

TAKE CARE!

Self-Care
for the Family
Caregiver™

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Easy Ways to Protect Your Health — Honest!

Sandy Padwo Rogers

You've heard it countless times before: Being a family caregiver is detrimental to your health. The science supports the claim. Caring for a chronically ill loved one increases your own chance of developing a chronic condition, impacts your immune system, increases symptoms of anxiety and depression, and leads to premature aging. It's a sobering picture.

So what is a family caregiver to do? First, recognize the facts. There is mounting evidence that family caregivers neglect their own health while they care for their loved ones. Think about it: When was the last time you were able to take a long walk, spend some time just relaxing, or even get a physical? If you are like most family caregivers, there's precious little time to take care of yourself. And yet, if you don't stay healthy and strong, how will you continue to care for your loved one?

"Taking care of yourself is a choice that all of us need to make," says Lillie Rosenthal, D.O., a board-certified physician specializing in physical medicine and rehabilitation in New York City. "Especially for family caregivers, who have to give so much of themselves to their loved ones, you have to make the decision to make good choices and to carve out some time for yourself. Taking care of yourself can be empowering in that it provides a sense of control over your life."



For those of you who are thinking, "That's easier said than done," here are a few tips that may help start you on the path to a healthier lifestyle.

Get Moving

You may have heard that regular physical exercise has been shown to reduce the risk of a number of chronic diseases and conditions, as well as the risk of heart attack and stroke. You may also know that physical activity promotes psychological well-being and reduces feelings of depression and anxiety. It's recommended that adults engage in at least 30 minutes of moderate-intensity physical activity most days of the week. But what about family caregivers, who often struggle to find 30 minutes of free time per

week let alone per day? You might be encouraged to learn that short bouts of physical activity are also beneficial, especially if you can do them several times per day. Even if it's just five minutes a day, the goal should be to do *something* rather than *nothing*.

There are simple things you can do to get your body moving in beneficial ways. Do you have five minutes? Take a walk around your house or walk up and down your stairs a few times during the day. You'll be surprised how many extra steps you can work into your day just by moving around your own home. (Wearing a pedometer can help you keep track of your steps and motivate you to add a few more each day.)

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Letter to the Editor

Healthcare Reform: What You Need to Know

Suzanne Mintz

President Obama has made reforming our healthcare system a top priority. He is also committed to making it less of a financial drain on the country. In Washington parlance, that means fixing Medicare, the government program that pays for healthcare for seniors and those with disabilities.

This is great news for family caregivers and their loved ones, who spend more out of pocket on healthcare than any other segment of the population. I'd say that as a group, caregiving families are more aware than anyone else that our healthcare system doesn't work all that well for people with chronic illnesses and conditions.

None of us knows exactly what reform will look like; it's still somewhat early in the process. There is a real upside to this because it means we have a unique opportunity to have our voices heard, to make a difference in the outcome, and to make life better and safer for ourselves and our loved ones. One thing is clear: Whatever legislation is passed will have to show savings. In the recent economic summit hosted by the president, it was made crystal clear that reducing the cost of healthcare is seen as the single best way to get the nation's deficit under control.

So what reforms should family caregivers ask for: Medicare to cover more items such as incontinence products, which can cost \$1,200 a year or more? How about a week of solid respite twice a year for family caregivers who provide extensive levels of care? There are lots of things that would make life easier for caregiving families.

I'm kind of mixing apples and oranges here because in America,

healthcare and long-term care are viewed as separate issues, partially because they are paid for and provided by different federal, state, and county agencies as well as community-based organizations and private insurers. In the examples above, covering the cost of incontinence products is a Medicare issue. Medicare is a federal program. Respite, if it were an automatic benefit for qualifying family caregivers, would fall under the purview of Medicaid, a combined federal and state program for disabled children and the poor.

The majority of Americans, including family caregivers, have their healthcare covered through their employer. Long-term care, which is the care that we provide, is covered by Medicaid, when it is covered at all. For kids, Medicaid covers a wide range of services; for adults, it usually means coverage for nursing home care. A relatively small percentage of Americans have private long-term care insurance. This is a rather longwinded way of saying that getting the changes we need to make life easier for ourselves and our loved ones is really complicated.

At NFCA, we think the most important thing for family caregivers to focus on when it comes to healthcare reform is comprehensive chronic illness care that ensures high-quality care coordination and continuity of care across settings.

"Huh?" you say. What does that have to do with helping family caregivers? The answer is, a great deal. In addition, this type of reform is "passable" because it can save Medicare a great deal of money. Generally, when we think of family caregiver-friendly legislation, we think of the National Family Care-

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The Help You Need May Be Closer Than You Think

The money-saving tips article in the winter 2009 issue of TAKE CARE! generated a number of additional ideas from readers (see the letter to the editor on page 15). One NFCA member, New Jersey CCAN representative Lauren Agoratus, informed NFCA that she has been fielding calls from family caregivers who are struggling with costly medical bills and other potentially devastating financial challenges. Some have even been forced into homelessness.

During these extraordinarily challenging times, family caregivers are particularly vulnerable. The following resources may provide the assistance that you and your loved one need and we encourage you to check them out. NFCA thanks Lauren for her contribution to this effort.

Are you having difficulty paying for food?

Feeding America, formerly known as America's Second Harvest, is the nation's leading domestic hunger-relief charity. Each year, the Feeding America network provides food assistance to more than 25 million low-income people facing hunger in the United States, including more than nine million children and nearly three million seniors. The Feeding America network consists of more than 200 food banks that serve all 50 states, the District of Columbia, and Puerto Rico. Feeding America also secures and distributes more than two billion pounds of donated food and grocery products annually. To find a food bank that serves your local community, go to <http://feedingamerica.org>.

Do you need help with your home energy bills?

The Low Income Home Energy As-

sistance Program (LIHEAP) is a federally-funded program that helps low-income households with their home energy bills. LIHEAP operates in the 50 states, the District of Columbia, Indian tribes or tribal organizations, and the U.S. territories. The LIHEAP program offers assistance in the form of bill payment, weatherization improvements, and energy-related home repairs.

For more information about LIHEAP, including where and how to apply, call toll free 866/674-6327 or visit <http://www.acf.hhs.gov/programs/ocs/liheap/grantees/states.html>.

Are you at risk of losing your home?

The U.S. Department of Housing and Urban Development (HUD) Web site, www.hud.gov, has information on everything from avoiding foreclosure (www.hud.gov/foreclosure) to applying for public housing assistance (www.hud.gov/offices/pih/pha/contacts) and the Section 8 Rental Voucher Program (www.hud.gov/progdesc/voucher.cfm).

The Obama administration's Homeowner Affordability and Stability Plan is designed to help borrowers who are already behind on their mortgage payments or who are struggling to keep their loans current. The plan offers assistance to as many as seven million to nine million homeowners who are making a good-faith effort to stay current on their mortgage payments. The "Making Home Affordable" program will help eligible borrowers refinance their loans into more affordable mortgages or will modify a borrower's mortgage payment to make it more affordable. Final eligibility for both programs will be determined by your mortgage lender based on your

financial situation and detailed guidelines outlined by the U.S. Department of the Treasury. For more information, talk with your lender or go to www.financialstability.gov/makinghomeaffordable.

Are you searching for federal benefits for which you may qualify?

GovBenefits.gov is the official benefits Web site of the federal government, with information on more than 1,000 benefit and assistance programs. This is a free, confidential tool that can help you find government benefits that you may be eligible to receive. Go to www.govbenefits.gov.

Are you a senior who could use assistance paying for prescription drugs, healthcare, meals, utilities, and other basic needs?

BenefitsCheckUp is the nation's most comprehensive Web-based service to screen for benefits programs for seniors with limited income and resources. Developed and maintained by the National Council on Aging (NCOA), BenefitsCheckUp includes more than 1,550 public and private benefits programs from all 50 states and the District of Columbia. Go to www.benefitscheckup.org.

Do you need help paying for prescription medications?

There are a number of programs available to help those who qualify pay for prescription drugs. Here are just a few:

Together Rx Access

The Together Rx Access Card is a free, easy-to-use card that offers savings of approximately 25 percent to 40 percent on more than 300 brand-

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The Help You Need

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name prescription products from some of the world's largest pharmaceutical companies. Savings also are available on a wide range of generic products.

To qualify for the Together Rx Access Card, applicants must be legal U.S. residents, not be eligible for Medicare, without public or private prescription drug coverage, and with incomes of up to \$30,000 for a single person or \$60,000 for a family of four (income eligibility is adjusted for family size). In addition to being part of the Together Rx Access program, each of the participating companies independently offers patient assistance programs (PAPs). People applying to the Together Rx Access program will be notified automatically if they may be eligible for further savings — and in some cases free medicines — through these PAPs. Call toll free 800/444-4106 or go to www.togetherrxaccess.com.

Partnership for Prescription Assistance

The Partnership for Prescription Assistance (PPA) — sponsored by America's pharmaceutical research companies — is the largest private-sector patient assistance effort helping low-income, uninsured, and underinsured patients get access to prescription assistance programs that offer medicines for free or nearly free. Patients can obtain their medicines through more than 475 public and private patient assistance programs, including 180 programs offered by pharmaceutical companies. More than 2,500 brand-name and generic prescription medicines are available through the participating programs. Patients can also receive information on government programs for which they may qualify, such as Medicare, Medicaid, and the

State Children's Health Insurance Program.

To speak with a trained specialist who can provide application assistance in English, Spanish, and more than 150 other languages, call toll free 888/4PPA-NOW (888/477-2669). To visit PPA's user-friendly Web site, go to www.pparx.org.

The Patient Advocate Foundation Co-Pay Relief Program (CPR)

The Patient Advocate Foundation Co-Pay Relief Program (CPR) is a patient assistance program designed to help insured patients with certain life-threatening or debilitating diseases cope with the significant out-of-pocket costs associated with their treatments. Patients who qualify financially and medically are provided with direct financial support for pharmaceutical co-payments. The program currently covers 18 disease categories. To learn more, call toll free 866/512-3861 or go to www.copays.org.

Are you elderly and/or disabled and in need of dental care?

The National Foundation of Dentistry for the Handicapped (NFDH), a charitable affiliate of the American Dental Association, arranges comprehensive dental treatment and long-term preventive services for needy disabled, elderly, or medically compromised individuals through a national network of direct service programs that involve nearly 13,000 volunteer dentists and 2,700 volunteer laboratories. Go to http://nfdh.org/joomla_nfdh/content/view/24/47.

Are you unable to afford a pair of prescription eye glasses?

New Eyes for the Needy is a non-profit organization that provides qualifying individuals vouchers that can be used to purchase new prescription eyeglasses. Last year, nearly 6,000 people in the U.S. were able to purchase prescription eyeglasses thanks to New Eyes for the Needy. Go to www.neweyesfortheneedy.org/users/individuals.html.

Do you need assistance paying for your telephone service?

The Low Income Program of the Universal Service Fund, administered by the Universal Service Administrative Company (USAC), provides discounts on basic, local telephone service to low-income households. To find out if you would qualify for assistance, go to www.lifelinesupport.org/li/low-income/lifelinesupport/browser. ■

The 2009 Federal Poverty Guidelines


Persons in family	48 contiguous states and D.C.		
	Alaska	Hawaii	
1	\$10,830	\$13,530	\$12,460
2	14,570	18,210	16,760
3	18,310	22,890	21,060
4	22,050	27,570	25,360
5	25,790	32,250	29,660
6	29,530	36,930	33,960
7	33,270	41,610	38,260
8	37,010	46,290	42,560
For each additional person, add	\$3,740	\$4,680	\$4,300

SOURCE: *Federal Register*, Vol. 74, No. 14, January 23, 2009, pp. 4199-4201.

The above poverty guidelines are updated periodically in the *Federal Register* by the U.S. Department of Health and Human Services under the authority of 42 U.S.C. 9902(2). The guidelines (or percentage multiples of the guidelines — for example, 125 percent or 185 percent of the guidelines) are used to determine financial eligibility for certain federal programs such as the Food Stamp Program, the Low Income Home Energy Assistance Program, and the State Children's Health Insurance Program. Many private programs also use percentage multiples of the federal poverty guidelines when determining eligibility criteria.

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a long time
Caregiver - We have
tried a lot of disposable
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J.W., Husband/Caregiver, Alton, IL

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before Incontinence Concerns!***



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

In keeping with the theme of this issue, NFCA is pleased to provide information on these wonderful new resources developed to help you protect your loved one's health, as well as your own.

Are you looking for advice on medication safety? The Institute for Safe Medication Practices (ISMP) recently launched ConsumerMedSafety.org, the first Web site exclusively designed to alert healthcare consumers to specific drug safety issues with a focus on medication error prevention. This interactive Web site provides visitors with reliable, expert advice on medication safety, as well as the first national error reporting program for patients.

The Web site features: a customized e-mail alert service that provides breaking news about the medications patients or family members are taking; confidential reporting for medication errors, near misses, and dangerous situations; advice from leading safety experts on how errors can be prevented; safety tools and resources; and an article library with important information about safe medication use and adverse drug reactions from ISMP's newsletter for consumers, *Safe Medicine*. To learn more, go to www.consumermedsafety.org.

Do you need help preparing for the "Next Step in Care"? To improve the working relationship between family caregivers and healthcare providers, the United Hospital Fund has launched the Next Step in Care Web site: www.nextstepincare.org. The Web site offers a range of guides and checklists designed to make patients' transitions between care settings smoother and safer.

Next Step in Care aims to help family caregivers better manage transitions in care, in part by helping providers and family caregivers to work more effectively together. Created and tested by the United Hospital Fund, its tools

can guide family caregivers in determining what issues to consider, how to seek assistance, how to manage medications, and how to better communicate with physicians and other healthcare professionals. For example, one guide ("What Do I Need as a Family Caregiver?") asks a number of basic questions designed to help providers and family caregivers assess how well prepared the family caregiver is; what training and support, if any, he or she may need; and what tasks the caregiver cannot manage alone.

The guides and checklists available on the Next Step in Care Web site were developed and tested by a team of current and former family caregivers, long-term care experts, and healthcare providers from hospitals, rehabilitation units in nursing homes, and home care agencies. In English and Spanish, these tools can be downloaded for free at www.nextstepincare.org.

Are you or your loved one in need of mental health care? The Massachusetts General Hospital Department of Psychiatry has launched a newly revamped mental health Web site for patients and families. The Web site provides authoritative information from psychiatry experts blended with filmed segments of patients and their loved ones candidly sharing their experiences on the journey toward wellness.

In video segments on the Web site, patients and family members share their unique and personal stories in an effort to reach people who may be feeling isolated or unsure about what they can do if they suspect they may need mental health care. In addition to the video segments, the site offers a comprehensive body of information, guidance and support resources. The material on the Web site comprises practical guidance, vetted by trusted sources, and drawn from the latest re-

search advances. Go to www.mood-andanxiety.org.

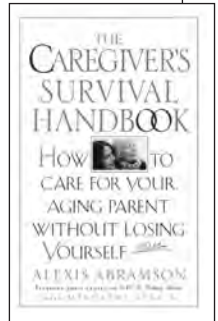
BOOK REVIEW

The Caregiver's Survival Handbook: How to Care for Your Aging Parent Without Losing Yourself by Alexis Abramson with Mary Anne Dunkin (Perigee/The Berkley Publishing Group — a Division of Penguin Group, 2004, \$15.95).

As a family caregiver, how often have you changed your plans, or even your life, for the benefit of the person you're caring for? Has family caregiving so taken over your life that you feel invisible? Then pick up *The Caregiver's Survival Handbook*. Echoing NFCA's mission, the book's goal is to "empower caregivers to speak up, get help and care for themselves first so that they can, in turn, care for others." It hits the ground running with chapters such as, "How can I juggle my various responsibilities?" to "Why do I feel so guilty?" and "Will I ever get my life back?" Filled with stories that illustrate caregiving's toll as well as the solutions that caregivers have come up with to take back their lives, this book poses the questions and offers concrete answers. Read it from start to finish or choose the chapter that speaks to you at that moment. As Ms. Abramson says, "Caregiving for an aging parent is one of the hardest jobs you will ever have." *The Caregiver's Survival Handbook* makes it a little easier.

The Caregiver's Survival Handbook: How to Care for Your Aging Parent Without Losing Yourself is available wherever books are sold, by calling 212/366-2000, or at www.penguin.com.

The Book Review was provided by CCAN representative Liz de Nesnera.



The Long-Term Care Conversation:

A GUIDE TO KNOWING WHERE TO BEGIN

“My husband has had Alzheimer’s for the past five years and much of that time I took care of him myself. Eventually, it became clear that it wasn’t safe to have him at home. One night he wandered out of the house, leaving all the doors open, and walked 10 miles before the police picked him up in the middle of a road. I awoke to find the police in my bedroom; the open doors made them worried that something had happened to ME. Another time he almost drank a bottle of cleaning fluid. Finally, it became too much. I had to place my husband in an assisted living facility.”



The above excerpt is from a telephone call to NFCA. The family caregiver was seeking advice about how to respond to people who questioned her decision to seek alternative housing for her husband. Experts would agree that she clearly made the right decision for her husband’s continued well-being, as well as her own.

How do you know when it’s time to begin a conversation about long-term care options? How do you evaluate what’s best for your loved one’s health and safety? What happens when your own health necessitates that Mom move out of your home and into alternative housing?

There may come a time in every caregiving situation when, either for your loved one’s safety or your own health, you need to consider the possibility of alternative housing, including assisted living, a group home, or possibly a nursing home. When that time comes, it would be helpful to know what your options are in terms of finding safe and affordable housing for your loved one. These decisions are never easy, but they can be less stressful if you have had time to do proper research and to confer with family members and friends whose assistance and opinions you value. With this in mind,

NFCA offers the following advice from SNAPforSeniors, a comprehensive national database for senior housing.

Long-Term Care Conversation Checklist

Having a conversation about long-term care with an aging loved one, or someone with a chronic or disabling condition of any age, can be difficult for any family caregiver. Initiating that conversation can be stressful and uncomfortable. Here are a few hints and checklists that may help you begin the conversation about housing options with your loved one.

1. Determine if it’s time to think about long-term care assistance.

Reasons to seek long-term care vary from person to person. In addition to potentially offering a safer and more comfortable environment for your loved one, long-term care may be necessary for your mental and physical health.

To ensure your loved one is able to contribute to decisions about his/her future, and to do so without a feeling of confrontation, introduce alternate housing options as early as possible, even before necessary. Evaluate your loved one’s lifestyle and health-re-

lated challenges. Be prepared to continue the conversation over time by sharing your observations and concerns, including any of the following physical and mental symptoms:

Physical Symptoms

- Are they able to move around easily given the physical layout of the home? For example, are stairs, carpet, bath/shower or door handles obstacles for mobility? Is the heating and lighting adequate for any sensory impairment, including hearing, sight and circulation problems?
- Are they experiencing balance issues, especially when changing positions? Are you concerned about them falling?
- If they fall, are you confident they would be able to call for help? Is there a reliable source to respond to a call at all times?
- Is your loved one repeatedly complaining of physical aches and pains?
- Are they experiencing frequent incontinence? Can they attend to the problem when this happens or is help needed?
- Do they have difficulty dressing, bathing or with personal hygiene such as hair and foot care?

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The Long-Term Care Conversation

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- Is your loved one experiencing frequent, significant sleep disturbances?
- Are they capable of cooking or preparing healthy meals?
- Has operating gadgets or appliances such as the can opener, stove or telephone become difficult?
- Have household chores become a burden? Are vacuuming, sweeping, taking out the garbage, and cleaning the dishes or bathroom being done in timely ways?
- Are finances such as bill payment, deposits, and investments being handled in a timely manner?
- Is your loved one still driving? If so, are you concerned about his/her and others' well-being? Is public transportation a safe and viable option?
- Are prescribed medications obtained and taken as indicated consistently?

Mental Symptoms

- Is your loved one demonstrating personality changes, including but not limited to:
 - Frequent irritability?
 - Insensitivity to others?
 - Disoriented to place and time?

Are You Connected to NFCA?

Are you receiving our monthly e-letters and announcements? If not, you are missing some VERY important caregiving information.

Our e-mails may be getting lost in your Junk mail folder, so please check it. Or, we may not have your e-mail address. Please send it to us TODAY at: e-letter@thefamilycaregiver.org. Or call 800/896-3650.

- Aggressive behaviors?
- Repetitive behaviors?
- Communicating with inappropriate language?
- Is your loved one socially withdrawn and not able or not wanting to get together with friends or family? Are there signs of depression?
- Does he/she express negative comments about himself/herself?
- Is your loved one demonstrating an inability to make decisions or making poor decisions?
- Is your loved one able to understand communication or instructions from others?

2. Schedule a family meeting.

A family meeting can move the topic of long-term care to a more focused discussion that can lead to a plan. Here is a checklist for planning your family meeting:

- Determine which family members should be involved directly or indirectly in decision making. This may include extended family members, close friends, or paid caregivers. Always include the person if he/she is capable of taking part in any decision making.
- Consider including an independent third party to play the role of mediator. This could be a minister or other member of the clergy, a social worker, or a case manager.
- If necessary, find a neutral place to hold the meeting.
- Prepare an agenda to help you stay focused. It may include:
 - A medical update
 - Sharing of feelings about the illness and caregiving
 - Daily caregiving needs
 - Financial concerns
 - Who will make decisions
 - What support role each person will play
 - What support you need as the primary caregiver
 - Next steps moving forward

3. Continue to involve family.

The move to a long-term care facility is an immense transition for any

family, so it's important to involve everyone relevant to the care recipient:

- Reach out to immediate family members to secure their input and support. For example, share online information about long-term care facilities to secure greater involvement and participation.
- Is there an unequal financial or time burden on one family member? If so, acknowledge the distribution of resources and discuss a strategy for achieving a balance that appeals to everyone.

4. Continue to engage your parent or loved one.

- Have ongoing conversations at times when your loved one is feeling best and there are few distractions.
- Introduce the idea of an overnight visit to a long-term care facility or an extended afternoon visit to get a feel for the various available options.

5. Begin researching long-term care options in your area.

- Find out as much as you can about the facilities in your area. Go to reputable Web sites, talk with your loved one's physicians, and ask friends and family members for referrals.
- Contact the facility to ask questions and schedule a site visit.
- Ask the facility you visit for a copy of its last annual licensing survey report.
- Contact your local senior ombudsman to get perspective from a trusted local resource.
- Check references from existing or prior residents or families. ■

Download a printable version of this Long-Term Care Conversation Checklist and search for senior housing options on the SNAPforSeniors housing locator at www.snapforseniors.com.

Protect Your Health

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Is your loved one able to leave the house? A walk around the block or in the park would provide you with the exercise you need while giving both of you a change of scenery and a mental break. If you are unable to leave your home, put on some music and dance for a few minutes. Dancing to music is a great way to get your daily exercise. Even better, studies have shown that just listening to music can alter your mood. Your loved one may also benefit from turning on that stereo — either by moving along with you or just enjoying a break in the routine. Other great exercises you can do at home with very little time include sit-ups and jumping rope. (Jumping rope has been shown to have huge cardiovascular benefits.)

Would you like to strengthen your arms and upper body? You don't need to buy expensive weights to begin a simple strength-training routine. Homemade weights can consist of soup cans, bags of rice, or laundry detergent containers filled with sand. Start slowly and build your resistance; you will soon see an increase in your muscle strength and endurance. (Check with your physician before beginning any type of strength-training program. You can find a variety of exercise DVDs at your local library.) And before you say that you are too tired to take a short walk, do a few sit-ups, jump rope or lift that bag of rice, remember this: Regular exercise actually gives you energy, improves your functional capacity, and helps stave off depression and the loss of cognitive function. "Caregiving is an athletic event and conditioning your body is so important," says Dr. Rosenthal. "The stronger you are, the more you can handle."

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Simple Techniques Help You Find Your Inner Peace

Marion Werner, M.Ed., CHTP, recommends the following relaxation techniques for their simplicity and effectiveness. Try them all and pick the one that works best for you. Do it twice a day if you can.

Breathing

Benefits: relaxation; calms the nervous system; harmonizes mind, body and spirit; can help with sleep, fatigue, pain and anxiety.

1. Find a quiet place.
2. Close your eyes and notice your breathing without trying to change it in any way.
3. Follow your breath as you inhale ... notice the turning point ... follow your breath back out as you exhale ... notice the turning point ...
4. Continue with your attention on your breathing in this way for up to 10 minutes. Feel your heart rate slow and yourself relax. You're in the present moment.

Imagery

Benefits: reduces stress, increases relaxation, reduces anxiety, and strengthens the capacity to draw on one's own emotional resources.

1. Find a quiet place in your home that is good for meditation — a favorite chair, a sofa, etc.
2. Close your eyes and imagine yourself in a place that you love and in which you feel comfortable and safe.
3. You may light a candle, put on music, or look at a favorite photo to help you find your special place.
4. Visualize the colors, feel the temperature, hear the sounds that you would experience in this place.
5. Stay in this place in your mind for at least one minute — five to 10 minutes is ideal.
6. Practice this exercise regularly so that you establish a routine. The more regulated it is, the better for your body.

Heart-Centering Meditation

This exercise can be used to help shift from a stressful emotional state to a more relaxed, peaceful one.

Benefits: relaxation, connection with your inner strength, inner peace and compassion, and helps access your inner wisdom.

1. Quiet your mind, quiet your body, and bring your awareness to your breath. Imagine that you are breathing in and out of your heart. Continue for several calming breaths.
2. Bring to mind someone who is easy to love and imagine them smiling at you. Feel the warmth of their smile, the warmth of their love. Receive this warming energy. Stay here as long as you like, receiving this kindness through your heart.
3. Imagine that you are sending warmth and love to the person in front of you. Stay here for a little while.
4. Feel the circle of receiving and sending love with this person as you breathe in and out of your heart.
5. Close the meditation in gratitude for the love you have received and the love in your heart.

You Are What You Eat

"It takes the same amount of time to make and eat a healthy meal as it does a fatty one," says Dr. Lillie Rosenthal. "Eating junky food is no way to treat your body."

The path to a healthier diet begins in the grocery store. Which direction do you turn when you enter the store? Do you go toward the fruits and vegetables or do you make a beeline for the processed foods? Do you pay attention to nutrition labels and portion sizes? Do you eat large quantities of red meat or have you added heart-healthy fish to your diet? Better yet, are you willing to try fish two times per week and to go meatless twice per week? A study published in 2008 found that people who eat a strict Mediterranean diet — a diet rich in olive oil, grains, fruits, nuts, vegetables and fish — are at less risk of developing heart disease, cancer, Parkinson's and Alzheimer's disease.

Just increasing your intake of fruits and vegetables will have beneficial effects on your health. According to the U.S. Department of Health and Human Services, people who eat a generous amount of fruits and vegetables as part of a healthful diet experience a reduced risk of chronic diseases, cardiovascular disease and stroke, type 2 diabetes, and certain cancers.

Want to learn more? Check out a healthy eating cookbook from your local library. You can also find a wealth of advice and ideas about good nutrition at these and other Web sites:

www.health.gov/DietaryGuidelines

s

www.nutrition.gov

www.mypyramid.gov

Protect Your Health

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Get Breathing

Have you ever thought about trying yoga or meditation? You don't need to join a class to get the benefits of these relaxation techniques. Check out a DVD or book on tape from your local library. These resources are free and provide all the instruction you need. (Don't have time to go to the library? Ask a friend, family member, neighbor or colleague to go for you.) Just five minutes in the morning, or any time during the day, is all that's required, although your goal should be to work up to three short sessions per day. "Breathing affects every cell in your body," says Dr. Rosenthal. "Find a comfortable place, close your eyes, and concentrate on relaxing your muscles from head to toe. The benefits of this type of progressive relaxation are huge."

Marion Werner, M.Ed., CHTP, agrees. In fact, Werner, who has a private healing touch and mind-body medicine practice in Washington, D.C., has spent years helping individuals learn the techniques that promote relaxation, reduce stress and anxiety, decrease pain, strengthen the ability to cope with illness, increase self-awareness and self-confidence, and access inner wisdom and strength. "Many of the practices that I teach are based on ideas that are thousands of years old," says Werner. "What I love about them is that they are really accessible, easy to learn, and free. They are also remarkably restorative in that they help create balance and a sense of well-being."

Werner teaches patients and their family members simple breathing techniques that can help ease anxiety, reduce the heart rate, and bring a sense of calm and control to what may be an otherwise chaotic existence. "Family caregivers don't get a

break," Werner says. "But all it takes is a few minutes in the morning and evening, or even once a day, to step out of the maelstrom and reconnect with your true self."

How can you get started? Werner recommends beginning with the easiest and greatest relaxation technique: breathing. Find a quiet and comfortable place and simply close your eyes and concentrate on your breathing; you will soon feel your breathing deepen and your body relax. (See page 9 for a number of relaxation techniques.) This activity can be done for as little as one minute a day, although Werner recommends 10 minutes twice per day for the most beneficial effects. "You can even involve your loved one with most of these exercises," she says. "The only contraindication would be a patient who has difficulty breathing because of his or her condition or illness."

The important thing to remember, says Werner, is to find the exercise that resonates with you. "Each one of us has a unique path to healing," she says. "All of these practices help us access a deeper healing wisdom that lies in each of us, a wiser voice inside us that is often obscured by the anxiety and overwhelming responsibilities of caregiving. When we get quiet, and allow our mind-body-spirit to connect and be in harmony, then we feel stronger, more loving, and more whole."

Get Started

Whether it's taking a short walk or meditating, the key is to begin taking care of yourself, even if you begin with baby steps. "It's never too little or too late to do something that would set you on a healthier path," says Dr. Rosenthal. "The personal rewards will be endless and priceless and your loved one will be better for it as well." ■

Sandy Padwo Rogers is the managing editor of TAKE CARE!

Healthcare Reform

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giver Support Program, the Lifespan Respite Care Act, and the Family and Medical Leave Act, all of which target family caregivers as a population to be helped. Don't get me wrong. Legislation that specifically helps family caregivers is essential, but it tends to treat the consequences of our being family care-

givers. It doesn't address the core issue, which is that the person we care for has a chronic illness or disability. It also adds to the costs of caring for those with disabilities, chronic illnesses, or the consequences of old age. It doesn't produce obvious savings.

Comprehensive care coordination and continuity of care, meanwhile, are all about minimizing problems that our fractured healthcare system causes, problems such as visits to the ER because of a medication interaction and the repeating of tests be-

cause one doctor doesn't know what another one ordered, or doesn't have access to the records. If our loved ones received high-quality chronic illness care — care that is continuous and coordinated regardless of whether they are at home or in a hospital, a rehab facility, or an assisted-living complex — they would be healthier and safer, and we who love and care for them would have somewhat less to do, be less stressed, have more time to take care of ourselves, and spend less money on

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A Care Coordination Case Study

Suzanne Mintz

The following true story illustrates the coordination that is required between parties and across settings when dealing with a chronic illness or disability. All of the areas of interaction and transition are underlined to show how many opportunities for error can occur if care is not coordinated properly. Nancy, the wife in this story, acted responsibly by providing the hospital with information about her husband's medications but also ended up doing the job that should be performed by a member of the professional healthcare team. Unfortunately, under our current healthcare system, this type of coordination is no one's responsibility and no one is paid to provide this service. While there were no mishaps in this story, there easily could have been and often are. No wonder that nearly 18 percent of Medicare patients return to the hospital within 30 days of discharge (Medicare Payment Advisory Commission Report to Congress, September 16, 2008). By promoting care coordination and continuity of care as part of any healthcare reform effort, NFCA's goal is to ensure that all healthcare encounters are error free.

Jack Lynch has MS. He doesn't take many medications: one to control his spasticity, one to control his cholesterol, and one to ward off urinary tract infections. The management of Jack's medications falls to his wife, Nancy.

Jack was hospitalized a few days last month for a urinary tract infection that obviously was stronger than the preventive medication he was taking. He was treated with an IV antibiotic. When Jack was admitted to the hospital, Nancy gave the admissions representative a list of all of Jack's medications, including each drug's name, dosage, and dosing instructions to put in his chart. She noted that he didn't have any allergies and that he also took a daily vitamin plus extra vitamin D. Nancy made it a point to check with Jack or the nurse each day to ensure that Jack was staying on schedule with his prescription medications. She brought the vitamins with her. In the hospital, Jack saw two different doctors: a hospitalist and an infection control specialist. Both doctors spoke directly to Jack's urologist. It wasn't clear if they spoke to each other. No one spoke to his primary care doctor.

When Jack was discharged, he was given a prescription for an oral

antibiotic. He was told to get a urine test when he finished the medication regimen. Nancy and Jack use the same family physician as their primary care provider. Nancy e-mailed their doctor to inform him about Jack's infection and hospital stay and to request that the lab work be done at his office. A few days after the test, Nancy called for the results and sent a fax to Jack's urologist so he would have the results for his file. She also followed up with him to find out if Jack should resume taking his prophylactic medication. She then forwarded all information to Jack's primary care physician for his file.

This episode of care went well due to Nancy's vigilance. But Nancy shouldn't have to do these things at all. Coordinating care and ensuring safe transitions across settings and between members of the healthcare team are the responsibilities of the professionals. That's why NFCA believes that paying for high-quality chronic illness care, which includes care coordination and continuity, must be an essential element of a re-designed healthcare system. It will keep our loved ones safer, enhance our quality of life and theirs, and lower healthcare costs. That's a pretty good package if you ask me. ■



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 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. His first book, *The Emotional Survival Guide for Caregivers — Looking After Yourself and Your Family While Helping an Aging Parent*, was published in June 2006 by Guilford Publications. Go to www.emotionalsurvivalguide.com to learn more.

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
e-mail: info@thefamilycaregiver.org
Subject Line: What Can I Do?

Q I am 36 years old and the father of a 10-year-old son. Six years ago my wife was diagnosed with brain cancer. She underwent a craniotomy and recovered well. After three years of recovery, she had her first recurrence (radiation and chemotherapy), then a second (more radiation and chemotherapy), then a third. She had a second craniotomy a few months ago and never fully recovered. She spent 92 days in three different hospitals and rehabilitation units. She is now back at home, in a hospital bed, on a feeding tube, and with toileting issues. She can get out only in a wheelchair. My mother-in-law helps during the day when I go to work. Over the years we have learned to deal with the cancer. However, after having her home and being the primary caregiver, I am getting to the point that we both feel like we are just surviving. Every day is hard, with meds given six times per day (most crushed through the PEG tube), as well as bathing, dressing, toileting, moving from point to point. The cognitive loss is the hardest to deal with; she is just not the same person anymore. I wonder about the feeling of living versus just surviving. I feel terrible about complaining, because I'm not the one going through the illness; but it is beginning to impact my normal state of mind. What can I do?

A You needn't feel "terrible" or guilty about complaining. Through this dreadful, long-running, and apparently deteriorating situation, you have steadfastly cared for your wife at home, demonstrating to her and your son the depth and durability of your love. The cumulative grind of eking out each day's survival would wear down anyone in your position. Guilt, in my opinion,

never enhances a caregiver's effectiveness. To the contrary, it too often prevents people from reaching out for help or altering caregiving plans in ways that would make caregiver burnout less likely to occur. Consequently, I'm all for putting guilt aside and actively considering your options.

Those options seem to be logistical and psychological. Here are some questions about the former that you may be thinking about:

Will continuing to provide care for your wife in your home during the years ahead have detrimental effects for you, your son, or even your wife? You probably downplay the fatigue and emotional duress that you are experiencing. But if your "normal state of mind" has already been affected by the recent medical crises, then there's some likelihood you'll become more debilitated as time goes on. You may feel strongly that your son needs his mother to be near him, but there may also come a point at which dealing (hands-on or just emotionally) with his mother's care needs will affect his normal development — for example, by impeding his interactions with peers or causing him to feel guilty about acting like a carefree and playful child. Your wife, too, may have qualms about continuing to be cared for at home, feeling that she is unfairly burdening you and her mother. That will make her more likely to become depressed.

At what point would such detrimental effects weigh more in the family's decision-making than the goal of keeping her at home? Different families have different tipping points. What's important is to have an open and frank discussion about what each family member is experiencing through the caregiving

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What Can I Do?

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process. The caregiving plan should be reviewed and refined regularly as the medical situation evolves.

Are there loving ways of providing care other than the ones you are currently employing? There are support services available in most communities for keeping an ill loved one in the home, including home health aides and medical day programs. For many families, placing their relative in a skilled nursing facility becomes the most loving thing they can do at a certain juncture in order to ensure that their loved one is safe and well cared for. There's no guilt or shame in at least contemplating such a move.

In terms of psychological options, you could regard your wife in a different way. To this end, psychologist Pauline Boss' "ambiguous loss" concept may prove helpful. According to Dr. Boss, a loss that is ambiguous — one in which a family member is simultaneously present and absent — causes enormous stress by preventing people from grieving fully. She suggests that people can best handle ambiguous loss by recognizing that inherent stress and then allowing themselves to mourn the person who is at least partly gone.

For instance, I once provided counseling for the daughter of a woman who'd had a devastating stroke that changed her personality and physical functioning. The daughter coped with the arduous caregiving for her mother by telling herself that the mother with whom she'd been close was now gone and that the mother who was left was a different person with whom she could have a different and less emotionally connected relationship.

That may sound extreme. But the fact that your wife is in your home and is impaired cognitively because

of the damage done by multiple surgeries and the cancer itself does mean that you probably are experiencing an ambiguous loss. It would be best to allow yourself to grieve the loss of your wife as you knew her as a means of better accepting the person for whom you are providing care. That should help you cope with the emotional toll — particularly the powerful sadness — of the everyday rigors of caregiving. It should also help prepare you for what additional losses may yet occur.

Q Is there any legal way to force siblings to help care for an elderly parent? We moved Mom close to me with the idea that my twin sister and her husband would share the care. Instead, my twin declared that she couldn't/wouldn't do anything for Mom. I tried to reason with her and give suggestions about what she could do, but she attacked me viciously. I've had no contact with her since.

When I moved Mom in with me for 11 months, my younger sister said that I would not be alone in caring for her, implying that she would take over when she retired in two years. Now, when I bring up that subject, she snaps at me or cuts me off. All she's done is help move Mom into my house and then into a HUD apartment building.

I spend much of my time driving Mom to appointments, doing her shopping, and checking on her. I was a caregiver to my husband during his nine-year battle with pancreatic cancer. He had been buried one week when my twin sister started this mess. She said that my husband left me well off and I could afford to do this for Mom. That's far from the truth. She never gave me any credit for all the financial help I had given Mom, which was substantial.

Each sister has health problems, as do their husbands. But so do I! I recently had major surgery. I made sure that both sisters had contact information for Mom's doctors, finan-

cial organizations, even a number they could call for transportation to doctors' appointments. The day after I came home from the hospital, I reminded Mom that if she had to see a doctor, she would have to call my twin sister. Mom replied that my twin sister was sick. I felt as if I had been slapped in the face!

I'm at the point where I resent having to do anything for Mom. I've considered trying to "divorce" my family so that someone else has to take care of her! What can I do?

A The short answer is that nothing legally can be done to force your sisters to do what they should be doing on their own accord — providing loving care to your mom. But this is much more than a legal issue. It speaks to psychological and moral considerations about how much any one family member is obliged to help another.

It sounds like you have taken what you consider to be your responsibility toward your mother very seriously. For that, you deserve high praise. Instead, you feel misled and abandoned by your sisters. Your mother, meanwhile, takes your selfless efforts for granted while coming to the defense of your sisters' selfishness. No one is offering you any hope for better in the future. No wonder you feel incensed.

Your choices are few. You could continue to appeal to your sisters for help. I'd suggest reaching out to each of them in writing with a frank, but not angry, letter in which you describe how caregiving is negatively affecting you. I'd state bluntly that their responses to your need for help will have an impact on your future relationships with them. If they heed your call, then you will continue to have loving relationships with them; if not, then those relationships will be greatly compromised. Yes, the stakes here are high and the risk great. But it seems you lose little if they reject you because what they are currently offering you is so paltry.

You could appeal to your mother to pressure your sisters to help her. She probably has more leverage to influence their decisions than you do. You likely will have to force your mom to this task, however. I'd tell her that just because you are widowed and your sisters are still married doesn't mean that you are forever available to her while they are always encumbered.

Finally, you could go on strike — or at least pull some job action. I'd suggest refusing to shop for her or drive her to her doctors' appointments. A crisis will quickly ensue. I doubt, though, that your mother will go hungry or that her medical needs will be neglected. Instead, I think your sisters will find some means of stepping up and helping her — that is, after they have failed to pressure you to take back your job. This, too, is a high stakes tactic, all the more unpleasant because it will surely anger your mother. But, in my opinion, this is the strategy most likely to change the family's current lopsided caregiving plan to one that is more equitable, sustainable, and fair. ■

I enjoyed the article "Money-Saving Tips for Family Caregivers" in the winter 2009 issue of *TAKE CARE!* I have another tip I'd like to pass along to family caregivers.

You talked about the library as a source of free entertainment, specifically mentioning movies and television shows. Most libraries also have great music collections as well as books on tape, which might be helpful for those with macular degeneration, as my mom had. Some libraries also have discounted or free passes to museums and attractions in the area. In our state, you can call or go online and reserve these passes, even if you live in another town. It might be a nice way to spend an afternoon with the person you are caring for, or maybe it's just respite time for the caregiver. Some libraries even have board games and jigsaw puzzles to lend. And most libraries have events going on at least once a week (whether it's an author coming in to do a talk, a flower arranging class, or

a cooking class) that are also all FREE. Lastly, most libraries subscribe to a number of databases where all kinds of information is available. One that I find of interest is *ancestry.org*. (Normally you'd have to pay for a subscription to this site, but if your library subscribes to it, you can use it for free!) Check with the reference librarians and they'd be happy to tell you about everything your library has to offer.

Your article mentioned canceling subscriptions to magazines you don't read. Libraries have extensive magazine collections, and you can borrow your favorites for up to three weeks!

I've been a realtor for 20 years. After my parents died and I was no longer a caregiver, I took up a part-time job as a reference librarian. I'd always been a library nerd; now I get to go there and get paid for it!

Sincerely,
Elizabeth Sivell Bowen
Farmington, CT

To Our Readers: Important News About the Summer Issue of *TAKE CARE!*

Today's economy is hurting NFCA, just as it is hurting many of you. One of our greatest expenses is the printing and mailing of *TAKE CARE!* four times per year. We deeply regret that we will not be able to print and mail our summer issue; however, it will be available online at www.thefamilycaregiver.org. We understand that many of you do not have access to the Internet and we hope you will ask a family member or friend to print the summer issue off the NFCA Web site for you to read.

We would very much appreciate your help at this difficult time. Please consider making a donation to NFCA. Your donation will help us continue printing and mailing *TAKE CARE!* No amount is too small and all donations will be gratefully accepted. Contributions can be made by calling 800/896-3650, by going online to www.thefamilycaregiver.org, or by sending a check to NFCA (see address on page 2).

Thank you for your understanding and support.

**IMPORTANT INFORMATION ABOUT
SUMMER ISSUE OF TAKE CARE!
SEE PAGE 15**



In 2000, 2.3 million older parents were living with their adult children. Today, there are nearly 4 million multigenerational homes in the U.S.¹

If you're considering moving an older parent or loved one in with your family, the Home Instead Senior Care[®] franchise network has created a guide to help you determine the best course. This guide is available **FREE** from your local Home Instead Senior Care office and features tips and advice from experts to help you create an emotionally healthy, financially sound and environmentally safe multigenerational residence.

The whole family can benefit from a little help outside the home. Whether it's a few hours a day or 24-hour long-term care, a Home Instead CAREGiverSM can provide companionship and conversation, offer medication reminders, monitor diet and eating, assist with transportation and much more.

1. U.S. Census Bureau: <http://www.census.gov/Press-Release/www/2001/cbo1cn182.html>

To receive your **FREE** copy of "Too Close for Comfort?" call your local Home Instead Senior Care office, or visit www.makewayformom.com.



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