

TAKE CARE!

Self-Care
for the Family
Caregiver™

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Getting the Help You Need

Paula S. McCarron

“**W**hat I learned from my own experience is that family caregivers are the ones holding everything together — and they’re paying a high price, including putting their own health at risk.”

These are the words of Sheila Warnock, who first became a family caregiver when her dear friend was diagnosed with cancer. For years, Warnock provided emotional and practical support to friend Susan Farrow and her family as Farrow dealt with a rare form of cancer that began in her salivary glands and moved into her bones. Warnock was just barely managing to keep her own life together while at the same time helping her friend. And then crisis hit: Warnock’s widowed mother slipped into what Warnock describes as a “long and painful decline.”

Just when it didn’t seem possible to continue caring for both her friend and her mother, Warnock received a life-transforming phone call. It was Farrow’s therapist inviting Warnock to attend a special meeting of 12 people who would become partners in caregiving.

“When people offer their help, they’re being generous. It’s an offer made from the heart,” says Nora Klaver, author of *MayDay!: Asking for Help in Times of Need* (Berrett-Koehler Publishers, 2007). “But I’m amazed at how often people will refuse help even when it’s generously

offered. It’s like a knee-jerk reaction.”

Why do people refuse to ask for or accept help?

Klaver says that often we are struggling with our fear. “We may fear damaging our relationships,” she says. “We may fear losing control. We might fear we will look weak or incapable of managing our own lives.”

Beyond fear, there are many other reasons why caregivers choose to “fly solo,” including:

- Caregivers are confronted with equally important tasks and conflicting demands.
- Finding and coordinating help adds to an already overloaded schedule.
- We may become lost in a maze of services and paperwork. By the time help becomes available, it may be too little or too late.
- Help from agencies is often limited due to qualifying criteria such as age, health condition, income, or even geographic location.
- Companion or chore services are often costly and rarely covered by insurance.
- Volunteer groups and faith communities may offer help but it may be sporadic or time-limited.
- We or our loved ones may be reluctant to open our lives and homes to strangers.

In addition to the caregiver’s reluctance to ask for help, there are those who want to help but don’t



know how or are frightened of getting too involved.

That’s what led Warnock to detail her caregiving experience in a book she co-authored with Cappy Caposela, another member of Farrow’s caregiving team. Their book, *Share The Care: How to Organize a Group to Care for Someone Who Is Seriously Ill* (Fireside, Revised and Updated 2004), provides tips on everything

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Emerging Resources Are Helping Caregivers Get What They Need Most: Time

Linda Taubenreuther

It seems that just about every list of tips for family caregivers ends with the earnest and oft-repeated advice, "Take time to care for yourself." NFCA gives this advice as well, while recognizing that the problem, of course, is "time" — or, rather, the lack of it.

No one who hasn't walked in a family caregiver's shoes can begin to imagine how time-intensive caregiving is. The irony is that when caregivers are asked to list the demands on their time, giving care is not always the biggest item on the list. Huge chunks of time get swallowed up by a mountain of other tasks, from detangling insurance and medical snarls to tracking down trustworthy resources for everything from skilled nursing help to home repairs. Lately, some glimmers of hope have appeared, in the form of entrepreneurial organizations that are finding new ways to meet these challenges.

Healthcare Advocacy, Doctor Visit Companion, and More

Dealing with insurance companies and medical providers is one of the most time-intensive — and exasperating — time robbers family caregivers face. Tedious automated phone systems, complex coverage guidelines, endless paperwork, and indifferent service fuel the frustration.

One company has made that problem its passion. For an annual fee of \$365, subscribers to Health Proponent get 24/7 access to a personal advocate (usually a registered nurse), backed by a team of doctors, seasoned insurance specialists, and healthcare experts. The fee covers assistance for you, your spouse, dependent children, parents, and parents-in-law.

Together, these caregiver proponents use their skills to provide a wide variety of services, including navigating medical care (helping you find a doctor and get an appointment) and being your advocate with your health insurance company. While the firm is relatively new, its parent company, Health Advocate, has been providing these services to millions of corporate employees for several years.

Sometimes, the solutions to insurance problems are simple. "One of the biggest reasons for denial is incomplete paperwork," says Health Proponent CEO Marty Rosen. "Getting approval can be as easy as resubmitting the form."

Even if a denial is justified, the team moves on to strategies a caregiver might not know about, have time to pursue, or have the clout to carry off. If the issue is medical equipment or drugs, for example, the team may explore government and community programs and grants, work to get discounts from equipment providers, or investigate pharmaceutical trials.

When it comes to finding and coordinating physicians and medical tests, the idea is to get patients to the right place at the right time without what Rosen terms "medical ping-ponging" — the bounced-around feeling all family caregivers know well.

In the end, one of the most valuable benefits of this kind of support is the huge relief of knowing that you're not alone.

Finding Elusive Help

Most caregivers can't count the number of times well-meaning people have urged them, "Get help! You simply can't do it all yourself!"

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Technology

Is Transforming Caregiving



Sandy Padwo Rogers

Imagine your husband's daily blood pressure and glucose readings being transmitted electronically to his physician from your own home. Imagine receiving a text message on your computer or cell phone that lets you know your 90-year-old mother, who lives 100 miles away, has eaten her breakfast and taken her morning medication. Imagine being able to leave for work each morning knowing that you can check on your disabled child via a video camera installed on your work computer.

All these scenarios may sound like nothing more than scenes from the latest science fiction movie. In fact, they are real examples of how technology is changing the face of healthcare and caregiving.

When we talk about using technology to make life easier for family caregivers, what many people don't realize is that nearly every one of us already uses some form of technology in our daily lives. Every time we log onto a computer to look up information or correspond with family or friends, every time we use our cell phones to reach out to someone, we are taking advantage of the latest technology. For family caregivers, the ability to research health topics online and to share information with others has already transformed the way you interact with medical professionals and provide care.

There are three types of emerging technologies that hold tremendous promise for family caregivers: safety, health and wellness, and social connectedness.

Safety Technologies

From fall detection and prevention devices to mobility aids, stove use detectors, door locks and wander management systems, safety-enhancing technologies are designed to help protect an individual from a variety of hazards. You may be concerned about your elderly mother, who lives alone and doesn't always remember to turn off her stove. Or you may have a child with cerebral palsy who would benefit from using a fall detector to alert you if he or she falls. "For the family caregiver, the safety of the care recipient is paramount and can be a source of anxiety," says Majd Alwan, Ph.D., director of the Center for Aging Services Technologies (CAST). "These technologies are designed to address this critical area."

Linda Barrett, Ph.D., a senior research advisor with AARP, recently conducted a national survey of older adults and family caregivers that brought to light their positive views on the use of technology as a way to ensure safety for the care recipient and to provide peace of mind for the family caregiver. The AARP Foundation *Healthy @ Home* report found that family caregivers in particular are searching for ways to save time, to ensure the safety of their loved ones, and to improve their own peace of mind.

While often marketed to those who care for an elderly relative, safety-enhancing technologies are not just for the aging population. Monitors can be used to check the vital signs of a sleeping child or a young adult. Wander management

systems work equally well whether keeping track of the whereabouts of a loved one with Alzheimer's or a child with a brain injury or other cognitive impairment. Specialized wheelchairs and walkers can enable young people to enjoy the independence they crave while providing older individuals the ability to navigate safely without the need for personal assistance.

For the family caregiver of an aging relative, especially if that caregiver does not live with the care recipient, personal emergency response systems and other safety technologies may make the difference between independent living and institutionalization.

Health and Wellness Technologies

Medication compliance systems, pulse and temperature readers, and telehealth devices that relay information directly to a physician's office are all examples of the growing array of health and wellness technologies. So are behavioral monitoring systems, which help assess an individual's ability to carry out activities of daily living. Once again, these devices are not just limited to seniors. "Health and wellness technologies allow the caregiver to act quickly on the information provided and to deliver needed support in a much more efficient fashion," says Dr. Alwan. "The devices act as a complement to the caregiver. They empower the

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caregiver to maximize his or her time and to reduce unnecessary visits or interventions. They also allow the caregiver to increase the social content of the interaction with the care recipient. Instead of spending time talking to Mom about her blood pressure reading, the caregiver already knows this information and so there can be a more meaningful exchange with the care recipient.”

Social Connectedness Technologies

Whether caring for your spouse, parent or child, all family caregivers can

benefit from technologies that enhance social connectedness. The Internet can be used to join support groups and e-communities, a number of which can be found on the Web sites of organizations dedicated to family caregivers. Social networking sites such as My Space or Facebook are also popular ways to connect with others. In addition, information can be shared via online message boards and chat rooms, which are often on the Web sites of disease- and condition-specific organizations. “The sharing of experiences and lessons is very powerful and can provide needed psychological support as well as helpful tips,” says Dr. Alwan.

Such devices as video phones and Web cameras not only allow caregivers and other family members to

maintain a more intimate connection with loved ones, they can be used as memory aids for those experiencing cognitive decline. For example, special devices attached to a phone can display information about a caller to an individual who is suffering from memory impairment.

Recent attention has been paid to a new generation of devices such as Paro, a robotic baby seal that interacts with patients in therapeutic settings, which seems to enhance the mental development and social skills of children with autism or Down syndrome as well as to help isolated seniors stave off depression.

The Intimidation Factor

Talking monitors, motion detectors, robotic companions — it can all

The Promise of Technology: One Family's Experience

Rick B. lives three hours away from his grandmother, but he sees her every day. With the help of a panoramic video camera mounted in his grandmother's family room, Rick can check on her whenever he chooses just by logging onto a secure Web site. Thanks to sensors placed strategically throughout his grandmother's home, Rick knows if she has gotten out of bed, if she's had breakfast, or if she's been visited by her beloved great grandchildren. Rick's mother and sister, who live in the same town as his grandmother, check on her several times a day as well — from their offices or homes. “This technology has provided us incredible peace of mind,” says Rick.

Life used to be much more stressful for Rick and his family. His 94-year-old grandmother, “Grandma Oak,” is a fiercely independent woman who lives alone. Nearly a year ago, Grandma Oak suddenly required hospitalization for multiple life-threatening health conditions, including congestive heart failure and kidney failure. Rick's family rallied and began providing 24/7 care with the help of hospice. After several weeks, Grandma Oak's symptoms diminished and hospice was no longer necessary. She still needed someone to watch over her daily, however, and the family couldn't do it alone. Since Grandma Oak made it clear that she would not leave her home and she didn't want strangers around all the time, they had to get creative. A bit of research on the Web led to the perfect solution.

Rick's family installed a home monitoring system for Grandma Oak. The technology allows family members to

monitor her in real time from any computer. If Grandma Oak deviates from her routine, the family members are alerted via a text message. “The system allows us to be very aware of what her needs are at all times,” says Rick. “My mom can check on my grandmother several times a day without having to take time off of work. And I still feel as if I'm a part of the caregiving team even though I'm three hours away.” While his mother and sister still visit his grandmother regularly and Rick often visits on weekends, not having to coordinate family members to provide 24-hour coverage has made all the difference.

A pleasant surprise that has come from using the technology is the amount of money it has saved Rick's family. “Instead of paying thousands of dollars per month for round-the-clock home health aides, we have someone go to her home only two to three days per week for just a few hours. Since the monitoring system costs less than \$75 per month, it's a significant savings.”

Finally, allowing aging services technology into their lives has provided a tremendous sense of relief for everyone. “We felt enormous guilt that we just couldn't do it all by ourselves,” says Rick. “We've been relieved of that guilt and we all still feel connected to my grandmother in a wonderful way.” ■

Editor's Note: Just days before TAKE CARE! went to press, Grandma Oak passed away. According to Rick, she died peacefully and with dignity in the comfort of her own home, which was her wish.

seem a little overwhelming. How does a family know where to begin? The first step should be an assessment of the care recipient's needs. Do you have an elderly parent who lives alone? He might benefit from something as simple as a personal emergency alert system. Does your sister's condition make her prone to falling? Fall prevention and detection devices may be the answer. Does your spouse often forget to take his medications? A medication compliance system would provide the reminders he needs while alerting you to any deviation from his medication routine. When evaluating your loved one's needs, it would be helpful to consult the medical professionals who are part of your loved one's healthcare team.

After determining what technologies might help, Dr. Alwan recommends that caregivers read the information found on reputable Web sites such as CAST or the Alliance for Technology Access. These sites are designed to provide objective information about the technologies being marketed and what they are designed to do.

Finally, look for technical devices that are easy-to-use with a well-designed interface. Keep in mind that the technology is only useful if it is used. Your care recipient must be willing to incorporate the device into his or her daily routine.

Addressing the Barriers to Assistive Technology

Studies by the AARP Foundation and CAST have shown that awareness and cost are barriers when it comes to the acceptance and use of technology. Dr. Barrett's 2007 national survey found that older adults and their caregivers would benefit from knowing more about the technological innovations that are available today. According to the *Healthy @ Home* report, "While older adults have a limited awareness of new technologies that could help them meet their goals, they would be will-

ing to use a wide variety of items to maintain social contact, gather information, be safe at home, and promote their personal health and wellness. Like older adults, family caregivers also say that they would be willing to use new technologies to meet their needs in the caregiving role." Dr. Alwan agrees, saying, "If it means they can remain in their homes, seniors are more open to using technology than their family caregivers expect them to be."

Learning about available technology is one thing. Affording it is an entirely different concern. Both family caregivers and their care recipients cite cost as a factor when it comes to utilizing available technology. "Cost is a big question for family

caregivers, especially for those who are struggling financially," says Dr. Alwan. To that end, CAST is calling on Medicare, Medicaid, and health plans for an evaluation of the cost-effectiveness and efficiency of these technologies. The Centers for Medicare & Medicaid Services (CMS) recently announced a Medicare pilot project that will provide physicians with incentives to use health information technology. The five-year program will help nearly 1,200 small practices in 12 regions implement electronic health records. "If the use of emerging technologies will improve efficiency, lead to better health outcomes, and reduce costs then medical profession-

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To Learn More

All of the organizations listed below have Web sites that contain helpful information on assistive technologies.

AARP (www.aarpmagazine.org/family/caregiving/caregiving_staying_connected.html) The March/April 2008 issue of *AARP The Magazine* offers a look at some of the technologies that are allowing family caregivers to stay connected to their care recipients.

ABLEDATA (www.abledata.com) provides objective information about assistive technology products and rehabilitation equipment.

Alliance for Technology Access (ATA) (www.ataccess.org) provides information and support services to children and adults with disabilities.

CAST The Center for Aging Services Technologies (www.agingtech.org) is leading the charge to expedite the development, evaluation and adoption of emerging technologies that can improve the aging experience. CAST is a program of the American Association of Homes and Services for the Aging (www.aahsa.org). The CAST Web site contains helpful documents and a technology clearinghouse, with links to specific vendors.

Family Center on Technology and Disability (www.fctd.info) supports organizations and programs that work with families of children and youth with disabilities.

The Savvy Senior (www.savvysenior.org) is a Web site devoted to providing information and resources for older Americans and their families.

Technology for Long-Term Care (www.TechForLTC.org) provides ready access to information on technologies that can help the elderly and the disabled. Family caregivers can use this Web site to find information on a variety of products.

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.

Are you looking for caregiving resources in your state? The National Center on Caregiving at Family Caregiver Alliance has launched the **Family Care Navigator**, a first-of-its-kind comprehensive online guide intended to help families in all 50 states and the District of Columbia locate government, nonprofit, and private caregiving support programs.

The easy-to-use Navigator lists programs for family caregivers as well as resources for older or disabled adults living at home or in a residential facility. It also includes information on government health and disability programs, legal resources, living arrangements, disease-specific organizations, frequently asked questions, a glossary, and much more. There is no charge to use the Navigator.

For people providing care to an older or disabled family member or friend, navigating the long-term care system can be difficult and confusing. Programs vary from state to state and community to community; caregivers can spend hours on the phone trying to locate appropriate services. The Family Caregiver Alliance created this new Web-based feature to guide family caregivers to the services and programs that can help.

To learn more, go to www.caregiver.org and click on Family Care Navigator: State by State Guide.

Do you want to compare hospitals in your area? Consumers now have a new tool to help make decisions about the quality and value of the health care available at local hospitals. The Centers for Medicare & Medicaid Services (CMS) worked with the Hospital Quality Alliance (HQA) to provide this information so that consumers would have more insight about the hospitals in their communities.

Hospital Compare provides information on how well hospitals provide recommended care for their adult pa-

tients for certain conditions or procedures. In addition to adding new information from Medicare patients about their hospital stays, CMS is adding information about the number of certain elective hospital procedures provided to those patients and what Medicare pays for those services. For the first time, consumers will have the three critical elements — quality information, patient satisfaction survey information, and pricing information for specific procedures — they need to make effective decisions.

To compare hospitals in your area, go to www.hospitalcompare.hhs.gov.

Are you caring for an older adult?

The U.S. Food and Drug Administration (FDA) has a free online newsletter aimed at older adults, their families and caregivers. *Maturity Health Matters* is published three times per year and focuses on FDA-approved products that help people live longer, more productive lives. The FDA's goal is to provide a source of unbiased and current information on many FDA-regulated medical products (biologics, cosmetics, foods, drugs, medical devices) and related health topics.

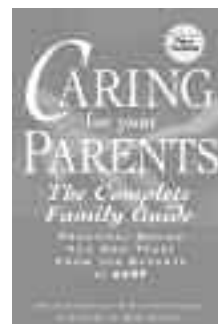
To learn more, go to www.fda.gov/cdrh/maturityhealthmatters.

BOOK REVIEW

Caring for Your Parents: The Complete Family Guide by Hugh Delehanty and Elinor Ginzler (AARP/Sterling Publishing, Revised and Expanded 2008, \$12.95).

"Have you gotten your AARP card yet?" How many times have you heard that at someone's birthday? Well, as we age, so do our parents. AARP, long synonymous with getting older, has tackled the issue of caring for our aging parents head-on with this newly revised and expanded book. What makes this more than just a "how-to"

book is that it goes beyond what is happening to our parents, to why it's happening. Chapters such as "The Body" and "The Brain" will help you understand the



physical reasons behind your father's sleeplessness or your mother's sensory changes. Living up to its *Family Guide* name, honest discussions and practical suggestions abound on dealing with sibling rivalry issues, cultural traditions, and the effects of caregiving on the entire family. Helpful information on managing the "Medicare Maze" and how to decide on living arrangements add to this book's value. It candidly addresses many of the challenges we face all along our family caregiving journey, from "Bringing up the Subject" to "The Shape of Tomorrow" after that last goodbye. And since no book on caregiving would be complete without essential "Care for the Caregiver" information, an entire chapter is devoted to this topic as well. Resources are listed at the end of each chapter, real family caregiving stories bring the issues to life, and checklists help you get organized. So, whether you have your AARP card or not, this book deserves a place on any caregiver's bookshelf.

Caring for Your Parents: The Complete Family Guide is available wherever books are sold, by calling 800/805-5489, or at www.sterlingpublishing.com.

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

Are you aware of a resource that would help other family caregivers? Let us know about it by e-mailing editor@thefamilycaregiver.org.

NFCA Celebrates Its 15th Anniversary and NFC Month 2008 ...

SpeakUp!

National Family Caregivers Month

During this special year, NFCA is hosting a FREE Family Caregiver Teleclass to teach family caregivers how to improve their communication with healthcare professionals and become better healthcare advocates for themselves and their loved ones.

Mark your calendars

- What:** Two one-hour educational sessions available by phone and Web.
When: Thursdays – November 6 and 13 at 2 p.m. Eastern time.
How: To register, go to NFCA's Web site at www.thefamilycaregiver.org for instructions. For those without Web access, call 800/896-3650.

Technology

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als shouldn't resist them, especially if insurers offer them proper incentives," says Dr. Alwan.

CAST and other organizations are also working to effect change in the reimbursement policies of both government and private insurers so that they either cover these technologies outright or provide tax credits to be used toward their purchase.

Family caregivers have additional reason for optimism when they look back at yesterday's technological innovations. "Take a look at the history of the calculator," explains Dr. Barrett. "It was once an expensive item that only a few could afford. Today, you can walk into just about any store and pick up an inexpensive calculator that does anything you need. As the technology gets

better and less expensive to produce, it becomes more available and affordable for the average consumer."

The Future of Technology in Caregiving

"We are finding that the point of care is moving away from traditional medical institutions to the home," says Dr. Barrett. While a rapidly growing senior population may be the catalyst for this change, all family caregivers stand to benefit from a society that recognizes the need to support those who care for their loved ones at home.

Robots that cook and do laundry will probably always be the stuff of dreams, but the future of service technologies is very bright. "I'm personally excited about the potential of embedding sensors to collect data continuously and unobtrusively," says Dr. Alwan. "This particular technology would overcome any lack of commitment, or noncompli-

ance issues, on the part of the user. This would include forgetting to take one's medications or blood pressure or intentionally refraining from using a particular device." Other studies include the use of walkers with sensors to help those with poor vision avoid obstacles. These walkers could also be used to assess balance and gait, allowing for a more objective evaluation of physical abilities.

As we have seen with the evolution of computers and the Internet, the possibilities for the future are endless. For those working on the next generation of technological advances, it really is about enhancing the patient's quality of life while making life easier for the family caregiver. Dr. Alwan explains, "I would like to see inventions that really have a profound societal impact proliferate." ■

Sandy Padwo Rogers is the managing editor of TAKE CARE!

Making a Difference



The Caregiver Community Action Network (CCAN) would not be successful if not for the dedicated individuals who are working every day to make a difference in the lives of family caregivers across the country. TAKE CARE! is pleased to profile one of those special volunteers, New Jersey CCANer Liz de Nesnera, who recently spoke with NFCA communications director Deborah Halpern.

When did you become a CCAN volunteer and why?

I became a CCANer in the summer of 2005. I had just gotten laid off from my “day job” and I was setting up my voice-over business. I thought this would be the perfect time to get more involved with NFCA.

I joined NFCA in 1995 after my mom suffered a massive hemorrhagic stroke. I’ve been caring for her ever since and she’s now showing serious signs of dementia. About a year after my mom’s stroke, my dad was diagnosed with Alzheimer’s. He passed away in early 2005 after being ravaged by the disease. So I have been a caregiver for nearly 14 years.

I’ve been impressed with NFCA since I joined — that it was started BY caregivers, FOR caregivers. I decided it was my turn to give back.

Has being a CCANer met your expectations?

Absolutely! I have met some amazing people who are all dedicated to helping family caregivers advocate not only for their loved ones, but also for THEMSELVES! I think that’s what has impressed me the most about my fellow CCANers — their dedication. Now I know that everyone has “a life” that they need to attend to, and being a family caregiver takes a toll. I’m so glad that I’m a CCANer because, while I’m dedicated to helping people in my community, I’m a part of an or-

ganization that “gets it” when I have to step back and spend more time on MY family caregiver role.

Is CCAN helpful to you personally?

Yes, because it’s a reminder to me that I have to take care of myself. I know it’s strange to say, but it’s true: Being an advocate for other family caregivers reminds me that I need to look out for myself as well. It’s also a great feeling to spread the message to people who aren’t aware of NFCA and all that the organization does. It makes me feel great when someone looks at the material I hand them and they smile and say, “This is great!”

How have you benefited from your experience as a family caregiver?

The main benefit is that I have come to realize that I can pretty much handle anything. I was 30 years old when I became a caregiver and I was thrust into a “sink or swim” situation of dealing with doctors, nurses, and the medical “system.” I have also become much more confident in what I know to be best for my mom.

As an example, when my mom got switched from one hospital floor to another right after her stroke, I saw the nurse start an IV and I decided to ask her what it was. “It’s a blood thinner,” she said. I almost fainted. “WHY are you giving my mother a blood thinner?” I asked. “Well, she just had a stroke, didn’t she?” was

the reply. Either the nurse or the doctor saw the word “stroke” on my mom’s chart and, since 90 percent of strokes are caused by clots, they assumed my mom needed a blood thinner. I immediately stopped the nurse and made her go check with the doctor since I really didn’t think that a blood thinner was appropriate for a hemorrhagic stroke patient. They stopped the blood thinner.

I was never shy, but since becoming a family caregiver I have become much more of an advocate.

How has being a CCANer allowed you to help other family caregivers?

One story sticks in my mind. I was asked to speak about caregiver stress and burnout to residents’ families at an assisted living facility. A woman walked in, sat down, crossed her arms, and dared me to tell her anything new. As I gave my presentation, I tried to draw her out a bit and to ask her questions about her situation in particular. By the end of the evening, she seemed a bit less tense, but I couldn’t really tell whether I had offered her any insight. The next day, the person who had hired me called to tell me that the woman who had dared me to help her had said that my talk had been the best caregiver talk she had ever attended and that I had really opened her eyes about how caring for herself could also help her care for her mom.

What are NFCA’s e-communities and how can people participate?

The e-communities are basically an online support system for family caregivers. They are an online resource set up by NFCA, divided by state, using the online Yahoo! Groups. The pilot program was started here in New Jersey and now

we also have e-communities for family caregivers in Michigan, Nebraska and Virginia. You can find information on the home page of NFCA's Web site: www.thefamilycaregiver.org.

It's sort of like e-mail, but where everyone in the group gets the e-mail and anyone can respond to it. In order to participate, post and reply to messages in these groups, you need to create a Yahoo ID. Once you've done that, you can ask your fellow caregivers questions, start a discussion, or just vent. It's a real community of people who are there for each other, even though you're not in the same room or even in the same town.

We hope to have an e-community for each state, but this is a start. It's a real extension of the NFCA mission of helping family caregivers help themselves.

Describe your most surprising experience as a CCAN volunteer.

What I have found most surprising is what a difference a group of volunteers can make. CCANers are a really committed group of people who do what they can to help family caregivers and they really make a difference. Lauren Agoratus, the other New Jersey CCANer, was instrumental in getting the New Jersey Family Leave Act passed. Bonnie Danowski of Arizona was also instrumental in getting caregiver legislation passed in her state. THAT is making a difference!

What is the best part about participating in the CCAN program?

I feel as if I'm part of something bigger, something that can make a difference one family caregiver at a time. Also, I know that what I do is appreciated. There have been times when I've had to step back because of my mom's condition and I've felt bad about not being able to do everything that I wanted to do as a CCANer, but everyone at NFCA is SO appreciative of what all the CCAN volunteers do.

Why should other family caregivers consider volunteering to be CCANers?

It's a great way to feel as if you're really doing some good in the world. I know that sounds lofty, but I really mean it. As family caregivers, we ALL have experiences and tales to tell about what we've been through. As a CCANer, I can share those experiences and help another family caregiver feel less alone.

Everyone has a skill that he or she can bring to the table. Whatever your skills or your passions, I'm sure we could use you in the CCAN program. As family caregivers, we "get it" when another family caregiver is stressed out. We "get it" when a family caregiver laughs at something that a non-caregiver wouldn't understand. Being a part of a group that shares in spreading the word about the importance of what family caregivers do and the role we play in society... what's not to recommend? ■

Make a difference in the lives of other family caregivers: Become a CCAN volunteer. More CCANers are needed everywhere, but we are specifically looking for volunteers in:

- Alaska
- Delaware
- Kansas
- Kentucky
- North and South Dakota
- Wyoming

For more information, contact Linda Jones, CCAN Director, at 248/358-1186 or linda_jones100@hotmail.com.

DON'T BE LEFT IN THE DARK

On February 17, 2009, **all TV stations will stop broadcasting analog signals** and will broadcast only in digital. **If you have an analog TV, you must make the digital transition.** Through March 31, 2009, all U.S. households may request up to two \$40 coupons to help pay for the cost of a certified converter box. For more information, visit www.DTV2009.gov or call toll free 888/388-2009.

New Brochure Highlights Medicare Benefits

If you are currently on Medicare, caring for someone on Medicare, or you will soon be eligible for Medicare, there is a new educational pamphlet out that is a must read. *Medicare's Preventive Care Services* contains information on free or low-cost preventive services and screenings as well as advice on managing cholesterol and ensuring heart health for you and your loved ones. Learn more about:

- Preventive physical exams during the first six months after enrolling in Medicare
- Screenings for cardiovascular disease, diabetes and prostate cancer, as well as Pap tests, mammograms, and much more
- Free annual flu shots

The brochure explains what Medicare covers as well as how you can reduce your risk of heart disease. To download a FREE copy of *Medicare's Preventive Care Services*, go to the NFCA Web site at www.thefamilycaregiver.org and click on "Caregiving Resources." To request a printed brochure via mail, send your request to NFCA, 10400 Connecticut Avenue, Suite 500, Kensington, Maryland 20895.

Getting Help

Continued from page 1

from the practicalities of tasks to the variable and emotional nature of caregiving.

“What the team does is focus on the *whole* family,” says Warnock. “For example, a group in California was created around the husband who is seriously ill, a young wife and two very young kids. The wife needed help understanding finances so the group found a certified financial planner to help. When child care was needed, group members were the babysitters.”

With deep satisfaction, Warnock reports that the *Share the Care*[™] concept is being used not only to assist individuals and families during times of illness but also in situations such as when one family needed help caring for newborn quadruplets, or when friends came together to lend support to a grieving family.

Pam Washek of Wayland, Massachusetts, has had her own experience of both needing help and giving help to others. In 2003, Washek was diagnosed with a cancerous tumor in her shoulder. As the young mother of three, Washek says, “I desperately needed help and accepting it allowed us to keep some normalcy in our lives when everything was very fragile.”

Through her experience, Washek met Jean Seiden, another resident of Wayland who had received meal preparation assistance from a network of friends, neighbors and community members during the time of her own health crisis. The two women spoke of the “angels” who had come forward to help and envisioned the creation of a network of “angels” who could lend a hand to other Wayland families facing a short-term crisis. Their dream led to the creation of the Wayland Angels, a volunteer network with more than 300 members providing everything from help with meals and shopping to yard work to child care or transportation (www.waylandangels.org).

“It’s a feel-good thing. You see in

(Continued on page 12)

Building a Caregiving Team

1. Talk With Your Family It’s important that everyone is receptive to receiving help. It’s also important to emphasize that help is being sought for the family as a whole, not simply to address the health concerns of the care recipient, or the stress of the caregiver.

2. Identify Needs List some specific needs for each member of the family. Estimate how often help is needed and how much time is required.

3. Enlist a Trusted Family Member or Friend to Serve as Coordinator Ask this person to serve as the “captain” or “key contact” for your caregiving team. This person will be the person entrusted to track what needs to be done and who has offered to do it. Key qualities of a good “captain” include: good organizational skills, ability to communicate clearly, and patience. The “captain” should also have good phone skills and, if possible, be somewhat computer savvy. Books like *Share The Care* can help. Go to www.sharethecare.org.

4. Be Ready to Accept Help While you may feel only a few people are needed to help, do allow others to join in the caregiving experience. Life events such as illness, vacations, or work demands may necessitate that some team members will not be able to fulfill their commitments, so it’s important to have more team members than you think you might need.

5. Be Creative Someone might want to plant a window box, offer a massage, or assist you with your laundry. Be sure to keep an open mind and heart to what gifts people wish to share — go beyond thinking about “what must be done” to creating a “wouldn’t it be great” list.

6. Communicate Changes As needs change or as your loved one’s condition changes, be sure to inform the “captain.” The people on your caregiving team are making an emotional investment in your family. They need, value, and rely upon good communication.

7. Consider Using Technology Some volunteers may be ideally suited to creating a Web page, uploading photos, doing computer research, sending e-mails, making phone calls, or setting up caregiving calendars on Web sites such as Lotsa Helping Hands (www.nfca.lotsahelpinghands.com/lhc/home/). Be inventive in how you welcome the assistance of volunteers who wish to help but who cannot or choose not to be “bedside.”

8. Express Gratitude Saying “thank you” can be done in many ways: a phone call, a note, an e-mail, or a hug. People may say that it’s not needed, but a “thank you” always says that our efforts are appreciated.

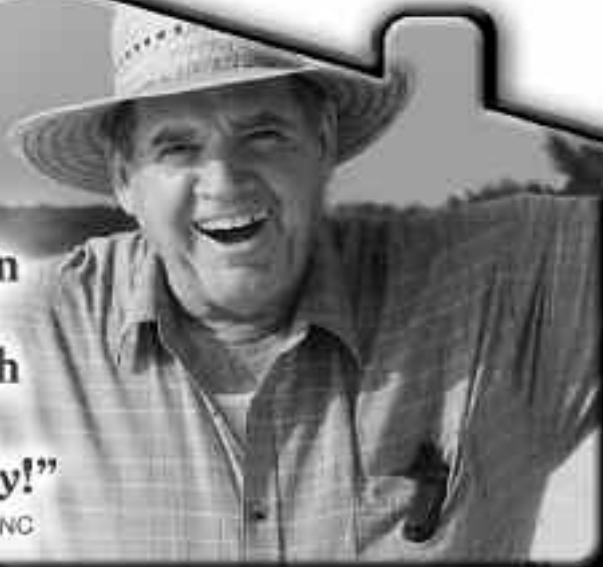
For more on reaching out for the help you need and how to create checklists for volunteers, go to www.thefamilycaregiver.org and click on “Caregiving Resources” and then “Tips and Tools.” NFCA’s “how-to” guides are available as free downloads.

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Getting Help

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the eyes of the people helping that they feel good about what they are doing ... and they want to do more," says Washek, who reports that there are now 14 other towns in Massachusetts that have created Angel Communities. "We're happy to help people learn how to set up an angel network," she says.

As the Wayland Angels network has grown, Washek has turned to technology to help keep everyone and everything coordinated. The "angels" were once coordinated via e-mail messages but now they rely upon a free, easy-to-use, private calendar system known as Lotsa Helping Hands.

"When Lotsa Helping Hands was created, it was the result of personal experiences that my business partner and I had in being caregivers," says co-founder Hal Chapel. "While many people were willing to help, it was difficult and time-consuming as

a caregiver to coordinate all of that help and manage to stay on top of what needed to be done."

"Managing the Lotsa Helping Hands calendar is not meant to be another job for the family caregiver," says Chapel. "It's meant to be the answer to a trusted friend or family member who asks, 'What can I do?'"

That friend or family member becomes the "lead coordinator." Coordinators are people who know the family well enough to help identify needs. The coordinator also allows approved "helpers" to access the Web site. Current postings of needs, a scheduling calendar, message boards, status updates, e-mail reminder notices, and even blogs are available to approved "helpers."

Chapel reports that more than 10,000 helping communities have been created through Lotsa Helping Hands. "It's difficult to ask for help once. It's even harder to keep asking for help many times. But with Lotsa Helping Hands, the family member is not asking for help. It's a place where people can see what is needed, determine what they can offer, and then come forward."

Coordinating Volunteers: Services That Can Help

Lotsa Helping Hands

www.nfca.lotsahelpinghands.com/ltc/home/

Share the Care

www.sharethecare.org

With resources like these available, family caregivers can determine how, when, and from whom they will accept help. That type of control over one's life might make all the difference between asking and not asking for help when it's needed.

And when is the *right* time to ask for help?

Nora Klaver suggests, "What seems to work best is to find some balance, some middle ground between being fiercely independent and falling into caregiver crisis." ■

Paula Sanders McCarron is a freelance writer whose healthcare background includes working in home care, hospice care, and elder care services. She resides in Massachusetts.

Five Ways to Expand Your Caregiving Team

Here is a sampling of what is available for creative caregivers who wish to expand their caregiving teams.

Dial 2-1-1

This phone number, where available, connects people with the community services and volunteer agencies in their area. United Way of America is spearheading the project to make this number available nationwide — approximately 75 percent of Americans are tied into the 211 information lines.

Think National, Call Local

Local chapters of national organizations may have volunteers who can lend support to your caregiving teams. Here's a sampling of what's out there: American Red Cross (Elderly Escort Program), National Hospice and Palliative Care Organization (hospice volunteers), Area

Agencies on Aging (Senior Companion Program), and transportation and visitation through the Disabled American Veterans' Voluntary Service Program.

Tap Into Faith Connections

Hundreds of communities have Faith in Action or Interfaith Caregiver volunteer organizations. Parish nurse programs may exist in your community, as well as faith-based organizations such as Catholic Social Services, Lutheran Social Services, or Jewish Family and Children's Services. Phone a local faith congregation or consult the phone book to learn what's available in your area. Most of these programs provide services to all, regardless of faith affiliation.

Don't Forget Social Circles and Acquaintances

Do you belong to a sports team or bowling league? A craft group or reading club? Do you carry membership in a professional association, an exercise group, or a gardening club? Any of these groups might be a source for adding members to your caregiving team.

Emerging Resources

Continued from page 2

As if the idea had never occurred to us.

Saying that is easy. Doing it isn't. Unless you can afford to phone the nearest home care agency and order up help as needed, you face a bewildering, disjointed, and time-consuming labyrinth of community services, government programs, and support organizations.

If you do find time to investigate these options, you're likely to encounter a lot of dead ends. One service is for seniors only, not the disabled (or vice-versa). Another says your income is too high to qualify (yet too low to afford paid home care). A third helpfully sends out a stack of paperwork that demands more time and information gathering than a tax return.

As the population ages, this problem is getting more attention. Local governments in particular are under increasing pressure to put coordinated programs, policies and services in place for the rising tide of seniors. This growing community focus is likely to benefit caregivers as a whole.

Some people, however, aren't waiting around for that to happen; they're taking matters into their own hands. One movement, dubbed "intentional communities" is gaining traction across the country. The idea is for residents of a neighborhood or community to form their own non-profit membership organization to secure the resources they'll need to "age in place." Everyone pays a fee to be eligible for services through the "village," as some of these communities are called.

One of the most successful of these communities is Beacon Hill Village, founded by longtime residents of Boston's Beacon Hill neighborhood. Services available with a subscrip-

tion to the Village include house-cleaning, errands, computer problem-solving, bill paying, transportation, weekly grocery shopping, home-delivered meals, medical advocacy and more. By partnering with providers, the Village is able to obtain these services for members at anywhere from 10 percent to 50 percent off the going rate. Annual membership for Beacon Hill Village costs \$580 per person and \$850 per household. Low- and moderate-income residents pay a significantly reduced fee and receive credit that can be used toward programs and services.

HouseWorks, a home care company based in Boston, Massachusetts, and Bethesda, Maryland, has been a strategic partner and the preferred home care provider for Beacon Hill Village since its inception in 2002. In addition to personal care, companionship, medication assistance, and skilled care, HouseWorks also offers home modification services in the Boston area.

HouseWorks is now involved in educating groups across the country about the intentional community movement. "We are witnessing a social revolution," says Andrea Cohen, HouseWorks' CEO. "Seniors and their adult children are much clearer about what they want and need to age in place, and intentional communities are a response to this trend."

In response to the thousands of phone calls and e-mails that have poured in during the past two years, Beacon Hill Village sponsored a conference in the spring of 2007 for community leaders from 27 states who were interested in learning how to organize their own village. Since late 2007, seven villages similar to Beacon Hill Village have opened across the country and more than 80 such villages are in the planning stages. The cost to join these other villages varies by area. At Capitol Hill Village in Washington, D.C., for instance, membership costs \$500

per year for an individual and \$750 per year for a household. The organization's goal is to provide as many services as possible by volunteers, thereby keeping total costs to the members as low as possible.

With efforts like these leading the way, workable solutions for time-starved family caregivers may be on the horizon. Who knows? Maybe we'll even be able to reach the impossible dream: time to care for the caregiver. ■

Linda Taubenreuther and her husband, Harald, live in Southern California, where they're partners in a home-based freelance writing and editing firm. Harald was diagnosed with MS in 1988.

To Learn More

Health Proponent

www.healthproponent.com
Toll-free: 866/93-WE-HELP
(866/939-3435)

HouseWorks

The "Intentional Communities" page on HouseWorks' Web site has frequently updated information and links.

www.house-works.com/innovations/communities.htm

Toll-free: 800/928-3393

(Greater Boston)

Toll-free: 866/238-8185

(Greater Washington)

Beacon Hill Village

The Village Concept: A Founder's Manual is a comprehensive guide to starting your own intentional community. The guide is available through Beacon Hill Village.

www.beaconhillvillage.org

Phone: 617/723-9713

Capitol Hill Village

www.capitolhillvillage.org

Phone: 202/543-1778

Online Discussion Group

<http://groups.google.com/group/beaconhillvillagemodel>



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:

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c/o TAKE CARE!
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e-mail: info@thefamilycaregiver.org
Subject Line: What Can I Do?

Q My aunt, who suffers from Alzheimer's, was widowed five years ago at the age of 86. She had no children but many nieces and nephews. When my aunt's husband died, three of her other nieces took her to a lawyer and had her make out her will listing them and me as beneficiaries. I was told not to tell anyone about this. (I was not included on the power of attorney, the co-executorships, or the healthcare proxy authorizations.) The nieces said my aunt expressly told them she only wanted to include the four of us in her will. The fact that her mind was clearly affected by Alzheimer's made this whole plan less than ethical and, to my way of thinking, dishonest. When I registered my strong disagreement with their actions, all hell broke loose.

Five years later, I have been pushed away and verbally abused at every turn by the two in charge, one of whom is my own sister. My aunt now requires a live-in aide, who was hired by the family and who has adopted the same kind of abusive behavior. Most other family members don't visit or call my aunt anymore because they don't want to be treated in this manner. My aunt is being denied contact with people who love her and can be a great asset to her life. What can I do?

A Caregiving can bring out the most loving spirit of family togetherness or the worst kind of divisive backbiting. Your family seems to be suffering the latter. As much as you care about your aunt and as determined as you are to help her, your options are few — take legal or psychological steps. Neither will be easy.

You can try to change this situation legally through two stratagems. First, you can challenge the veracity

of the documents that she signed five years ago, which gave others control over her affairs, by arguing that she was already incompetent at the time because of dementia. But unless there are medical records from that period that substantiate her incapacity to make legal decisions, you probably will not be able to convince a judge to invalidate those documents. The judge may assume that, in the absence of evidence to the contrary, she was competent to pick those relatives whom she chose to make decisions for her.

Secondly, you can argue that the relatives who are now serving as power of attorney are not currently caring for your aunt properly — in other words, they're not fulfilling their legal responsibilities. But here, too, the burden of proof would be high. You'd have to contact Protective Services in the county where your aunt lives in order to initiate an investigation into whether her live-in aide is abusive or neglectful. Even if those charges were found to be true, the county wouldn't likely petition a judge to take the power of attorney away from your sister and cousin; rather, it would probably just seek to require that they hire another aide.

In essence, these legal ploys are long shots. In the unlikely event that a court would wrest legal control of your aunt's affairs away from the current powers of attorney, there is no guarantee they'd turn to you to be her protector. What is guaranteed is that, with your attempt to overturn the current legal setup, you will provoke the ire of your sister and cousins. You then might be the target of their retaliation. For example, they could prevent you from having contact with your aunt at all for the rest of her life.

The best psychological strategy is almost as difficult and will probably be unpalatable to you. Yet it's the course I'd enthusiastically suggest: Co-opt your sister and cousins. Rather than challenging their power to control your aunt, support it. Praise them for the job they are doing. Offer to help take care of your aunt in the manner that they deem best for her. Befriend the live-in aide. In this way, you will have a better chance of insinuating yourself in your aunt's life and making yourself indispensable to her and to those people who presently hold the reins of her life. In my opinion, that is your only viable option for gaining any influence in this situation and putting yourself in a position to help your aunt. If you believe that noble ends can justify repugnant means, then hold your nose and pitch in.

Q I am 48 years old and the primary caregiver for both my daughters. One is 24 and has mental retardation and the other is 19 and has mental retardation, cerebral palsy, and she is deaf. Both girls are totally dependent when it comes to basic daily living needs. They are nonverbal and incontinent. One is tube fed and has a wheelchair; the other is able to feed herself and can walk. I work full time and find myself exhausted at the end of the day. I know it's only going to get harder as I get older. I love my girls more than anything and they are a source of great joy but there are times when I imagine what it would have been like if they were typical. I'm married and my husband is a huge help, but we both long for time for ourselves. Just recently my 75-year-old mother moved in with us. She is currently in good health but that can change in a heartbeat. I would like to connect with other parents of disabled adult children. It would be nice to talk to someone who truly understands our situation. I am also concerned about my daughters' future. What can I do?

A You and your husband have been unstintingly giving parents. Yet you are rightly concerned that the future may hold uncertainties that can overwhelm your capacities to continue to give. Devising contingency plans for those uncertainties will be difficult but necessary. Let's take each worry you raise and consider possible solutions:

You will lose steam/grow old/burn out: While you've been indefatigable taking care of your daughters, mother and husband, you sense that your supply of energy is not endlessly limitless, particularly as you age and care demands increase. You allude to several solutions in your question. Joining a support group for parents of adult children with developmental disabilities would provide you with acknowledgment for and understanding of the hard work you do. I'd contact your county's Office of Mental Retardation to see if there are groups that meet locally; there may also be online groups and chat rooms for caregivers who have similar experiences as you. You also reflect upon the need to have more time for yourself and for you and your husband. I agree and would urge you to find means of obtaining respite care so that you can carve out protected time to replenish yourself on a regular basis. Yes, that would probably mean that you set limits on the amount of caregiving you do. But that's the only effective strategy I know for sustaining yourself as a committed caregiver over the long haul.

Your mother will need more help as she ages: As a healthy senior, your mother may even be helping you with the care of your daughters at this point. But you rightly anticipate that that can change quickly. I would recommend that you begin having conversations with her now about the care she'd be willing to receive if she becomes less self-sufficient. Ideally, she'd agree up front to accepting services like home health aides or adult day care programs, so

that the brunt of her care won't fall on your shoulders. She may even agree to live in a supportive environment, such as an assisted living or long-term care facility. The idea is for you to ensure now that you won't have to feel responsible for all her care in the future. Again, creating those limits will help sustain you through the substantial caregiving that you will continue to provide.

Your daughters' need for care will not lessen, even though your energies will: One of the most wrenching decisions that parents of developmentally disabled adults face is whether to have their children move into highly structured and supervised group home settings. In many cases, parents put off such placement until they are aged and their children are in their 40s or 50s. Even then, it's a decision that's rife with guilt. In my clinical experience working with such families, the children themselves adjust best to the group home if they are in their 20s – 30s, at the latest. As a matter of fact, most of these children thrive in their new environments in which they depend less on their parents, learn new skills and grow.

Your letter doesn't indicate whether you and your husband have ever weighed group home placement for your daughters. And, yet, they are at an optimal age for considering it. If you decide to have them move, you will not be abandoning them or shirking your parental duties; rather, I expect that you will still see them almost daily and will be integrally involved in their lives. But you will be reducing your caregiving just enough to create much-needed time and energy to devote to yourself and your marriage. And you will be providing a chance for your daughters to develop new capabilities as they face new challenges. It's a difficult choice to contemplate. When you talk with other parents in support groups, be sure to inquire about their own emotionally fraught deliberations over this major decision. ■

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