

## FIVE TIPS FOR WELL PARTNERS

by Susie Blackmun

A healthy marriage is a partnership. After the initial courtship phase, you settle in and develop your unspoken roles—the responsibilities, routines, and degree of dependence upon or independence from one another. A balance is worked out that gives a rhythm to your lives.

When your life partner becomes chronically ill, your shared life changes forever. That's a simple statement, but an all-encompassing one. The change is unplanned and uninvited, and it permeates every facet of your lives together. Your carefully cultivated balance is destroyed, emotions are apt to overrule reason, and everything seems out of control.

Out of the ensuing chaos a new balance must be established. Why do some couples achieve this more quickly than others? From interviews with dozens of people who have had to rearrange the furniture of their lives around a chronic illness, a pattern of coping strategies emerged.

*"When your life partner becomes chronically ill, your shared life changes forever. That's a simple statement, but an all-encompassing one."*

■ *Recognizing the importance of teamwork.* Psychologically healthy couples work together as a team, educating themselves about the illness and widening their circle of teamwork to include family and friends—and, of course, medical personnel. The primary doctor is generally the quarterback. Because of the uniqueness of environmental illness, the quarterback is often a specialist in multiple chemical sensitivities. He or she can go a long way toward pulling the team together. One example: Until he fully understood the nature of her illness, Beth's husband George was suspicious of her. To get him on Beth's side, the doctor asked George to witness an allergy demonstration. When the offending substance was injected under Beth's skin, George witnessed firsthand the dizziness and mental confusion it provoked. For the first time he could clearly see that his wife had a medical problem, not a psychiatric one, and from then on he was a loyal ally.

■ *Confronting the emotional roller coaster.* Chronic illness brings with it an endless series of emotional reactions: fear, anger, depression, resentment, relief, resignation. "You go through a complete evolution," says one patient. For those who periodically face a crisis, this evolution can happen

## What About The Children?

It has been hard enough for you, an adult, to cope with what is happening at home. What about those members of your family who are even less well-equipped to deal with a major change? What about the children?

Psychologist Dr. Nancy Coniaris of Framingham, Massachusetts, says, "When a chronic illness occurs in the family during the formative years of the children's lives, it gets woven into their very being." For many children the worry of having an ill parent manifests itself in some behavioral manner: depression, dropping grades, fears and phobias, eating and sleeping problems, wildness, and irresponsibility. What can you do if your children show signs of serious stress?

- *Keep an open pipeline.* Remember that communication is all-important. Find out what is going on in their lives, and encourage them to be open by being open about your own feelings.
- *Educate the family* about the illness and its accompanying emotional strain. There are many books available, even for small children, that deal with feelings and with illness. Don't underestimate your child's capacity to understand.
- *Involve your children* in the caretaking to help them feel a part of a solid family structure.
- *Change family activities* if one parent is restricted in physical activity. Otherwise there will be a lot of "because of's," such as, "We can't take a vacation, go to a movie, have a party because of Mom's illness." Reading aloud, playing games, or just talking and cuddling will help maintain a close-knit family structure.
- *Maximize your support system.* Make the most of your family and friends, trying to maximize everyone's impact on the children.
- *Inform the school,* so that the teachers will realize that the children are going to be in a fragile emotional state. If the reason for behavioral problems or failing grades is understood in advance, these can be dealt with before they get out of hand.
- *Periodically take the emotional temperature of each child.* Make a date to go out together or to do something fun at home together, if you can't leave the house. Spend time alone together, enjoying each other's company, each of you seeing how the other is doing.
- *Keep the family laughing.* Laughter is a natural tension release, and humor will lighten up the atmosphere at home.
- *Get professional help,* if necessary. If your children's problems are serious, persistent, and beyond your ability to cope with, consider some outside assistance.—SB □

over and over. "It's very difficult to keep our marriage together," says Katy, who routinely ends up in intensive care fighting for her life. "We just get some kind of balance, and then *crash*, I'm back in the hospital. Each time I come home again, the adjustments are tremendous."

Anger and resentment are the most destructive emotions faced by the well spouse, while guilt is perhaps the most insidious emotion faced by the patient. Guilt often stems from the long-term financial impact of serious illness, which can be the single most devastating change of all.

Beth's multiple chemical sensitivities developed only a month after her wedding, and she spent the next eight years confined to home. "I feel enormously guilty," she admits. "We would have a substantially different lifestyle if this hadn't happened. For a long time we were so poor that the house was falling down and the furniture was falling apart. I was so ashamed. Everywhere I looked there was something to remind me of our dire poverty, and that it was all my fault. I also feel enormously guilty for the adverse impact that I've had on my husband's life."

**C**oping couples can admit to and discuss all of these negative feelings. The caregiver makes sure that his or her anger is directed at the condition itself, rather than at the individual who has it, and both people channel the energy from negative emotions into healthy outlets. Beth, for instance, compensates for her illness by putting extra effort into her work in order to ease the financial strain on her husband. She has covered all expenses connected with her illness, including the cost of changing the house heating system from gas to electric, buying an electric water heater, and installing additional insulation and storm windows. "That was a way to buy my way out of some of my guilt," she says.

■ *Caring for the caregiver.* The increased dependency of a husband or wife is a factor that can play havoc with taking care of yourself. It is expected that you and the person you married will become somewhat dependent on one another, but when illness increases that dependency to a degree that you never envisioned when you took your marriage vows, it's hard to know where to draw the line.

Caregivers often assume so much responsibility that they cease having a life of their own. They lose sight of the fact that if they are not on top of things and happy about who they are, they can't look after someone else with any degree of competency. Entertainment, friends working out, and other personal activities form the backbone of long-term caregiving survival, yet they are the things we most often push aside when the going gets tough. Those caregivers who sacrifice everything to the needs of their husbands or wives often end up living in a cocoon of despair, while those who have outside interests, a strong support system of friends, and physical or creative outlets seem to cope the best.

Use a multitude of treats to ensure your survival: a long, hot bubble bath with candlelight and music; a round of golf or a hike through the woods; dinner or a movie with a friend; a workout at the gym; a massage or manicure. Decide what is possible and then make the time. And as soon as you

have savored the moment of one treat, plan the next. Looking forward to these moments of pleasure is part of the process of survival.

Work is another facet of life that can suffer when one's partner is confined to home, and it is usually the number-one culprit for stirring up resentment. Human nature makes us envious and possessive when our loved one's work seems to take on more importance than the primary relationship. But work is vital to survival—emotional as well as financial. Work enhances self-image, which can otherwise become battered from all the changes at home. Being valued by people out there in the real world helps build self-esteem.

"My commitment to work never diminished," says one woman who charged on with her career even though her husband became jealous of how much it ate into their time together. "I did it as much for him as for myself, because I believed I needed to remain the same person he had married."

■ *Reaching out for help.* Because they don't know how long the caregiving will go on or how much stamina will be needed over the long haul, spouses who cope learn how to pace themselves. They conserve energy for important activities and use outside help from the start so that they do not wear themselves out.

"Try to get as much help as you can," one caregiver advises. "Either pay for it or line up your friends. There were times when I felt as if I were choreographing a long play that was my life. You come on stage now, and you exit.' I really did wind up utilizing and managing the people in my life to help me get through the week."

With MCS, asking for help can be a problem because of the need to protect the environmentally safe home. However, help can still be enlisted. Hire someone to mow the lawn. Draft neighbors to include some of your errand-running along with their own. Don't want to impose on them for a special need? Use a courier service.

The patient's help can be enlisted as well. Dr. Kitty Stein, a Boston-area psychologist who counsels many chronically ill people, tries to get the ill person to take part in looking out for the caregiver: "The sick person often feels that they're the only one in need. If they learn of other needs, they might be able to help in the problem-solving effort," she says. "As a therapist, I sometimes collaborate with the ill person to help the caregiver: 'You and I have to figure out a way to help this person get her hair done, or whatever it is that is needed.'"

An additional benefit of this approach is that once the patient becomes an ally, the problem of guilt is alleviated.

■ *Keeping the illness in its proper perspective.* Caring for a person with chronic illness is a stressful, long-term commitment. You cannot put every ounce of your energy, day after day, into the care of someone else. According to Atlanta clinical psychologist Dr. Jeannie Shaw: "The care/sacrifice/treatment should be appropriate for the wound: If somebody's bone is sticking through their skin, you're not going to say, 'I have to go to the office.' But if your partner is simply depressed and irritable, you don't stay home just to try to cheer them up. We tend to diminish disabled people by

thinking they can't do things for themselves, physical and mental."

It is not easy to keep from being pulled into the patient's whirlpool of discomfort, disabilities, and fear, when his or her whole attention zeroes in on each new symptom and what it might mean. It can become so consuming that the caregiver grows weary of hearing about it. One couple made a pact to help keep things under control. She agreed to share only those details of her illness that affected him. They chose a place in the dining room where she would take him every day when he came home from work and tell him everything she thought he needed to know. They also imposed a time limit on these conversations.

Chronic illness brings with it a death, of sorts. It is the death of health and independence, of the life that was led, and of the normal, healthy relationship two people once enjoyed. When patient and caregiver accept these losses, the pain of denying the presence of the illness, of railing against it in anger, and of being depressed by it is lessened considerably. The struggle against acknowledging the limitations it imposes goes away.

Two people whose lives have lost balance do not have to lose interest in the outside world. Instead of focusing on what they can no longer do, they can concentrate on what is possible. □

*Susie Blackmun is a freelance writer living in Orlando, Florida. She has a BS in psychology from DePauw University and is co-author, with Beverly Kievman of For Better or for Worse: A Couple's Guide to Dealing with Chronic Illness, in which portions of the above article originally appeared.*