

spouses often benefit from an opportunity to discuss their feelings regarding marriage to an individual with continued health needs and possibly a limited life span. Health insurance coverage is a critical issue for chronically ill children because of their enormous health care costs over time. The Affordable Care Act allows young adults to remain on their parents insurance until they are 26 years old and prevents private insurance carriers from denying them coverage. Life insurance is another dilemma, especially when children have serious conditions, such as congenital heart anomalies.

Perspectives on the Care of Children at the End of Life

Although most childhood illnesses and many injuries and other trauma respond favorably to treatment, some do not. When a child and family face a prolonged and life-limiting illness, health professionals must confront the challenge of providing the best possible care to meet the physical, psychological, spiritual, and emotional needs of the child and family during the uncertain course of the illness and at the time of death. When death is sudden and unexpected, nurses are challenged to respond to grief and shock in families and provide comfort and support in the absence of a prior relationship.

Many factors affect the causes of death that nurses are likely to encounter in children, including developmental factors, medical advances and technology, and changing social patterns. In infants, the leading causes of death are congenital anomalies, respiratory distress syndrome, disorders related to short gestation and low birth weight, and sudden infant death syndrome ([Kochanek, Murphy, Xu, et al, 2014](#)) (see [Chapter 1](#)). The leading causes of death in children 5 to 9 years old include injuries (accidents), malignant neoplasms, congenital anomalies, assault (homicide), and heart disease. In children 10 to 14 years old, suicide is the third leading cause of death after injuries (accidents) and malignant neoplasms. In youths 15 to 19 years old, assault (homicide), suicide, malignant neoplasms, and heart disease follow accidents as the most prevalent causes of death ([Anderson and Smith, 2005](#)).