

Chronic Illness

Stressors and Impact on Parents—Donna Marsh (205) 939-6601

Approximately 31% of children under the age of 18 years are affected by one or more chronic illnesses that interfere with daily functioning (Newacheck, 1994). Parents who care for these children often are overwhelmed by the initial impact of learning that their child has a chronic illness and do not realize how the long-term stressors of dealing with chronic illness will not only effect the diagnosed child but the entire family.

Listed below are some of the stressors you may have experienced yourself due to having a child with a chronic illness.

Stressors observed in parents with a chronically ill child

Time of diagnosis:

- Difficulty to comprehend
- Uncertainty
- Potential outcome
- Separation from child
- Altered parenting role
- Role changes
- Less ability to protect child
- Sharing the information-who do we tell

Responses of parent:

- Shock
- Disbelief
- Denial
- Anger
- Despair
- Depression
- Frustration
- Confusion
- Guilt
- Lack of confidence

During Developmental Transitions

- Chronic sorrow due to child's challenges developmentally
- Periodic grieving
- Adaptation to dealing with changes
- Risk periods: 12-15 months when walking usually accomplished
- 24-36 months— speech issues may be observed
- 6 years – school begins
- Adolescence to 21 years adult role issues/independence
- Siblings-pass by diagnosed child developmentally

Ongoing Health Issues

- Day to Day Treatment
- Chronic Burden of Care
- Financial
- Role change
- Marital strain
- Lifestyle modifications
- Depression
- Anxiety

Illness worsens/hospitalization

- Coping with the changes
- Change in lifestyle
- Disruption of routine
- Demands on parents
- Sense of powerlessness
- Constant worry
- Uncertainty

Coping is “constantly changing cognitive and behavioral efforts to manage specific external and internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus & Folkman, 1984, p. 141). The experts report that coping has two functions: (a) the regulation of emotional responses (emotional coping) and (b) the solving of problems (functional coping) (Lazarus & Folkman, 1984; Moos & Schaefer, 1986; Butter, 1981).

Studies indicate that parents who cope well have a positive influence on the child’s outcomes. Also, Cayse, 1994; Killer, 1991, Sterling, 1990 stated that the parents’ coping behaviors largely determine the effectiveness in managing parental roles and facilitating family adaptation in dealing with a chronic illness. In addition, when parents experience stressful events such as a child’s chronic illness, they tend to use more coping behaviors than parents who experience less stressful events (Patterson, McCubbin, & Warwick, 1990). Emotional coping behaviors are needed for enhancing self-esteem, self fulfillment and managing overall well being. When caring for the chronically ill child, there is less time for positive self-fulfilling activities. To increase the coping skills of these parents counseling can provide the following:

Educational opportunities – to learn about the disease and management of symptoms.

This has been shown to decrease parental and child anxiety, increase compliance with the medication and treatment regimens, decrease preventable problems, and increase feelings of control (Baldaia, 1996).

Individual therapy – at the time of diagnosis, developmental changes, progression of the disease, hospitalization, and often ongoing to reduce anxiety, depression, and increase coping skills.

Problem solving skills – to assist the parent in learning more about problem solving; Ie; identifying the problem, determining options, evaluating options and choosing the best option, implementing, and seeing what worked.

If you find that you are having difficulty coping due to the stressors involved with the chronic illness of your child, please call me at 939-6601 to set up an appointment so we can discuss what coping skills you want to improve.