

# TAKE CARE!

Self-Care  
for the Family  
Caregiver™

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## Becoming a Confident Family Caregiver



Sandy Padwo Rogers

How do you define “confidence”? The average dictionary uses the words “self-assurance,” “self-reliance,” and “certainty.” Ask family caregivers what “confidence” means to them and you’re likely to hear a slightly different description, one that includes such words as “perseverance,” “patience,” and “courage.”

What makes someone confident? We all have things at which we excel, things we are comfortable doing. We all have areas in which we feel knowledgeable and capable. Even the most competent and confident individual, though, can be plagued by feelings of self-doubt and fear when faced with an unfamiliar or extremely stressful situation. Not only are these feelings perfectly normal, they are universal.

Carol Levine, director of the Families and Health Care Project for the United Hospital Fund and a former family caregiver for her husband, says that when it comes to dealing with the healthcare system in particular, you might as well be trying to navigate an alien world. “The system is not set up to be friendly to patients or their families,” she says. “It’s a highly stressful experience and can send even the most confident person into a tailspin. Even medical professionals find it difficult when they are on the receiving end of healthcare delivery.”

Just ask Beth Deckert, a registered nurse whose own confidence level was severely tested when she found herself in the role of family caregiver. “Before my husband was diagnosed with MS, I thought that I could get through any challenge or obstacle because I believed in myself

and my abilities,” she says. “But my confidence plummeted when my husband spent eight days in the hospital. Part of me was exhausted and part of me was angry, resentful, and riddled with guilt. Mostly, though, I was frustrated with the hospital system and how ignorant the system was of the families’ needs. I wasn’t given information about the plan of care unless I asked. I wasn’t offered a place to rest until it became evident I was staying. I felt alone despite the enormity of the walls that made up the institution. To make matters even worse, I realized that as a nurse, I had treated family members the same way I was being treated.” Beth’s words make it easy to wonder: If a practicing medical professional doesn’t feel confident when dealing with the healthcare system, how can anyone else expect to?

According to Carol Levine, one of the first steps to becoming a more confident family caregiver is recognizing the fact that it’s not you but,

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## Lifespan Respite Care: One Woman's Fight

Suzanne Mintz

On the very last day of the 109th Congress (December 8, 2006), family caregivers won a great victory: A five-year effort to gain passage of the Lifespan Respite Care Act came to a happy — albeit nail-biting and, to some, a surprise — conclusion, with a voice vote in the Senate. Two days prior, on December 6, the same bill was passed in the House of Representatives. On December 21, it was signed into law by President Bush.

This effort was spearheaded by Jill Kagan of the National Respite Coalition, a small organization with limited funds. Jill was passionate about her work and had an in-depth understanding of the political process, having spent most of her 25-year career as deputy director of a congressional committee (10 years), head of a national advocacy organization, and as a policy consultant to other national and state organizations.

Armed with her passion and experience, Jill pulled together a core group of about 40 diverse organizations, including the National Family Caregivers Association (NFCA), in January 2001. The first meeting was held in an overcrowded conference room at the Easter Seals Washington, D.C., office. There were representatives from the disability community, the aging network, various disease groups, and caregiver organizations. On the phone were the head of the Oregon Respite Care Program, which had been in opera-

tion since 1997, and state Sen. Dennis Byars, a member of the Nebraska Legislature. They shared with the group their experiences getting lifespan respite care legislation passed in their respective states.

All family caregivers crave respite.

When asked what they need, the answer given most often is: "Time for myself." Finding that time is never easy: It's too expensive, the providers are not well-trained, caregivers feel guilty about wanting to get away, the waiting list for public programs is very long, and the list goes on.

Lifespan respite programs are designed to break down those barriers. They pull together all the diverse funding sources for respite that exist in their state because the value of the total pool really is worth more than the sum of its parts. The pool of funding creates far more flexibility in meeting the needs of individual family caregivers. They provide "one-stop" shopping for entry into the system; yet they function on the community level. They train respite workers, both paid and volunteer. They bring together an array of community groups and family caregivers to guide their activities and provide diverse services. They raise the public consciousness about the need for respite for caregiving families, and, when possible, provide critical funding sources for family caregivers who don't qualify for any other respite program.

Now with the passage of the federal Lifespan Respite Care Act, many more states will have the

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*"Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it's the only thing that ever has."*

— Margaret Mead

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# Siblings, Torn Over Caring for Mother, Learn to Work Out Differences

Rebecca Morris

The glass exploded when it hit the pavement, sending horseradish into the air, where it mixed with Seattle rain and fell from the sky.

It was then, after throwing a jar of my favorite condiment at my brother, that I knew I was really stressed. The smell lingered over my mother's Wallingford neighborhood for a week.

This was shortly after I had moved back to Seattle from New York City, in part to help with the care of our then-94-year-old mother. I don't remember what we were arguing about that night, but our differences are usually about how much or how little time I have to contribute to her care.

I work one full-time and two part-time jobs (my brother, Sterling, is retired). I am alone, having been widowed twice (my brother has a partner). I have struggled financially (my brother owns two homes, in Belltown and Palm Springs). I don't know many people here (Sterling has friends in Seattle he's known 45 years). Not that I ever feel sorry for myself or anything.

## The Constant Caregiver

As we work hard to sort this out, we are not alone. People 85 and older are the fastest-growing segment of the population. Nearly 80 percent of them are cared for by family members. Women — usually daughters — are still the most common caregivers, but the number of men assuming the task is increasing.

Sterling and I do not suffer in si-



Rebecca Morris (left), her mother, Lucille, and her brother, Sterling.

lence. We both unload on friends; mine call him obsessed because of his 24-hour-a-day focus on our mother; his think he is devoted and that I am not pulling my weight.

Our parents had been married many years when they adopted Sterling as a newborn. Four years later — surprise — me. Sterling says his dedication to our mother now is a thank-you, a payback for adopting him and giving him a good life. He says he feels an obligation.

My father's death was quick. He was almost 91 when he began to have chest pains. In one week's time, he

went from the hospital to a nursing home, where he died after just three days. Our mother just turned 96, and Sterling says her longevity is why he works so hard at maintaining her quality of life. "They don't die," he says, speaking of her and her cousins. "They live, and live, and live, and live."

## That Can-Do Nature

While we may be untraditional in that Sterling is the primary caregiver, we are absolutely traditional in other

ways. Linguistics professor and author Deborah Tannen says women want to talk, but men want to *do*.

He is magnificent at it.

He decorates my mother's apartment for Christmas. He bundles her up and speeds her around Green Lake in her wheelchair. He has her pucker so he can touch up her lipstick. He makes sure the back of her hair is combed. He gives her an injection of insulin in the morning, and has breakfast with her seven days a week.

Our mother feels a sense of security with Sterling that I don't think she feels with me. He can lean close, speak directly into her ear and convince her to take the pill, roll up her sleeve, drink this, try harder.

I have been lucky to have been on the receiving end of his doing. In 1979 and 1980, my husband Frank Conley, a Seattle radio news anchor, was dying of a brain tumor, and I was taking care of him at home. Sterling and a friend would come to our house and cut the grass, trim the shrubs and weed.

I have heard Mother tell people that Sterling is her best friend; it doesn't wound me. There have been enough times that she has said to me, "Becky, I don't know what I

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## Siblings

Continued from page 3

would do without you.” She doesn’t make me feel bad for being gone for years; I don’t think Sterling has forgiven me.

And, in fact, there are some things I do well for my mother. I buy her pretty panties and bras. She loves to play gin rummy, and I have more patience than Sterling does at cards. I give her showers, and I take off rouge when she has had a heavy hand.

It is when Sterling is burned out, or I am overwhelmed, that we fight. Our biggest argument is about having help, having others do some of what we do now. But assisted living is expensive, and she really doesn’t need it.

So we play a game that could be called, “Who Has It Worse?” The rules require that we have immature conversations about which of us is under the most stress. Another game we play is, “Who Can Hang Up the Phone First in Anger?”

If only Supernanny Jo Frost visited baby boomers. She could send us to the “naughty corner,” we’d shed a few tears and then we’d play nice.

### The Meaning Behind

#### The Message

The sibling relationship is one of the most challenging in life, says author Tannen, whose books include “You Just Don’t Understand:

Women and Men in Conversation,” and “I Only Say This Because I Love You: Talking to Your Parents, Partner, Sibs, and Kids When You’re All Adults.”

She said siblings can find themselves stuck in old childhood patterns. Family baggage and childhood rivalry gets unpacked when a parent is elderly or dying.

The key to improving relationships, Tannen says, is to distinguish between the message and the metamessage.

“Every utterance has one or more messages,” she says. “There is the meaning of the words, but also the

history of the relationship, the tone of voice, the timing and what the speaker means — the metamessage.

“What we say, and what we hear, are often two different things,” she says. “What the speaker means, and how the message is interpreted, can be different.”

This is true with Sterling and me. It drives him crazy that I ask questions — of the surgeon, a nurse, the physical therapist. I’ve been a reporter all my life, and I don’t know how not to; I’m just looking for information.

Sterling, however, may feel I’m undermining him when I ask questions, or that I’m not confident of his care or decisions.

If we can listen for the metamessage, the powerful stuff families say that makes us crazy, we may be able to act like the adults we are.

### A Learning Process

To manage my stress (and stay out of the naughty corner), I try to keep a few hours of the day for myself, hoping they won’t notice that I didn’t drop by. It is a relief not to see them. It is a relief to see them.

Sterling and I are learning. He is better at asking if I can help, and I am hoping to cut back on work so that I don’t feel as overwhelmed when he does ask.

Recently, when my mother was recuperating at his condo, Sterling cooked a pot roast and invited me over. I asked if I should bring horse-radish, but he said no, he had some.

I think — I hope — that we both laughed. ■

*Rebecca Morris is an award-winning broadcast and print journalist. This article first appeared in the Seattle Times on Feb. 8, 2007. Morris is working on a book about relationships between siblings when they take care of their parents. She can be reached at sibscaregiving@aol.com.*

“The sibling relationship

is one of the most

challenging in life.”

## Do You Still Have Questions About Medicare Prescription Drug Coverage?

Now consumers, caregivers and healthcare professionals across the country can access the timeliest Medicare information and resources, including state-specific information on picking the right plans, how to file an appeal, and what to do about the prescription drug coverage gap.

The Medicare Rights Center (MRC) has made its award-winning Web tool, Medicare Interactive, available to the public to help you navigate the Medicare maze. Medicare Interactive lets you search within broad topics, look up basic information, or seek out specific terms. Find answers to your prescription drug coverage (Part D) questions and more.

Visit [www.medicarerights.org/help.html](http://www.medicarerights.org/help.html) today!

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.

**Does your loved one have a life-limiting condition for which you could use some free legal advice?** The American Health Lawyers Association ([www.healthlawyers.org](http://www.healthlawyers.org)) has published an informational guide that is available to the public at no cost. *The Guide to Legal Issues in Life-Limiting Conditions* provides an overview of the practical and legal issues that arise when having to place a loved one in assisted living, nursing home, or hospice arrangements.

With a forward by Dr. Ira Byock, a nationally recognized expert on palliative medicine, the *Guide* tackles such topics as Independent Living at Home or in a Retirement Community, Long-Term Care Options, What to Expect Upon Admission to a Healthcare Facility, and Palliative and Hospice Care.

To download the *Guide* or a series of one-page summaries based on the *Guide*, go to [www.healthlawyers.org/lifelimiting](http://www.healthlawyers.org/lifelimiting). You can also call 202/833-0756 for more information.

**Do you have a child with a disability?** The National Dissemination Center for Children with Disabilities (NICHCY) provides families, students, educators, and others with information on topics regarding children and youth with disabilities, from birth through age 22. This includes research-based information about effective practices for educating and providing services to children with disabilities, information about how the No Child Left Behind Act (NCLB) affects children with disabilities, and information about educational research programs and initiatives involving children with disabilities.

NICHCY is operated through a cooperative agreement between the Academy for Educational Development (AED) and the Office of Special Education Programs (OSEP), U.S.

Department of Education. NICHCY's information specialists have backgrounds in special education and other disability-related areas, and have worked as teachers, advocates, researchers, trainers, and social workers.

NICHCY's Web site contains links to resource pages on a variety of topics, publications, state resources, and more. NICHCY also offers a toll-free number and bilingual services. Go to <http://www.nichcy.org> or call 800/695-0285.

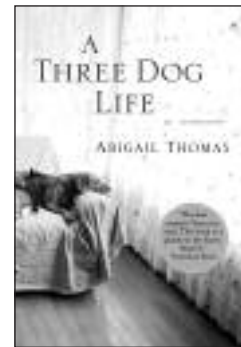
**Are you evaluating long-term care options for your loved one?** As a family caregiver, you are already providing help with your loved one's basic daily activities like bathing, dressing, or using the bathroom independently. But have you thought about what would happen if some day you needed help providing this care?

The U.S. Department of Health and Human Services has developed a new Web site, [www.longtermcare.gov](http://www.longtermcare.gov), aimed at providing information and resources to help you and your family plan for future long-term care (LTC) needs. The National Clearinghouse for Long-Term Care Information is primarily intended as an information and planning resource for individuals who don't yet require long-term care, but the Web site includes information on services and financing options that can be helpful to all individuals. Included are sections on understanding LTC, planning for LTC, and paying for LTC. The site also contains a comprehensive glossary of terms and a link to a variety of resources.

Call 800/Medicare for more information or go to [www.longtermcare.gov](http://www.longtermcare.gov).

#### BOOK REVIEW

**A Three Dog Life** by Abigail Thomas (Harcourt, Inc., 2006, \$22.00) Like many caregivers who are shoved into



the path of oncoming tragedy, Abigail Thomas remembers exactly when her whole life changed. Her husband, Rich, was hit by a car while out

walking their dog. The accident shattered her husband's skull and any semblance of normalcy for Thomas. But when you become a family caregiver, your very definition of "normal" changes. That's the beauty of this book. This is not a depressing blow-by-blow account of the author's caregiving experience. This is a book about how, despite her husband's accident, despite the rages and unstable mental state that forced her to place him in an institution, Thomas was able to "put a life together with my family and friends and dogs." This, she realized, despite her initial guilt, was OK. It wasn't about negating the accident or the deep love she still feels for her husband; it was about honoring her new life *now*. "I wish he were whole," she says. "But I love my life." These are words to live by. We can't change what happened to our loved ones. So why can't we try to enjoy the lives we have fashioned for ourselves — *in spite of* being family caregivers? Abigail Thomas shows us it's OK to have a life — our own life. It's a lesson many caregivers need to hear and take to heart.

*A Three Dog Life* is available wherever books are sold and at [www.harcourtbooks.com](http://www.harcourtbooks.com).

*The Book Review for this issue of TAKE CARE! was provided by CCAN representative Liz de Nesnera.*

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## Confident Family Caregiver

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rather, the system that's faulty, and that you are not alone in your feelings. "You have to learn to work in a world that isn't designed to be helpful," she says. The key is to acknowledge that in most situations, learning to work in that world and to build that confidence is going to take time. There are some things you can do, however, to ease the process.

### Get to Know Yourself

Learning to be a confident caregiver begins with a bit of self reflection. What are your strengths and weaknesses? What are you good at? In what areas do you need help? Recognizing your own strengths and limitations doesn't diminish your effectiveness as a family caregiver. In fact, this type of self-analysis is an important step in becoming a better caregiver for your loved one.

Are you naturally curious, always wanting to understand things as best

you can? If the answer is "yes," then you'll likely have an easier time gathering the information you need to make caregiving choices.

Are you comfortable dealing with situations on your own or do you feel better when you have someone with you, supporting you in what you do? If you feel intimidated in healthcare settings, it may be helpful to have someone you trust with you during these types of encounters, especially if you are dealing with a healthcare "crisis." This individual will be able to remember the information presented with more objectivity and can help you keep the facts straight. Try to find a family member or friend who is willing to serve as your healthcare buddy, especially in a time of crisis. Just having that extra support can make a caregiver feel more in control and capable of dealing with whatever comes along.

Knowing your strengths and weaknesses allows you to set boundaries and can give you the confidence to know when to say "no" and when to ask for help — things many family caregivers find very hard to do.

Being aware of your strengths and weaknesses and how they may change as you age is a very important step in becoming a confident and capable caregiver.

Knowing yourself and understanding the circumstances that surround you is the first step. But becoming a more confident family caregiver shouldn't end there.

### Do Your Research

You can gain confidence in yourself by being prepared. One way to ensure that you are prepared is through research. Research takes many forms. One of the most important types of research you can do is to find out as much as you can about your loved one's illness or condition. Knowledge is power and being armed with an understanding of what you are dealing with definitely provides you with a powerful tool for conversing with the various medical professionals taking care of your loved one.

Just as it's important to research your loved one's illness or condition, it's equally important to understand the language of healthcare. We can all imagine how uncomfortable it would be to visit a foreign country without the benefit of knowing how to speak the language; the same goes for your dealings with medical professionals. This doesn't mean you need to receive medical training. Rather, learning a little about medical terms that you may be hearing and being able to use those terms appropriately will help you feel more in control and will put you on more equal footing with those with whom you must communicate. If you want to be treated as a true partner in the healthcare team, do the research and learn the language of the other members of the team.

Research isn't only about gathering formal information, however; it's just as much about gaining an understanding of how the environments you will encounter work:

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### Use the Internet Wisely

The World Wide Web is our instantaneous link to a wealth of information and ideas. It is also a source of vast amounts of misinformation. Therefore, it is extremely important when working online to get into the habit of using a few safeguards:

- Stick with reputable organizations. Go to Web sites of government agencies, non-profit organizations, and other entities known for their integrity and their public service orientation. (NFCA has a list on its Web site. Go to [www.thefamilycaregiver.org](http://www.thefamilycaregiver.org).)
- Steer clear of information presented by groups with whom you are unfamiliar. The Internet has made it possible for just about anyone to publicize their ideas regardless of whether or not they are based on scientific evidence. Be vigilant.
- Try to find more than one source for the information being presented. If the information you find is reliable, then confirming it on another Web site should pose no problem.
- Keep in mind the source of the information being presented to you. Be on the lookout for any potential bias that may exist on the part of a site's sponsor.



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1. Ring H, Hausdorf JM, The immediate effects of a new FES Neuroprosthesis on Gait stability and symmetry, 15th European Congress of Physical and Rehabilitation Medicine, Madrid Spain, May 2006 (conference proceedings)

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*B.P., a Wisconsin resident, has been living with foot drop since his stroke four years ago. The L300 has re-energized his recovery.*

*"It allows me to lift my foot higher---it was really neat because it allows my leg to be more flexible" he says.*



## Confident Family Caregiver

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doctors' offices, the ER, or an adult day care center, for example. Understanding their rules and practices will make you feel more in command of your caregiving situation and help you get the information you need and the respect you deserve that much more quickly and with less hassle.

### Find an Ally

According to Carol Levine, when dealing with the healthcare system, it's extremely helpful to find an ally within the system itself. It could be a nurse in the physician's office with whom you feel a special connection, a social worker at the hospital, or even your loved one's physician. This individual will be more familiar with the system in general and can help answer your questions and give you the inside story on what's happening and why. "Look for someone who is willing to share their experience and provide guidance," says Levine. "These people are out there and they can keep you from feeling incompetent."

### Learn How to Express Yourself

Family caregivers don't always communicate well. It's easy to understand why. Confusion, stress, and

#### Learn How to Communicate Effectively

NFCA created the Communicating Effectively with Healthcare Professionals (CE) program to give family caregivers the tools they need to be effective members of the healthcare team. To read helpful CE articles, go to [www.thefamilycaregiver.org](http://www.thefamilycaregiver.org) and click on Caregiving Resources.

anger can get in the way of good communication. When communicating on behalf of your loved one, however, it's crucial that you learn to communicate clearly and to avoid putting the individual on the other end of the conversation on the defensive. Stay focused on clear goals and concrete questions when talking with physicians and other healthcare professionals. Control any impulse you have to express

anger. Instead, learn to express yourself in a way that is likely to get the results you want. What do you want to accomplish in the short term? What are your immediate goals? By expressing those goals calmly and clearly, you are more likely to get the results you want. Remember, it's in the best interests of your loved one to handle the situation at hand. You can always seek redress later if necessary.

In terms of communicating your loved one's needs, you have a vital role to play. In the healthcare setting, it's important to show respect for the training and knowledge that the physician brings to the table. Don't forget, however, that you have an expertise that is just as valuable in that you know your loved one better than anyone else.

Because of your expertise, and because of the role you play in your loved one's care, you have the right to be treated as an equal partner in the healthcare team. To ensure a successful healthcare encounter, you need to take charge of the process. If that means politely refusing to leave a doctor's office until all of your questions are answered, that is your right. If it means insisting that you get a second opinion before you and your loved one make a major healthcare decision, that is your right as well. Don't underestimate your role in your loved one's care. After all, if you don't look out for his or her best interests, who will?

### Be Proactive

There are concrete actions you can take to feel more prepared and in control, especially in the event of a healthcare crisis. One proactive step you can take is to ensure that you and your loved one have the legal paperwork necessary for making critical medical decisions. No one likes to deal with these things, but proactive people make it their business to find a way.

Every family caregiver should have a folder of important papers, including the following legal documents:

- A durable power of attorney for healthcare.
- An advance medical directive or living will.
- A do-not-resuscitate order (DNR), if desired.
- Authorization forms for the release of information for office visits, operations, and other medical procedures.

All of the legal documents you will need are easy to complete and may be obtained from your local hospital, your attorney, or your state's attorney general's office. Keep in mind that the legal requirements for, and the effect of, these documents vary from state to state. Once you have the proper documents completed, make sure they are easily accessible in the event your loved one must be hospitalized.

Proactive people always have a better chance of staying on top of a situation, but being proactive doesn't come naturally to all of us. If being proactive isn't in your nature, then you need to find a family member or friend who is. This is especially important if you want to feel at least somewhat in charge of what happens to you and your loved one.

### Give Yourself Time

Gaining confidence takes time and courage. "To be a true advocate, you

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## March Brings CCANers to Chicago

Deborah Halpern

**N**FCA's dedicated state volunteers, Caregiver Community Action Network representatives (CCANers), regularly attend meetings and conferences on family caregiving issues. During the week of March 5, CCANers from across the country converged on Chicago to participate in several important industry conferences, including the First National Conference for Caregiving Coalitions and the joint conference of the American Society on Aging (ASA) and the National Council on Aging (NCOA).

These conferences presented a wonderful opportunity for CCANers from across the country to get together, with most of us meeting each other in person for the first time. Three CCANers served as speakers at the NCOA/ASA conference, including Eboni Green from the Senior Caregiver Support Group in Omaha, Nebraska; Carolyn Anderson from Ann Arbor, Michigan; and John Paul Marosy from Bringing Elder Care Home in Worcester, Massachusetts.



*Above, left to right: John Paul Marosy, Massachusetts, and Mark Paley, Illinois*

*Below, left to right: Eboni Green, Nebraska, and Maria Meyer, California*



*Left: Joanne Cruz, Michigan, (left) and Wilma Schmitz, Missouri*



Eboni Green participated in the New Ventures in Leadership program, where she talked about a program model promoting self-advocacy for caregivers so they can better support their aging loved ones. Carolyn Anderson addressed issues surrounding young caregivers and, for the fourth year in a row, presented, "Why Doesn't Grandma Know Me? Talking with Children and Teens About

Alzheimer's, Related Dementias and Memory Loss." This presentation walks adults through the various developmental stages so they are better able to communicate effectively at a child's or teen's cognitive level.

John Paul Marosy presented "Empowering the Employed Family Caregiver: A Train-the-Trainer Approach." He was also one of five panelists at the "Balancing Elder Care in the Workplace" conference.

Other CCANers attending the NCOA/ASA conference included Rose Trosper from Arkansas, Maria Meyer from California, Wilma Schmitz from Missouri, Joanne Cruz and Linda Jones from Michigan, and, from the host city of Chicago, Maya Hennessey and Mark Paley. Suzanne Mintz, NFCA's president and co-founder, was also in attendance.



*Left to right: Linda Jones, Michigan, Suzanne Mintz, president of NFCA, and Carolyn Anderson, Michigan*

For all who attended, it was a time to network and to learn from the leaders in the field. For the CCANers in particular, it was a fabulous opportunity to get to know one another. Two special CCAN dinners allowed these representatives to enjoy good food and great conversation. It was wonderful to learn about the many similarities in everyone's work, as well as to exchange stories and examples of issues CCANers face as they work with family caregivers in a wide variety of settings. For many of the CCANers in attendance, these dinners offered the first opportunity to meet with Suzanne Mintz. It was the perfect setting to talk about the

CCAN program in general, to present issues that CCANers would like addressed in upcoming training sessions, and to discuss CCANers' views on the future growth of the CCAN initiative. ■

*Deborah Halpern is NFCA's communications director.*

For more information on the Caregiver Community Action Network, contact Linda Jones at [linda\\_jones100@hotmail.com](mailto:linda_jones100@hotmail.com) or 248/358-1186.

## S U R V E Y

### *Family caregivers' opinions of gerotechnology*

Are you a caregiver who is:

- 45 to 60 years old
- Caring for or helping an older adult relative or friend (age 65 or over) with some of their daily activities (e.g., shopping, healthcare, personal care)

If so, you are eligible to participate in a survey on baby boomer caregivers, conducted by researchers at the Center for Health Aging Research, Oregon State University.

This is a national study that polls baby boomer caregivers about issues of caregiving tasks, stress, burden and gerotechnologies (both communication and monitoring) that can help support caregiving.

Participation in this survey involves completion of a Web-based survey at your convenience.

This survey is available at the following location:  
**[www.stat.oregonstate.edu/caregiversurvey/](http://www.stat.oregonstate.edu/caregiversurvey/)**

To learn more, please go to the Web address above or e-mail [atiya.mahmood@oregonstate.edu](mailto:atiya.mahmood@oregonstate.edu).

## STATISTICS WORTH NOTING

- The **number of hours** a family caregiver dedicates to providing care increases with the age of the caregiver.  
— *Partnership for Solutions. Chronic conditions: Making the case for ongoing care. Baltimore: Johns Hopkins University, 2002. Go to [www.partnershipforsolutions.org/DMS/files/chronicbook2002.pdf](http://www.partnershipforsolutions.org/DMS/files/chronicbook2002.pdf).*
- **Ten percent** of employed family caregivers go from full-time to part-time jobs because of their caregiving responsibilities. Nearly 60 percent of family caregivers report that they have to go to work late, leave early, or take time off during the day to provide care.  
— *National Alliance for Caregiving and AARP, Caregiving in the U.S., 2004. Go to [www.caregiving.org/data/04finalreport.pdf](http://www.caregiving.org/data/04finalreport.pdf).*
- Family caregivers experiencing extreme stress have been shown to age prematurely. This level of stress can take as much as **10 years** off a family caregiver's life.  
— *Elissa S. Epel, Ph.D., Dept. of Psychiatry, University of California, San Francisco, et al., Proceedings of the National Academy of Sciences of the United States of America, Dec. 7, 2004;101(49): 17312-5.*
- Caregiving families (families in which one member has a disability) have **median incomes that are more than 15 percent lower** than non-caregiving families. In every state and the District of Columbia, the poverty rate is higher among families with members with a disability than among families without.  
— *Disability and American Families: 2000, Census 2000 Special Reports, July 2005.*

## Confident Family Caregiver

Continued from page 8

have to be willing to put yourself out there a little bit," says Carol Levine. "Advocates are not always the favorite person in the room, but theirs is a necessary and important job. Over time, you learn to understand the system and to navigate it as best you can."

For Beth Deckert, time spent learning how to navigate the system as a family caregiver rather than a nurse allowed her to gain a new confidence that she has put to good use. "Several months after my husband's hospitalization, I realized that because of the struggles I had endured I had gained a new level of confidence that I wanted to use to help others," she says. "I had struggled greatly not just on a physical level but on an emotional and spiritual level as well. But I realized that I

had survived that tough time. I believed in myself enough to contact the vice president of nursing at the hospital I worked for and I shared with her what family members encounter when they have a loved one in the hospital. Before I knew it, we were discussing possible opportunities to support families. That was a true beginning for me, and it was based on a new level of confidence I had never before experienced."

What many family caregivers have discovered is that "confidence" in caregiving will mean different things to different people. As Beth Deckert explains, "Confidence isn't just one thing. It's something that's built one step at a time. It's having the confidence to say 'no' to the way things are as well as having the confidence to keep focused on the opportunities that exist within the challenges." ■

*Sandy Padwo Rogers is the managing editor of TAKE CARE!*

## Do you receive NFCA's monthly E-letter?

If not, you are missing out on this important membership benefit. Send your name, e-mail address, and membership number (located on the newsletter mailing label) to [communications@thefamilycaregiver.org](mailto:communications@thefamilycaregiver.org). Providing this information will ensure your access to this and other benefits of membership.

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- An enhanced search engine to help you find your favorite pages quickly
- Access to the NFCA store ... and so much more!



[www.thefamilycaregiver.org](http://www.thefamilycaregiver.org)

Empowering YOU and other family caregivers through  
Education, Support, and a Public Voice

## It Doesn't Have to Be This Hard

Continued from page 2

opportunity to develop programs for their citizens. It wasn't easy getting this far, and the fight isn't over yet. Once a bill is passed, the money to fund it has to be appropriated by Congress — an effort that is going on now.

Helping Jill now, as before, are NFCA, Easter Seals, the Alzheimer's Association, the National Multiple Sclerosis Society, and over 175 national, state, and local groups and their incredible memberships. I'm proud to say that whenever Jill has asked for grassroots support, NFCA members have joined with thousands of other family caregivers and respite supporters across the country to send e-mails and make phone calls to let legislators know the importance of respite.

Jill Kagan's efforts to expand respite opportunities for family caregivers are a very real example of how to use public policy to affect the day-to-day lives of family caregivers. Jill's work proves that one person — working tirelessly, pulling together a team, finding ways through the maze of politics to build a path to consensus, creating a sense of urgency, harnessing support from Republicans and Democrats, and keeping the momentum going — really can change the world.

There are now four states with respite care programs and several others that are making great progress on getting legislation passed. (See the winter 2007 issue of TAKE CARE! for a profile of CCAN volunteer Bonnie Danowski of Arizona and her efforts in this area.) Hopefully, your state won't be far behind. ■

*Suzanne Mintz is the president and co-founder of NFCA.*


## To learn more about the Lifespan Respite Care Act of 2006 (H.R.3248.ENR)

**go to:** [www.thomas.gov/home/multicongress/multicongress.html](http://www.thomas.gov/home/multicongress/multicongress.html)

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**click on:** "109th Congress," "Enrolled Bills Sent to the President," "Both House and Senate"


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TAKE CARE! Spring 2007 13



*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](http://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](mailto:info@thefamilycaregiver.org)  
 Subject Line: What Can I Do?

**Q** I'm 48 years old, an only child, and the sole caregiver for my father. I have no job, no friends, no income, and no life outside of my caregiving. I can't find any programs that will help support me as a caregiver or help my father with his needs, except for programs that cost more money than I can afford. I can't help but wonder who will be there for me after my father passes away. How do I rebuild a life for myself when I was never able to have one in the first place? I feel as if I'm going to be left on the roadside of life. What can I do?

**A** You seem to have two main concerns: How can you garner support for caring for your father? Will that support disappear upon your father's demise? Let's examine them one at a time.

The place to start identifying support when taking care of an elderly parent is by contacting your county's Area Agency on Aging (AAA). You can go to [www.n4a.org](http://www.n4a.org) and use the "Eldercare Locator" or call 800/677-1116 to get the phone numbers and e-mail addresses of the AAA nearest to your father's home. The AAA in his region will likely offer senior centers, Meals on Wheels programs, home health services, and case management at little or no cost. It should also have a Family Caregiver Support Program that may include caregiver support groups and monthly stipends to pay for equipment, home health aides, and other support services. Through the senior centers and support groups, you will likely meet other adult children who are caring for their parents. They may become your compatriots and confidants in struggling with this arduous work.

If the AAA's support isn't enough, I'd suggest checking out the Web sites of the NFCA and other organizations dedicated to enhancing caregiver well-being. Many of them have online discussion groups or chat rooms where caregivers can converse, conspire and complain. Some have specific "mentoring" programs in which newer caregivers are paired up with more experienced caregivers of like circumstances for guidance and encouragement. Again, all this should cost you little but the time and energy you invest in reaching out.

As to your second question, research suggests that most caregivers, whether they're comfortable admitting it or not, feel a sense of relief upon the death of the care recipient. However, a smaller percentage of them become depressed in response to the loss of their loved one as well as to the loss of what had been a gratifying and meaningful role as a caregiver. Given your comments and questions, perhaps you are concerned that you may fall into that latter category. The key for you will be developing a sense of yourself and your purpose in this world that no longer involves your meeting your father's needs and wishes. One means of grieving your losses and reinventing yourself will be discussing how you are feeling at a bereavement support group; most hospice programs and hospitals sponsor them. Another may be seeking individual counseling. Your physician or health insurer can make an appropriate referral. If money is an issue, you can contact your county's department of mental health to see if there are any counseling centers in your area that offer treatment on a sliding-scale fee schedule.

Caregiving can often feel like a trap from which it seems impossible to escape. But with the right help from others, it can be a cocoon from which, with time, a different you emerges.

**Q** We have an 85-year-old mother who is frail and aging. She is unable to walk and wants round-the-clock caregiving. Our dad is 90 and in good health, but not active in the caregiving. We have hired 24-hour sitters who stay with Mom at all times and attend to personal care as well as feeding. There are four daughters who all work full time. One daughter lives 30 miles away and is the care coordinator. She feels there must be a family member present the majority of the time along with the 24-hour sitters. The other three daughters live 350 miles away and farther. We are taking time off work, sometimes without pay, and driving or flying home to share in the caregiving about four days per week.

Our only role is to cook meals, clean and consult on healthcare and prescription medications. Our mother expects us to attend to her bedside demands and answer her questions 22 hours per day. She wears the sitters down and they leave when they no longer can cope. She also becomes very upset if someone is not in the room at all times. On the days when no daughters are present (about two days per week) the sitters can't even take breaks. Mom also makes very hurtful statements when she isn't happy. Between the all-night activity, which is overwhelming, and the hurtful statements, she is driving her daughters away. I believe that we have become enablers and are not helping matters. I would like to see our mother become trusting of the sitters and less demanding. What can we do to avoid dividing the family and keep harmony?

.....  
**“One-sided arrangements  
rarely work over  
the long haul.”**  
.....

**A** When family members devise a caregiving plan, they usually try to come up with an arrangement that's fair and equitable to everyone involved. What's missing from the plan that you and your loved ones have made is any semblance of fairness or equity. To so privilege the preferences of one family member — in this case, the care recipient — places an onerous burden on the rest of the brood that can only generate resentment. In short, this isn't a caregiving plan that can be sustained without doing harm.

Why does this happen in families? It occurs sometimes because a parent feels entitled to being waited on hand and foot by her children on the basis of all that she did for them when they were young. More typically, a parent selflessly waited on her parent years ago and now feels that her children owe her the same regal treatment. Occasionally, the children themselves will feel that they are supposed to sacrifice their own lives for what they regard as the parent's well-being. Regardless of which rationale is used, such one-sided arrangements rarely work over the long haul. Mutual consideration, cooperation and support aren't simply matters of politeness; they're a more effective survival strategy for keeping all family members replenished and capable as they cope with the infirmities of old age.

I would suggest that you and your siblings set up a meeting in person or via a conference call to discuss the state of your caregiving plan. If there's a general consensus that the plan as is isn't working for everyone, then generate potential changes to make it more sustainable. Changes may include inviting your parents to live with one of you, having them move to an assisted living facility, or rethinking how you are using the home health aides. I would then recommend that all of you meet with

your mother in person to present your concerns and ideas for solutions. She may very well react negatively to such a meeting; she may even go so far as to accuse you of neglecting her in her time of need. Please respond to her without anger or guilt by firmly and calmly telling her that the best way you can take care of her and your father is by coming up with a plan that doesn't burn out anyone. If she still demurs (and she will), please tell her that change is necessary and that you would like her input on what the new caregiving plan should be.

No caregiver needs to meet the needs of a care-recipient perfectly. It's not even possible. We merely have to strive to be caregivers who are sensitive and reasonable. You sound like conscientious people whose efforts to help your mom — even if you're catering to her less — will be plenty good enough.

**Q** I am the primary caregiver for my young daughter, who suffers from diabetes that requires constant monitoring. My husband is very supportive and helps when he can, but my daughter and I are very close and she prefers to be with me. She gets upset when I'm not around. My husband has offered to care for my daughter for a weekend so that I can get some much-needed respite. While I know in my heart that they can both survive a weekend without me, I'm feeling extremely guilty about leaving. My daughter has also asked me not to go. How do I assuage my daughter's fears and my own guilt so that I can get the rest I need? I don't think I'm capable of letting go, even for a weekend.

**A** Parents have paradoxical duties. On the one hand, they're supposed to protect their children; on the other, they must help them grow to be self-sufficient. When a child develops a chronic illness such as diabetes, her parents

*(Continued on page 16)*

## What Can I Do?

Continued from page 15

frequently feel that they've failed to provide adequate protection and respond by redoubling their efforts to shield and succor her. Unfortunately, this means that they consequently may fall short in their efforts to foster the child's independence and confidence in her own capabilities.

Surely, you love your daughter and want to do all you can to please and protect her. But part of helping her grow into a self-sufficient person means encouraging her to trust people other than her mother. Learning to trust and rely on her father would be a good start toward teaching her to adapt to others' ways as a means of better dealing with the world at large. In all likelihood, she will learn to become more comfortable relating to her father without your presence, especially if you wholeheartedly support their relationship. It would then be important to teach her to rely on other caregivers — grandparents, teachers, babysitters, etc. — as a way for her to continue growing as a socially competent being.

With these thoughts in mind, it isn't necessary for you to take a weekend respite if doing so will be traumatic for you and her. What is crucial, though, is that you incorporate father-daughter time into your family's weekly schedule. The less anxiety you have about separating from her, the more readily she'll accept it. She may protest, but rest assured that you will be fulfilling your parental obligation to help her grow. ■



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