

## Box 17-2

### Adaptive Tasks of Parents Having Children with Chronic Conditions

1. Accept the child's condition.
2. Manage the child's condition on a day-to-day basis.
3. Meet the child's normal developmental needs.
4. Meet the developmental needs of other family members.
5. Cope with ongoing stress and periodic crises.
6. Assist family members to manage their feelings.
7. Educate others about the child's condition.
8. Establish a support system.

From Canam C: Common adaptive tasks facing parents of children with chronic conditions, *J Adv Nurs* 18:46-53, 1993.

Often the impact of a child's medical or developmental condition is first experienced as a crisis at the time of diagnosis, which may occur at birth, after a long period of diagnostic testing, or immediately after a tragic injury. But the impact may also be felt before the diagnosis is made, when parents are aware that something is wrong with their child but before medical confirmation ([Smaldone and Ritholz, 2011](#); [Thomlinson, 2002](#); [Whitehead and Gosling, 2003](#)).

The diagnosis and initial discharge home are critical times for parents ([Coffey, 2006](#)). Several factors can make this particularly difficult, including a long duration of uncertainty in the diagnostic process, negative perceptions of chronic illness, insufficient information, and lack of mutual trust between parents and their child's health care team ([Huang, Kenzik, Sanjeev, et al, 2010](#); [LeGrow, Hodnett, Stremler, et al, 2014](#); [Monterosso, Kristjanson, Aoun, et al, 2007](#); [Nuutila and Salanterä, 2006](#)). Parental feelings of shock, helplessness, isolation, fear, and depression are common