Taking Care While Caregiving

Barbara Thornton rises at 5:00 a.m. daily. As dawn breaks, this Boston WHI participant helps her husband, Bill, to the bathroom. She follows with a change of linens on his hospital bed, a bath for him, and administering his medicines through a tube. Barbara helps him dress and move to the family room, where she gives Bill his breathing treatment. Activity shifts to the kitchen as Barbara prepares breakfast and lays out more medications for her terminally ill spouse. During Bill's after-breakfast nap, Barbara manages to quickly take a shower, get dressed, start laundry, tackle the dishes, and vacuum their Massachusetts home. Lunchtime brings another meal and more medications. In the afternoon, Bill has a second nap, and often Barbara sneaks a quick nap, too. By 4:00, another round of medicine is needed and Barbara makes dinner. Barbara gets her mate into bed about 7:00 p.m. Since it's the only long period of free time in her day, she often stays up until after 11:00, even though Bill's needs awaken her throughout the night.

Round-the-clock care has dominated the last four of Barbara and Bill's 56 years of marriage. A stroke in 1996 brought a downward spiral to Bill's health. "He's had about everything you can possibly have," says Barbara, referring to a slew of health worries from pneumonia to seizures, and now bone cancer.

"I don't have time for my own enjoyment," Barbara says. "Some days, the mail comes, the newspaper comes, and I never even think to get either one."

Bill's emotional state greatly affects Barbara's outlook: "People don't realize how the patient affects..."

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the caregiver as much as anything. I think most caregivers can put up with a lot of things if the patient is fairly happy, but usually they’re not. I’m back in the days of having a two-year-old...he’s happy, sad, difficult, impossible.”

Barbara recently began to get some support and time away from her role. Hospice nurses care for Bill a few hours each week. The nurses are encouraging her to take a long overdue vacation, too. Friends also make a difference. “My friends have been wonderful,” Barbara says. “I get at least one call a day.” One friend, a nurse, spends a day with Bill each month while Barbara consults for the insurance company she retired from. “The thing that saves me the most is work,” she acknowledges. “It puts me back in another world. I can fully forget our situation; it’s the only time I do.”

Barbara’s circumstances, as well as her fatigue and concerns, are not unique. The National Council on Aging estimates that more than 7 million adult Americans provide unpaid care to disabled adults in their communities. Most caregivers are middle-aged adults who care for a parent or in-laws, or spouses, like Barbara, who care for a partner requiring 24-hour supervision. Almost 75% of caregivers are women.

This form of health care, while very important, can also be very stressful. Caregivers may suffer from physical problems such as muscle strain and back pain from lifting or carrying, or mental health concerns like depression and anxiety. The Journal of the American Medical Association recently reported on research on elderly caregivers who felt emotional strain related to caring for their aging spouses. The study showed they were at a higher risk of death than their same-age peers who were not caregivers.

WHI participant Delores Smithson knows about emotional strain. Her husband had a stroke in 1991 and now suffers from dementia, as well as diabetes, heart disease, and emphysema. “The stroke changed his personality,” Delores admits. “Before that, he loved to be on the go. He tried to be very helpful. Now it’s, ‘Get my coffee!’ It’s hard because he is a different person.”

Despite Bill’s demands and irritability, Delores feels blessed because he’s still able to walk and leave the house, and he can be left alone for brief periods. Almost daily, Delores takes her spouse to the local senior center, where he socializes, exercises, and eats. Meanwhile, Delores runs errands or goes to an exercise class for her arthritis. Their children also help care for Bill and provide moral support for Delores. She gardens, prays, and writes in her journal to deal with the emotional ups and downs of caregiving. Most of all, she says, “I take it one day at a time.”

There aren’t easy answers or quick solutions to the stresses of taking care of someone. Experts on aging suggest a few ways to ease the burden:

Ask for help. In her book, How To Care for Aging Parents, Virginia Morris writes: “If there were such a thing as Caregivers Anonymous, the first step in the program would be to get rid of that little voice inside
you that says, 'I can do it all, I am responsible for everything, and whatever I do, it's never enough.'” Make a list of what you'd like help with and when you need it. Check on community resources (see “Where To Find Help” at the bottom of this page), adult daycare centers, and family or friends who can help out on a regular basis. Check your relative's medical insurer to see if any in-home support is covered.

- Learn as much as you can about your relative's illness(es). Information allows you to make good decisions and you'll learn what's normal or expected in the situation.
- Keep an inventory of the patient's medical conditions and treatment plans, including medications, special diets, and a phone list of health care providers.
- Organize paperwork so you can easily find insurance records, bank accounts, and wills. You may need an attorney's help to sort out who makes decisions about health care and finances.
- Don't take on more than you can handle. In-home care is not always the best option. Verlita Conner, a participant at the WHI Nevada Clinical Center, realized that bringing her 91-year-old mother to live with her was not a good idea. “You have to put guilt aside and do what you and the doctor think is best,” Verlita says. “You have to be realistic if it causes the family too much stress.” Her mother could no longer live alone, but round-the-clock in-home care was too expensive. An assisted living facility proved the best solution.
- Take care of yourself. Research indicates that caregivers find it hard to look after their own health and are less likely to take preventive steps to maintain their health. Adopt healthy habits like a well-balanced diet, limited alcohol, regular medical exams, plenty of rest, and, if possible, exercise. Schedule a break for yourself to do things you enjoy. Look into "respite" or hospice care, which provides substitute caregivers. If the stress mounts, consider joining a support group or talking with a therapist (see “Where To Find Help,” below).
- If you are employed outside the home, check on your eldercare benefits. Many companies offer dependent care accounts, flexible hours, and family illness days. There are also laws which protect job security if you must take leave to care for a seriously ill parent or spouse.

Where To Find Help

Eldercare Locator
Call 1-800-677-1116 to connect with an agency in your community with local resources:
transportation, volunteers serving seniors, home care, respite care, nursing homes, and other
caregiver services.

Books
Eldercare: The Best Resources to Help You Help
Your Aging Relatives by Marty & Martha Richards,
The Complete Eldercare Planner: When to Start,
Which Questions to Ask and How to Find Help by
Caregiver’s Reprieve: A Guide to Emotional Survival When
You’re Caring for Someone You Love by Avrene Brandt,
Caregiver’s Handbook by Visiting Nurses Association, DK
Counting on Kindness: The Dilemmas of Dependancy by

Web Sites
caregiverzone.com
careinformation.com
caregiving.com
healthfinder.gov/smartchoices/prevention/caregiver.htm

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Of all these ideas, taking care of yourself is probably the most important. Joan Greathouse, a WHI consultant on aging, offers this advice: “Picture yourself on an airplane, sitting next to a child. If something goes wrong with the flight, and the oxygen masks drop down, the crew will tell you that it's your responsibility to put your mask on first and then the child’s.” If you love the person you’re taking care of, she says, you’ve simply got to take care of yourself first.

Vital Signs

Stroke
A stroke, or “brain attack,” occurs after the blood supply to the brain is interrupted. Stroke is the number one cause of disability and the third leading cause of death in this country, but a 1998 study showed that most people can’t identify even one symptom of stroke. And the people most likely to suffer a stroke—those over 75 years old—are the least likely to know its symptoms and whether they’re at risk for having one.

Quick action can mean the difference between tragedy and recovery when it comes to strokes. Heed these warning signs, says the American Heart Association:

- Sudden weakness or numbness in the face, arm, or leg on one side of the body
- Sudden loss of consciousness (“blacking out”)
- Confusion
- Loss of speech, or trouble talking or understanding others
- Unexplained vomiting, or difficulty in swallowing
- Sudden dimming, loss of vision, or double vision, particularly in only one eye
- Sudden, severe headache with no known cause (often described as the worst headache in a person’s life)
- Unexplained dizziness, unsteadiness or sudden falls, especially along with any of the other symptoms

If you notice any of these symptoms, get help by calling 9-1-1 or the emergency response number for your area. A study of response times showed that people with stroke signs who called medics got to the hospital two to three times faster than those who called their doctors or tried to get to the hospital on their own. With strokes, minutes matter.
Charting Her Own Course

When Alma Morrison and her husband, Ray, sail the Maine coast or the Cape Cod Canal, they take turns being captain. Since sailing is one of her lifelong passions, Alma isn’t content to let someone else take charge all of the time. As skipper, she takes the helm and decides the routes. Not surprisingly, Alma brings this pursuit of interests and willingness to lead into the rest of her life.

Back on land, the 64-year-old Boston WHI participant takes charge in other ways. For about 20 years, she’s volunteered for her local chapter of the United Nations Association (UNA), spending the last five years as a member of their board of directors. The UNA is a citizen-based organization dedicated to educating Americans about the United Nations and global issues.

“I’ve always been interested in government and international affairs,” explains Alma. “I got involved in this organization so I could be with other people who are also interested. I could also help explain the United Nations, which I think is very often misunderstood.”

With 23,000 members nationwide, UNA combines grassroots outreach with high-level policy studies. Pressing international problems are addressed. Alma works on public programs about the United Nations and the role of the United States.

The U.N. General Assembly designated 1999 as the “International Year of Older Persons” in recognition of the fact that by 2030, every third person in many industrialized nations will be over 60. Alma helped with Boston’s celebration last year. “It was a wonderful experience for me,” she recalls. “I worked with many groups that address senior issues. I met a lot of people who are very involved in life and have been all their lives—really nifty people.”

So did Alma learn any secrets of successful aging? “I don’t know how you start successfully aging,” she admits. “The people who do it have had very positive lives all along. I’m sure it’s much easier to continue on as your life has been, for as long as your health holds out and you do what you can to help it hold out.”

“The key is to keep doing whatever you enjoy. Keep in touch with the world. One of the things that’s important to me is being where there are all ages around...children, young people.” She continues: “I think activities for older people should be integrated with young people. Choices should be available, like combining day care centers and senior centers.”

Alma’s life is a picture of involvement and advocacy. While raising four sons, she was elected to the local school board for six years. She worked for the Massachusetts Department of Public Health and for several advocacy groups. Alma most recently labored for Common Cause, an organization focused on campaign finance reform and governmental ethics and accountability.

With her love of causes, Alma was a natural fit for WHI. As a member of the Dietary and Hormone studies, she hopes to make a contribution to the scientific understanding of women’s medical problems.

In WHI and the rest of her life, Alma simply enjoys community activism. “It feels like you’re doing something worthwhile for other people,” she says. “I’m working for what I consider to be a better world. It’s a lot of fun!”
Control Group Scoop

Being a randomized, control group participant in WHI can be a difficult role to play.

You filled out all the paperwork, answered all the questions, met all of the requirements, and then you were assigned, at random, to one of two groups. In the Dietary Study, some women were taught new eating patterns, and others were not. Some women in the Hormone Study take hormones, while others take inactive pills. Calcium/Vitamin D Study participants either take vitamins or inactive pills. Of course, participants taking study pills don't know which group they're in. What does it mean? Why doesn't everyone get picked for the active groups in the study?

You've heard the expression, "You can't compare apples and oranges." A randomized, controlled clinical trial ensures we're comparing apples with apples! The women in WHI are of similar age and health. Assigning them by chance to the active or control group is part of what makes WHI such an important study. This type of clinical trial—the gold standard for medical research—and the careful comparison of the two groups makes the findings more scientifically accurate. Having the computer make the assignments increases the chance that the only difference between participants is their diet and/or pills.

Using two groups (control and active/intervention) will allow researchers to compare the two groups and see if eating patterns, hormones, or calcium/Vitamin D supplementation affected the health of the women in WHI. In the Hormone and Calcium/Vitamin D Studies, both researchers and participants do not know which group—control or comparison—a particular participant is assigned to (a "double-blind" study). To make the study results accurate and unbiased, you and the researchers cannot know which group you are in until the study is completely over.

It is common for the Dietary Study participants who know they are in the control group to feel disappointed. They may wonder, "Am I really contributing?" or think, "I'm not as important as someone asked to make changes." Control group participants often underestimate their value to WHI. There would not be a study without them! Both control and intervention groups are extremely important to WHI's study results.

Please fill out all forms and attend clinic visits. The information you provide will benefit generations of women to come.
**For Your Health**

- True or false: Most back pain is caused by accidents or heavy lifting. False! Experts say muscle spasms, brought on by inactivity or emotional stress, are as likely a cause. When back pain hits, over-the-counter pain relievers like ibuprofen or aspirin reduce swelling. Applying ice packs for 15 minutes every three hours, may also help.

- Color is not always a reliable way to tell if food is fully cooked. Use a food thermometer to make sure your foods are cooked safely. The following temperatures must be reached to ensure harmful bacteria is killed:
  - Ground beef: 160°F
  - Pork: 160°F
  - Whole poultry and thighs: 180°F
  - Poultry breasts: 170°F
  - Ground poultry: 160°F
  - Most seafood & fish: 145°F
  - Egg dishes or casseroles with eggs: 160°F

- Keep watch if you have young grandchildren or nieces and nephews around your home exercise equipment. Kids have a dangerous fascination with spinning wheels, resulting in thousands of injuries annually from home workout machines. Try closing doors to rooms with such equipment or blocking access with boxes or furniture.

- If you dial 9-1-1 (or your community's emergency number) and you reach a recording, do not hang up; you'll be routed to a call taker within a few seconds. If you hang up, the call taker will try to call you back to determine if there's an emergency.

- Travel safety tip: Never answer your hotel or motel room door without verifying who it is. If a person claims to be an employee, call the front desk and ask if a staff member is supposed to enter your room, and for what purpose.

- Twice as many Americans die from the flu every year as die from AIDS, breast cancer, or prostate cancer, according to the U.S. Centers for Disease Control and Prevention. Annual flu shots are critical for folks over 65 years old, as well as for everyone who has a chronic medical condition like heart disease or asthma. Only those who have a severe egg allergy should not get a flu shot. Anyone severely ill with a fever should recover before getting a flu shot. Talk with your doctor about this important immunization.

- Houseplants serve as natural air filters. They remove small amounts of indoor air pollutants such as carbon monoxide and formaldehyde (a carbon monoxide detector is still a wise investment, though). To improve your indoor air, try one of these plants: aloe vera, Chinese evergreen, elephant-ear philodendron, English ivy, ficus, golden pothos, corn plant, peace lily, or spider plant.

- If gripping a toothbrush is difficult due to arthritis, here's an inexpensive solution: Slip the plastic spool from a roll of adding machine tape over the toothbrush handle. This enlarges the gripping surface, making brushing easier. Ask for a used adding machine tape spool at a local accountant's or tax preparer's office.

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**Letters**

We'd love to hear feedback on the newsletter and your story ideas. We regret that we cannot answer questions about individual medical conditions. Send a letter to: 

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