

TAKE CARE!™

Self-Care
for the Family
Caregiver

VOLUME 14, NUMBER 3 • FALL 2005



Financial Management: A Guide For Family Caregivers

Paula McCarron

Have you ever calculated the cost of caring? Certainly as a family caregiver, your service to your loved one is beyond measure in terms of the love, depth of care, and concern you offer. If you were to take a look at some of the “real” dollar costs of caring, however, here’s what you would learn:

- In 2000, the typical working family caregiver lost approximately \$109 per day in wages and health benefits due to the need to provide full-time care at home.¹
- The value of “free care” provided by family caregivers is estimated to be \$257 billion a year. That is twice the amount actually spent on home care and nursing home services by the government or private insurance combined.²

■ Insurance experts estimate that about one-third of all long-term care services are paid for by individuals out of their own savings or investments.³

■ The national average wage for a health aide is \$18 an hour⁴ and the average cost of a one-month stay in an assisted living home is \$2,524.⁵

Confronted with facts like these, it’s clear that being a family caregiver without a financial plan is risky business — for both you and your loved one.

Whether you are providing care for a child, spouse or parent, you are your care recipient’s most important asset. That’s why it’s necessary that a financial plan be put in place in case you can no longer continue providing care, either temporarily or permanently.

With that in mind, every family caregiver should consider two crucial questions:

1. How can you ensure that your loved one’s needs are met if you become disabled or ill, or you die?
2. What kinds of financial protections and insurance can you put into place now to protect yourself and your loved one down the road?

Know Your Options

“It’s important to know your options, whether or not you choose to use them,” says Jay Bell, vice president of education with the National Endowment for Financial Education. To know your options, you first need to know your assets. Assets typically include: earnings, pension funds, Social Security benefits, property such as homes or land, insurance, retirement funds, etc.

Mark Darrell, C.F.P., of Darrell Financial, a financial planning firm

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Patient Safety Act is Signed

NFCA President Suzanne Mintz represented the patient/family community at the signing of the Patient Safety and Quality Improvement Act of 2005 in Washington, DC, on July 29th. This legislation makes it easier for members of the medical community to prevent medical mistakes from happening by allowing them to share information more easily. It will also raise the bar on expectations for ongoing patient safety efforts. Other attendees at the signing included Secretary of the Department of Health and Human Services Mike Leavitt, Sen. Michael Enzi (R-WY), Sen. Ted Kennedy (D-MA), Sen. James Jeffords (I-VT) and Rep. Michael Bilirakis (R-FL).



Remember NFCA in Your Year-End Giving

As you consider your year-end giving, please remember NFCA with a generous donation. Help us help you. If you work for the federal government, you can donate to NFCA through the CFC. Our number is 2575. You can also donate online at www.thefamilycaregiver.org. All donations are tax deductible.

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everyone know,
helped everyone
care. It was a
Godsend.
— Sheila H.*

*CarePages has
provided me with
a support system
and an afford-
able way to
communicate
with those who
are far from me.
— Angela F.*

TAKE CARE!

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Making a Difference: One Family Caregiver at a Time

One of the goals of the National Family Caregivers Association is to empower our members to take action to better their own lives and the lives of other caregiving families. This goal is one of four areas of focus established by NFCA as part of its 10-year plan, the others being education, support, and advocacy.

How can an individual family caregiver make a difference? This may be a question that many family caregivers ask themselves, especially if they are feeling overwhelmed by the daily demands of caregiving. One NFCA member may have an answer, as relayed in a recent letter sent to NFCA:

"I am a member of NFCA and receive your newsletter. Your organization has inspired me to speak out about being a caregiver. I want to thank you again for being there, and for empowering me. Not too long ago, I read a restaurant review. It sounded like a place that my husband and I would like to visit. My husband has multiple sclerosis and uses a walker full-time. I wrote the reviewer asking if it would be easy for my husband to get around the restaurant, as we were interested in going there. I also suggested that she include this type of information in future restaurant reviews to benefit people in the same situation. Not only did she write back informing us that we would be able to navigate this particular restaurant, she said she thought it was a great idea to start including in her reviews if the restaurants were easily accessible for folks who may be using a walker, wheelchair, etc. (Not just the bathrooms but the whole layout.) I have to believe I would not have taken the time to write the initial e-mail if I had not become involved with your organization. I wanted to share this with



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One of NFCA's goals is to
.....
empower our members to take
.....
action to better their own lives.
.....

you to let you know that you do make a difference in countless ways, big and small." — Robin Francis

With the hope that Robin's experience might be helpful to other family caregivers, we decided to ask her what inspired her to speak out and to make a difference.

How did your involvement with NFCA empower you to speak out?

I finally realized that I am not alone. Before I became aware of NFCA, I rarely spoke of my needs to strangers, or even to my friends and family. I didn't want them to see me as a complainer. I was afraid of alienating myself. After reading your newsletters, I realized I was not complaining or being selfish; I was speaking out, not only for myself, but for many, many other people in the same situation.

What made you decide to take the particular action you did? How do you feel about the results?

I felt it was important to start looking for ways to make life easier for my husband. I realized that we always

visited the same restaurants because we knew my husband could get around them easily. I felt that in some way, this habit was isolating us — and our lives were already a bit isolated as it was. Why continue to limit ourselves? I also felt that by reaching out to someone who had a lot more power — appearing in a major newspaper — I would be able to effect a bigger change. As it turned out, the reviewer was awakened to a new perspective, and also agreed to start sharing this information with her readers each week. I felt very good about the results.

In what other ways have you advocated on behalf of yourself and other family caregivers?

When I speak with friends and family who are in a similar situation — usually dealing with aging parents — I encourage them to join NFCA. I explain that the Web site and newsletter are educational, informative, and comforting. I also write letters thanking various organizations that have helped my husband and me in some way or another. My goal is to let those who have helped us know that they have made a difference in our lives. I believe this will inspire others to take a greater interest in helping the next caregiver or disabled individual, especially when they are called upon to do so.

What can other family caregivers learn from your experience?

It's important for all family caregivers to think about their needs. Don't feel guilty about acknowledging that you have them. Be willing to ask for help and resist the thought that you are asking for some special privilege. ■

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.

Would you like to find out how your hospital rates? The Department of Health and Human Services has launched a new Web site designed to provide consumers with information on how well hospitals care for adult patients. Hospital Compare was created through the efforts of the Centers for Medicare and Medicaid Services (CMS) and organizations that represent hospitals, doctors, employers, accrediting organizations, other federal agencies, and the public. The Web site uses voluntary, self-reported information from hospitals on three major causes of morbidity and mortality — heart attack, heart failure, and pneumonia — to show how often participating hospitals provide the recommended care for adults with one of those three conditions.

The Web site contains hospital information, quality measures, and patient tools. Consumers can search for hospitals by state, county, city, zip code, or by name. Information is provided for both acute-care hospitals (general hospitals) and critical access hospitals (small, remote hospitals). To learn more, visit Hospital Compare at www.hospitalcompare.hhs.gov.

Are you interested in finding ways to assist a loved one with his/her dental care? The U.S. Department of Health and Human Services, the National Institutes of Health (NIH), and the National Institute of Dental and Craniofacial Research have collaborated to produce a booklet that you may find helpful. *Dental Care Every Day: A Caregiver's Guide* (OP-82) offers practical solutions to assist a loved one with dental care. The booklet explores assistive devices, offers suggestions on how to help your loved one floss, and outlines proper positions for you and your loved one when performing dental care. You can obtain a free copy of this booklet by contacting the National Oral Health

Information Clearinghouse at (301) 402-7364, or visiting <https://ice.iqolutions.com/nohic/pubsorder> on the Web.

Are you looking for housing for your elderly loved one? A Place for Mom is the nation's largest eldercare referral service, serving families who are searching for care and housing options for elderly loved ones. Founded in 2000, the organization's mission is to provide families with information and referrals to care communities that meet their needs. Experienced family advisors help clients sort through the many care options available today, including assisted living facilities, nursing homes, retirement communities, home care, and hospice. A Place for Mom currently has over 10,000 long-term care communities participating in its referral network. The service, which is provided at no charge to consumers, has helped nearly 50,000 families find appropriate eldercare. Go to www.aplaceformom.com or call 877/MOM-DAD9 (877/666-3239).

BOOK REVIEW



Getting to Know Ruben Plotnick

by Roz Rosenbluth (Flashlight Press, 2005, \$15.95). Many parents worry about the effect a live-in elderly

grandparent or other relative will have upon family life. *Getting to Know Ruben Plotnick* addresses some of these issues in a delightful and entertaining manner. The book successfully presents behavior children may observe in older relatives in a non-threatening and respectful way, while addressing the child's feelings with sensitivity.

Young David lives with his parents, sister, and grandmother Rosie. He and his family are used to Grandma

Rosie's strange habits: calling him "little boy" instead of David; arguing with Grandpa Nate when she plays checkers, although he died five years ago; suddenly calling out, "Nate, let's waltz." But when Ruben Plotnick, the coolest kid in class, invites himself to David's house, David is worried. How will Ruben react to Grandma Rosie's unpredictable behavior? Will the popular but zany Ruben imitate her in class the next day? Will he laugh out loud if she demands a dance?

David tries to keep Grandma and Ruben separated. But when the inevitable happens and Grandma calls out, "Nate, let's waltz," David is relieved as he watches Ruben rise to the occasion and dance around the kitchen with Grandma. David learns that besides being the coolest kid in class, Ruben is a compassionate kid with a truly warm heart.

By the title that she chooses, Roz Rosenbluth shines a spotlight on the theme that we can really only get to know people when we see them in different situations. But there is another, equally important theme: family life need not be disrupted by including someone a little unusual. Although the cover states that the book is for ages 5 to 9, older children and adults will relate to the message of love and acceptance as well.

Getting to Know Ruben Plotnick is available at major booksellers and through Independent Publishing Group, www.ipgbook.com or 800/888-4741.

NFCA wishes to thank Eboni Green (Resources) and Susan Bria (Book Review) for their contributions to the summer 2005 issue of TAKE CARE! Eboni Green also contributed to the Resources for this issue and the Book Review was provided by Susan Bria.



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Financial Management

Continued from page 1

based in Baltimore, Maryland, agrees. The process of financial planning, Darrell explains, involves a review of one's assets, discussion of options, creation of a plan for the future, and education on the kinds and amounts of insurance that may be needed to ensure that future. "Eighty percent of families are living paycheck to paycheck," says Darrell. "They tell me they can't afford to go on vacation much less spend money on insurance. But even if they can't do everything, they can often do something. And it's better to have something in the event you need it than to end up with nothing."

When it comes to replacing the long-term care services you provide your loved one (or planning on how to cover your own needs in the future), Darrell notes there are four basic avenues to pursue:

1. Use your savings.
2. Convert an asset into cash.

Choosing a Financial Planner

Most certified financial planners offer a free initial consultation. "That way the planner can learn a bit more about your situation and you can determine if you feel comfortable with the planner," says Mark Darrell. Use that time to ask about fees, types of services provided, and what kinds of reports you will receive. Know if you are paying for services based on hourly rates or if there are any additional costs or fees. No matter what kind of financial planner you choose to hire, it's critical to check on his or her background. Asking friends or attorneys for referrals can be one way to find a good financial planner. Ask about credentials, education and experience to be sure you are hiring a planner who understands your particular needs.

3. Obtain assistance from family.
4. Make use of insurance.

Start Saving Today

Family caregivers assume that nothing is going to happen to them; unfortunately, that isn't always true. If something does happen, you need to be prepared. Funding a replacement for YOU could be an expensive proposition. The most important step you can take now is to create a savings plan that you can draw from quickly in the event of an emergency. But don't stop there. Start saving today to ensure that you have adequate income for your retirement. To build retirement savings, you might consider setting up an IRA or contributing to a 401(k) plan through your employer. Many employers will match employee contributions to a 401(k) plan, either dollar-for-dollar or with some percentage of each dollar saved. Both IRAs and 401(k) plans allow you to build for the future while enjoying some tax savings now. No matter how much or how little you have to contribute, the key is to begin to save something today. IRAs and 401(k) plans can be tapped in an emergency, although this may not be the best option because of possible tax consequences. As noted above, it is better to have more liquid savings available.

Converting Assets Into Cash

The quickest way to convert assets into cash is to sell something that is relatively liquid: stock or mutual funds, for example. Less liquid financial assets include CDs, IRAs, 401(k) plans, or other retirement accounts. Before you sell any financial asset, it's important to look at the big picture. There may be penalties for early withdrawals, or taxes to pay, all of which means you could actually lose money. So look before you leap and understand all of the ramifications of your decision.

The biggest asset most of us have is our home; there are a number of

ways to convert some of its value into cash. Home equity loans let you write checks whenever you want based on a pre-approved line of credit that is tied to the amount of equity you have accrued in your home. Once established, a home equity loan makes the money readily available. This is a loan, however, and the money must be repaid, with interest.

A relatively new way to convert your home's equity into cash is the reverse mortgage. It provides tax-free income to eligible individuals 62 years of age or older and allows homeowners to stay in their homes as long as they like, without adding new mortgage payments.

"The reverse mortgage is aptly named because the payment stream is 'reversed.' Instead of making monthly payments to a lender, as with a regular mortgage, a lender makes payments to you," says Peter Bell, executive director of the National Reverse Mortgage Lenders Association. Reverse mortgages are complicated; anyone who is considering one must first meet with an approved counselor to ensure they understand all of the ramifications of this type of mortgage. The counselor's job is to educate you about reverse mortgages, to inform you of other options available, and to assist you in determining which particular reverse mortgage product best fits your needs.

Protect Your Income in the Event of Disability

If you are in the workforce, disability insurance is one level of protection that can keep income flowing if you are unable to work due to illness, injury or disability. While there is no disability insurance that will cover 100 percent of your income, you may be able to secure enough coverage to replace 60 percent to 80 percent of your income.

Disability insurance is often offered by employers at very minimal

(Continued on page 10)

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National Family Caregivers Month
November 2005

Caring Every Day

Believe. Protect. Reach Out.

The Caring Every Day Campaign encourages family caregivers to Believe in themselves. Protect their health. Reach out for help. We are extremely grateful to the companies, foundations, and organizations that are supporting this initiative and encourage you to learn more about them at our Web site www.thefamilycaregiver.org.

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NFC MONTH 2005 ORGANIZATIONS

ALLIED ORGANIZATIONS:

American Stroke Association

ENDORING ORGANIZATIONS

ALS Association

Alzheimer's Foundation of America

American Association for Geriatric
Psychiatry

American Association for Homecare

American Association on Mental
Retardation

American Board for Certification in
Orthotics & Prosthetics

American Cancer Society

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Association of Community Health Centers

Catholic Charities USA

Catholic Health Association

Children of Aging Parents

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Resource Center

Easter Seals

Family Caregiver Alliance/ National Center
on Caregiving

Family Voices

Generations United

Hospice Foundation of America

Huntington's Disease Society of America

Lupus Foundation of America, Inc.

Mather Lifeways Institute on Aging

Myositis Association

National Academy of Elder Law Attorneys

National Alliance for Caregiving

National Association for Home Care &

Hospice

National Association of Area Agencies on
Aging

National Association of Councils on
Developmental Disabilities

National Association For Continence

National Citizens' Coalition for Nursing
Home Reform

National Coalition for Assistive and Rehab
Technology

National Council on the Aging

National Health Council

National Hospice and Palliative Care
Organization

National Mental Health Association

National Multiple Sclerosis Society

National Organization for Empowering
Caregivers

National Organization for Rare Disorders

National Parkinson Foundation

National Partnership for Women & Families

National Private Duty Association

National Respite Coalition

National Stroke Association

Paralyzed Veterans of America

Transverse Myelitis Association

Tuberous Sclerosis Alliance

United Cerebral Palsy

United Ostomy Association, Inc.

U.S. Administration on Aging

Well Spouse Association

Wellness Community

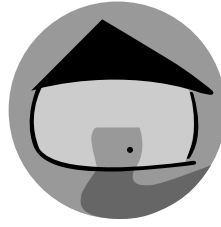
Women's Heart Foundation

LAUNCH EVENT

The Caring Every Day Campaign will be officially launched

November 3 at the start of the National Caregivers Conference at the Trump Taj Mahal Resort in Atlantic City, NJ.

This two-day educational event for professional and family caregivers is sponsored by the Family Support Center of NJ. For more information or to register go to: www.nationalcaregiversconference.org or call 732/528-8080.



Take Comfort in Knowledge

November 3-4, 2005
Trump Taj Mahal Resort
Atlantic City, NJ

Family Caregivers, NFC Month and The New Medicare Rx Benefit

It may be coincidence or it may be fate, but NFC Month 2005 also marks the start of the initial enrollment period for Medicare's new drug coverage. Beginning November 15, people with Medicare can sign up for one of the new prescription drug plans that are available in their area, and by all accounts family caregivers will play a big role in this process.

If you are one of the five million family caregivers who are eligible for Medicare, or you are caring for someone who is, it is important that you learn as much as you can about the new program, even if you or your loved one don't use many prescription medications now. Significant savings are to be had both now and in the future, because early enrollees will pay a lower monthly premium than those who sign up after the initial open enrollment period.

Because each person's situation is unique, it will require some effort to get the facts straight about the program; but help is available.

The Centers for Medicare and Medicaid Services (CMS), the agency that is responsible for the program, has a toll-free number and a Web site, 800/MEDICARE and www.medicare.gov. There are also a number of new Web sites that are very consumer-friendly. They are all interactive and designed with the

low-tech user in mind. Information is presented in a way that makes the details of the new Rx coverage easy to understand, and they all will be updated as new information becomes available.

NFCA is pleased to be able to offer its members direct access to these very helpful Web sites. Just go to www.thefamilycaregiver.org to get started. Each site has a slightly different approach, but all are very helpful and we recommend them highly.

www.MedicareRxMatters.org

Designed to help users make decisions about the new Medicare prescription drug plan, this site has three specific portals: one for family caregivers, one for people with Medicare, and one for professionals. The Web site provides an overview, easy-to-understand steps, and information to assist users in making personal decisions about Medicare prescription drug coverage. The site will also include information on formularies, prescription drug prices, calendars of events and deadlines, and examples of how the new prescription drug coverage program will impact people's drug costs.

www.medicareinteractive.org

Medicare Interactive (MI) is a user-friendly resource from the Medicare Rights Center—an independent nonprofit that has over 15 years of experience counseling and educating

people with Medicare—that provides easy-to-understand information about Medicare. MI outlines the new Medicare drug benefit and posts regular updates on how the new benefit will affect or work with existing state and private drug coverage. MI also explains how to access other Medicare benefits like home care, nursing home and therapy services. It is designed for people with all levels of Medicare knowledge.

www.maprx.info

This site, created by a coalition of patient advocacy, family caregiver, and health professional organizations (Medicare Access for Patients Rx — MAPRx), provides answers to questions frequently asked by beneficiaries and caregivers about the new prescription drug coverage. The Web site tool, MedicareRxConnect, is designed specifically for family caregivers and others who will help those with Medicare make decisions, and includes special information links for people with chronic diseases or disability. The site allows users to get quick information needed to compare Medicare prescription coverage with other drug coverage, to determine factors to consider when selecting a plan, and to connect with insurance counselors and other state/local resources. ■

Medicare Rx Dates to Remember

October 2005 The "Medicare & You 2006" handbook is mailed to people with Medicare. It will provide detailed information about the prescription drug plans that will be available. Plans begin marketing October 1.

November 15, 2005 Initial Enrollment Period for Medicare Drug Coverage begins.

January 1, 2006 Medicare Prescription Drug Coverage begins.

May 15, 2006 Initial Enrollment Period ends.

RESOURCES

Publications:

- **The Complete Eldercare Planner** by Joy Loverde (Three Rivers Press; 2nd edition, 2000).
- **Personal Finance for Dummies, 4th Edition** by Eric Tyson, M.B.A. (Wiley Publishing, Inc., 2003).
- **With Open Arms: Embracing a Bright Financial Future for You and Your Child**

A 72-page financial guide for adults caring for children with disabilities or other special needs. The booklet is available as a free download from www.easterseals.com or for purchase (\$5) by phoning 800/221-6827.

National Association of Insurance Commissioners (NAIC)

Phone: 816/783-8300

Web site: www.naic.org

NAIC will help you locate your state's insurance commissioner's office. NAIC also offers consumer guides on the purchase of life insurance, long-term care insurance, and other types of insurance. Check out the NAIC publication "A Shopper's Guide to Long-Term Care Insurance."

National Endowment for Financial Education

Web site: www.nefe.org

Many informative and "reader-friendly" articles are available on this Web site.

Check out the "financial health" of the insurance company you choose:

- A.M. Best Company
Web site: www.ambest.com
- Weiss Ratings
Web site:
www.weissratings.com

Financial Management

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cost, and can also be purchased privately. It may be available as a rider on an existing life insurance plan or through a group or professional association. You can also purchase an individual plan from an insurance broker or get competitive quotes by shopping for rates online. No matter what you choose to do, be sure to check with your state's insurance commissioner's office to find out if the agent and company are licensed to operate in your state.

Some people may think they will qualify for disability benefits under Social Security; however, Social Security disability is very limited, as it does not allow for "partial" or "temporary" disability. In addition to restrictive eligibility criteria, it can take up to five months to qualify for benefits and up to two years to process claims.

When purchasing disability insurance, be sure to ask these questions:

- What is the company's definition of disability?
- Who makes the determination of disability?
- When do benefits begin?
- What percentage of income would be replaced and for how long?
- Does the plan factor for inflation?
- Does the plan cover only illness or accident, or both?
- Can the policy be renewed? Is there a clause addressing non-cancellation?

Disability insurance premiums vary greatly depending on your occupation, age, income, elimination periods, etc. As with any insurance product, it is best to shop around.

Don't Overlook the Importance of Life Insurance

If you don't already have a life insurance policy in place, consider the following questions:

- If you die, who is going to fill your shoes as a family caregiver so that

your loved one continues to receive the care that he or she needs?

- Where will the money come from to provide the services that you have been providing for "free"?

For many family caregivers, a life insurance policy can offer peace of mind that their loved ones' needs, as well as their own future care needs, will be met.

"There's no rule of thumb about what kind of policy to buy or in what amounts," says Darrell. "You've got to consider every situation independently on its own terms. That's why I suggest that people seek the help of a broker who can represent many companies and many plans instead of an agent who works only for one company."

Just like agents who represent only one company, brokers are paid through a built-in fee whenever an insurance plan is sold. Unlike agents, brokers do not represent any one company and, therefore, can show you a variety of plans from several companies. To find a broker, contact your state's insurance commissioner's office or get referrals from trusted family members or friends.

How can life insurance help you meet your long-term care needs? First, family caregivers can purchase life insurance to ensure an adequate income for their care recipients or to help cover the costs of obtaining long-term care services if the family caregiver should die. Second, there are ways for care recipients to make use of their own life insurance policies to fund their long-term care costs. A care recipient may be eligible to make a tax-free cash withdrawal to fund long-term care expenses under some policies. Any remaining funds are paid to heirs when the policyholder dies.

Another option is to obtain a viatical settlement. This is more commonly used for an individual who has a limited life expectancy. Here's how it works: Mary names the viatical company as the sole beneficiary

of her life insurance policy and, in return, she receives an immediate cash payout of up to 85 percent of the policy's face value. When Mary dies, the viatical company will receive the policy's death benefit.

"Before anyone opts for any of these kinds of settlements, it's important to know the possible penalties involved and the tax consequences," says Darrell. "That's why every decision must be made with the view of the whole financial picture." In fact, according to Darrell, any time you move money around or cash out an investment, it's important to look at the whole picture. "Otherwise," he says, "you might actually end up losing money."

Consider Buying Long-Term Care Insurance

Whereas disability insurance can replace some of your income if you are laid up for a time, long-term care insurance can cover the costs of your own care needs. Long-term care insurance is not for everyone, though. "It's really designed for people who have the desire and need to protect assets," says Keith Eig, of Greenberg, Wexler and Eig, an insurance consulting business in Maryland. Family caregivers may want to consider this type of insurance as a way to maintain control over how and where care is received in the future. Because of the variations in benefits and types of coverage, however, long-term care insurance is both complicated and expensive, notes Eig. "You want to be sure to choose a company that is making you a promise it can live up to," says Eig. "That means you need to shop carefully."

Some long-term care policies will provide a set level of reimbursement for each day, whether or not you actually spend the money on needed services; other plans will provide reimbursement for actual dollars spent. Some plans offer fixed periods of benefit duration while others offer lifetime coverage.

Long-term care insurance typically covers services such as home health aides, adult day services, assisted living homes, and nursing home care. However, some policies may cover only services provided by a registered nurse or a certified home health aide while others may allow for the hire of a family member or friend. In some situations, the insurance company will arrange for a care manager who will pre-approve all services. Under other policies, an individual may receive a fixed "payout" — for example, \$200 a day — that may be used in any way that the individual chooses. It's important to know the maximum benefit limit of the policy as well as the duration of the coverage period.


The Bottom Line

Ensuring a financially healthy future for you and your loved one will take research, analysis, and the willingness to make some difficult decisions. It's not necessary to do everything today; but it is necessary to begin to take the steps that will help you and your loved one be better prepared for whatever the future holds. As a family caregiver, you know better than anyone that the next health crisis is not a matter of "if," but "when." Laying the groundwork today will help you ensure that your financial needs — and those of your loved one — are met tomorrow. ■

Paula McCarron is a freelance health writer living in Massachusetts. She has been involved in nursing home, hospice, and home-based care for more than 20 years.

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Constraint-Induced Therapies

<h3 style="text-align: center;">Constraint-Induced Movement Therapy (CIMT) and the SaeboFlex orthosis</h3> <ul style="list-style-type: none"> ● Stroke and brain injury survivors can now receive the therapy proven to significantly improve the use of their impaired hands and arms. CIMT is intensive: 6 hours a day, 5 days a week, for 2-3 weeks. For participants with significant movement, their hands and arms become more functional. ● For patients who lack the required movement for CIMT, we offer the FTM/SaeboFlex orthosis in combination with CIMT. Most patients obtain gross grasping and releasing while wearing the SaeboFlex during the 2-3 weeks. ● While the costs of these therapies are not usually covered by insurance, payment options are available. <p style="font-size: small; text-align: center;">Intensive results may vary. Individualized evaluation required for all therapies.</p>	<h3 style="text-align: center;">Constraint-Induced Aphasia TherapySM (CIAT)</h3> <ul style="list-style-type: none"> ● Based on the principles of CIMT, patients with aphasia or speech disorders can now push their recovery forward with this intensive treatment. ● CIAT therapists work with groups of 2-3 patients per session, for 3½ hours per day, 5 days a week, with a 2-week minimum. Some participants begin to communicate better in only 2-4 weeks, even years post-stroke.
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CCAN Representative Lauren Agoratus: Family Caregiver, Volunteer, Advocate

Laura Agoratus began serving as a Caregiver Community Action Network (CCAN) volunteer long before there even was a CCAN. For years, Lauren has been working behind the scenes locally and nationally in an effort to better the lives of other family caregivers. In recognition of her dedication to NFCA's cause, her enthusiasm, and her tenacity, TAKE CARE! is pleased to profile this remarkable volunteer.



Lauren Agoratus with daughter Stephanie and husband Steven.

You became an "unofficial" NFCA representative for your state even before there was a CCAN. What part of the NFCA message did you identify with and what inspired you to become so involved in spreading that message?

My daughter was born with a rare form of kidney disease and we were, literally, in survival mode the first three years of her life. One of the very first conferences I was able to attend was hosted by the National Organization for Rare Disorders and Suzanne Mintz was speaking. I listened to Suzanne's message about how to care for yourself while caring for another. She spoke about taking care of oneself first and gave the example of being on an airplane and giving yourself the oxygen first in an emergency, because in most cases you can help your care recipient but he/she can't help you. I thought back to when I had almost been hospitalized due to physical exhaustion and realized I wouldn't do anybody any good running on empty; I had to take care of myself so that I could care for my daughter.

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.

That was the message I started spreading to others as a volunteer, because although there was information for caregivers, this was the first time I heard about resources for the caregivers themselves.

Why is it so important for family caregivers to self-identify?

Too many times, caregivers (especially women) think that they're just being a good wife, mother, or daughter. They have to realize they have an extra role. Not everyone routinely visits hospitals, provides personal care, or assists with physical therapy exercises in their daily life. There needs to be recognition of and support for this additional role.

How have you been helped by acknowledging your role as a family caregiver?

Acknowledging that you are a family caregiver also means knowing when to ask for help. My husband

had been working overtime to keep us afloat financially, but I did finally ask for his help when I was almost hospitalized myself. I realized I was in trouble when I thought being hospitalized might be a nice break, like a vacation. We both worked, even though it was I who ended up home on leave most of the time. My daughter was homebound until around age 6. At one point, I was actually working two jobs (when she was eventually allowed to attend school and

evenings/weekends when my husband could watch her) to pay for her medical bills. I'm now doing what I love. I am employed full-time at the Statewide Parent Advocacy Network, New Jersey's Parent Training and Information Center thanks to a grant.

With everything that is on your plate, how do you find the time and energy to be involved in so many organizations and activities?

My daughter is my inspiration. People have said that she's lucky to have me, but I feel lucky to have her. I am involved in healthcare advocacy as well as special education advocacy. I became an advocate because I found myself struggling first with the medical and then the educational systems that were supposed to be helping our family. I decided to help others in the same situation.

What are some of the accomplishments of which you are most proud?

I am on the editorial advisory board of Exceptional Parent magazine. I recently finished my term on our State Interagency Coordinating Council for early intervention, and I

am privileged to be the designee for Sen. Diane Allen on the Map to Inclusive Childcare project.

I'm honored to be a guest member on the American Academy of Pediatrics (AAP) Committee for Children with Disabilities here in New Jersey. I am also helping other families of children with challenging behaviors by teaching a class for the New Jersey chapter of the National Alliance for the Mentally Ill (NAMI) and recently received a volunteer award from that organization.

Do you find time for yourself?

I'm honestly still working on that one. But I find that NFCA helps as the "flip side of the coin." I advocate for special children but there needs to be advocacy for all caregivers. For the first five years after my daughter was born, I put off things like physicals, dental exams, and eye exams. When we finally got respite,

I got my hair cut for the first time in eight years! I know that sounds silly, but we don't do things other folks consider typical — going to the movies or even renting a video, eating out, etc.

How can other family caregivers learn to empower themselves the way you have?

Information is empowerment. During the first 10 months of my daughter's life, the main thing I did was make \$700 worth of phone calls to find out everything I could about her condition. Caregivers won't feel so hopeless or helpless if they know what they're dealing with.

How have you been helped by reaching out to others for support?

When my daughter received a secondary diagnosis of autism at age 7, I knew exactly what to do. I went back to the Exceptional Parent

resource guide and called all the national organizations that dealt with autism, just like I had years ago with kidney disease. I also joined a support group, because I felt like I was "back at square one," almost like I had a new child. That's what all caregivers need: information and support. ■

NFCA's Caregiver Community Action Network (CCAN) is our state-based network of volunteers dedicated to helping family caregivers in their community and state. There are now CCAN representatives or mentors in 24 states. A few states have multiple representatives. If you would like to contact the CCAN representative in your area, call NFCA at 800/896-3650 or visit our Web site at www.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 sister has been serving as my mother's part-time caregiver, as my mother still lives alone. I live 3,000 miles from them, but have been acting as an emotional support for my sister and trying to provide practical advice as well. We have different ways of coping with my mother's dementia, but we have managed to work together on all decisions regarding her care. I have been feeling the guilt of the long-distance caregiver while simultaneously being emotionally drained from supporting my sister, who is the on-site caregiver. My mother is in need of more and more care seemingly by the day. My sister seems overwhelmed, and I am frustrated that more is not being done. Short of making repeated trips cross country, what can I do to ensure my mom is truly getting the care she needs?

A The long-distance caregiver is frequently a controversial figure in family circles. While she invariably means well, she's often maligned by the on-site caregivers for several reasons: She's told she has no business trying to throw her weight around from afar because she's not close enough to the situation to really understand it. When she says in her own defense she has a job and/or family that keeps her at a distance, she's told she should never have moved away. If she becomes so frustrated by these criticisms that she decides to turn her back on caregiving by not coming home or calling regularly, she's then lambasted for abandoning her parent(s) and siblings.

As unfair as this all seems, there are probably some germs of truth to these criticisms. Long-distance caregivers are sometimes the offspring who, years before, moved far away to

escape their families of origin. When aging parents become seriously ill, they do have a tendency to charge on to the scene out of nowhere like self-styled Marines hitting the beach. If they decline providing care with the rationales they're too far and too busy, siblings rightfully feel abandoned and angry. Yet long-distance caregivers have an important role to play in a family's overall caregiving plan because of a distinct advantage: Their distance allows them to see the forest for the trees when those closer to the scene are too focused on the wood-grained detail of every caregiving task to perceive how the family as a whole is managing.

It is on the basis of your more distant perspective that I'd reach out to your sister. I'd call her, or, better yet, fly home specifically to meet with her in order to relate what you're seeing from your 3,000-mile vantage point. After telling her how dedicated and loving a caregiving job she's doing, broach your concerns about how mother's decline is affecting your sister's well-being. If she responds by saying you aren't there every day and therefore don't understand, tell her that not being there every day may actually help you more readily see the incremental changes that are slowly occurring. If she argues that your mother isn't as bad as you contend, cite instances of how Mom has changed from one of your visits to the next — even if your sibling has been unaware of these changes. If your sister counters that she herself isn't struggling nearly as much as you imply, offer observations of how burnt out she sounds on the phone and appears during your infrequent visits. Above all else, tell her you love her and your mother and want to do your ut-

most to help them, including getting your mom more help in her home or considering other living arrangements.

Keep in mind that this discussion will likely need to be repeated in subsequent conversations before your sister will trust what you're saying and embrace getting more help. Your credibility as a concerned, far-sighted, long-distance caregiver will depend upon how well you convey that they're always close in your thoughts. Call and visit as often as feasible.

Q I'm a 60-year-old mother caring for my 30-year-old daughter who became chronically ill after college graduation. She has dysautonomia, an illness that makes it difficult to remain upright without fainting symptoms. She is homebound and since a recent surgery, has needed help with many activities of daily living. I am finding it very hard to find and keep supportive friends, as many people don't understand the nature of her illness. The friends I had before my daughter got sick have all disappeared. Our local congregation has not been supportive. I've looked at community support groups, but they don't seem to fit my situation. Between my full-time work, caregiving, and maintaining a household, I have been unable to keep up with the few activities I have tried. I feel stuck and am unable to think outside the box to figure out how I can reduce my isolation and find support. What can I do?

A There are many distressing and frustrating aspects of your caregiving situation: contending with a rare and little-understood disabling illness; missing others' concerted caring and support; suffering exhaustion of your store of ideas. What comes across in your question, though, is the steadfastness of your commitment to caring for your daughter and your continued hopes

for better; otherwise you'd be shutting down in resignation rather than reaching out for new possibilities. Without knowing more about what you've already tried, it's difficult to give you advice that's germane. But I suggest you reflect on three areas of consideration.

The first involves the resources you're trying to tap. Most of us initially turn to family and local supports. If you've diligently contacted all available relatives, neighbors, church groups, and other local organizations and received insufficient responses, then, in the age of the Internet, you should try national or even international supports next. Are there Web sites devoted to dysautonomia or related diseases that could offer you and your daughter medical information, chat rooms, and geographically organized contact lists? While these resources likely won't provide you with hands-on help, they can supply practical advice to replenish your store of ideas. More importantly, they can offer empathy from people who can understand your predicament more surely than anyone else. I've met many caregivers who've developed deep friendships with fellow caregivers in this manner, with whom they correspond on a daily basis.

The second consideration is how you've attempted to tap existing resources. While it's true that you can't squeeze blood from a stone, most of us are not surrounded by stones. We generally can derive some sustenance from the people in our lives if they're approached with the right combination of cajoling, diplomacy, and acceptance of who they are and whatever they have to offer. I'd ask yourself a series of tough questions: Am I making it as easy as I can for others to help me and my daughter in the limited ways in which they're capable? Am I withdrawing my requests for help because I feel judged or pitied by them? Am I feeling rejected by them because they lack the experience to

understand my situation and, therefore, are slow to respond? By seriously pondering the answers to these questions, you may conclude that your reactions to others' responses may have prevented you from getting any help from them at all. If this turns out to be the case, please consider trying to reach out to them again with lower expectations of their potential contributions and greater forbearance of their inadequacies.

The third consideration has to do with your daughter's life. Reading your brief description of her reminded me of Laura Hillenbrand, the author of the bestselling book *Seabiscuit*. Ms. Hillenbrand has suffered from severe chronic fatigue syndrome with disabling dizziness for many years and has had to spend long stretches of time confined to bed. Yet, with the help of her spouse, she's been able to write articles and a book, do interviews, and conduct some semblance of a professional and social life. Of course, few of us have her prodigious writing talents. But I wonder if there are productive and satisfying roles your daughter can still play, even if she remains homebound. If so, then it may relieve some of her dependence upon you and consequently decrease the pressure you're feeling as her mother and caregiver. The more vital her life becomes, the more revitalized you'll feel over time.

Q Sometimes when I am very tired or frustrated, I lose patience and am rough with my husband. I know it isn't his fault that he is disabled, but, nevertheless, his disability manifests itself in his body, so that is where I focus my emotions. I want to shake him, and sometimes I do. I scare myself sometimes and then I feel guilty and want to cry. I do understand how a family caregiver can be moved to what might seem like abusive action by someone else. How do I handle my emotions

(Continued on page 16)

What Can I Do?

Continued from page 15

when I feel as if they are about to get the better of me?

A The cardinal sign that a caregiving plan isn't working and a caregiver is in trouble is when physical violence occurs. In those situations, the caregiving plan must be immediately revised for the protection of both the patient and caregiver, who each may be physically hurt but are certain to be psychologically damaged by such altercations. While it's understandable that pressures build and tempers flare, safety must be ensured. When tensions continue to lead to shaking, slapping, hitting, kicking or hair-pulling, then we can say that caregiving has ceased to be caring and has become a source of mutual endangerment.

It's crucial to meet with your family physician to talk frankly about what has happened and what you've been feeling. Increased anger, heightened agitation, and decreased impulse control are common symptoms of major depression. Appropriate treatment, including counseling, may help you get your feelings back under control and allow you to manage your anger without lashing out physically.

In terms of your specific question about handling your emotions when they're about to get the better of you, you may attempt the following: Try to recall who your husband has been throughout your years of marriage, not just the impaired man he's become; the more you can allow yourself to empathize with his losses, the more your anger will be transformed into sadness and violence will be reduced. Try to remember who you've been — a person of love and dignity with a desire to help, not hurt, others. Identify those moments or interactions with your husband when tensions tend to be highest — for instance, toileting in the middle of the night or getting in and out of the car — and then devise specific plans for decreasing those tensions, or, if that's not possible, refraining from inflaming each other. If you try these strategies and still are on the verge of shaking him at times, then quickly remove your-

self from those situations by going into another room, leaving the house for a walk around the block, or picking up the phone and venting to a friend. Those will be acts of kindness, not abandonment. If all else fails and violence persists, then ceasing to provide care to him any longer and instead making other caregiving arrangements will be the kindest act of all. ■

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