

Caregiving: Coping with a chronically ill spouse

Author Maggie Strong had been married for ten years and was the mother of two when her husband, Ted, was diagnosed with multiple sclerosis (MS), a progressive form of neuromuscular degeneration. Over the next 12 years, as Ted's health deteriorated, she took over "the man's" jobs around the house, nursed her husband, worried about the family budget—all the while stifling feelings of rage, anxiety, guilt and fear.

Strong's experiences, which she recounts in her book *Mainstay* (Little, Brown and Company), mirror those of more than seven million "well spouses" in the United States—an estimated 70 percent of whom are women—whose partners are suffering from chronic diseases such as MS, cancer, diabetes, kidney disease, post-polio syndrome, coronary diseases, stroke, arthritis, pulmonary diseases, AIDS, spinal-cord injuries and Parkinson's and Alzheimer's diseases. These men and women can spend as long as 30 years in silent, self-imposed isolation as they helplessly watch their loved ones deteriorate. Often they have to give medication, handle high-tech medical equipment and feed, bathe, dress, lift, carry—even diaper—their partners.

Not surprisingly, well spouses frequently develop their own medical problems and other signs of stress overload such as chronic fatigue, headaches, irritability and insomnia.

Caregiving's Toll

Family and friends, and sometimes even health-care professionals, often do not realize that as the patient's health declines, the illness exacts an equally steep price from the caretaking spouse. Jimmie Holland, M.D., chief of psychiatry at Memorial Sloan Kettering Cancer Center in New York City, tells of a study in which patients were compared with their caretaking partners. "The levels of depression were absolutely the same," she says. "We now look at the spouse even if there are no obvious problems."

Making the Adjustment

How caretakers adjust depends on a number of factors, not the least of which is the nature of their spouse's disease: how quickly it hits, how it progresses,

whether it's fatal and how disabling it will be. John Rolland, M.D., a psychiatrist who founded the Center for Illness in Families in New Haven, Connecticut, adds that the "degree of ambiguity" is also an important issue. With a spinal-cord injury, for example, once the diagnosis is confirmed, the family knows what's in store. But with a disease like MS, "families are left in limbo over a period of time." The sick spouse is ill for years with an unpredictable disease, which can worsen suddenly and then go into remission.

Dr. Rolland starts his counseling with an intensive interview about the family's history. "Getting a sense of what the couple's relationship was like before the illness, how they communicate, how roles are structured, how they are at problem solving, gives me a sense of how they will cope," he explains.

Most experts agree that situations in which the brain and personality are affected, as in Alzheimer's disease and certain kinds of strokes, are particularly hard on the well spouse. "You're suddenly directing someone else's life—a person you looked up to and once had a good relationship with," explains Peter Rabins, M.D., associate professor of psychiatry at Johns Hopkins School of Medicine and coauthor of *The 36-Hour Day* (Warner Books), a book about caring for people with Alzheimer's disease. Regardless of the illness, Dr. Rabins says, "People who have faced difficulties before and have done well in these situations are more likely to do better in caregiving roles."

Strategies for Coping

"The well spouses don't have to do everything themselves," emphasizes Sister Rosemary Moynihan, assistant director of social work at Memorial Sloan Kettering Cancer Center. "Some of them are reticent about bringing in help because they feel it means they're withdrawing or being unfaithful, or that it somehow implies the patient is getting sicker." In reality, Sister Rosemary says, it gives them more quality time in the relationship.

First, the caregiver must acknowledge

the need for help and realize that she is not a failure if she doesn't want to—or can't—do all the nursing herself. The burden is often too great for one person alone. Though many feel guilty talking about their negative feelings—such as anger at being consumed by caregiving activities—or asking to have the burden eased, a loving extended family and close friends can offer great relief. They can help out with home-maintenance tasks (cutting the lawn, putting up storm windows) or take kids on outings, visit with the ill person for an afternoon or even provide financial assistance. And, most important, they can listen.

"Caretakers can eliminate stress by talking. It's normal to have feelings—and it's okay to express them," assures Lucy Waletzky, M.D., director of the Medical Illness Counseling Center in Washington, D.C. She also urges people to be realistic about the future. What will happen if the ill spouse becomes increasingly incapacitated or dies? It's better that the caregiver talk about such possibilities now—ideally, with her mate. Dr. Waletzky adds, "Both spouses have to plan ahead practically, emotionally, spiritually, rather than wait for a crisis." Dr. Rabins suggests that caregivers talk to a lawyer about the possibility of transferring the ill spouse's decision-making power and assets if he becomes incompetent, and inquire about nursing-home care. In short, caregivers should arm themselves with information.

"The more they understand and contribute to (please turn to page 110)

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treatment decisions, the more they feel like they're part of the process," Dr. Holland contends. "It's important that spouses of patients be told about possible complications to watch for, and be given numbers to call in case of emergencies." Groups sponsored by the various disease organizations are good sources of information, but meetings may frighten those whose spouses are newly diagnosed.

Maggie Strong's personal prescription for avoiding "burnout," recommended by most professionals as well, is physical activity. During the early days of Ted's illness, she swam at the local Y; today she does yoga regularly and goes hiking. "If you're not physically active, think of beginning a fitness routine that fits your schedule and interests," advises Dr. Rabins.

Outside Care

What a spouse can handle, physically and emotionally, may change as the illness progresses. For example, a man may be too heavy for his wife to lift, or it may become advisable—if the family can afford it—to hire someone else to take care of "basic nursing functions," which include bladder and bowel care. Myron Eisenberg, Ph.D., chief of the Psychology Service at the VA Hospital in Hampton, Virginia, points out, "Some intimate forms of activities are best done by an outsider. It helps the disabled person maintain a separateness and keeps her or him from feeling like a child." Eisenberg adds that many local volunteer organizations and community and church groups can provide these types of services.

The experts suggest day-care programs sponsored by local groups or hospitals. These programs provide daily physical and social activities at an out-

side facility. "Respite care" is a relatively new alternative. The ill person can be cared for in the home or in a hospital, hospice or nursing home, for anywhere from a few hours to a few weeks. Respite care gives the patient a change of scenery and the caretaker a much-needed breather—perhaps their first "vacation" in years.

Of course, outside help can be expensive. Although the law states that anyone receiving Social Security disability payments for two years is eligible for Medicare, it's not that simple. The Medicare Catastrophic Coverage Act of 1988 increased some of the allowances for home-health services and incorporated 80 hours of daytime respite care, but this new law is complex and confusing. So is Medicaid—to qualify for this federal aid, many spouses must divest themselves of all their assets. For others, the financial toll of caring for the chronically ill finally enables them to receive the benefits. Unfortunately, since provisions for financial support vary from state to state, in both cases generalizations are impossible. Contact the local Social Security Administration or a lawyer familiar with your state's guidelines.

Sharing the Pain

Perhaps the greatest source of information—not to mention moral support—is what Maggie Strong calls "someone else with a like language who doesn't make you feel guilty." Strong has founded the Well Spouse Foundation, which includes a network of local support groups as well as a newsletter.

Attending "Well Spouse" or other peer-support meetings can give previously isolated and uninformed caregivers a way to learn the tricks of the trade, vent feelings and have fun. Strong says, "We need to laugh. We also want to be open-eyed and realistic. Our goal is to maximize the marriage and create our own space."

Well spouses often feel guilty about

having separate activities. Still, Dr. Rabins insists, "Allowing time for yourself makes you a better caregiver. But many spouses become consumed. They tell me, 'No one else can take care of him the way I do.'" Dr. Rabins's answer seems to crystallize the problem of caretakers who think they're indispensable: "You're right—and it's probably going to kill you!"

"But if you break down the overwhelming task of caregiving into specific components, you can begin to find solutions to them," he adds.

Where to Go for Help

National Institutes of Health, 9000 Rockville Pike, Bethesda, MD 20892; 301-496-4000. Contact specific institutes that work under this national agency for up-to-date information about a particular disease. Also call national organizations, such as the American Cancer Society or the Alzheimer's Association (look in the Yellow Pages under "associations," or consult the *Encyclopedia of Associations* at a library). They can tell you about support groups as well.

Well Spouse Foundation, c/o Joanne Watral, P.O. Box 58022, Pittsburgh, PA 15209. Subscribe to the newsletter and ask for meeting locations.

Children of Aging Parents, 2761 Trenton Road, Levittown, PA 19056. Chronically ill, disabled and aging people have similar problems. This support group also gives advice for adults with dependent spouses. For an information packet, send a self-addressed, stamped, business-size envelope and \$1.

Office on Aging. Look in your local phone book under U.S. Government listings, Health and Human Services Department. It's a good place to get help assessing your needs and to scout for community resources.

National Association of State Units on Aging, Attention: Cindy Wellons, 2033 K St., N.W., Suite 304, Washington, DC 20006; 202-785-0707. Send a self-addressed, stamped envelope, or call, for a directory of state agencies on aging that can help locate adult day-care centers or other services for older people.

American Association of Retired Persons, Fulfillment EE 062, 1909 K St., N.W., Washington, DC 20049. Send a postcard requesting these brochures: "A Path for Caregivers" (#D12957) and "A Checklist—Caregivers" (#D12895).

Visiting Nurse Association. Check your local phone book.

Health and Human Services Department and Social Security Administration. Call for information about how Medicare and Medicaid work in your state. ■

IF YOUR SPOUSE IS HOMEBOUND

A chronically ill person may find your house full of hidden dangers. Here are some easy ways to make your home safer and more comfortable:

- If the ill person is confined to bed, make sure a TV, radio and telephone are accessible, as well as reading material, a lamp, call bell, water pitcher and glass, and clock.
- Install grab bars or handrails in hallways and in bathrooms, next to the toilet and in the shower.
- Reduce the danger of falls by removing shag carpets and scatter rugs. Cover slick floors.

- Prepare a plan of escape for the bedridden person in case of fire.
- Place a bench in the bathtub.
- To keep a patient from dropping his cane, make wrist straps using tape, cloth or rope.
- Use Velcro, foam rubber or cloth to enlarge handles of knives, forks and spoons. This enables a weak person to hold the utensils with less effort and more control.
- Change door handles to a lever style for easier opening.
- Use a water bed, air mattress or foam padding to prevent bedsores.

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