

TAKE CARE!

Self-Care
for the Family
Caregiver™

VOL. 16 | NO. 3 | FALL 2007

Coping With Caregiver Depression

Content for this article was drawn from the family caregivers and depression section of the NFCA Web site.

Have you ever suffered from major depression? Have you ever experienced consecutive weeks when nothing seemed right, when it wasn't a question of your glass being half empty or half full because you couldn't even see anything inside worth measuring?

If you answered "yes," you're definitely not alone. Family caregivers suffer from major depression much more frequently than the rest of the population. That's a fact. It's also true that when a family caregiver suffers from depression, there are two people at risk: the family caregiver and the family member or friend for whom she or he cares.

Caregivers and Depression

The statistics are sobering. According to a study published in 2002 by the *American Journal of Public Health*:

- Family caregivers who provide care 36 or more hours weekly are more likely than non-caregivers to experience symptoms of depression or anxiety.
- Family caregiving spouses experience symptoms of depression or anxiety at a rate six times higher than non-caregivers.
- Family caregivers caring for a parent experience symptoms of



depression or anxiety at a rate that is twice as high as non-caregivers.

For those caring for a loved one who is suffering from Alzheimer's disease or another form of dementia, the statistics are more alarming. According to the Alzheimer's Association, depression is found in up to 50 percent of Alzheimer's caregivers.

Defining Major Depression

Major depression is significantly more than feeling sad, unhappy, or moody. Most people experience these feelings for short periods. Major depression is a mood disorder in which feelings of sadness, loss, anger, or frustration interfere with everyday life for an extended period of time. Major depression requires a doctor's supervision.

A family caregiver who is suffering from major depression experiences a combination of at least five of the following consistently for at least a two-week period:

- Depressed mood, loss of interest or pleasure in most daily activities

- Significant change in weight or change in appetite
- Trouble sleeping or excessive sleeping
- Feeling tired and a lack of energy
- Feelings of hopelessness and helplessness
- Feelings of worthlessness, self-hate, and inappropriate guilt
- Feelings of low self-esteem

(Continued on page 6)

INSIDE

	2
<i>It Doesn't Have to Be This Hard</i>	
	3
<i>Speak Up</i>	
	4
<i>Resources, Reviews & Whatnot</i>	
	8
<i>National Family Caregivers Month 2007</i>	
	12
<i>CCAN Update</i>	
	13
<i>Your CCAN Representatives</i>	
	14
<i>What Can I Do? Caregiver Questions</i>	

The Healthcare Nightmare

Suzanne Mintz

My friend Fran* is living a family caregiver's nightmare. As I write this, Fran's husband, Bill*, has been either in the hospital or a post-acute facility for four months. Fran can count on one hand the number of nights she has made it home before 11 p.m.

Bill has been a high-maintenance diabetic for a long time. What I mean by that is his blood sugar level is erratic and so his insulin needs to be monitored and tweaked fairly often. He also has many of the comorbidities (the medical term for additional chronic conditions) that typically go along with diabetes, such as high cholesterol and hypertension.

Bill sees multiple doctors — so many that the list sounds like a dictionary of medical specialties. He has a primary care physician, a cardiologist, an endocrinologist, a neurologist, an ophthalmologist, a podiatrist, a vascular surgeon, and a wound care specialist to treat his various conditions.

Bill had a triple bypass back in the mid-'80s. Subsequently, he's also had two strokes and a seizure, resulting in some impairment of his right arm and occasional short-term memory lapses. His condition eventually resulted in him retiring earlier than he expected. Most recently, he developed a diabetic ulcer on his right foot that was not responding to medication despite many months of treatment. Eventually his foot began to swell and cause him great pain. Despite this, no new actions were taken. When Bill's pain became un-

bearable, Fran took him to the ER; he was admitted to the hospital right away. The diagnosis: The ulcer was infected. And that is when the nightmare began.

There isn't enough room here to give you a highly detailed description of everything that occurred, but this synopsis will give you a sense of Fran and Bill's ordeal.

Shortly after Bill entered the hospital, the ulcer, which started as a small irritation of the skin, very quickly turned into a hole the size of a quarter that reached all the way down to the bone. Fran can't help asking herself, "Why did this happen?" It's not that she hadn't taken Bill to the doctor, didn't follow directions for medicating the ulcer. Unfortunately, she's never received a good answer. One reason Fran thinks it happened is that many different podiatry residents were treating Bill. No one appeared to check the history of what went before, nor prepped the one who came after. It was like a revolving door, and the lead podiatrist wasn't monitoring the case as fully as he should have been. It's no wonder that Bill developed an infection that went undetected until his trip to the ER, and then progressed from cellulitis to osteomyelitis after being admitted to the hospital.

Fran was forced to become the unofficial coordinator of all of Bill's care, keeping his primary care physician up to date, trying to set up actual team meetings, and watching the aides and nurses as they treated Bill because it was not uncommon for them to forget to review his chart for new instructions that might have been entered or to use the wrong medication on Bill's wound. Fran was responsible for coordinating Bill's care, but she didn't have the training necessary or the re-

(Continued on page 11)

TAKE CARE!

is published four times a year by the National Family Caregivers Association, a not-for-profit corporation. For membership information or to respond to articles, contact:

NFCA
10400 Connecticut Avenue, Suite 500
Kensington, MD 20895-3944
Phone: 301/942-6430 800/896-3650
Fax: 301/942-2302
Email: info@thefamilycaregiver.org
Internet: www.thefamilycaregiver.org

NFCA Honorary Board

John Breaux (D-LA)
US Senate, retired
Ken Dychtwald, PhD
President/CEO, Age Wave, L.L.C.
Chuck Grassley (R-IA)
US Senate
Barbara Mikulski (D-MD)
US Senate
Irene Pollin, MSW
Founder, Linda Pollin Institute
Harvard Medical School
Olympia Snowe (R-ME)
US Senate
Judy Woodruff
Journalist, PBS Special Correspondent,
Family Caregiver
Dana Reeve
Honorary Board Member 2000-2006

NFCA Board of Directors

Eric Fig, CPA, Chair
Jim Paglia, Vice Chair
Andrea Cohen, Secretary
Jon Shanfield, Treasurer

Directors

Hal Chapel
Linda Jones, RN
Suzanne Mintz
Corrine Parver*

TAKE CARE! Newsletter Staff

Suzanne Mintz, Publisher
Sandy Rogers, Editor in Chief
Cynthia Fowler, Art Director
Christal Willingham,
Production Manager/Advertising

*Serves as chair of the Advisory Board

The suggestions contained and resources referenced in TAKE CARE! are for informational purposes only. Be certain to consult a trained professional or attorney before taking any actions in follow-up to information that you learn or read in TAKE CARE! NFCA shall not be liable for any damages or any other liability that may occur in connection with caregiving decisions or actions undertaken by readers of TAKE CARE!

Copyright © 2007. National Family Caregivers Association. All rights reserved. No part of this publication may be reproduced in any form or by any electronic or mechanical means without permission in writing from the publisher.

ISSN # 1085-374X

* Names have been changed to protect the privacy of the individuals involved.

Speak Up!

On the simplest level, “Speak Up” means raising the sound of our voice so others can better hear us. Speaking up is how we solve problems. It’s how we learn. It’s how we educate. It’s how we bring about change.

During the course of a typical day, we probably all speak up quite a bit. When it comes to family caregiving, however, many of us tend to be very quiet. We don’t tell our children that we need help caring for their dad. We don’t tell our boss that we need a more flexible schedule. We don’t speak up to question a doctor when our gut tells us we should.

Speaking up tends to be hard for family caregivers because we are on uncertain ground. We question our knowledge and our actions and we don’t get to talk with other family caregivers all that much to boost our confidence. We don’t tend to think that maybe the difficulties we face have nothing to do with our own actions but, rather, with the fact that we really are swimming upstream as we try to make life better and easier for our loved ones and ourselves.

How do we Speak Up, on behalf of ourselves, our loved ones, and all family caregivers? How do we get more of what we need without coming across as difficult?

- We need to come from a place of confidence, to say to ourselves, “I can do this.”
- We need to come from a place of anger — not too much, as that can be counterproductive, but just enough to say, “I’m not going to take this anymore,” or, “I’m not going to do this anymore.”
- We need to come from a place of knowledge so we can speak with some authority.
- We need to believe that speaking up for our rights is critical if we,

and our loved ones, are going to journey down the crooked path of caregiving without tripping and falling each time we turn a corner.

Here are some tips and suggestions to help you Speak Up for respect, for support, for information, for help, and for the rights of all family caregivers.

1. Believe in Yourself

If you believe in yourself, you can Speak Up by making active choices that are in your own best interests, including:

- Self-identifying as a family caregiver
- Recognizing your strengths and acknowledging your limitations
- Learning to say “no”
- Commanding respect from health-care providers

2. Protect Your Health by Speaking Up for Your Right To

- A good night’s sleep
- A respite holiday
- Time and energy to exercise
- Regular checkups to ensure that if something is wrong you catch it early
- A life of your own apart from caregiving

3. Reach Out for Help by Speaking Up for Your Right To

- Recognition that family caregiving is more than a one-person job
- Care coordinator services to help you navigate the confusing pathways of our health and social support systems and ensure continuity of your loved one’s care
- Financial assistance so you can purchase help in the marketplace
- Community-based supports designed to help caregiving families
- Regular respite opportunities



4. Speak Up for Your Rights And the Rights of All Family Caregivers

- Speak up for adequate education and training in the skills you will need as a family caregiver
- Speak up for affordable health insurance if you are not getting it through your employer
- Speak up for financial support to protect you from impoverishment in your later years
- Speak up for annual assessments of your own needs and the means for meeting them

Helen Keller, a woman who, despite blindness and deafness, became one of the most inspirational people of our age and a noted public spokesperson for the dignity of the disabled, said: “If we all do a little it will add up to a lot.” There are more than 50 million family caregivers in America; that adds up to a lot of voices. ■

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 or is someone you know uninsured? The Foundation for Health Coverage Education has developed a new Web site designed to help those who are uninsured identify what insurance options may be available to them. The Foundation's Health Coverage Eligibility Tool is an interactive Web program that helps individuals locate public and private health plans for which they may qualify, including free or low-cost health benefits. Users can find state-specific information as well as information for the District of Columbia. Help is available via the Foundation's toll-free help line or Web site. The Web site also offers an easy link to a free guide to public and private health options for each state.

To get help over the phone, call the uninsured help line at 800/234-1317 and speak to a live operator 24 hours a day, seven days a week. Operators speak multiple languages. To access the Foundation's Web site, go to www.coverageforall.org.

Do you or your loved one have Medicare? The Centers for Medicare & Medicaid Services (CMS) has a secure online service designed to help you access your personal Medicare information. Mymedicare.gov is a secure Web site that provides people with Medicare easy access to personalized information about benefits; claims information; eligibility for and utilization of preventive services; prescription drug plan choices and enrollment options; provider quality measurements; and a variety of other personalized health management tools.

CMS has recently added new functionality to help beneficiaries track their eligibility for and utilization of preventive services. CMS will send beneficiaries who provide their e-mail address an e-mail reminder when they are eligible for one of their preventive services. The notification will encour-

age more Medicare beneficiaries to take advantage of covered preventive services.

Mymedicare.gov is a great tool to help people keep track of their Medicare benefits. To learn more, go to www.mymedicare.gov.

Are you concerned about patient safety? Consumers Advancing Patient Safety (CAPS) has launched a new online resource where patients and healthcare providers can share information and collaborate to make patient care safer.

The CAPS Web site links members with a global network of consumers, healthcare providers, policymakers, researchers and others committed to a partnership approach to improving healthcare safety.

The new portal features a collection of tools created by and for users concerned with issues relating to patient safety. CAPS members who have experienced medical harm/error are invited to share their stories. The CAPS Web site also contains extensive resources, regularly updated with information primarily for a non-clinician audience, with an emphasis on providing tools, educational materials, and lessons learned from consumers to healthcare providers. The site includes a discussion board to facilitate networking and links to other patient safety organizations.

To find out how you can join CAPS for free and take advantage of this new resource, go to www.patientsafety.org.

BOOK REVIEW

When Roles Reverse: A Guide to Parenting Your Parents by Jim Comer (Hampton Roads Publishing Company, 2006, \$17.95).

The term "parenting your parents" is a controversial one. Some care-



givers find it on target; others feel it's disrespectful. Whether you approve of the term or not, suspend semantics and mine this book's wealth

of inspiration and information. Like many caregivers, Jim Comer found himself at a caregiver's crossroads: remain a long-distance caregiver or make the move back home to take over his ailing parents' care. Jim moved back to Texas. In part one of his book, Jim recounts with love, humor and respect the frustrations involved in caring for his parents. Whoever thought that hearing aids could become the focus of one's days! It's important to note that Jim didn't move in with his parents but, instead, found a safe and loving placement for them. Jim's story proves that even if you "place" your parents, you are still their caregiver. Part two is dedicated to providing information on all aspects of elder care. His list of "Fifty Questions That Will Save You Time, Money and Tears" is an invaluable family communication tool. Interviews with family caregivers, nursing home administrators, assisted living facility owners, lawyers and others involved in elder care provide resources that all caregivers can use. As Jim says, "Caring for your parents: There's no one right way." This book can help you find your way.

When Roles Reverse: A Guide to Parenting Your Parents is available wherever books are sold or at www.hrpub.com.

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

The Home-Caring Brand® 
TRANQUILITY®
Incontinence Products

“Emphasis on Excellence!”



Loving Caregivers Know...

...effectively managing incontinence makes a world of difference for their loved ones - and themselves.

...Tranquility - the Home-Caring Brand® delivers unsurpassed absorbency, odor elimination and leakage protection.



**Call 866-865-6055 for FREE Samples
or visit www.tranquilityproducts.com**

Caregiver Depression

Continued from page 1

- Sudden outbreaks of anger
- Difficulty thinking, concentrating, or making decisions
- Recurring thoughts of death or suicide

Major depression does NOT include:

- Substance-induced depressed moods (e.g., drugs or alcohol)
- Schizoaffective disorder or another similar diagnosis
- Feelings of loss brought about by the death of a loved one

Forms of Depression

Depression is generally ranked in terms of severity: mild, moderate, or severe. The degree of your depres-

sion, which your doctor can determine, influences how you are treated. The primary types of depression include:

- **Major depression:** Five or more of the symptoms listed above must be present for at least two weeks. Major depression tends to continue for at least six months.
- **Minor depression:** Characterized by less than five depressive symptoms present for at least two weeks.
- **Dysthymia:** A chronic, generally milder form of depression; although it lasts longer, sometimes for as long as two years.
- **Atypical depression:** Depression accompanied by unusual symptoms such as hallucinations or delusions.
- **Bipolar disorder:** With this condition, moods cycle between mania and depression.
- **Seasonal affective disorder**

(SAD): Often referred to as the "winter blues," SAD is a form of depression that comes and goes with the changing of the seasons.

- **Adjustment disorders:** An abnormal or excessive reaction to a life stressor. Symptoms typically begin within three months of the identifiable stressor and usually abate within six months.

Common Causes of Depression For Family Caregivers

Depression is a nature-nurture phenomenon. That means that it's a matter of genes and environment interacting to produce the depressive changes. As arduous as family caregiving can be, if you become depressed it is more than likely that you have a genetic vulnerability to developing depression. The stress associated with family caregiving, in conjunction with your innate tendency to become depressed, can re-

The **Official** *Family Caregiver Bumper Sticker!*

Stand Up! Speak Up!



Order Yours Today!

Only \$4.97 each (+\$0.75 s/h)
To order online visit:
www.CaregiversCommunity.com
(Bulk pricing available)

To Order By Mail:
Send Check or Money Order Payable to:
Reservoir Road Productions
PO Box 71 - Pompton Lakes NJ 07442
Include your Name, Address, Phone & Email
We never sell, rent or share customer info!

Senior Life Settlements

Do you or a loved one have life insurance that you no longer need or want?

Did you know you can sell your policy for cash TODAY?

Did you know the proceeds can be used for any reason, including providing care for a loved one?

Call us to discover the hidden value of life insurance. For over 10 years Money For Life has been helping families meet the ever-rising cost of caring for a loved one.

Call today for a free consultation.
301/656-8622



A New Look at Life Insurance

sult in the development of major depression. Yet, even with a genetic predisposition, it is usually a stressful or unhappy life event that triggers the onset of a depressive episode.

Factors that increase a family caregiver's likelihood of becoming debilitated by depression include:

- Tending a loved one with disruptive behavior
- Personality changes caused by neurological conditions
- Having frequent conflict with the healthcare team
- Lacking available social and emotional support

Addressing Barriers to Care

Although it has long been recognized that mental illness is a real medical condition that responds to treatment, countless individuals still face unnecessary barriers to care. These barriers may be self-imposed: Caregivers are too embarrassed to talk about what they are experiencing or they may be afraid to seek treatment for fear of ostracism by family or friends or discrimination at work. Barriers also come in the form of lack of access to qualified mental health professionals and inadequate insurance coverage.

It's an unfortunate fact that, despite the tremendous advances many mental health advocates have made raising awareness and acceptance of these illnesses as biologically based diseases, health insurers still do not provide the same level of benefits for mental health services as they do for other medical and surgical services. This lack of parity continues to be the focus of such organizations as the National Alliance on Mental Illness (NAMI), an organization that is determined to win mental health parity at both the state and national level. In fact, NAMI has published the first comprehensive state-by-state analysis of mental healthcare systems, scoring every U.S. state on 39 specific criteria that result in an overall grade and four sub-category grades. Sadly, the national average

Resources That Can Help

■ Depression-screening.org

(Hosted by the National Mental Health Association)

<http://www.depression-screening.org>

Includes, in addition to the self-screener, video testimonials and additional information on major depression.

■ Depression and Bipolar Support Alliance

<http://www.dbsalliance.org>

Frequently updated with events, advocacy, training, and other news.

■ Psych Central

<http://psychcentral.com/disorders/sx22.htm>

Breaks depression symptoms into general and specific episodes and includes resources for specific groups (women, children, and teenagers).

■ Depression Is Real Coalition

<http://depressionisreal.org/depression-resources.html>

Offers many links to "find support" and targets specific demographics.

■ Mayo Clinic

<http://mayoclinic.com/health/depression/DN99999>

Provides videos, a doctor Q & A, and treatments.

grade for our mental healthcare system is a D. Only five states received grades in the B range while eight received F's. To find out how your state scored, go to www.nami.org, click on "Inform Yourself" and then "Grading the States."

While organizations such as NAMI continue to push for health insurance parity, education, and support for those suffering from depression and other mental illnesses, family caregivers can help themselves by speaking up for their own needs, seeking treatment, and speaking out on behalf of others.

Coping With Depression: Speak Up for Your Needs

What can you do to prevent depression? Speaking up for your needs and getting support is essential. As a family caregiver, you should reach out for logistical help, for social support, and for emotional support. Don't wait until you are feeling strained to ask for help. That means:

- Don't be afraid to ask for logistical

help from those closest to you.

Try to involve the entire family in care planning (and giving) from the outset. You may not be able to, but your life will be so much easier if you can.

- Find sources of emotional support. Inquire about help that may be available to you through church and community supports. Find a caregiving buddy, a support group you can attend, or an online caregiver group. The more connected you feel to other like-minded, supportive people, the less likely you are to become isolated, depleted, and depressed.
- Try to take care of yourself by eating right, getting the right amount of sleep, and exercising. We know it's not easy to do these things when you are family caregiver, but it's essential that you try. They are essential to your physical and mental well-being.
- Set personal goals, both short-term (take a walk every day) and

(Continued on page 10)

SpeakUp

National Family Caregivers Month

REACH OUT
PROTECT
BELIEVE

NFC Month — observed every November — is a nationally recognized time to focus attention on the more than 50 million family caregivers who provide 80 percent of our nation's long-term care services. That amounts to more than \$306 billion in "free caregiving services" annually. During NFC Month, family caregivers are encouraged to SPEAK UP for stronger public policies that address caregiving issues and to increase community programs that support caregiving families. During NFC Month, and every day, the National Family Caregivers Association encourages family caregivers to:

- Believe** in Yourself.
- Protect** Your Health.
- Reach Out** for Help.
- Speak Up** for Your Rights.

To learn more about how you can become involved in NFC Month, visit www.thefamilycaregiver.org.

The Joint Commission has an award-winning patient safety program entitled SpeakUp. This program educates patients about how to be active participants in their care.

NFCA's theme and graphics for National Family Caregivers Month 2007 parallel the Joint Commission's program and encourage family caregivers to speak up for their rights in multiple ways.

To find out more about the Joint Commission's patient safety SpeakUp program, click on www.jointcommission.org/GeneralPublic/Speak+Up.

CARING PARTNERS



NFC MONTH FRIENDS

INTEL | MetLife Foundation | Teva Neuroscience | Tranquility Incontinence Products

ALLIED ORGANIZATIONS

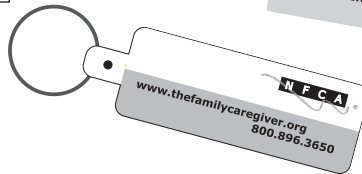
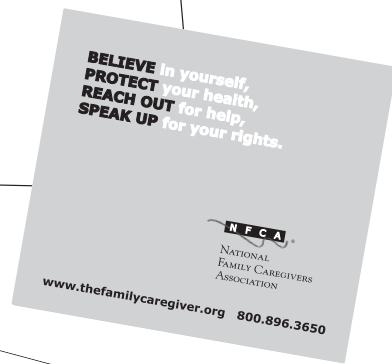
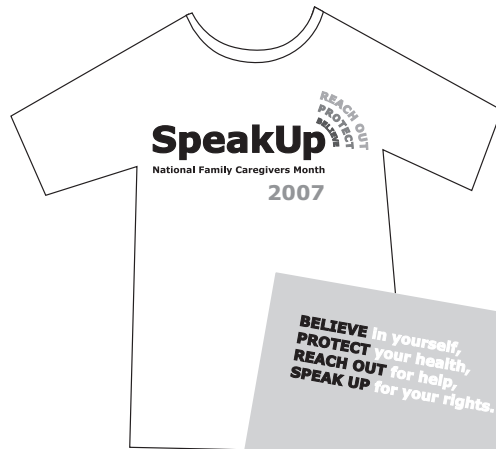
American Stroke Association: A division of the American Heart Association

ENDORISING ORGANIZATIONS

Administration on Aging
Allergy & Asthma Network Mothers of Asthmatics
ALS Association
Alzheimer's Association
Alzheimer's Foundation of America
American Academy of Nurse Practitioners
American Academy of Physician Assistants
American Association for Geriatric Psychiatry
American Autoimmune Related Diseases Association
American Counseling Association
American Self-Help Group Clearinghouse
Aroostook Agency on Aging
Catholic Health Association
Chapel Hill Training Outreach
Christopher and Dana Reeve Foundation/Paralysis Resource Ctr

Consumer Consortium on Assisted Living
Consumers Advancing Patient Safety
Disaboom
Disease Management Association of America
Easter Seals
Family Caregiver Alliance/National Center on Caregiving
Family Voices
Generations United
Geriatric Mental Health Foundation
Hawaii Caregivers Institute for Social Responsibility
Huntington's Disease Society of America
Lupus Foundation of America
Mather Lifeways
Medically Induced Trauma Support Services
National Alliance for Caregiving
National Association for Contingence
National Association for Home Care & Hospice
National Association of Councils on Developmental Disabilities
National Bone Marrow Transplant
National Council on Aging

National Health Council
National Hospice and Palliative Care Organization
National Multiple Sclerosis Society
National Organization for Empowering Caregivers
National Organization for Rare Disorders
National Pain Foundation
National Patient Safety Foundation
Neuroscience Institute of the Pacific
New Jersey Foundation for Aging
Paralyzed Veterans of America
Partnership for Patient Safety
Pediatric Adolescent Gastroesophageal Reflux Association
Rosalynn Carter Institute for Caregiving
Share the Caregiving, Inc.
The Simon Foundation for Contingence
Statewide Parent Advocacy Network
The Transverse Myelitis Association
United Cerebral Palsy
United Ostomy Associations of America, Inc.
Well Spouse Association
WE MOVE



**Celebrate with:
posters
tee shirts
mouse pads
key chains and more**

Order now at www.thefamilycaregiver.org.

Caregiver Depression

Continued from page 7

long-term (develop more of an ongoing support network).

- Think of things that will make you feel better and do at least one of them.
- Plan ahead as much as possible. You will be less likely to become depressed if you proactively determine what you are willing and able to do and what you feel limited in doing. Another way to plan ahead is to develop a “What If I Can’t Provide Care” emergency plan. While most family caregivers don’t want to believe anything serious will happen to them, the reality is that the very fact that you *are* a caregiver means that you are more prone to illness than non-caregivers. Take the time now to create a list of tasks that need to be done in any given week. Group your tasks into cate-

You Can Help Others

Do you know a family caregiver who is showing signs of depression? There are simple things you can do to help:

- Approach the family caregiver, gently, and recommend an evaluation by her/his primary care physician.
- Immediately pitch in to help with that family caregiver’s caregiving responsibilities.
- Help the family caregiver find resources and support groups, which help to ease feelings of stress and the sense of isolation that accompanies the caregiving role.
- Send the family caregiver a card every day to demonstrate that she/he is loved.

gories such as personal care for your loved one, transportation, household chores, etc. Developing this plan will help you feel more in control and less stressed.

- Watch for signs of depression. If you think you are suffering from major depression, see your doctor right away. Major depression is a serious illness that can be treated with talk therapy and/or medication. Left unchecked, it can impact the care you provide your loved one as well as your own well-being.

Seek Treatment

If you think you are dealing with major depression, you must take time to think about yourself, your future, and your personal life goals in order to move forward.

- Talk to your doctor to get a diagnosis and discuss treatment options.
- Consider medication therapy. Research the pros and cons of any therapy on the World Wide Web (make sure you go to reputable sources for this information).
- Consider individual or group therapy.
- Talk to other family caregivers who have suffered from depression. Find out what they learned from their experience; but remember that everyone is different and every experience is unique.

Speak Out on Behalf of Others

We all have a role to play when it comes to overcoming the stigma of mental illness. Talking about our experiences openly and honestly, joining advocacy groups, and speaking up when we see disparities in the way depression is treated are all things we can do to make a difference.

The willingness of many celebrities and other public figures to speak out about their experiences with mental illness has helped bring these conditions out in the open. But you don’t have to be in the public eye to

Screen Yourself

Taking a depression screening test is one of the quickest and easiest ways to determine whether you are experiencing symptoms of major depression. While only a doctor can diagnose whether you are truly suffering from depression, a depression screener can provide you with an indication if you might be and will help you determine if it’s time to check with your doctor.

To find a depression screener, go to www.thefamilycaregiver.org, scroll down to Events and Announcements, and then click on “Family Caregivers and Depression: Symptoms and Hope.”

help others, nor do you have to shout out from the rooftops. You can start with smaller steps. Just talking with your doctor, your family, and your friends is an important first step. If you feel you’re ready to play a larger role, join an advocacy group. NAMI’s StigmaBusters seeks to “fight inaccurate and hurtful representations of mental illness.” You can join StigmaBusters by going to www.nami.org and clicking on “Take Action.” You can also make phone calls, write letters, and help educate others on the harm that results when we stigmatize mental illness.

Finally, you can help others who may be suffering from depression by sharing your experiences, offering support, and encouraging them to seek the help they need. By helping others, you will also be helping yourself. ■

Funding for the development of the family caregivers and depression pages on NFCA’s Web site was made possible by an unrestricted educational grant from Forest Laboratories.

Healthcare Nightmare

Continued from page 2

spect of the medical personnel involved. And all this was on top of her full-time job.

The long and the short of it is that the wound was not healing, no matter what was tried. The doctors huddled and presented Bill and Fran with bad news. The blood flow to Bill's foot was virtually nonexistent and things would be getting worse, not better, as more and more ulcers occurred. The prognosis was pretty grim. There was an operation that could possibly open an artery above Bill's ankle and restore the blood flow, but Bill was not a good candidate for it since two of his arteries were blocked with plaque and the third one that goes to the foot was too small. The medical team advised amputating Bill's leg all the way to the thigh. The other option was amputating pieces of it at a time as the problem progressed.

In this partial description you can easily see some of the numerous problems and frustrations that Fran encountered while trying to get good care for her husband. Here is a list of those and more.

- Residents without proper supervision, which led to mismanaged care
- Nurses not checking charts and therefore applying the wrong medication
- Nurses not checking charts and therefore forgetting to provide ongoing, daily medications
- Healthcare by body part as opposed to treatment of the whole person
- Lack of consideration of the impact of Bill's diabetes on proposed treatments
- Medication interactions that caused Bill to lose cognition
- Bureaucratic runarounds instead of honest answers

- Bureaucratic runarounds because no one wanted to take responsibility
- A lack of a patient advocate until it was too late to do any good
- Extreme resistance when Fran said she wanted to get an outside opinion on the recommendation to amputate Bill's leg

Need I go on? Fran is a fighter and an amazing advocate for Bill. She finally prevailed, and, through a combination of cunning and good luck, was able to get a copy of Bill's medical records from hospital A and managed to get him transferred to hospital B.

The good news is that hospital B was able to operate on Bill and to restore blood flow to his right foot, the lack of which was preventing the healing of his ulcer and causing the intense pain Bill was experiencing. (Remember that hospital A was not recommending this be done.)

I've been listing out the problems Bill and Fran experienced in a straightforward and factual way, which does not let you see the anguish and frustration, the exhaustion, and the fear on my friend's face. Nor can you know the intense physical pain that Bill went through and his sense of utter helplessness. Ultimately, it was determined that although Bill's leg could be saved, his toes needed to be amputated. He was transferred a few weeks ago to a rehab center where a rather inconsistent medical staff needs constant oversight and Fran is afraid to leave until all treatments have been finished for the evening and Bill is going to sleep.

This is chronic illness care in America today — a workforce shortage and poorly trained personnel on the one hand, and well-trained but

poorly supervised personnel on the other. Care is disjointed, at best, and there is little, if any, teamwork that addresses the patient as a whole.

There is also no coordination. Many things need to change in order for our loved ones to receive good chronic illness care; one of the most important things is to add a care coordinator, or healthcare navigator, to the medical team, especially in complex cases like Bill's.

This person (or team of people) would be responsible for ensuring that all the other team members know fully their patient's situation and converse together

regarding treatment options, with all of the variables and their implications on the table. The coordinator would be responsible for cutting through bureaucratic rigmarole to get things done in a timely manner. She would be an advocate for Bill across all settings — whether from one floor to another in the same building or across town to a different one — and then to home so that information is not lost during the transfer, something that occurs all too frequently today.

She would work in partnership with Fran to ensure that Bill gets the highest quality, safest care possible, and the products, equipment and social support services he needs. She would also keep an eye on Fran to make sure that Fran is taking good care of herself.

There are some people who think that if Medicare paid for comprehensive care coordination services for its sickest members, so much money would be saved that Medicare would not have the financial problems it does. We won't know until we try, but it is the best chance we have for making sure our loved

(Continued on page 16)

“It's important for family caregivers to speak up ... and demand that the presidential candidates discuss their plans to better address the needs of families dealing with chronic illness or disability.”

Preparing for National Family Caregivers Month 2007

Debby Halpern

National Family Caregivers Month (NFC Month) is a time when family caregivers are encouraged to take action to improve their own health and well-being by speaking up for their rights. In recognition of NFC Month 2007, CCANers will distribute 25,000 FREE educational gift bags to family caregivers. The gift bags will include educational brochures as well as an array of other great tools and resources. The NFC Month free gift bag program is made possible, for the second year in a row, thanks to the generous support of Eisai Inc.

CCANers are planning a variety of additional outreach activities during NFC Month. For example, in Pennsylvania, CCANers are working with several organizations to sponsor a forum for family caregivers that will be held at the University of Pittsburgh's Child Welfare Training Program.



Michigan's CCANers gathered recently with NFCA's Stephe McMahon to share information and ideas. Pictured are: (top row, left to right) Melanie West, Carol Hilf, Sue Hasenau, Linda Jones and Elaine Simpson, and (bottom row, left to right) Jane Cortez, Stephe McMahon, Carolyn Anderson, Joanne Cruz and Jennifer Kirkland.

In Michigan, CCAN volunteers are generating letters to the mayors and/or county executives of each municipality in which there is a

current NFCA member. When proclamations are announced, the CCANers plan to reach out to the family caregivers from those communities and invite them to attend the ceremonies. In this way, CCANers will celebrate publicly the efforts of individual family caregivers in their own communities.

These are only a few highlights of the activities CCANers will be participating in this November. If you are interested in receiving free NFC Month gift bags or you are looking for other opportunities to celebrate family caregivers, contact a CCANer near you (see the accompanying list) or call 800/896-3650.

We are always looking for more dedicated volunteers. For more information on the CCAN program, contact Linda Jones at 248/358-1186 or linda_jones100@hotmail.com. ■

Debby Halpern is NFCA's communications director.

Remember NFCA in Your Year-End Giving

As you consider your year-end giving, please remember NFCA with a generous donation. Your donations help us help you.

Employees of the federal government, postal service, and U.S. military can help caregiving families by participating in the world's largest workplace giving campaign: the **Combined Federal Campaign (CFC)**. If you are a federal/postal/military employee and would like to give to the National Family Caregivers Association through the CFC, please enter code **#11221** on your pledge card during the workplace giving campaign.

NFCA also makes it easy to donate via our Web site. Just go to

www.thefamilycaregiver.org

All donations are tax deductible.

Your CCAN Representatives

ALABAMA

Clarissa F. Smith, PhD, MAR, OTR/L - Birmingham, AL
E-mail: clarissafsmith@aol.com

ARIZONA

Bonnie Danowski - Scottsdale, AZ
E-mail: bjdanowski@cox.net

Lois von Halle - Scottsdale, AZ
E-mail: lvh314@aol.com

ARKANSAS

Jean Cosgrove - Fayetteville, AR
E-mail: jcosgrove@aaanwar.org

Rose Marie Trosper - Jonesboro, AR
E-mail: rtrosper@eaaaa.org

CALIFORNIA

Sheila Christopher - Moreno Valley, CA
E-mail: sheilac@friendsofthefamily.us

Irene Angela Clemente - Long Beach, CA
E-mail: irene.clemente@noblecare-online.com

Cynthia R. Drake - Anaheim, CA
E-mail: cindidrake@gmail.com

Maria Meyer - San Francisco, CA
E-mail: mmeyer@comfortofhome.com

Rose Muema (BA) - San Diego, CA
E-mail: nrspada@yahoo.com

Tonya E. York - San Jose, CA
E-mail: tonyayork@msn.com

COLORADO

DeeAnn Groves - Greeley, CO
E-mail: DGGroves5@aol.com

CONNECTICUT

Janet Girardat - Stratford, CT
E-mail: janet.girardat@atriasenior-living.com

FLORIDA

Mary Kiso, RN, BSN - Bay Pines, FL
E-mail: mkiso@tampabay.rr.com

Connie Siskowski, PhD, RN, MPA - Boca Raton, FL
E-mail: consisko@bellsouth.net

GEORGIA

Sybil Ingram-Campbell, MT (ASCP), PhD - Stone Mountain, GA
E-mail: sybil_im@juno.com

Sandi Comer-Cooper - Atlanta, GA
E-mail: scooper@rightathome-atl.net

HAWAII

John "Keoni" Devereaux, Jr., PhD - Honolulu, HI
E-mail: jdeverea@hawaii.edu

ILLINOIS

Maya Hennessey - Chicago, IL
E-mail: mayahennessey@sbcglobal.net

Evelyn R. Morgan - Chicago, IL
E-mail: evelihelp@sbcglobal.net

Judith J. McCann, RN, DNSc - Chicago, IL
E-mail: judy_j_mccann@rush.edu

Mark Paley, RPh - Chicago, IL
E-mail: Mpaley@ForGoodHealth.com

IOWA

Stacey Bartz - Cedar Falls, IA
E-mail: Staceybartz@yahoo.com

KANSAS

Catherine (Cat) Minor - Overland Park, KS
E-mail: kittycat13132004@yahoo.com

MAINE

Sharon Berz, LCSW - Presque Isle, ME
E-mail: sberz@aroostookaging.org

MARYLAND

Chloe Giampaolo ~JonPaul, MEd - Bowie, MD
E-mail: eldercare101@aol.com

Robyn Rosenfeld-Aburrow - Potomac, MD
E-mail: runaboutllc@aol.com

MASSACHUSETTS

Leslie Ahern, MS - Boston, MA
E-mail: lahern@tiac.net

Maura Capriccio, CSA, CLTC - Westford, MA
E-mail: mcapriccio@comcast.net

Jane Handler - Brighton, MA
E-mail: hanja75@yahoo.com

John Paul Marosy - Worcester, MA
E-mail: jpmarosy@charter.net

MICHIGAN

Carolyn Anderson, MA, MSW - Ann Arbor, MI
E-mail: cja2663@sbcglobal.net

Joanne Corbo Cruz, MSW, LMSW - Troy, MI
E-mail: jcorbo72@hotmail.com

Carol Hilf - West Bloomfield, MI
E-mail: carolhifl@yahoo.com

Susan M. Hasenau, PhD - Livonia, MI
E-mail: Shasenau@madonna.edu

Linda Jones, RN - Southfield, MI
E-mail: linda_jones100@hotmail.com

Jennifer M. Kirkland - Rochester Hills, MI
E-mail: jkirkland1002@yahoo.com

Melanie West - Farmington Hills, MI
E-mail: mwest@westcg.com

Elaine M. Simpson - Beverly Hills, MI
E-mail: esimpson@senioroptions-solutions.com

MINNESOTA

Allen C. Willman - Duluth, MN
E-mail: acwillman@yahoo.com

MISSOURI

Wilma Schmitz, MA - Saint Louis, MO
E-mail: wilma@agingconcerns-stl.com

NEBRASKA

Eboni I. Green, RN, MS - Omaha, NE
E-mail: caregiversupport@aol.com

NEW HAMPSHIRE

Velma Harrison - Canterbury, NH
E-mail: vlharrison@verizon.net

NEW JERSEY

Lauren Agoratus - Mercerville, NJ
E-mail: familyvoicesnj@aol.com

Liz de Nesnera - Pompton Lakes, NJ
E-mail: liz@caregiverscommunity.com

NEW YORK

Shirley K. Poll - West New York, NJ
E-mail: SPcares2@aol.com

Bernadette Vinci - Port Chester, NY
E-mail: bv1216@aol.com

NORTH CAROLINA

Jamal Donaldson Briggs - Charlotte, NC
E-mail: jamal.briggs@gmail.com

Michele Murphy - Raleigh, NC
E-mail: mmurphy@bellsouth.net

Tereasa W. Owens, RNC - Charlotte, NC
E-mail: pinnaclecaremgr@msn.com

OHIO

Rose Walker-Smith - Dublin, OH
E-mail: rmwalk@earthlink.net

PENNSYLVANIA

David A. Ritter - Hummelstown, PA
E-mail: dritter@wradvisors.com

Patricia L. Gadsden - Harrisburg, PA
E-mail: pgadsden@aol.com

PUERTO RICO

Glenn Patron - San Juan, PR
E-mail: glennpatron@yahoo.com

SOUTH CAROLINA

Barbara Williams - Myrtle Beach, SC
E-mail: bwilliams58@sc.rr.com

SOUTH DAKOTA

Beth Deckert - Tea, SD
E-mail: deckmb@iw.net

TENNESSEE

Karen Hernan - Goodlettsville, TN
E-mail: kahernan@bellsouth.net

Paul Lindsley - Nashville, TN
E-mail: plindsley@stthomas.org

Stephanie Ogunleye Hancock, RN, PhD - Spring Hill, TN
E-mail: drsthompson1214@aol.com

TEXAS

Evangelina Vela - Houston, TX
E-mail: evanvela@infohiwy.net

VIRGINIA

Carol La Fauci, APRN, GNP - Norfolk, VA
E-mail: clafauci@verizon.net

Mary Theresa Vasquez, RN - Alexandria, VA
E-mail: terry16900@aol.com

WASHINGTON

Don Duckett - Puyallup, WA
E-mail: dduckett@peoplepc.com

John Rains - Cowiche, WA
E-mail: johnr@rainsalot.org

WEST VIRGINIA

Robin Straight, MSW - Fairmont, WV
E-mail: robinssmsw.lcsw@mindspring.com

WISCONSIN

Bette A. Koch - West Bend, WI
E-mail: bkoch@milwpc.com



What Can I Do? is a question and answer column aimed at helping to meet the needs of individual readers. Answers to questions in this issue were provided by Barry Jacobs, PsyD, Director of Behavioral Sciences for the Crozer-Keystone Family Practice Residency Program of Springfield, PA. Dr. Jacobs is a clinical psychologist who specializes in family caregiving issues. His first book, *The Emotional Survival Guide for Caregivers — Looking After Yourself and Your Family While Helping an Aging Parent*, was published in June 2006 by Guilford Publications. Go to www.emotionalsurvivalguide.com to learn more.

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

What Can I Do?
 c/o TAKE CARE!
 10400 Connecticut Ave., Suite 500
 Kensington, MD 20895-3944
 e-mail: info@thefamilycaregiver.org
 Subject Line: What Can I Do?

Q I am the mother of a 27-year-old daughter who suffered a TBI (brain injury) in a car accident two years ago. My daughter is totally dependent on me and I care for her at home. I get no help from family. It's been very challenging to say the least. Sometimes I actually see myself at my daughter's funeral even though I still have hope; I feel guilty for that. I just don't know what to do.

A I have no doubt that the challenges you face are many. Traumatic brain injuries can cause a range of problems, from physical difficulties with walking and coordination to cognitive impairments of memory, speech and reasoning. If your daughter's car accident occurred two years ago, then the likelihood she'll make further significant recovery from her deficits is small. The good news is that she probably won't get worse or die from her TBI (unless she is suffering from a dire complication such as uncontrollable seizures). The bad news is that she likely will need the same level of care and supervision for the rest of her life. For caregivers such as yourself, the toughest challenge usually isn't supplying hands-on help but mourning the loss of the child you knew and for whom you had such hopes.

In an ideal world, family members would step forward to help you with this arduous task of helping your daughter. The fact that those ideal conditions don't often exist suggests that many family members are caught up in their own lives, avoid sadness whenever possible, and/or find tragedy so close to home overwhelming. Whatever their reasons may be, if your relatives haven't offered care thus far, then they're not likely to be more forthcoming during the long years of disability ahead. It

would be better to seek succor outside your family.

The Family Caregiver Alliance has put together a fact sheet on resources for TBI caregivers that can be accessed at http://caregiver.org/caregiver/jsp/content_node.jsp?nodeid=579. Among its many suggestions are to contact the Brain Injury Association of America (www.biausa.org) to learn about whether your state has a taxpayer-funded TBI program to pay for services for your daughter or to find out whether there is a Center for Independent Living (CIL) in your area where she might learn to become more self-sufficient. There is also contact information on philanthropies that help families deal with TBI, as well as general information on applying for disability income. These are good places to start to explore what combination of resources might be most beneficial for your daughter's and your specific situation.

Another source of assistance is for-profit agencies — for example, ReMed, based in Pennsylvania — that specialize in vocational and psychological services on an outpatient or residential basis for TBI survivors. Not surprisingly, these agencies also frequently sponsor TBI caregiver education and support groups; they could give you the emotional backing that your family hasn't.

Unfortunately, no amount of resources will make caring for your daughter easy. Please be good to yourself. If your daughter can't express gratitude for the care you're providing, remind yourself frequently that you're being an exceptionally devoted mother.

Q I've been a full-time caregiver for my elderly parents for more than five years. My father died

from skin cancer last summer after spending his final days in a hospice. Mom is not in good health and has dementia. I'm not an only child, but it seems that way because my three sisters won't help at all, even though two of them live in town. I'm very angry with them because they get to have a life but I don't. I have to hire an aide just to get a day off. I think my sisters are jealous because I get free room and board, which I earn by running the household, doing all the chores, paying all the bills, and being a caregiver. Mom pays me very poorly. She recently gave me power of attorney, which angered my three lazy sisters. They blamed me when Mom ended up in the hospital recently with a bad infection. I'm not a nurse, but I do the best I can. I hate how my sisters act toward me. At times I regret being a caregiver, but I know I've given my parents better care than they would have received in an expensive, crowded nursing home. Why is it that one family member ends up being the caregiver when there are other siblings who could help but won't? Are all families this dysfunctional?

A The old expression, "It takes one mother to care for 10 children, but 10 children can't care for one mother," leaves out an important explanation: The most common impediment to the children giving care is that they are reacting to their mother's decline by arguing about how to proceed rather than coordinating their efforts. I don't doubt that you have been wronged by your sisters. But let's reflect on the effects of your acrimonious relations with them. You are very angry with them; my guess is that they have their rationales for being very angry at you, as well. You call them "lazy"; they insinuate that you're a freeloader. As Mom's dementia worsens, she'll need more help and you will, too. But because you and your sisters are each entrenched in starkly polarized positions, there will be lit-

tle possibility for reconciliation for the sake of Mom's care. If this impasse holds until Mom's death, there will be too much bitterness for reconciling with them afterwards. You will lose her and them forever.

My bias, as you can tell, is for you to reach out to your sisters before it's too late. You may not be able to prove that you are right and they are wrong but you stand to garner more important payoffs — improved care for your mother and the chance that your sisters will listen to you to a greater degree and even empathize with you. It's crucial, though, to reach out to them in a strategic fashion. First, I'd ask a trusted family friend — for example, a pastor or neighbor — to convene a family meeting with all your siblings in order to discuss what's best for Mom. Second, I'd recommend that you initiate conversations with your sisters individually about the upcoming

meeting; you are more likely to decrease hostilities on an individual basis than in the group setting. Third, encourage the meeting's facilitator to keep the focus of the meeting on present needs rather than past snubs. For instance, it would be important for all family members to share approximately the same view of your mother's condition and prognosis. Fourth, have the facilitator help the family devise a caregiving plan in which everyone plays some role, even if those roles aren't equal. My hope is that this will lead to some working relationship among you that will be sustainable over time. My dream is that working together will lead you to talking together and even finding ways of loving each other again.

You have the opportunity to make your dysfunctional family a little more functional. Wouldn't that be your parents' fondest wish? ■



If you were hurt and couldn't speak, who would help your loved one?

Everyone... if you were wearing ID jewelry designed for family caregivers like you.

NFCA is partnering with American Medical ID to create ID bracelets, pendants and dog tags that clearly alert people to the fact that you have a loved one who needs help.

Mention NFCA & get a 10% discount off your purchase.

(Deeper discounts on multiple purchases.) With each purchase, NFCA will benefit, too, by receiving a 10% donation from AMID.

Don't wait. Buy your specially designed ID jewelry today.



800/363-5985 or
www.IdentifyYourself.com/nfca
(use **NFCA** as the code when prompted)



NATIONAL
FAMILY CAREGIVERS
ASSOCIATION

10400 Connecticut Avenue, Suite 500
Kensington, MD 20895-3944

Please make note of your membership number located on your address label. Knowing this number will help you gain the most from your NFCA membership.

Nonprofit Org.
U.S. Postage
PAID
Silver Spring, MD
Permit No. 3958

Healthcare Nightmare

Continued from page 11

ones get the kind of care they need and deserve and that we, too, receive the care and support we need and deserve.

It's important for family caregivers to speak up about these issues and demand that the presidential candidates discuss their plans to better address the needs of families dealing with chronic illness or disability. Now is our chance. Now is our opportunity to be recognized for the very hard work that we do. Now is the time to transform our healthcare system so that it is fully responsive to the needs of those with chronic conditions and their family caregivers. ■

A Family Caregiver Speaks Up...

IT DOESN'T HAVE TO BE THIS HARD

A revised and updated edition of
LOVE, HONOR & VALUE

By Suzanne Mintz, NFCA's President & Co-founder

"Suzanne Mintz has written the perfect book for everyone who ever has or ever will take care of a loved one — parent, spouse, child or sibling. With her own powerful personal story, she tackles the range of emotions and the challenges facing every caregiver. And most important, she offers advice on how to ask for help. As the mother of a son with a disability, I only wish I'd read Suzanne's book before I brought him home from the hospital."

— *Judy Woodruff, Senior Correspondent for the NewsHour with Jim Lehrer*

25% discount for NFCA members member/\$11.20, nonmember/\$14.95

Order online at www.thefamilycaregiver.org

