioning, feeding, skin care, and range-of-motion exercises when appropriate. They are taught CIC technique when it is prescribed. Parents also need to know the signs of complications (urinary, neurologic, orthopedic) and how to obtain assistance when needed.

The mother who wishes to breastfeed the infant is encouraged to do so, because this will be beneficial. Shortly after delivery, the mother is started on a program of pumping to initiate and maintain milk supply until the infant is stable enough to begin breastfeeding ([Hurtekant and Spatz, 2007](#)). This process may require considerable support from nurses, physicians, and family members because of separation from the infant for surgical care and recovery.

The long-range planning with and support of the parents and newborn begin in the hospital continuing throughout childhood and even into young adulthood. The life expectancy of children with SB extends well into adulthood; therefore, planning should involve long-term goals and plans for optimum function as an adult. Discussion about aspects of adulthood such as receiving educational or vocational training and education, living independently, having a mate, having sexual relationships, and bearing and rearing children is important and should not be overlooked ([Rowe and Jadhav, 2008](#)). The unique service needs of adolescents with SB as they attempt to gain independence from family and establish lives of their own have not been adequately addressed in the literature ([Sawyer and Macnee, 2010](#)). [Betz, Linroth, Butler, and colleagues \(2010\)](#) interviewed young people with SB making the transition to adulthood. Some common themes that emerged among these young people were as follows: (1) challenges in preparation for self-management; (2) limited social relationships; (3) awareness of their cognitive challenges; and (4) the cost of independence. Nurses assume an important role as central members of the health team. As care managers and coordinators, nurses review information with the family, take responsibility for family teaching, and act as a liaison between inpatient and outpatient services. The child may require numerous hospitalizations over the years, and each one will be a source of