

TAKE CARE!TM

Self-Care
for the Family
Caregiver

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Tax Tips for Family Caregivers

Cecily Slater, CPA

April 15 will probably never win any prizes as a favorite day for most Americans. As a caregiver, however, you may find that you are entitled to deductions or credits that can help take some of the sting out of the dreaded tax day. Tax rules change, so take these tips as a guide, but always check with a tax professional when you are getting ready to file.

Medical Expense Deductions – General Principles

For a deduction to qualify as a medical expense, you must have spent money to alleviate or prevent a physical or mental defect or illness. Common deductions include:

- Medical insurance premiums (unless pre-tax);
- Prescription medicines;
- Doctors' bills;
- Hospital fees for services and/or room and board; and
- Travel to and from medical appointments.

You can deduct only medical and dental expenses that are in excess of 7.5 percent of your adjusted gross income (AGI). For example, if your AGI is \$25,000 and your medical expenses add up to \$2,000, you will be able to deduct only \$125. That's the difference between the \$2,000 you spent and \$1,875, which is 7.5 percent of \$25,000.

There's another catch: You can deduct only those amounts for which you have not been reimbursed by private insurance or Medicare. If you are in the upper



tax brackets, some itemized deductions are phased out altogether. Deductible medical expenses are not subject to this reduction, however.

Special Expenses

You can claim the following special items as medical deductions:

- Oxygen and oxygen equipment;
- Special schools or homes for the mentally or physically disabled when recommended by a doctor;
- Artificial limbs;
- False teeth;
- Eyeglasses;
- Wheelchairs and repairs;
- Crutches;
- Costs and care of guide dogs for aiding the disabled;
- Braille books and magazines if they are more expensive than regular books and magazines; and
- Hearing aids and the batteries to operate them.

You can also deduct expenses for

equipment or improvements you've made to your home for medical reasons, but the IRS will reduce these deductions by the amount such improvements increase the value of your home. Typical equipment and improvements added initially for medical reasons include:

- Ramps;
- Widened doorways and hallways;
- Grab bars in bathrooms;
- Elevators, stair glides, etc.;
- Air conditioning; and
- Accessible shower stalls.

Unfortunately, health club dues and dancing or swimming lessons are not deductible, even if recommended by a doctor.

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Medicare Rolls Out New Preventive Benefits for Seniors and the Disabled

As any family caregiver knows, preventing medical problems before they start is one of the most valuable things we can do for our loved ones and ourselves. It has not always been easy, however, to get insurance coverage for the types of preventive services that all of us need and want.

For seniors who are new to the Medicare program and those who are getting ready to become Medicare beneficiaries, there is good news. You now have greater access to more prevention-focused benefits than ever before. Starting on January 1, 2005, people with Medicare can take advantage of three important new benefits: a one-time "Welcome to Medicare" physical exam, cardiovascular screening, and diabetes screening.

One-Time "Welcome to Medicare" Physical Exam

If your Medicare Part B coverage begins on or after January 1, 2005, Medicare will cover a one-time preventive physical exam within the first six months that you have Part B. The exam will include a thorough review of your health; education and counseling about the preventive services you need, like certain screenings and shots; and referrals for other care if you need it. The "Welcome to Medicare" physical exam is a great way to talk with your doctor about your family history and how to stay healthy.

Cardiovascular Screening

Medicare covers cardiovascular screenings that check your cholesterol and other blood fat (lipid) levels. High levels of cholesterol can increase your risk for heart disease and stroke. Knowing your cholesterol levels is the first step toward establishing a healthy lifestyle, like changing your diet and getting regular exercise.

Diabetes Screening

Diabetes is a medical condition in which your body doesn't make enough insulin or has a reduced response to insulin. Because your body needs insulin to use sugar properly, people with diabetes have blood sugar levels that are too high, and a high blood sugar level is not good for your health. Talk with your doctor to see if this screening is right for you and how often it's covered by Medicare.

All of these important screenings can help you and your loved one address potential health problems before they start. For more specific information about these benefits and other Medicare preventive services, get a free copy of the "Guide to Medicare's Preventive Services" (CMS Pub. No. 10110) on the Web at www.medicare.gov. Just select "Publications." Or call 800/MEDICARE (800/633-4227). TTY users should call 877/486-2048. ■

"Dreams are renewable. No matter what our age or condition, there are still untapped possibilities within us and new beauty waiting to be born."

— Dr. Dale Turner

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Finding Help Through Faith Communities

Paula S. McCarron

Six out of 10 Americans say religion is “very important” to them and believe that faith can solve “all or most of today’s problems,” according to a June 2004 Gallup Poll. A study by John Hopkins University found that 41 percent of family caregivers are willing to accept help from outside sources, but say they would prefer such help come from local community or religious organizations.¹ It’s clear that many Americans place a high degree of trust in their faith beliefs and in the faith community. When family caregivers turn to the faith community for help, however, what kind of assistance do they find?

Let’s start at the local level. While 80 percent of congregations in the United States report that they offer some form of caregiving assistance, most admit they are serving small numbers of people and have a limited range of services to offer, such as visits to hospitalized or homebound members, or volunteer support in providing meals, transportation or child care.² While valuable, these services tend to be sporadic, short-term, and not focused on supporting family caregivers. Too often there is no consistent effort made to find, train, and support volunteers. For these reasons, caregiving families who need long-term care and assistance are often not served.

Take the story of Ellen Mejias, a family caregiver in Land O’ Lakes, Florida, who shared her experiences as part of the NFCA Caregiver Story Project. Mejias wrote, “I sat in a Catholic church office when I was six months pregnant with my fourth child. My other children were at my side. My mother lay at my home recovering from open-heart surgery

and my dad was preparing to go in for his right knee replacement, which would take months of rehab. I begged them for someone to come to my home and help me out. I was told that would be too much of a liability. Thanks to all those frivolous lawsuits that made others rich, no one would dare step in my house to volunteer because they might get sued. I was crying so much and the children were making so much noise that the priest in the next room got up to close his office door.”

Realizing that stories like Ellen’s are not unique, and to better meet the needs of their members and the community, many faith communities are investing time, energy, and resources in creating new caregiving programs on their own or in partnership with others. Many of these services specifically take into account the needs of family caregivers and individuals who are coping with chronic illness, disability, and the effects of aging.

Along with organizations that are faith-specific, there are a number of interfaith groups that provide some form of support for family caregivers. Keep in mind that many faith-specific organizations have programs that are open to everyone. Listed below are some of the services that are available to family caregivers and/or the elderly or disabled living alone. Given the thousands of local services, it is impossible to provide a complete list of what is available. Be sure to contact your local faith community, senior center, United Way agency, and the Area Agency on Aging to learn what other services may be available in your area.

International Parish Nurse Resource Center

Parish nursing, an ecumenical and

international movement, reclaims the historic roots of health and healing found in many religious traditions. While based upon Judeo-Christian traditions, parish nursing is consistent with the basic teaching of all faiths. To date, 7,000 nurses have “graduated” from the parish nurse program.

Parish nurses serve as educators, referral agents, and advocates. They may be involved in home visits, coordinating volunteers, organizing health fairs, facilitating support groups, or helping people find resources. Many serve as volunteers. Others may be employed either by a congregation or medical center.

Parish nurse Elizabeth Johnson, R.N., B.S.N., of St. James Lutheran Church in Rock Island, Illinois, says, “Generally, it’s hard for people to ask for help. But here, people know me. They say it’s more comfortable to come to me than to have to go to a stranger.”

Johnson also coordinates health-related events for the benefit of community members. “We invite all the other groups in the neighborhood. We’ve got several nearby, including a Greek Orthodox church and a Jewish center.”

Shepherd Centers of America

Founded in 1972, Shepherd Centers are dedicated to promoting a new vision of aging that includes meaningful opportunities and independent living for older adults. Located in 20 states and 75 communities, Shepherd Centers offer life-long learning, wellness, and fellowship activities for mid-life and older adults.

Community-based and interfaith, Shepherd Centers are open to all members of the community. In some communities, Shepherd Center volunteers provide handyman services, home visits, and transportation to help older adults continue living in their own homes. Caregiver support groups, educational forums, and adult day services may also be

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Faith Communities

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offered. Some centers are aligned with Faith in Action programs.

Faith in Action

Faith in Action volunteers of every faith, including Catholics, Hindus, Jews, Muslims, and Protestants, are working together to improve the lives of their neighbors with long-term health needs. Through Faith in Action, volunteers help people remain independent by providing assistance with the tasks of everyday living, such as food shopping, trans-

portation, light housekeeping, and yard work. There are currently more than 1,000 Faith in Action programs in the U.S.

One of the newest programs is Faith in Action, Hart Felt Ministries, located in Jacksonville, Florida. Founder Jane Hart says she recalls a life-changing conversation when her mother once asked her, "Jane Alice, how do you foresee your future?" Hart says she knew then that she wanted to work with the elderly, particularly to help elders remain in their own homes.

Hart served as a congregational volunteer and then as a hospice volunteer. With no knowledge of Faith in Action, she started to develop a non-profit organization that would provide home care assistance to frail elders. Through her research, she discovered her dreams matched the vision of The Robert Wood Johnson Foundation, which provides start-up grants to new Faith in Action programs.

Now in its first months of operation, Faith in Action, Hart Felt Ministries is already providing services to elders and other adults coping with illness and disability, and their family caregivers. Already a handful of volunteers are active with the program and it is hoped that 25 volunteers will be trained and assigned in the next few months.

When it comes to helping family caregivers and the homebound, Connie Siskowski of Boca Respite of Boca Raton, Florida, says, "We see people who are hungry and we see people who are homeless, but typically we don't see people who are homebound. They're an invisible population, living behind closed doors. We don't often know who they are or who needs our help."

Boca Respite is a network of community agencies, religious organizations, and volunteers working together to help homebound individuals and family caregivers. It, too, was started with a Faith in Action grant. Currently 90 volunteers pro-

vide care and assistance for 250 people in 160 households in Boca Raton.

Siskowski describes a family caregiver who spent his retirement savings caring for his wife. Now living alone and in need of help himself, he doesn't have the money to pay for services, which, unfortunately, is the case with many family caregivers. Luckily for him, help is being provided by Boca Respite volunteers. Siskowski also sees a greater purpose being served: "We're here to help people live independently and with dignity."

Stephen Ministries

Stephen Ministers provide one-to-one supportive and spiritual care to individuals experiencing a life challenge such as illness, hospitalization, or death of a loved one. Service continues for as long as desired by the person being served.

Rev. Kenneth Haugk called upon the members of his congregation for assistance when he realized that people in his church and the community needed more care than he alone could provide. Rev. Haugk created the first team of Stephen Ministers in 1975. Since that time, more than 450,000 lay volunteers have participated in Stephen Ministry training, which involves 50 hours of initial training. Stephen Ministers can be found in 9,000 congregations and represent 100 Christian denominations. Generally, support is offered in face-to-face visits and phone calls.

Association of Jewish Family and Children's Agencies

Tracing their roots back to the 19th century, Jewish Family and Children's Agencies began by assisting Jewish refugees and immigrants, orphans, the poor and needy. Today, Jewish Family and Children's Agencies provide health and social services to people of all ages and faiths.

Located in 30 states, these agencies offer many services of benefit to

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FINDING HELP

The Association of Jewish Family and Children's Agencies

800/634-7346 (toll-free)
www.ajfca.org

Catholic Charities

Contact a neighborhood Catholic church or the Diocese in your area, or: 703/549-1390
www.catholiccharitiesinfo.org

Faith in Action

877/324-8411 (toll-free)
www.fiavolunteers.org

International Parish Nurse Resource Center

314/918-2559
www.ipnrc.parishnurses.org

Lutheran Services

The national organization's Web site provides an address and phone directory to local services, as well as the ability to search by services needed. 800/664-3848 (toll-free)
www.lutheranservices.org

Shepherd's Centers

800/547-7073 (toll-free)
www.shepherdcenters.org

Stephen Ministries

314/428-2600
www.stephenministries.org

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Faith Communities

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family caregivers and their loved ones, including care coordination, transportation, family counseling, support groups, and home visits. Two unique services are home-delivered kosher meals and specialized services for Holocaust survivors. Another service is The Elder Support Network, which offers help to elders whose families live far away. Services vary by community. Some services are covered by insurance or require payment while others are available on a sliding fee basis or at no cost.

Colleen Mallen, senior services coordinator for the Jewish Family Service of San Diego, says, "We get calls from doctors, workers in healthcare facilities, family members, and community agencies. One thing people need to know is that we're here to serve everyone."

In addition to the Jewish Family and Children's Agencies, there are other initiatives under way in the Jewish community. Rabbi Arthur Address, director of the Union for Reform Judaism's Department of Jewish Family Concerns, describes

Do You Want to Enlist the Support of Your Faith-Based Organization?

The National Family Caregivers Association has a brochure specifically designed to help faith-based organizations establish support services for family caregivers. "Supporting Caregiving Families, A Guide for Congregations and Parishes" can be obtained by contacting NFCA at 800/896-3650. NFCA also has developed interfaith and faith-based services to honor family caregivers, as well as instructions on how to organize a service.

the Sacred Aging project, which has as one of its components a section on asking congregations to develop programs that support family caregivers. Among the project's initiatives are the development of special rituals and programs for "shomers," or caregivers, and blessings for caregivers and families who are dealing with mental illness. In addition, Rabbi Address and Rabbi Hara Person are co-editors of the book *That You May Live Long: Caring for Our Aging Parents, Caring for Ourselves*. The book is the first of its type in the Jewish community that deals with caring for aging parents and the caregiver. A study guide for congregations, based on the book, has recently been completed.

Catholic Charities USA

Founded in 1910 as the National Conference of Catholic Charities, Catholic Charities USA is one of the nation's largest social service networks. Various Catholic Charities agencies provide a wide range of services, including emergency assistance, housing assistance, and parenting education. Catholic Charities often work alongside other agencies. The services of each Catholic Charities agency are unique to the needs of the community, and are available to all, regardless of religious belief.

In Joliet, Illinois, seniors can find help with money management or utilize adult day services. In Albany, New York, the Caregivers Respite program offers everything from friendly visiting to respite to home maintenance. Catholic Social Service in Phoenix, Arizona, offers home health services of aides, nurses, and social workers for persons age 60 and older. In Cincinnati, Ohio, the Caregiver Assistance Network provides caregiver education and training, support groups, a "CARE line," and consultation services.

Lutheran Services in America

Lutheran Services in America (LSA) is an alliance of the Evangeli-

cal Lutheran Church in America, The Lutheran Church - Missouri Synod, and their related social ministry organizations. Lutheran service agencies can be found in 3,000 communities throughout the United States and the Caribbean.

Lutheran Service agencies provide assistance to six million individuals annually. Services are provided without regard for religious affiliation. Many services are provided on a donation basis, a sliding scale fee, or at no cost. Some services are covered by insurance.

The extent of services available in each community varies. For example, Lutheran congregations in Montana are working to create groups of volunteers to support rural caregivers and their loved ones. In other communities, services may range from caregiver support groups to respite care to adult day services or assisted living facilities.

Each of the organizations listed above provides some type of information, resources, and training. It's important to remember that as with any service organization, you may not always find the exact help you need depending on your particular situation. Since these organizations may use different terms to describe their services, be specific about the type of help you are seeking. Keep in mind that it may take a bit of extra effort to find these services or similar services in your community. In the end, the search is always worthwhile because you invariably learn something new; and, if you are able to locate the help you need, you just may find the answer to your prayers. ■

Paula McCarron is a freelance writer living in Florida.

References:

¹ "A Great Need, A Greater Reservoir of Good Will," Harris Interactive and The Johns Hopkins University for the Faith in Action program.

² Independent Sector, 1996.

As its title implies, the purpose of this column is to provide you with helpful information, tap into new networks, or learn about available products and services.

Are you looking for appropriate housing options for your loved one?

A free online screening tool may assist you in doing just that. It prompts you to answer questions about such things as your loved one's mobility, nutrition, medications, and mental and behavioral status. Once you have answered the questions, an interpretation of your score is displayed, offering the most appropriate living options depending on the type of care your loved one may need. This tool is quick, easy to use, and can give you an idea about where to start when looking for housing options for a person with special needs. You may also use this site to locate care facilities in your community. Go to: www.seniorhousingnet.com/seniors/select_care/evaluate.jhtml.

Do you need a safety ID card for your loved one in case of emergency?

The Law Enforcement Awareness Network has developed Safety Identification Cards for both children and adults. These cards are designed to give first responders the information they need to better provide timely and appropriate services to your care recipient. The Safety ID Card provides space for critical information, a recent photograph, and thumbprints. The card can be updated as needed as the person's condition changes. These cards can be downloaded at: www.leanonus.org. Just click on "Safety Cards." If you cannot download a PDF file, you may request that cards be sent to you via mail at no cost. If you don't have Internet access, send a note to L.E.A.N. On Us, PO Box 182338, Shelby Township, MI 48318.

Are you caring for a loved one with Parkinson's disease?

ParkinsonsHealth.com is a Web site devoted to helping you learn all you can about Parkinson's disease and how it may affect your loved one. The

Web site includes a section devoted to helping family caregivers. NFCA is proud to have provided input on the creation of this special family caregiver section. To find out more, go to www.parkinsonshealth.com and click on "Caregivers."

Would you like an inspirational calendar for 2005? One is available from www.exploringspasticity.com or by calling 800/731-2921. What makes this calendar so special is that it contains the personal experiences and thoughts of 12 individuals who live with spasticity every day. Their comments were selected from a slew of entries sent to Medtronic Corporation, the originators of the calendar. Whether spasticity is a symptom you and your loved one live with or not, this calendar will prove thought provoking and inspiring.

BOOK REVIEW

Share The Care: How to Organize a Group to Care for Someone Who Is Seriously Ill, by Cappy Capossela and Sheila Warnock (Fireside Books/Simon & Schuster Trade Paperback, Nov. 2004, \$14.00) is an updated edition of a highly acclaimed book written by two women who were part of a caregiving group for a terminally ill friend. They later guided others in forming their own groups and first published their model in 1995.



The book is a road map for forming a caregiving team for someone with a serious illness, whether terminal or temporary, or for an elderly person without family nearby, and to help relieve emotional, physical, psychological, and financial stress on family caregivers.

Specific and detailed suggestions guide the reader through such areas as:

- Assessing the sick person's needs and those of their caregiving family;
- Identifying relatives, friends, neighbors, and others to invite to join together as a caregiver "family";
- Holding a meeting to bond the group, organize them, and get started;
- Assisting with doctors' visits, hospital admissions, medications, and more;
- Making the home safe and comfortable;
- Helping from a distance;
- Confronting feelings — the patient's, your own, and the group's; and
- Taking a new look at healing — as opposed to finding a cure.

When Cappy Capossela was diagnosed with a brain tumor in 2002, Sheila Warnock put their caregiving model into practice once again. After Cappy's death, Sheila created sharethecaregiving, Inc., a not-for-profit organization that educates the public about this proven option for caregivers. Information and forms to help you start a Share The Care group can be found at: www.sharethecare.org.

"Share The Care is one of the best books ever written to help family caregivers. I was wowed by the first edition, and this one is even better. Family caregiving is more than a one-person job, and the Share The Care model is the best way I know to balance the load and thereby let caregiving families know they are definitely not alone. A must read for family caregivers and all who care about them."

— Suzanne Mintz,
NFCA president/co-founder

Resources for this issue were compiled by CCAN representative Eboni Green (Nebraska) and the Book Review was provided by CCAN representative Susan Bria (Connecticut).

A Tribute to Christopher Reeve



FOR SEVERAL YEARS, THE CHRISTOPHER REEVE PARALYSIS FOUNDATION has generously provided grants to NFCA, first to create the National Family Caregiver Story Project, and then to sustain it. The Story Project is a Web-based initiative that allows family caregivers to share their stories, express their feelings, and state their needs. Participating in the project

helps lessen the isolation of family caregivers and creates a repository of stories that are highly effective in explaining to policy makers what it really means to live with, and care for, someone with a disability or chronic illness.

When Christopher Reeve passed away on October 10, 2004, nearly a decade after being paralyzed in a horseback riding accident, he left behind a legacy of courage, undaunted determination, and hope that will inspire those who knew him for years to come. As a tribute to Christopher's life and the work that he and his wife, Dana, have done, we are printing a few stories of family caregivers whose loved ones, like Christopher Reeve, have suffered a spinal cord injury.

Ratrina Rhodes

Arbyrd, Missouri

I am the 27-year-old single mother of Scarlett, who is 8 years old and is paralyzed from the chest down. This was the result of a drunk driver hitting her and my mother four years ago. Scarlett uses a wheelchair. She cannot transfer herself. I also must do several diaper changes, breathing treatments, and physical therapy on her myself each day.

Since Scarlett's accident, I have lost my job due to a lack of assistance for caregiving. I have given up my hope of finishing my last two years of college. Scarlett is a wonderful light to this world. I am only afraid that I will not be able to give her the things I once had hopes of because of having to give up my own life to care for her.

Being a caregiver is hard. I would like to meet and marry someone

someday. This is hard because I am always at home, or in a hospital or doctor's office. I also have lost touch with several friends and family members because it is too hard and painful for them to see our lives now.

I love my daughter very much and am so thankful I still have her with me. She is my entire life now, my child, my best friend, and my most cherished loved one.

Some things I wish for:

1. Financial assistance for caregivers who would like to work and continue their education.
2. Assistance purchasing supplies.
3. Financial assistance for a wheelchair ramp to our house.
4. Assistance with reliable transportation.
5. Better opportunities for my daughter. (We live in a rural area with no help or organizations.)

Jane Brager

Ijamsville, Maryland

In his professional life, my husband, Jim, was a banker. In his leisure life, Jim was an outdoorsman, a horse lover, and an avid fox hunter. In 1996, when a "jumping a log" accident while fox hunting resulted in a C5-C6 spinal cord injury, my husband, then 64, became a quadriplegic and I, at 55, became a caregiver. A single "moment in time" changed our golden retirement years into a whirlwind of rehab, struggle, medical education, insurance puzzles, successes, and setbacks. As patient and caregiver, we each had our separate issues. We were united, however, in our determination to achieve as much recovery as was humanly possible.

Our blessings are many. We have seven grown children who are concerned and helpful. We live in an

area with excellent medical facilities. We have adequate insurance coverage. We had always been “savers,” which has allowed us to employ CNA help for weekday mornings. We have educated ourselves and sought out many alternative therapies that have resulted in an amazing recovery of movement and function in my husband’s daily living. We receive emotional support from friends, family, and our church.

What’s the problem? Caregiving is an emotionally exhausting occupation, even when done with love and devotion in your heart. The six letter word “RESPITE” fills me with frustration and anger. Every magazine article, newsletter (including TAKE CARE!), and book extols the virtues of respite time for caregivers. Every caregiver knows the importance of time off, change of scene, and uninterrupted sleep.

Some things I wish for:

This caregiver’s needs and wishes are HELP with finding and arranging RESPITE time.

The question is: How can we make respite time more available to caregivers? Could home health agencies provide respite teams (three eight-hour shifts or two 12-hour shifts) to work weekends? Could associations, such as NFCA, partner with government agencies, PVA, etc. to provide funding for a respite team program? Could we develop a business model for a respite team program with a national nursing home facility to provide in-home care or in-patient care for a short stay? Could we encourage hospitals to provide respite teams as part of home care assistance?

Betty Swope

Lake Charles, Louisiana

I am a single mother of a 29-year-old son with a spinal cord injury. It happened when he was 21,

exactly when most spinal cord injuries occur. It’s a hard, tough, lonely life. It seems like there is no one in your corner, no back-up system, no one to comfort you when your loved one becomes more ill and you have to become a “super mom.” I’ve wondered for years why there isn’t more help for caregivers, and a place to go when we hurt — physically and mentally. With all the budget cuts these days, I wonder if our injured loved ones will fall further into the cracks. I wonder every day what will happen to my son when I become too old to lift him, when my bones become brittle, and when my eyesight fades away. It won’t be long. Nine years without a nurse’s aid or personal care attendant takes a toll on a body. I’m scared for me, but I’m more scared for my son. We have two people on one government check, SSI, which doesn’t go far.

Some things I wish for:

Every caregiver reaches a point of exhaustion. We need more people to help the caregiver. I haven’t had a day off in nine years. Most jobs would have given me at least one week off in nine years. We need to get some help for single moms who need support in so many ways.

Mary Virgilis

San Jose, California

I am a 48-year-old caregiver for my husband, Steve, who is 53. Seven years ago, my husband’s spinal cord was damaged during revision spinal surgery. The injury was “incomplete,” but it has ruined our lives completely. Steve suffers daily, incapacitating neuropathic pain: He describes it as if he is sitting in an electric chair and someone is fiddling with the switch. It comes and goes unpredictably; the frequency, duration, and strength of the pain are also unpredictable. Steve takes medications that make him very

sleepy so he does not participate in many of our family’s activities; nor can he work, although he is a well-trained and previously very successful technical writer. The burden of caring for our three children — now 22, 19 and 16 — has fallen on me. Two years after his injury, I suffered a herniated disc in my back. I had little time to recuperate from my own back surgery. We tried to live on two disability incomes but we ended up in bankruptcy. I now have a good job working as a nurse case manager for worker’s compensation injured clients as well as other patients needing home care. My experiences have made me a much more understanding and supportive nurse. I am bitter, however, that my 20-year career in the operating room was cut short. Steve agonizes over the loss of control of his body functions and intimacy, and the fabric of our marriage is frayed and tattered where it was once strong and growing. Our children have suffered, too, and the hope for our future fades with every day as Steve sinks deeper and deeper into his depression.

Some things I wish for:

A house that we own, not rent, fully redesigned and adaptable so Steve can work on his projects to give him something else to focus on other than what he is no longer able to do, with wide hallways so I’m not patching plaster every other weekend, and a housekeeper so I can keep working and actually rest when I get home. We were on the right track to owning our own home and working together raising our children when our world collapsed. ■

To view the Story Project Web site and read additional stories, or to submit your own, go to: www.thefamilycaregiver.org/who and click on “National Family Caregiver Story Project.”

Statistics Worth Noting

- A new survey finds that **85% of working women** consider leave to care for a sick family member to be an important part of their employee benefit plan.

— Source: *Business and Professional Women's (BWP) Foundation, Fall 2003-Spring 2004 Survey.*

- “Women who are family caregivers are **2.5 times more likely** than non-caregivers to live in poverty and five times more likely to receive Supplemental Security Income (SSI).”

— Source: *University of Michigan Health and Retirement Study, sponsored by the National Institute of Aging.*

- Women caregivers tend to provide more assistance with their loved one's basic physical needs while men are more likely to help with activities such as managing finances. Both men and women report that it is harder to deal with a loved one's cognitive and emotional difficulties than with that loved one's physical needs.

— Source: *The Employee Caregiver Study, Professors Barbara Shadden and Ro DiBrezzo, University of Arkansas.*

- The quality of care delivered by health plans that publicly report on their performance improved markedly in 2003. The U.S. healthcare system as a whole, however, remains plagued by deadly “quality gaps” that contribute to **42,000 to 79,000 avoidable deaths every year**. The findings suggest that the system is deeply polarized, delivering excellent care to some people and generally poor care to others.

— Source: *National Committee for Quality Assurance (NCQA): State of Health Care Quality, 2004 report.*

“Flexibility” Is Not Always Possible

The fall issue of *TAKE CARE!* contained an article by David Williams, who is living with multiple sclerosis. There are also some insightful tips from Fran, his wife, for the family caregiver. My husband has multiple sclerosis and I work outside of the home to provide the medical benefits that we both need. I had to take exception to Fran's last piece of advice, “to have lots of flexibility” in your schedule. This is not possible for many of us who would like to continue to keep the job that provides us with the benefits and salary we need to earn for our family. I would like to see this issue brought to the forefront for the caregiver.

We need more time off without the danger of being the first one to be laid off because of multiple absences: maybe something like an accepted amount of days off throughout the year, as is accepted for maternity/family leave — the difference being that it's not always possible to schedule or predict when the caregiver will need the time off. I am thinking not just about regularly scheduled appointments, but the emergencies or problems that arise with anyone living with a chronic illness.

I am fortunate in that I have found a local organization that visits my husband twice a week and they are able to help him out in many ways. But I also feel very strongly about being able to attend his doctors' visits, as I need to be informed for my own piece of mind, as well as being able to communicate this information to his family. Men don't always want to ask the tough questions, or deal with certain aspects of their care head on. (Ladies, you know what I'm talking about!) In the end, caregivers are given lots of kudos for what they do, but unless we speak up and tell people what we

need, we will continue to be tired, and subject to illness because we are mentally and physically run down. It's just not enough to take time out for yourself and not feel guilty when you finally get to take that bubble bath, or have a trusted friend or family member help out with your loved one's daily needs from time to time. We have to do more, say more, and be recognized in more ways than just pats on the back for what we do. Our contributions — basically our lives — are given unselfishly. We are an invaluable resource for our loved ones and society, and as the baby boomers continue to age, our numbers will continue to grow.

Robin Francis

Help Is Available for Veterans and Their Families

In regards to your Q&A column in the summer 2004 issue, please advise your readers that to help cut through “government bureaucracy” due to war injuries, they should contact:

National Headquarters
Disabled American Veterans
P.O. Box 14301
Cincinnati, Ohio 45250-0301
Toll-Free Phone: 877/426-2838
Fax: 859/441-1416
Web site: www.dav.org

This organization has national, state, and local service officers who are certified to assist veterans and their families in getting through the “government bureaucracy” as soon as possible.

Roy Green
Adjutant/Service Officer

TAKE CARE! welcomes your feedback. Send your letters to: NFCA, 10400 Connecticut Avenue, Suite 500, Kensington, Maryland 20895; or e-mail them to communications@thefamilycaregiver.org.

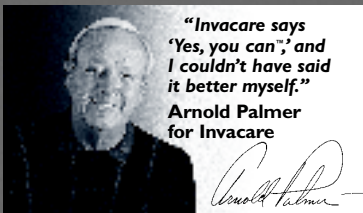
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What Can I Do? is a question and answer column aimed at helping to meet the needs of individual readers.

Answers to questions in this issue were provided by Dr. Barry Jacobs, PsyD, Director of Behavioral Sciences for the Crozer-Keystone Family Practice Residency Program of Springfield, PA. Dr. Jacobs is a clinical psychologist who specializes in family caregiving issues.

If you have a question you would like us to answer, please send it to:

What Can I Do?
c/o TAKE CARE!
10400 Connecticut Ave., Suite 500
Kensington, MD 20895-3944

Q My husband suffered a stroke recently and his personality has changed dramatically. He has become verbally abusive and I'm afraid the verbal abuse might turn physical. I want to be there for him but I don't know how much more I can take. What can I do?

A What could be more demoralizing than to be castigated or even threatened by the loved one to whom you've devoted yourself? There may be specific means, though, of understanding and curbing his behavior and assuring your safety. Before giving up on caregiving, there are neurological and psychological interventions to consider.

Patients who suffer brain damage from a slowly progressing disease, such as Alzheimer's dementia, or a sudden event, such as a head trauma or stroke, often experience changes not only in overall personality but in specific cognitive functions, including emotional expressiveness, self-control, capacity for insight into their own deficits, and ability to empathize with others. For example, a rule of thumb with stroke victims is that those who've had damage to the left side and frontal regions of their brains are usually more depressive afterwards. Those with right-sided damage may be more emotionally inexpressive (what doctors call "flat") or prone to sudden shifts in emotions (called "lability"), including vicious tirades. While some of these symptoms may remit along with other stroke-induced deficits (e.g., difficulties with walking, talking, and swallowing) over six months or more, many patients will be left vastly different people than they were before medical cataclysm struck.

I would strongly recommend conferring about your husband's behavior with his neurologist, psychiatrist, or, best yet, neuropsychiatrist (a physician who specializes in the behavioral and mood changes due to neurological problems). He or she may prescribe for him a low dose of an atypical anti-psychotic medication, such as Risperdal, to better control his agitation and decrease his outbursts. Or the doctor may subscribe to the old adage that "anger is depression turned outwards" and give your husband an antidepressant to ease his frustrations and mitigate his attacks upon you. Such drug interventions are frequently successful in these kinds of cases.

Marital counseling may also be helpful, if conducted by a therapist conversant with relationship issues common among the neurologically impaired. Your husband may gain greater awareness of his frustrations and insight into the hurtful impact of his words and actions. You may glean particular strategies for setting limits with him. For instance, you may learn to avoid specific stressors (e.g., loud noises, crowds of people) that, reasonably or not, seem to stoke his ire. You may also learn to cue him when you note his frustrations rising so that he can begin to exert greater self-control over his impulses. Finally, you can be coached to firmly say to him that you won't tolerate verbal abuse and will leave the room or house if he persists.

Fortunately, verbal abuse is not necessarily a harbinger of physical abuse. However, if your husband should ever raise his hands to you, throw things at you or — heaven forbid — wield a weapon in your direction, then your first duty is to

protect yourself. Leave and get help. Call the police if need be. Caregivers are not whipping posts. You are not required to take punches while giving love.

Q I live with my 75-year-old mother who is controlling and threatens to report me for elder abuse. She uses her poor health as an excuse not to do things. I am single and I refuse to use my work time to meet her needs. No other family member wants to deal with her for fear that she will ruin their marriages. I had a relationship when she moved in and she insisted on giving me her two cents. I need my own life back and she needs some type of social worker. What can I do?

A If the best predictor of the future is the past, then our family relationships prior to a medical crisis will shape our family caregiving. Caregiver and care-recipient will fight the disease together when mutual positive regard has been long-standing. But when the relationship has been characterized by mutual ambivalence, caregiving will be fraught with misgivings and mistrust and family members will fight each other. Late-life caregiving can provide conditions for relatives to rework previously strained relationships. (I have witnessed adult children finally win the longed-for approval of ill parents who'd always begrudged them.) But such transformations are the exceptions, not the rule. When medical peril leads to increased dependence, bad relationships frequently get worse.

The tone of your question suggests that your relationship with your mother has been, at best, ambivalent. It probably has not helped matters recently that your mother seems to employ whatever control she can muster over you and your siblings in order to extract the care that she feels is owed her. She may

feel justified but you rightly feel trod upon. The guilt she incites in you will likely only hold you in thrall for so long. If you are like most family caregivers in such situations, then you will ultimately become fed up and quit.

Before that point, I'd suggest having a long, frank discussion with her. Begin by stating that you appreciate that she is your mother but also acknowledge that you haven't always seen eye to eye with one another. Tell her that you think this may be one of those times when you may not come to agreement about what is best. Then say that you want to help her during her old age but not at the expense of your own life. Ask her if she has any thoughts about how you can strike a balance between taking care of her and caring for yourself. If she reacts positively to this line of conversation, then you may have some basis for caregiving in a sustainable fashion. She may agree, for instance, to hiring help to provide some of the care she needs. If she reacts negatively, though, then you may have to advise her that you can no longer play the role with her that she wishes.

I'd also initiate discussions with your other family members. Point out that the decision they make about providing care to your mother has other ramifications — namely, their relationships with you. Pushing mother away will be tantamount to pushing you away. Coming forward to provide some help for her will amount to caring for you. Remind them that they don't have to subject themselves to mother's manipulations if they are clear in their own minds about what they are willing to offer and what liberties they are not willing to allow her to take.

These discussions are likely to be very tough. In a best-case outcome, mother will ease up on you and your relatives will step up to help. In the worst-case, mother will cry foul and your relatives will turn a deaf ear. Either way, you will have at least taken a strong stance on what you are and are not willing to do, and what considerations you expect from your loved ones. Stating this clearly and emphatically will be your first step toward getting your own life back. Moving out of mother's house may be the second. ■



Would You Like to Learn to Communicate More Effectively With Healthcare Professionals?

There are more than 435 people around the country who have been trained to give NFCA's Communicating Effectively workshop. To find out if one of them is planning a workshop in your area, go to NFCA's new Web site, www.thefamilycaregiver.org/education, and click on "Communicating Effectively."

Tax Tips

Continued from page 1

Nursing Home Care

Nursing home expenses, per se, are not deductible, but medical expenses incurred in a nursing home are. This includes the cost of meals and lodging while the patient is in the nursing home, so long as the main reason for being there is to get medical (not simply personal) care.

Nursing, Therapeutic, and/or Aide Service

Wages you pay for an attendant who provides nursing and/or personal care services are deductible as medical expenses. These services include such nursing activities as giving medication and changing dressings, and typical personal care services

such as bathing and grooming the patient.

If you provide room and board, these may also be deductible, but typical household services such as cooking and cleaning do not qualify as medical deductions.

“Typical household services such as cooking and cleaning do not qualify as medical deductions.”

For Whom Can You Claim Medical Deductions?

You can take medical expense deductions for yourself, your spouse, and your dependents.

A person generally qualifies as a depend-

ent for medical expense deductions if he or she meets all of the following criteria:

- Is related to you;
- Lived with you for the entire year as a member of your household;
- Was a U.S. citizen or resident, or a resident of Canada or Mexico, for at least part of the calendar year for which you are filing taxes; and

■ You provided over half of that person's total support for the calendar year. If you and someone else are providing more than half a dependent's support, but no one alone provides more than half, you can use what's called a “multiple support agreement” to claim the dependent, but only if one of the parties to the multiple support agreement can claim medical expenses for the dependent person. In the case

of divorced parents, however, the child is considered a dependent of both parents for the medical expense deduction.

Where to Get Help

Tax law is confusing at best. If you want some additional information, here are ways to get it:

The Internal Revenue Service offers a number of publications that can help you understand the deductions and tax credits to which you may be entitled. Some of the most helpful include:

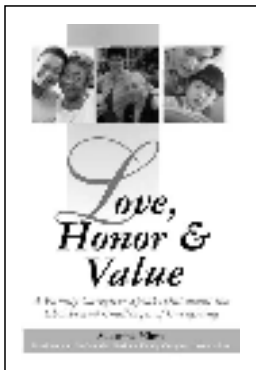
- Your Federal Income Tax (Publication 17)
- Medical and Dental Expenses (Publication 502)
- Credit for the Elderly or Disabled (Publication 554)
- Tax Rules for Children and Dependents (Publication 929)

To order these publications, call 800/TAX-FORM.

The IRS will also answer taxpayer questions if they are not too complicated or controversial. You must realize, however, that while the IRS will try to guide you in finding the answers you need, it does not offer tax advice. To find the Taxpayer Service Number for your area, check the local phone book under the IRS listings.

There is only one place to go for individual tax advice and that is to a tax professional. If you are confused about what deductions or credits may apply to you, or if you need help preparing your return, you may find it beneficial to consult someone who specializes in this area. There are a number of tax services available, and you can find their numbers in the phone book, but the best reference may well be word of mouth. Talk to people you know and respect and ask them for a referral. ■

Cecily Slater is a certified public accountant who has been providing tax and financial planning advice to individuals and businesses in the greater Washington, DC, area since 1979.



Love, Honor & Value: A Family Caregiver Speaks Out About the Choices and Challenges of Caregiving

By Suzanne Geffen Mintz
President and Co-founder
of NFCA

“I recently purchased *Love, Honor, & Value* to help me get perspective on my mom's issues. I read it in two days! What an amazing resource...provides the perfect mix of personal stories, national perspective and useful resources. ...It is so well written and engaging and helped me with many of the problems that I am trying to sort out.”

—Michelle Baker, Chevy Chase, MD

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Call 800/896-3650 or order online at www.thefamilycaregiver.org.

All proceeds due the author will be donated to NFCA.

Advice From Your CCAN Representatives

How many times have you wished you could talk with someone who has walked in your shoes? As a family caregiver, you often receive advice from well-meaning friends and loved ones. No one, however, can really understand the challenges you face as a family caregiver better than another family caregiver. With this in mind, *TAKE CARE!* went to our CCAN representatives, all current or former family caregivers, with a very important question:

What is the single most important piece of advice you would give to other family caregivers?

Here are their answers.

■ Search out and get to know other family caregivers. There you will find a home where you can listen, talk, laugh, cry, and find appreciation, support, knowledge, wisdom, courage, love, and hope for today and tomorrow. And don't forget to care for yourself.

— *Bonnie Danowski (AZ)*

■ Strive for balance. That means being involved and on top of things but not trying to do everything yourself. It also means leaving a little time (even an hour) for fun and relaxation so that you don't burn out.

— *Susan Bria (CT)*

■ Find the things — even the little things — that are bothering you that you can change and work on changing them ... one at a time. Reward yourself as you go! And always have a Plan B for yourself and the one in your care.

— *Connie Siskowski (FL)*

■ Accept help. When others ask, "What can I do?" tell them! Asking for help is not a sign of weakness. It is a necessity.

— *Stacey Bartz (IA)*

■ Anything brittle breaks when bent. Unless we want to crumble, we should stay flexible, get help when we need it, and do the best we can.

— *Eboni Green (NE)*

■ Inform yourself about your care recipient's condition. Information is empowerment. If you know what you're dealing with, you won't feel helpless and hopeless.

— *Lauren Agoratus (NJ)*

■ The three most important things:
1) Prioritize (You must decide what needs to come first, and some things may not get done.)

2) Energize (Make time to exercise, take vitamins, and eat well. Listen to music and read books that help you to enjoy your day.)

3) "Humor-ize" (Laugh with the person for whom you are caring.)

— *Bernadette Vinci (NY)*

■ The number one thing that a family caregiver needs to do is to build a team of people to help the family caregiver with the patient. The family caregiver's quality of life and survival will depend on this group.

— *Shirley Poll (NY)*

■ Learn as much as you can about your loved one's illness. Not only is every disease different, but how that disease or illness affects each person is different. You can take better care of someone if you understand their illness and how it affects them.

— *Paul Lindsley (TN)*

■ I think the advice is pretty basic and straightforward: The Serenity Prayer says a good deal to caregivers about the courage to change what we can and the wisdom to know the difference. Allowing yourself the peace to say "no" when appropriate and keeping your own needs in mind is not being selfish or self-centered. As caregivers, we must take care of ourselves, and accepting that we cannot change "all" is a major step for many. Allow yourself to learn from the person you are caring for; a good deal can be learned about living from someone with a chronic illness, and after they have passed the time will come when you will remember that person as someone who has lived, not someone who has died.

— *Robin Straight (WV)*

A state-by-state listing of CCAN representatives appears on page 16 of this issue.

Are you interested in becoming a CCAN representative for your area?

Please call Linda Jones at 248/358-1186 or email linda_jones100@hotmail.com.

Arizona

Ms. Bonnie Danowski
bjdanowski@cox.net
Ms. Lois von Halle
lvh314@aol.com

California

Dr. Nancy Miller
nmiller@ucla.edu
Ms. Maria Meyer
mmeyer@comfortofhome.com
Ms. Rose Muema
rose6n3muema@yahoo.com

Colorado

Ms. Evie Rosen
eviebudd@centurytel.net

Connecticut

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Ms. Robin Straight, SMSW, LCSW
robinssmsw.lcsw@mindspring.com

TAKE CARE

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