

# The Impact of Chronic Illness on the Family

By Erika Lawrence, PhD

Many different coping strategies can help family members deal with the stresses of chronic illness. But when coping strategies aren't enough, help should be sought.



A family develops a kind of homeostasis — a normal dynamic and routine — that is disrupted when a member of that family develops a chronic illness. Indeed, chronic illness changes family members' roles, responsibilities and boundaries. It disrupts their self-images and self-esteem. It results in uncertain and unpredictable futures. And it triggers distressing emotions — anxiety, depression, resentments, feelings of helplessness, as well as illness-related factors such as permanent changes in physical appearance or bodily functioning.

How a family responds to chronic illness varies based on the age and developmental stage of the ill individual, the strength and coping mechanisms of the family, and the family life-cycle stage. There are many different ways that a chronic illness can affect a family. The person who is chronically ill may feel guilty about the demands his or her illness makes on the family. He or she may resent the change in roles and responsibilities caused by the limitations imposed by the illness, and he or she must deal with the threat to his or her autonomy and the need to depend on healthy family members.

The spouse or partner of a person with a chronic illness can be faced with dual challenges: 1) as the primary provider of support to the ill partner and 2) as a family member who needs support in coping with the illness-related stresses he or she is experiencing. The burdens of being the primary caregiver may take their toll. The spouse may feel trapped while trying to balance dependence and autonomy of the patient with his or her own needs. He or she may feel tired or emotionally drained by the long duration of the illness or the extent of the caregiver workload. The spouse may struggle with feeling powerless when his or her partner is in pain, or by the pressure to be emotionally strong. There may be concerns about the consequences of the illness for the spouse, his or her partner and, if relevant, the children. And, he or she may have to restructure family roles and responsibilities as the disease progresses or presents new challenges.

Having a child with a chronic illness affects the parents in unique ways as well. Some studies suggest that having a child with a chronic illness has a negative impact on the relationship, including lack of time with the spouse, communication problems, higher divorce rates, increased relationship conflict, increased role strain, and decreased relationship satisfaction. Yet, other studies indicate that there are no effects, and still others have found positive effects including increased closeness, greater cohesion and increased support. Indeed, rates of divorce are lower

among couples who have a child with a chronic illness. However, the impact that having a child with a chronic illness has on the adult relationship depends on the severity, course and prognosis of the illness, as well as on the quality of the relationship before the child became ill.

Given all of these adjustment demands, one might expect that the presence of a chronic illness would inevitably result in significant emotional difficulties and breakdown in family functioning. But, despite the presence of conditions and situations that are clearly traumatic and disruptive, a substantial proportion of families make satisfactory if not magnificent adjustments.

## *The person who is chronically ill may feel guilty about the demands his or her illness makes on the family.*

### **Effective Ways for Couples to Cope**

Most people talk about coping as problem-focused (taking care of what needs to get done) or emotion-focused (trying to reduce emotional distress). However, there is a third type of coping that is critical for couples or families faced with a chronic illness: "relationship-focused coping." Relationship-focused coping means focusing on maintaining the quality of the relationship as part of the coping process. When faced with a stressful situation, each partner may attend to the other's emotional needs in order to maintain the integrity of the relationship. Partners endeavor to manage their own distress without creating upset or problems for the other partner. Relationship-focused coping involves a balance between self and other, with the goal of maintaining the integrity of the relationship above either spouse's needs. Effective strategies include negotiating or compromising, considering the other person's perspective and being empathic. Specific strategies include:

*View the illness as a couple or family problem:* If both partners take a relationship perspective, they see the illness as a problem for the relationship, rather than just a problem

for one individual. They talk about the relationship as a way to cope and maintain the relationship. Couples who become aware of and discuss the relationship implications of a partner's illness can anticipate how their relationship may change and prepare for the difficulties they may face. Couples who are resilient when faced with a chronic illness believe that they are in it together and serve as each other's confidante, advisor and sounding board. Therefore, their attention should focus on the relationship as its own entity. For example, if the caregiver is thinking about how difficult it must be for his or her partner to be ill, then the focus is on the partner within the relationship but not on the relationship itself. With "relationship awareness," the caregiver focuses on the relationship by telling his or her partner that the difficulties posed by the illness are "their" difficulties, thereby taking a relationship perspective in dealing with the illness.

## *Couples' coping strategies can be effective if they are similar or complementary.*

*Use similar or complementary coping strategies:* The goal of couple coping is to maximize the fit between partners' coping styles in order to most effectively cope as a couple. Strategies that work in direct opposition or cancel out each other lead to poorer family dynamics. Couples' coping strategies can be effective if they are similar or complementary, though. If partners use similar coping strategies, it might be easier to contend with stress. Coping efforts are coordinated and mutually reinforcing — that is, one partner's efforts do not impede the other's efforts. Complementary coping styles can be effective when they work together to reach a desired goal, e.g., by filling a coping "gap." In fact, complementary strategies may be more effective than similar strategies because the couple, as a unit, has a broader coping repertoire.

What if each partner has very different coping strategies? Partners need to be aware of and talk about their own and their partner's coping styles. The goal is to understand and respect each other's ways of coping. Also, given that each has different coping styles, it is especially important to compromise, communicate about feelings to each other,

give each other time alone, and reassure each other of their love and concern.

One relationship-focused coping strategy is protective buffering, which involves "hiding concerns, denying worries and yielding to the partner to avoid disagreements." Although protective buffering is ostensibly used to avoid disagreements and "protect" the relationship, it can negatively affect the person using it because the partner may feel constrained in expressing negative emotions or worries. However, protective buffering doesn't appear to harm the partner being "protected." In general, it is necessary to balance taking care of oneself and the partner — for both the individuals and for the relationship.

### **Effective Ways for the Whole Family to Cope**

*Communicate with each other:* Family members should communicate constructively about the illness and treatment. They should use active and empathic listening skills and consider other family members' perspectives. When sharing something sensitive, they should be mindful of what is being communicated, how it is being said, and when it is communicated in relation to the others' level of reception. They need to talk openly about the chronic illness, but not allow talk of the illness to dominate the family members' daily lives.

*Support each other:* Effective support in a family involves more than just "being supportive." First, different people want different types of support: Some people want practical help, others want to be listened to, and still others want to know that the other family members think they are strong enough or capable enough to handle things. More support is not necessarily better. What kind of support the family member wants needs to be understood and then provided. Second, family members need to learn to ask for the kind of help or support that is wanted. Each member of the family wants some kind of support. Others tend to provide the kind of support they would want, but they may not know what the others want. It shouldn't be assumed that family members can read each other's minds.

*Increase and lean on social support outside of the family.* It is well-known that having a social support network outside of the family benefits all members of the family, both physically and psychologically. Sometimes, just knowing they are available if needed — even if they are not turned to — can be helpful.

*Integrate tasks of illness into the family's daily routine.* This will help the family develop a coordinated, cooperative

approach to dealing with the multiple demands of the illness and its treatment.

*Take care of family members' physical and psychological health.* This is important for every family member. They need to learn relaxation or mediation techniques, exercise regularly, take some time alone, take time to get away from it all as a family, take walks and plan fun activities.

*Find the new normal:* The goal is to move from crisis management to incorporating the illness into the family's daily lives. The fact is that life will never be exactly the same as it was before. Therefore, family members should challenge themselves to define what a "normal" family life is now. They should struggle to find ways to understand and make meaning of the experience.

## *Family therapy is particularly helpful early on.*

### **When Should Help Be Sought?**

If a significant amount of time has passed (a year or more), and "yes" can be said to one of the following, it may be time for a family to seek help:

- When the chronic illness colors every aspect of a family's interactions.
- When partners have different coping strategies and cannot find common ground regarding the many demands of the illness.
- When one or more family members routinely withdraws into silence. This may or may not be helpful for the person, but it will not be helpful for the couple's relationship or for the family.
- When one or more family members routinely takes on a reactive, anxiety-driven, tell-all communicative style of coping.
- When a family is still stuck in the "crisis phase" and not the ongoing process of adapting to a "new normal."

There are many different kinds of help out there. Family therapy is particularly helpful early on. It has been shown to promote positive adjustment for families. It can help educate families about the person's specific chronic illness and teach family members effective coping skills.

Child or adolescent therapy can be used to educate a child about his or her illness, and to teach stress-

management techniques to promote healthy coping skills and create a buffer against stress. Child therapy also is recommended to help children or adolescents express and learn to cope with their emotions (fear, anger, sadness) when a parent is ill.

Group therapy or support groups can help caregivers, patients or parents of children with a chronic illness by reducing stress.

Certain types of couple therapy have been shown to be very effective at improving couples' coping skills, at helping couples learn to engage in relationship-focused coping strategies, and at improving communication and support skills. Couple therapy has been shown to improve patients', caregivers' and couple health and functioning.

Make sure to find someone who is specifically trained in the type of therapy that is being sought — not someone who "does it all." Also, ask if the therapist is specifically qualified to work with families in which one member is chronically ill. You have unique challenges to face and need an expert.

### **Coping Is Possible**

Chronic illness can be extremely disruptive to family life. But, it can be possible to maintain a homeostasis by using the many coping strategies available, as well as seeking help when necessary. ■

**ERIKA LAWRENCE, PhD**, is an associate professor in the department of psychology at the University of Iowa.

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