

Adjustment to serious disability

When parents have to deal with the fact of having a significantly disabled child, grief may never disappear, even in well adjusted families.

Families who manage well can still experience chronic sorrow, and with each developmental stage that the child goes through (for example, when the disabled child starts in a special rather than an ordinary school) there is potential new grief for the parents.

It is not always possible to predict which stages or events will be most demanding for families.

The impact on the child and family will depend on the meaning attributed to that stage.

- Progress on the following dimensions is indicative of the degree of positive adaptation to the ongoing burden of illness and disability:
- Can the parent acknowledge their sense of loss?
- How coherently can the parent speak of the experience of first hearing the diagnosis? Has the parent got beyond angry or frustrated searching for an explanation for the misfortune? eg, finding someone to blame.
- Can the parent accurately represent the child's abilities?
- Is there evidence of family members moving on in their own lives (given the practical constraints caused by the disability)?
- Can the parent see the changes to family life that have resulted from the disability? Is there a realistic appraisal (neither too negative nor too positive) about the benefits vs costs to the parent of the illness experience?