

Effects of Having a Chronically Ill Child on Relationships

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"Great Expectations"

Job Description for Parents of Medically-Fragile Children (Yale School of Nursing, 2004)

Responsibilities:

- 1. Managing the illness**
- 2. Identifying, accessing, and coordinating resources**
- 3. Maintaining the family unit**
- 4. Maintaining oneself – physical, emotional and spiritual health**

The Impact of a Child's Chronic Illness on Marriage --- Key Points

- **A child's disability does have a large impact, but the impact may be detrimental, beneficial, or a combination of effects**
- **Having a medically-fragile child *amplifies* what occurs in a more typical family and marriage**
- **Marriage is more complicated**
- **As marital partners, we need to develop even better skills than others need to have (similar to parenting)**

Individual Challenges

- **Managing Grief**
- **Maintaining Perspective**
- **Protecting a corner of life for yourself**
- **Finding sources of strength and meaning**
- **Coping with uncertainty**
- **Managing guilt, fear and shame**
- **Finding healthy support outside the marriage**

Couples' Challenges

- **(Re)Establishing a bond despite the tendency of child's condition to be “all encompassing”**
- **Accepting differences in emotional reactions to child's illness**
- **Adjusting to roles that meet family needs in a matter that feels fair to both partners**
- **Retaining nuances of romance**
- **Developing a creative vision for the future**
- **Being a team**

External Supports

- **Obtaining respite from others to permit time away from parenting**
- **Receiving competent medical, educational, and rehabilitation services**
- **Forming relationships with others who can provide support, enjoyment, and emotional intimacy**



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