

- **Gradual acceptance:** The parents place necessary and realistic restrictions on the child, encourage self-care activities, and promote reasonable physical and social abilities.

Reintegration and Acknowledgment

For many families, the adjustment process culminates in the development of realistic expectations for the child and reintegration of family life with the illness or complex condition in a manageable perspective. Because a large portion of this phase is one of grief for a loss, total resolution is not possible until the child dies or leaves home as an independent adult. Therefore one can regard adjustment as “increased comfort” with everyday living rather than a complete resolution.

This adjustment phase also involves social reintegration in which the family broadens its activities to include relationships outside of the home with the child as an acceptable and participating member of the group. This last criterion often differentiates the reaction of gradual acceptance during the adjustment period from total acceptance or perhaps is more descriptive of the acknowledgment process.

Many parents of children with chronic illnesses experience **chronic sorrow**, which are feelings of sorrow and loss that recur in waves over time. As the child's condition progresses, parents experience repeated losses that represent further declines and new caregiving demands. Consequently, families must be assessed on an ongoing basis and offered appropriate support and resources as their needs change over time (Bettle and Latimer, 2009; Gordon, 2009). This represents a critical period of time because the manner in which the nursing and medical team approach and provide support can directly impact the experience of complicated grief after the death of the child. Complicated grief, which is characterized as persistent distress and chronic stress response, may last 6 months or longer after the death of a child and has a significant impact on quality of life of the family left behind (Meert, Shear, Newth, et al, 2011). *Persistent complex bereavement disorder* is a new diagnostic entity included in the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychological Association, 2013).