

# TAKE CARE!

Self-Care  
for the Family  
Caregiver™

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## Protecting Your Loved One From Medical Error: One Woman's Campaign to Help Others

Sandy Padwo Rogers

**I**lene Corina is passionate about patient safety. She has reason to be. In 1990, when Corina's son, Michael, was just 2<sup>1</sup>/<sub>2</sub> years old, he underwent what was supposed to be a routine tonsillectomy. There was nothing routine about it.

The surgery was performed on a Tuesday. On Thursday, Corina took Michael back to the surgeon because she noticed bleeding in his mouth. The surgeon cauterized the spot but no further checkup was performed. By Saturday morning Michael was vomiting blood; Corina rushed him to the emergency room. After a brief exam, she was told nothing was wrong and was sent home. Late Saturday she took Michael to a medical clinic only to be sent home again. Spotting more blood in his teeth on Sunday, as well as what Corina thought were clear signs that Michael was suffering from an infection, she rushed him to yet another emergency clinic. She was told he had nothing more than a rash. Frustrated and fearful, she once again took Michael home.

Exactly one week after his surgery, Corina took Michael back to his



surgeon for a post-operative exam. She was hopeful that perhaps she would finally get to the bottom of things. After examining Michael, however, the surgeon said he saw no evidence of bleeding or any other complication from the surgery. Feeling a bit more relaxed having heard the word of her son's surgeon, Corina took Michael home. It would be their last trip to the doctor. Michael died in his mother's arms the following day. The cause of death was blood loss.

What the Corina family experienced was a total failure of the healthcare system at multiple levels. From the surgeon who performed Michael's surgery and examined him the day before he died to the physicians in the emergency room who insisted that his worsening symptoms were not serious, the mistakes compounded until it was too late.

After Michael's death, Ilene Corina tried desperately to have conversations with the physicians

who examined him the week after his surgery, as well as the surgeon who performed the surgery. She was met with a wall of silence. "I was a grieving mother and I needed to understand how this happened," she says. "I needed to know that I had done everything I was supposed to do to help my son. No one would talk to me." To this day, Corina has been unable to get anyone to take responsibility for the incomprehensible series of medical errors that resulted in Michael's death. "After hiring an attorney, I finally received a report indicating that what happened to Michael wasn't my fault," says Corina. "But no one in the medical community ever acknowledged the errors they made that led to Michael's death."

According to the Institute of Medicine's 1999 report *To Err Is*

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## Caregiver Disorder: An Unacknowledged Illness

Suzanne Mintz

I first wrote an article about caregiver disorder in 1996. It was the first article I had ever written advocating recognition of family caregivers. I decided it was high time to look back at what I wrote to see how relevant the information and commentary is today. The question is: In the past dozen years, has the medical community recognized that "Caregiver Disorder" exists and that it is a legitimate expression of the physical and emotional impact of family caregiving on the health and well-being of the caregivers themselves?

My 1996 article began:

*Family caregivers are ill-served by our current healthcare system. I suspect this isn't intentional, but, rather, a byproduct of neglect. The symptoms of our distress and common illness are not categorized. We are not the subjects of ongoing medical research, nor are articles typically written about us in medical journals. There is not a known disease or condition called "Caregiver Disorder." We are, for all intents and purposes, invisible to the formal healthcare system.*

Today, we are still seen as the sad-faced people who come to visit our loved ones in the hospital. We are the ones who drive them to physical therapy, administer medicine at home, and have power of medical attorney. We are family. No thought is given to the fact that in some circumstances we might actually be patients ourselves.

*That needs to change. Society and our healthcare providers need to recognize that illness and disability are a family affair, that when someone we love receives a diagnosis of multiple sclerosis, Alzheimer's, cerebral palsy, spinal cord injury or the like, family caregivers, especially if they are provid-*

*ing intensive levels of care, can develop their own condition that is equally in need of diagnosis and treatment.*

I am happy to report that there has been some progress made in the last 12 years. Although there is still no condition actually identified as "Caregiver Disorder," there has been, and continues to be, medical research on the impact of family caregiving on a caregiver's own health. In fact, there was a conference in Washington, D.C., entitled "Family Caregiving as a Public Health Issue." The research that has been published all points to the negative effects of extreme stress. Here are some of the statistics:

- Elderly spousal caregivers with a history of chronic illness themselves who are experiencing caregiving-related stress have a **63 percent higher mortality rate** than their non-caregiving peers.  
— *Journal of the American Medical Association*, December 15, 1999.
- Family caregivers who provide care 36 or more hours weekly are more likely than non-caregivers to experience symptoms of depression or anxiety. For spouses, the rate is six times higher; for those caring for a parent, the rate is **twice as high**.  
— "Reverberation of family illness: A longitudinal assessment of informal caregiver and mental health status in the nurses' health study." *American Journal of Public Health*, 92:305-1311, 2002.
- 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**.  
— *Proceedings of the National Academy of Sciences*, December 2004.

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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

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# In Case of Fire

## *Escape Planning for Family Caregivers*

**W**e hear the stories every day: A house fire claims a life when someone becomes trapped inside. Too often, the victims are ill, disabled, or aged and are unable to get out in time. In the most tragic of cases, their family caregivers lose their lives as well as they struggle to save their loved ones.

Fires claim the lives of approximately 4,000 Americans each year according to the Federal Emergency Management Agency (FEMA). Given this alarming figure, it's a bit surprising to learn that a 2004 Harris Interactive Survey conducted for the National Fire Protection Association (NFPA) found that less than one-quarter of households have actually developed and practiced a home fire escape plan.

It takes less than five minutes for a fire to become life-threatening. Heat and smoke can make you disoriented and drowsy, burn your lungs, and cause asphyxiation, which is the leading cause of fire deaths. Because there is so little time to react, escape planning is a must for every household, and especially for caregiving households.

It goes without saying that when dealing with an older adult or a loved one with a mobility issue, get-

ting out of harm's way may be easier said than done. People who are blind or deaf also have more challenges than the rest of us. According to NFPA, individuals 65 and older are twice as likely to be killed or injured by fires compared to the population at large. It would seem that the same would hold true for those with disabilities, regardless of age.

The fire prevention and evacuation tips below were compiled from information published by the U.S. Fire Administration (USFA) and NFPA. Take a few minutes to review these tips with your family members and to practice your escape plan. If you are a long-distance caregiver, make sure you identify someone who can help your care recipient do the same.

### **Protect Your Family: Tips for Caregiving Households**

There are a few simple steps that every household should take to help ensure that no one becomes the victim of a fire. There are also special considerations for caregiving families:

- Install smoke alarms on every level of your home, including outside bedrooms, at the top of open stairways or at the bottom of enclosed stairs, and near the kitchen. Test

and clean your smoke alarms each month and replace batteries at least once per year. Replace the entire smoke alarm every 10 years. There are special smoke alarms for those who are deaf or hearing impaired.

- Keep a phone in your bedroom so you can immediately connect with emergency personnel.
- Make sure you can easily open all windows and doors from the inside. Locks and pins should also be easy to open. Security bars on doors and windows should have emergency release devices.
- Review escape routes with your family. Identify at least two escape routes from every room in your home and determine which would be practical for your loved one. There may be limited options. Hold a fire escape drill at least once a year and make sure that the smoke alarm wakes everyone in the house. If your residence has more than one level, keep an escape ladder near a window on the upper level. Practice setting up the ladder so that you can do it quickly and correctly. Your loved one may not be able to escape this way, but you or others in your household might.

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## In Case of Fire

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- If your loved one uses a wheelchair, scooter or walker, make note of which doorways and exits are wide enough for it to pass through. Identify an individual to help your loved one in the event of an emergency (yourself, another family member, a neighbor or another outside source). Designate a back-up person as well.
- Consider installing a sprinkler system in your home. A residential sprinkler is the best defense against fire fatalities. If you are considering a home renovation or addition, or you are buying a new home, the addition of a sprinkler system should be considered.
- Contact your local fire department's non-emergency number

and explain your loved one's special needs. Ask if your fire department conducts home safety inspections and schedule one if possible. Ask if your fire department keeps special needs information on file.

### In an Emergency

For emergency crews responding to a fire, knowing that there is a possible rescue situation before they arrive on the scene may make the difference between life and death. Tim Diehl, a battalion chief with the Howard County, Maryland, Department of Fire and Rescue, advises family caregivers to be prepared to relay the following information to the emergency dispatcher:

- Your address. It is also advisable to identify the house or building by some manner other than the address.
- The number of individuals in the home.

- The fact that someone will need to be rescued and where this person is located in the home.

Chief Diehl also stresses the importance of getting out of the home immediately rather than trying to extinguish a fire yourself. "The fire extinguisher shouldn't be the first line of defense," he says. "People don't realize that they lose precious time when they try to put out a fire themselves. The number one priority should be to get out and to let the emergency dispatcher know if anyone is trapped in the home and what room that individual is in."

### Escaping From Tall Buildings \*

Sometimes the safest thing you can do in a tall building fire is to stay put and wait for the firefighters. To increase fire safety for apartment dwellers, NFPA offers the following guidelines:

- **Know the Plan.** Make sure that you're familiar with your building's evacuation plan, which should illustrate what residents are supposed to do in the event of an emergency. The evacuation plan should be posted in places where all residents can see and review it, and the building management should hold a fire drill with occupants at least once a year. Most states also require that buildings periodically test their fire safety systems as well. Be sure to participate when your building drills take place. When looking for an apartment or high-rise home, look for one with an automatic sprinkler system. Sprinklers can extinguish a home fire in less time than it takes for the fire department to arrive.
- **Practice Is Key.** Whether your building has one floor or 50, it's essential that you and your family are prepared to respond to a fire alarm. Identify all of the exits in your building and mark the various stairways too, in case one is blocked by fire.

### FIRE SAFETY TIPS

- Don't leave cooking food on the stove top unattended.
- Never use an oven to heat your home.
- Keep all storage at least three feet away from furnaces and hot water heaters.
- Keep space heaters three feet from anything that can burn and unplug them when you shut them off, leave your room, or go to bed.
- Ask smokers to smoke outside.
- Keep matches and lighters out of the reach of children.
- Inspect electrical cords and replace or repair loose or frayed cords.
- Don't overload electrical outlets or extension cords.
- Keep your clothes dryer lint traps clean.
- Keep fireplaces, chimney and wood stoves clear of debris and clean them semi-annually.
- Extinguish candles when leaving the room or going to sleep.
- Prepare and practice a home fire escape plan.
- Install smoke alarms.
- Test smoke alarms monthly.
- If you must escape through smoke, get low and go.

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## In Case of Fire

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- **Never Use the Elevator.** In case of fire, always use the stairs to get out, never the elevator. If your loved one can't use the stairs, find out if the building has a designated location — often a specific stairwell — that is equipped to help get a handicapped person down the stairs or to serve as a “safe haven.” Insist that management include getting your loved one down the stairs as part of the regular fire drill.
- **Stay Low.** Smoke from a fire is toxic and deadly no matter what kind of structure you live in. When you hold your fire drill, everyone in the family should practice getting low and going under the smoke to the exit. In

the event of a fire, if all stairwells are filled with smoke, stay in your apartment and wait for the firefighters.

- **Seal Yourself in for Safety.** If you can't exit an apartment building due to smoke or fire in the hallway, call the fire department to report your exact location and gather in a room with a window to await their arrival. Close all doors between you and the fire. Use duct tape or towels to create a seal around the door and over air vents in order to keep smoke from coming in.
- **Stay by the Window.** If possible, you should open your windows at the top and the bottom so fresh air can get in. Don't break the window — if smoke enters the room from outside the building, you won't be able to protect yourself.
- **Signal to Firefighters.** Wave a flashlight or light-colored cloth at

the window to let the fire department know where you are located.

When a fire breaks out, every second counts; this is especially true for caregiving families. More than 82 percent of fire fatalities occur in people's homes. Many of these deaths are preventable. While most people think that bad things aren't going to happen to them, family caregivers know all too well that bad things do happen — to everyone. There are actions you can and should take to reduce the risk of a fire in your home and to increase your family's odds of surviving a fire. Creating a fire escape plan is one proactive and important thing you can do. ■

*\* The safety tips found under “Escaping From Tall Buildings” are reprinted with permission from the National Fire Protection Association Web site [www.nfpa.org](http://www.nfpa.org). Copyright © 2008 NFPA. All rights reserved.*

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### FOR MORE ON EMERGENCY PREPAREDNESS

- **American Red Cross**  
[www.prepare.org](http://www.prepare.org)  
Designed to help Americans prepare for disasters, this Web site has materials specifically designed for the following vulnerable populations: seniors, children, people with disabilities, and animal and pet owners. Preparedness materials are available in English and multiple foreign languages.
- **National Fire Protection Association (NFPA)**  
[www.nfpa.org](http://www.nfpa.org)  
NFPA is the nonprofit authority on fire, electrical, and building safety.
- **Ready.gov**  
[www.ready.gov](http://www.ready.gov)  
Ready.gov is a public service campaign by the U.S. Department of Homeland Security to help Americans respond to a variety of emergencies. Materials are in English and Spanish.
- **U.S. Fire Administration, U.S. Department of Homeland Security**  
[www.usfa.fema.gov](http://www.usfa.fema.gov)  
This Web site offers abundant fire prevention and safety information in English and Spanish.

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 monitoring the medication use of an older adult?** The National Council on Patient Information and Education (NCPIE), a nonprofit coalition of more than 100 organizations working to improve communication on the appropriate use of medicines, is sponsoring a national education awareness campaign to promote safe and appropriate medicine use among America's older adults. Medication Use Safety Training for Seniors™ (MUST for Seniors™) contains a wide range of information and educational resources for older adult medicine users and their caregivers. The campaign Web site provides downloadable program materials, including medication safety tips, worksheets, and video stories aimed at addressing a variety of medication issues.

MUST for Seniors™ is an interactive program designed to promote safe and appropriate medicine use by giving older adults and caregivers the tools and know-how to avoid medication misuse, recognize and manage common side effects in consultation with their healthcare providers, and improve medicine use knowledge, attitudes, and skills to avoid medication errors. Go to [www.mustforseniors.org](http://www.mustforseniors.org).

**Is your loved one in pain?** Purdue Pharma L.P. is proud to announce a revitalized and redesigned Partners Against Pain® Web site. Partners Against Pain®, an alliance of patients, caregivers, and healthcare providers, provides the latest information on the management of pain. The Web site offers pain assessment guides, interviews with pain management specialists, questions to ask your doctor, and much more. The information and resources provided are presented in an easy-to-navigate and updated format. Check back often for new information as well as updated resources

and programs. Go to [www.partner-sagainstpain.com](http://www.partner-sagainstpain.com).

**Are you looking for caregiver assistance in your state?** The National Center on Caregiving at Family Caregiver Alliance has a new addition to its online resource, Caregiving Across the States. This interactive database includes a separate profile for each state and the District of Columbia. Profiles contain the state's background characteristics related to caregiving and aging, as well as information on publicly-funded caregiver support programs. New state-by-state data include such information as average costs of adult day services, home healthcare, nursing homes or assisted living facilities, as well as the number of family caregivers and total caregiving hours for each state. Caregivers can access information they need to seek assistance and benefits for themselves and their loved ones.

To learn more about the family caregiving landscape in your state, go to [www.caregiver.org](http://www.caregiver.org) and click on "50-State Searchable Resource Map: Caregiving Across the States."

## BOOK REVIEW

**The End-of-Life Handbook: A Compassionate Guide to Connecting with and Caring for a Dying Loved One** by David B. Feldman, Ph.D., and S. Andrew Lasher, Jr., M.D. (New Harbinger Publications, 2007, \$15.95).

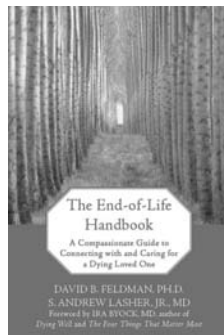
Given the title, some family caregivers may not want to read this book. They should anyway. As explained in the book, it's natural that when it

comes to "end-of-life" issues, many family caregivers succumb to a certain amount of denial. But with *The End-of-Life Handbook*, family caregivers can move forward, from whatever stage of the caregiving journey they happen to be at. The book is filled with easy-to-understand, straight-to-the-point, and, yes, compassionate information on dealing with family caregiving in general, and end-of-life issues in particular. Each chapter starts with a short story about a family facing an important issue related to the end of life. The rest of the chapter then explains how to address that specific issue. Chapters deal with subjects ranging from "understanding and coming to terms with bad news" to "making sense of the medical system and its many faces." (Do you really know the difference between an attending, a resident, and a specialist?) The book also covers such topics as "facing your feelings about caring for and losing a loved one" and "discovering life after loss." It answers many of the questions you may be too embarrassed or too tired to ask. Exercises and checklists included throughout the book help the reader implement what's been discussed. From the practical to the intensely personal, *The End-of-Life Handbook* may have been written for those in the final stages of caregiving, but any family caregiver will benefit from reading this concise, easy-to-digest book.

*The End-of-Life Handbook* is available wherever books are sold, by calling 800/748-6273, or at [www.newharbinger.com](http://www.newharbinger.com).

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

**Are you aware of a resource that would help other family caregivers? Let us know about it by e-mailing [editor@thefamilycaregiver.org](mailto:editor@thefamilycaregiver.org).**



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## Protecting Your Loved One

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Human, preventable medical errors in hospitals claim the lives of between 44,000 and 98,000 people each year. A 2006 report from the Institute of Medicine found that medication errors harm at least 1.5 million people every year.

As part of her effort to heal, Corina vowed to do everything in her power to prevent another family from experiencing the tragic consequences of medical errors. "People don't realize that they can be injured or die from the healthcare system,"

she says. "We need to speak up and advocate for each other. If everyone would speak up, it would be easier for all of us to protect our families."

In 1997, Corina began aggressively lobbying the New York Legislature to pass patient safety legislation. She developed a patient safety education program for the community. And she initiated a monthly support group for families that had experienced medical errors. It all culminated in the founding of PULSE of New York (Persons United Limiting Substandards and Errors in Healthcare), a grass-roots, nonprofit 501(c)(3) organization dedicated to raising awareness about patient safety and reducing medical errors through advocacy, education, and support.

"The idea behind PULSE is to teach family members how to become the patient's advocate," says Corina. "People at the bedside in the hospital have no patient safety education. Some don't know what an advocate is, or that a patient even needs an advocate. Our focus is to teach family members and friends how to become advocates for their loved ones."

Corina, herself, put her hard-earned knowledge to good use when she gave birth to her third son in 1993. "My third pregnancy was threatened by early complications," she recalls. "After weeks of bed rest, Matthew was born at 23 weeks gestation and weighed just 1 pound, 7 ounces. Because of what I had learned from Michael's death, I immediately became his caregiver and advocate. I took notes to share with each specialist so that everyone was on the same page. I shared Michael's story with Matthew's medical team and it seemed to bring us all together, making us closer and helping us work harder to save Matthew." Five months after his birth, Matthew left the hospital. Today, he is a perfectly healthy teenager who shows no signs of his early struggle.

### Patient Safety Tips From PULSE

PULSE asked healthcare professionals to share the most important precautions that should be followed to avoid medical errors, medication errors, and infections. Here are a few of their suggestions:

- Hand washing and hand sanitizing are crucial to patient safety and avoiding the spread of infections. Make sure everyone who touches your loved one has washed their hands.
- Understand the treatment plan and expected outcomes for all conditions.
- Don't be afraid to ask anyone involved in your loved one's care to repeat or explain what they said to you.
- Make sure that all of your loved one's doctors know about all medications your loved one is taking, including prescription, over-the-counter medicines, and dietary supplements such as vitamins and herbs.
- Before leaving the pharmacy, open the bag and check the name on the prescription and the name of the medication. Be sure you understand the instructions. Ask if there may be any interactions with other medications your loved one is taking.
- Write down questions before entering a hospital or doctor's office.
- If needed, ask another family member or a friend to be your loved one's "advocate" when visiting the doctor or hospital. An advocate will help you listen to what the doctor and staff say and will help get your questions answered, helping to ensure safe care.
- If your loved one undergoes a test, do not assume that no news is good news. Call the doctor's office and ask for the results.
- Make sure that all health professionals involved in your loved one's care receive his or her important health information either in written form or verbally.
- If your loved one feels worse during or after receiving care, contact the doctor right away. Keep notes of when you call and who you speak to. You should receive a call back from the doctor, nurse or pharmacist.

### Ensuring Your Loved One's Safety

When it comes to safeguarding your loved one (or yourself) in a healthcare environment, it's important to begin a dialogue early and to ask the right questions. "Before your loved one goes to the hospital, find out who will be in charge of his or her care," says Corina. "Find out who you can call with questions or concerns and how to reach this individual. It's important that you feel you have the authority to be a part of the healthcare team."

It's also OK to let people know that they will be held accountable, says Corina. "It's possible to be respectful yet forceful," she says, adding that one way to keep your loved one safe is to understand how and when errors tend to occur. For

example, asking everyone who enters the hospital room if they washed their hands prior to touching your loved one is a perfectly acceptable question that can help stem the spread of hospital-based infections.

Corina tells the story of her husband's experience in the hospital after the loss of their son. "A few years ago my husband had to undergo knee surgery. After what happened to Michael, I was terrified at the thought of his hospitalization," she says. "One of the things I did to help ensure he wouldn't get an infection in the hospital was to bring alcohol to sanitize every surface in the room. Every time I cleaned off the call button, a nurse would come in the room. She would turn the call button off without washing her hands and I would proceed to clean it again, which in turn set off the alarm at the nurses' station. After several episodes of this, I finally expressed to the nurse that I was not about to stop cleaning the call button so we had to decide how to deal with the fact that it would go off each time I did."

**Enlisting an Advocate to Help You**  
While family caregivers are often the ones who are called upon to serve as their loved ones' advocates, sometimes it's necessary to appoint another family member or friend to fulfill this role (e.g., when the family caregiver is sick). According to the PULSE Patient Safety Network Council, a patient advocate is someone who will "help oversee the patient's needs, care, and safety while creating an objective partnership between patient, family, and healthcare provider." The advocate's role should be to raise the level of communication with the medical team. It's important for the advocate to be free of bias or preconceived notions when acting as a liaison between the patient and healthcare professionals.

It's also important to discuss the advocate's role with the patient so that everyone is clear on what the

advocate's responsibilities will be. For example, while part of the advocate's role may be to participate in doctor visits, there will be times when it's not appropriate for the advocate to be present during a conversation with a physician. "The doctor needs a certain amount of private time with the patient," says Corina. "It's part of the advocate's job to understand what the patient needs and to be respectful of those needs. The patient must always come first."

Some of the duties the patient advocate may assume include:

- Accompanying the patient to the doctor's office, for medical tests, and to the hospital.
- Ensuring that everyone has the necessary information and forms they need.
- Acting as a liaison between the patient and the healthcare professional. (The patient should clearly identify the advocate to all clinicians and family members.)
- Keeping a list of questions for the patient's physicians, along with answers and instructions regarding follow up.
- Keeping track of all pertinent medical records and test results.
- Helping the patient and his/her family organize and understand lists of instructions.
- Making decisions for the patient when requested (requires a healthcare proxy).
- Keeping a list of all medications, including the reason the medication was prescribed and by whom, frequency of use and dosage information, start and stop dates, and patient allergies or adverse reactions.
- Verifying the necessity of all medical procedures or tests and that they are performed correctly.
- Assisting the patient with activities of daily living.
- Maintaining a list of all family members and friends who are helping the patient, including their contact information.

## Patient Safety Resources

**Agency for Healthcare Research and Quality** This agency is part of the U.S. Department of Health and Human Services. The Web site contains a section for consumers and patients.

[www.ahrq.gov/consumer](http://www.ahrq.gov/consumer)

**Consumers Advancing Patient Safety (CAPS)** A consumer-oriented, not-for-profit organization that serves as the collective voice for individuals, families, and healers who suffer harm in healthcare encounters.

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

**National Patient Safety Foundation (NPSF)** An independent, not-for-profit 501(c)(3) consumer organization whose mission is to improve patient safety.

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

**PULSE** A nonprofit 501(c)(3) organization working to improve patient safety and reduce the rate of medical errors using real-life stories and experiences.

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

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

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

**The Joint Commission** An independent, not-for-profit organization that serves as the nation's predominant standards-setting and accrediting body in healthcare.

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

## Communicating With Medical Professionals

"No matter what people say, the lines of communication between patients and healthcare professionals are still not open," says Corina, who stresses the importance of communicating respectfully if you want to be treated as a member of the healthcare team. She explains, "Patients and their advocates need to know

*(Continued on page 10)*

## Protecting Your Loved One

Continued from page 9

that it's OK to ask questions, but you should always be polite and show respect. The patient and the patient advocate have a role to play in making this a collaborative and respectful relationship."

There are simple things family caregivers and patient advocates can do to improve communication with medical professionals:

- Write questions down so you won't forget them.
- Be clear about what you want to say to the doctor. Provide accurate and detailed information. Try not to ramble.
- Be completely honest with the doctor. Never hide information.
- If you have lots of things to talk about, make a consultation appointment so the doctor can allow enough time to meet with you in an unhurried way.

- Educate yourself about your loved one's disease or disability. With all the information on the Internet, it's easier than ever before.
- Learn the routine at the doctor's office and/or the hospital so you can make the system work for you, not against you.
- Recognize that not all questions have answers — especially those beginning with "why."
- Separate your anger and sense of impotence about not being able to help your loved one as much as you would like from your feelings about the doctor. Remember, you are both on the same side.
- Appreciate what the doctor is doing to help and say "thank you" from time to time.

### Making a Difference

Ilene Corina is committed to helping improve patient safety within the healthcare system. Her dream is to see an organization like PULSE in every state, where family members and others can be educated on how to be effective patient advocates.

### To Learn More



Ilene Corina

To learn more about Ilene Corina's efforts to educate others about patient safety, including information about her workshops and other speaking engagements, go to [www.patientsafetyadvocate.org](http://www.patientsafetyadvocate.org).

To read NFCA's publications related to patient safety, go to [www.thefamilycaregiver.org](http://www.thefamilycaregiver.org) and click on "Caregiving Resources" at the top and then "Tips and Tools." Caregivers who want a single copy of any of these pamphlets should send a self-addressed, stamped envelope to NFCA. Please indicate which pamphlet you wish to receive.

## Speak Up With NFCA



In celebration of NFCA's 15th anniversary, we encourage family caregivers to Speak Up for their rights.

This year, Speak Up about:

- Your own needs as a family caregiver
- The rights of your loved one
- The rights of all family caregivers

For 15 years, we have been helping family caregivers make their lives easier. This year, help us continue our important work; consider making a donation to NFCA using the enclosed envelope.

Thank you.

"When I began my journey to become better educated and to help educate others, I found that there was just not enough information out there," she says. "This was not about good and bad doctors; it was about opening doors and understanding our role and responsibility in a complex system." To that end, Ilene Corina is determined to open as many doors as possible. ■

Sandy Padwo Rogers is the managing editor of TAKE CARE!

*Editor's Note: NFCA wishes to thank Ilene Corina and PULSE for allowing us to reprint a portion of the patient advocate information above from "Family Centered Patient Advocacy: A Training Manual," by Ilene Corina and Eve Shapiro, PULSE of New York, 2007. Additional information for this article was provided by PULSE of America, [www.pulseamerica.org](http://www.pulseamerica.org).*

## CCANers Reach Out to Family Caregivers Across the Country

Deborah Halpern

NFCA's Caregiver Community Action Network currently includes 82 volunteers in 33 states and Puerto Rico. Today's CCANers are actively involved in everything from legislative advocacy to helping family caregivers one on one. It's important for NFCA's caregiving community to know that for many family caregivers across the country, there are CCANers in your cities and states who are there to help you.

Over the past few months, several CCANers have been working hard to pass legislation in their states that would make life easier for family caregivers. Lauren Agoratus, a New Jersey CCANer, is part of the New Jersey Time to Care Coalition, which is promoting family leave insurance for family caregivers. The coalition has met with legislators, testified before the Senate, sponsored a Lobby Day in Trenton, and held press conferences at the Statehouse. Lauren has written letters to the editor and Op-Ed pieces; she has also been interviewed by local newspapers, television and radio stations as part of her effort to publicize the need for family leave insurance.

Another example of the public policy work that CCANers are involved in comes from Bonnie Danowski from Scottsdale, Arizona. Bonnie explains, "Respite time is critical for all of us who provide care for people with disabilities and frail elders. My husband, Jim, was diagnosed with multiple sclerosis 37 years ago. I know firsthand how important respite can be for our health and well-being. Because of the indisputable evidence of the value of respite and the knowledge that I couldn't do it alone, I agreed to

chair a committee in a broad-based organization, Valley Interfaith Project, to address this issue through legislation." Bonnie worked to develop a coalition of caregivers, religious congregations, providers, and other organizations. The coalition met with state agencies, the governor's office, the business community, educators, and researchers and then lobbied legislators and testified at state hearings. As a result of the coalition's efforts, the Arizona Lifespan Respite Care Program was signed into law at the end of Arizona's 2007 legislative session. The legislation provides respite for caregiving families who've never qualified for services before.

Other CCANers are making a difference by serving individual family caregivers on a personal level. Judy McCann regularly receives e-mails from family caregivers in Illinois who find her name on the CCAN page of the NFCA Web site. Judy shares one story in particular that demonstrates how CCANers can literally change the lives of family caregivers and their loved ones:

"The gentleman, Dave, is a caregiver for his wife, who has Alzheimer's disease. Dave is in his 70s but owns a business and is there every day. He was unsuccessful in locating adult day care or companion services for his wife so he had been taking her to work with him but keeping her in the car all day because she was too disruptive to take inside the business. Sadly, his wife sat in the car while he worked. Dave contacted me by e-mail after finding my name on the CCAN page of the

NFCA Web site. I helped him find a day-care program in his small town in southern Illinois that would take people with dementia and his wife

now spends four days a week there."

Many times family caregivers simply don't know the right questions to ask. CCANers can help these caregivers understand what they need and then direct them to the best resources. If you would like to connect to a CCANer in your area,

visit the NFCA Web site at [www.thefamilycaregiver.org](http://www.thefamilycaregiver.org) and click on "Volunteer Network – CCAN" at the top of the page.

If you are interested in joining the CCAN volunteers, we are always looking to expand our network. NFCA's CCANers have a wide variety of backgrounds and experiences, from healthcare professionals to homemakers to teachers and community activists. The experience all CCANers share is that they currently are or have been family caregivers themselves.

We are currently looking for CCAN volunteers in the following areas: San Antonio, Dallas/Ft. Worth, and Austin in Texas; Philadelphia; Indianapolis; Jacksonville, Florida; and Memphis, Tennessee. We are also in need of CCANers in Louisiana and Kentucky. While we welcome volunteers from all over the country, these areas are most in need. For more information on the CCAN program, contact Linda Jones at 248/358-1186 or [linda\\_jones100@hotmail.com](mailto:linda_jones100@hotmail.com). ■

Deborah Halpern is NFCA's communications director.

*"For many family caregivers across the country, there are CCANers in your cities and states who are there to help you."*



*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** Our 89-year-old mother, who lives on her own, was robbed in the middle of the night by two young women, one of whom had been employed previously to care for her for a short period. The former aide knew how to jimmy the back door open and knew where Mom kept her cash. Initially we thought the theft only involved cash and medicine. A day later we realized that Mom's wallet with debit card had been stolen as well, and someone was on their way to extracting thousands of dollars from Mom's accounts. The women were caught and confessed to planning this because they knew how easy it would be. The unintended gift that my mother gave them was a PIN number far too easy to guess, given they had all the contents of her wallet. Luckily, the bank, a small local one, replaced Mom's funds immediately. Even so, we feel outrage that this former aide acted so cruelly towards our very vulnerable mother. We also feel guilty that we didn't do more to protect Mom. (We allowed her to keep a less secure door to allay her concerns about us being able to reach her at all times. To protect her privacy, we didn't ask if her PIN number was secure or if she really needed to carry her Social Security card in her wallet.) What can we do?

**A** This unfortunate situation raises three difficult questions that commonly confront caregiving family members: Can you trust the home health aides you've hired to provide care for your loved one? What is the right balance between allowing your loved one to exercise her own judgment and stepping in to tell her what to do for her own protection? Are you responsible when your loved one suffers an adverse

consequence? Let's explore them one at a time:

It made perfect sense for you and your mother to have hired home health aides in the past to assist her with such activities as dressing, grooming and toileting. Such aides are the shock troops of our health system, providing front-line, hands-on care to the frail and disabled in a generally competent and compassionate manner. Without them, families would be even more strained and our nursing homes more filled. Aides who steal are probably rare. But, like the bad apple in the barrel, a few rotten deeds spoil the appetites of patients and family members for all home health personnel. As a result, some families resist hiring them, even if home health services would make a significant difference in their loved one's daily lives. If you can ever muster the courage to risk using home health aides again, consider this advice: Seek and call the references for any prospective aide. Hire aides that work for home health agencies; even though the hourly cost will be greater, you will have some peace of mind that the workers have been vetted by the agency director. Try to hire all aides for a probationary period; make sure they're well trained, reliable and a good fit before committing to having them in your loved one's home on an ongoing basis. Finally, safeguard your mother's valuables — just to be sure. In the best-case scenario, the home health aide, over time, will become a trustworthy, even cherished, friend.

When it comes to making decisions such as hiring an aide, caregivers often struggle with choosing on their own or giving the care recipient her prerogative. Because every caregiving situation is different, there's no clear way to proceed that's

always best. In my observation, families tend to bend over backwards, whenever possible, to allow their loved ones to retain the dignity of making decisions that impact them directly. Retaining that dignity is no small matter; without it, care recipients are likely to become demoralized and depressed. Even when safety is at issue — for instance, when questions arise about someone's driving capabilities — family members frequently err on the side of allowing their loved ones to take risks. Surely, this is not always the wisest approach. Generally speaking, however, caregivers do make the hard decisions prior to any disaster occurring.

In your situation with your mother, there wasn't really a clear-cut safety issue at stake. Rather than provoke conflict with her and possibly make her feel diminished, you were guilty, at worst, of complicity in trusting her aides. Given that most aides are trustworthy, this was a reasonable choice. Though the outcome of that choice turned out to be unpleasant and upsetting, it was not a life-and-death matter. Your mother was probably chagrined about being robbed but she still retained the dignity of having the power to make her own mistakes.

Which brings us to the last question: Should you feel responsible that things worked out poorly? If there was a significant probability that an adverse outcome could occur, then the answer might be yes. But the odds that she would be robbed were very small. You erred on the side of allowing your mother the privilege of being the person she wants to be. In my opinion, you did right.

**Q** My husband and I moved in with my grandmother a year ago to give her 24-hour care. She has dementia and can't be by herself. Her kids pick her up on Friday night and bring her home on Sunday. During the week, I buy all the food, fix all of her meals, clean up after her, do all the laundry and housework,

and take her blood pressure, dispense her medications, etc. I also do her hair and make-up and take her to the doctor. I am not paying rent to her. Grandma pays her own electric, water and gas. When I was working at a bank I made \$2,500 per month. Our rent and bills were approximately \$800 per month. My grandmother's children feel that since I don't pay rent, I'm being paid for providing 24-hour care. I feel that I should be paid for my time. My aunts and uncles don't want to give up their jobs or homes to take care of her. I think they are ready to put her in a home. They make me feel bad for thinking that I should be paid something for my time. Her kids have not called me once in the past year to see if I need anything. On top of providing care, we take my grandmother out to eat or to the movies. I don't believe her children recognize the value of what I am doing for their mother. What can I do?

**A** Your aunts and uncles are either extraordinarily naïve or they are taking extreme advantage of you. They should realize that the monetary value of the care you are providing is tens of thousands of dollars per year and that the rent money you are saving is a small fraction of that. You have good cause to be angry at them. Yet expressing that anger is only going to harden their miserly stance and won't bring you any closer to gaining their support and acknowledgment for your generous work. You'll need to be cunning and patient.

I suggest that you ask for a small stipend — a mere pittance, really — to help you pay for specific living expenses, such as food and entertainment costs. By getting them to pay anything, you will be setting a precedent of having them contribute to the upkeep of their mother's household. It then will be easier to approach them to increase that stipend in the future as other expenses are incurred. I also strongly recommend

that you discuss your request with key members of the family individually before unveiling the proposal to your aunts and uncles as a whole. By winning over individuals (or at least neutralizing their opposition), you will increase the chances of getting a fair hearing and a positive response from the larger group.

If that fails, I'd suggest calling their bluff. Tell them that you can no longer care for your grandmother in her home without impoverishing yourself and your husband. Suggest to them that you will stay in the house only for as long as they need to make other caregiving arrangements. My guess is that this would set off some kind of panic among them. Even if some of them are in favor of placing their mother in a nursing home, they will blanch at the likely price tag — all of her assets, most particularly the proceeds from the necessary sale of her house. In essence, by institutionalizing her, they will be sacrificing their inheritance. Call me cynical, but I think that this financial pressure will sway them. My guess is that they will suddenly find the means to pay you to continue caring for her. Whatever they offer, ask for double. ■

#### **DON'T BE LEFT IN THE DARK**

After February 17, 2009, all TV stations will stop broadcasting analog signals and will broadcast only in digital.

**Any analog television that uses a rooftop antenna or "rabbit ears" will not work after this date.**

Televisions connected to cable, satellite or other pay services should continue to work after the transition, but subscribers are urged to check with their provider.

**If you have an analog TV, you must make the digital transition.** From now through March 31, 2009, all U.S. households may request up to two \$40 coupons to help pay for the cost of a certified converter box.

Don't wait. For more information about the TV Converter Box Coupon Program, visit [www.DTV2009.gov](http://www.DTV2009.gov) or call toll free 888/388-2009.

## Working From Home

The article "Working From Home" in the winter 2008 issue garnered quite a response from our readers. NFCA received a number of e-mails and phone calls from members who wanted to share their experiences in an attempt to help their fellow family caregivers. We are pleased to share some of those letters with you and hope that they provide helpful advice and, perhaps, a little inspiration.

Your article on working at home for family caregivers was one of the best I have seen! My husband and I had to chuckle ... I work for five of the companies you listed. (My personal favorite is [www.intrep.com](http://www.intrep.com).) I wish I had a complete list like this one two years ago when I began to look for work-from-home opportunities.

There are a couple of points I would add. There may be some nominal start-up fees (for background checks only) and you'll need a dedicated landline and Internet access. You will also need a quiet place to work. The impression given to any caller for any client must be that you are calling from a professional business atmosphere — no noisy kids, no barking dogs, no ringing phones, etc.

Just like any career change, a transition period is necessary. There is also a learning curve, especially with the customer service/direct response employers (like LiveOps and West at Home). Start with one or two companies and work them part time around your current job. Take a couple of months to learn the ropes and the rules, and to work on your sales skills ... after a few months, you will be ready to switch to just working at home!

Finally, make no mistake that working from home, while more convenient, is still just that — work.

There are standards that vary for each company and, as an independent contractor with some companies, you are your own boss. But I have never been happier and the control I have over my schedule and my income is comforting, especially when dealing with a disabled family member and the stress that goes along with that.

I was a restaurant manager for decades before my husband became disabled from Adhesive Arachnoiditis. The companies listed in the article have actually allowed me to make more income from home than I did before, to save money on expenses (no more gas bills, fancy lunches and work clothes), and still to have time for my husband's appointments and needs, my kids, and my sanity.

The BEST sight I have found for all current work-at-home opportunities is [www.ratracerebellion.com](http://www.ratracerebellion.com). It has new leads every day, and a complete listing of the major companies that are always accepting applications!

— Deborah Baldwin  
Leavenworth, Kansas

My wife, Phyllis, has had MS for more than 25 years and is now bedridden. We've had to make many adaptations and one of the latest was working from home. I retired in December 2007, but I worked from home for the last three years of my career.

I supervised the purchase of capital equipment for a major manufac-

turer and my coworkers were spread out geographically. The transition to working at home occurred gradually. We relied heavily on e-mail and online approvals and I used Remote Secure Access (RSA) to log into the company's systems from home.

With high-speed Internet access and today's inexpensive "all-in-one" printer-scanner-copier-fax machines, there are a lot of ways to get things done.

While I never made a big deal about it, I never tried to "hide" the fact that I was working from home. I made sure that all who needed it had my home phone number and my cell phone number. I never heard of any complaints that I was difficult to reach or failed to answer any request in a timely manner.

I should include a word of caution: You will need to make it clear to your friends and acquaintances that you are WORKING from home. Just because you're there does not make you available for casual visits. You must give your full attention to your job to maintain your end of the agreement.

— Jimmy Johnson  
Germantown, Ohio

I'm a 51-year-old mother of two wonderful sons. When my youngest son was 3 years old, (he's 30 now), he was hit by a car. He suffered a broken collar bone and a brain injury. He was in a coma for three months and in the hospital for a year. He had to relearn everything — how to walk, talk, eat, dress, etc.

I've been his caregiver ever since. He has done very well, including graduating high school, but he would have a very hard time living on his own and so we live together.

Just before the car accident, I separated from my husband and started a new life with my sons. For several years I had a dog grooming shop at home but after years of back-breaking work I had to stop grooming dogs. In October 2007 I started my own Watkins business. It's an excellent opportunity for people who either can't or don't want to be out in the typical 40-hour work situation. Whether people like to garden, bake, entertain, pamper themselves, or just try something unique, Watkins has products for them. This business can be "formed to fit" around a caregiver's needs. Although we love those we are caring for, it also can give us opportunities to get out and about with new, fresh faces ... a little time out for ourselves, if you will, but at hours that are flexible.

Because this business can be run in so many ways, I thought it might be a help to some of the caregivers out there. Anyone interested can check out these Web sites:

<http://123jeanne.com> or  
[www.watkinsonline.com/irons](http://www.watkinsonline.com/irons).

— Jeanne M. Irons  
Watkins Independent Associate  
Exmore, Virginia

I've been caring for my husband for the past nine years. He fell down our basement stairs, suffered a traumatic brain injury, and needs 24-hour care. For financial reasons I had to look for additional income where I could work from home. With the help of the MOM Team, I've partnered up with an international wellness company and I set up customer accounts for them right from home. I set my own hours and there was no large investment, no inventory, no complicated paperwork, no billing or collections, and it was risk free. It has changed my life for the better for

so many reasons! Anyone interested in learning more can visit my Web site:

[www.behomeandmakemoney.com](http://www.behomeandmakemoney.com).

— Kim Cornelius  
Milwaukee, Wisconsin

I am the primary caregiver for my 90-year-old mother. I wanted to let NFCA readers know that a good home-based business is selling Avon products.

— Linda Errichetti  
Staten Island, New York

*Editor's Note: We hope these letters will provide our readers with a few more ideas about how to make money working from home. Please note that the suggestions from readers contained above are based on their own experiences. NFCA is not responsible for the accuracy of any of the above information.*

## Caregiver Disorder

*Continued from page 2*

- Family caregivers report having a chronic condition at **more than twice** the rate of non-caregivers.

— *Informal Caregiving: Compassion in Action*. Washington, D.C.: Department of Health and Human Services, 1998.

I purposely included a portion of the source information for each statistic because I wanted you to see the prestigious journals that have published these studies. So yes, finally, the medical community recognizes what family caregivers have been saying for years: Family caregiving has a negative effect on the caregiver's health and well-being.

There has been some progress made legislatively as well, not in terms of healthcare itself but, rather, in the social service realm. In 2000,

Congress passed and the president signed into law the National Family Caregiver Support Program to provide services through Area Agencies on Aging to family caregivers of the elderly. The program has been beneficial and it was just reauthorized for an additional five years. In December 2006, the House and Senate passed the Lifespan Respite Care Act, which will help states set up respite care offices and pool all the information about respite programs together in one place so that family caregivers have an easier time actually getting some. Advocates are still trying to have money appropriated to fund the bill.

Passing two pieces of legislation that help family caregivers is all good, but we still have a long way to go, especially when it comes to the health of family caregivers. When I first wrote this article, some people admonished me for "medicalizing"

family caregiving; now we know that this role *does* have medical consequences. So what is going to be done about it?

I think a good place to begin is by identifying family caregivers on medical charts — our own and those of our loved ones. How can a physician effectively treat a patient with a disability or chronic illness unless she knows the circumstances of that person's life? It's easy enough to have the question on intake forms: Do you have a family member or friend who assists you in your daily activities? Are you caring for a family member or friend who has a chronic or disabling condition? Two simple questions, that's all it would take to at least move us out of the shadows of medical care.

I want my personal physician to write "family caregiver" on my chart so he takes this fact into considera-

*(Continued on page 16)*

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## Caregiver Disorder

Continued from page 15

tion when examining and treating me. I want my husband's healthcare providers to acknowledge me as his family caregiver and to examine me verbally, to watch out for symptoms in me that might spell trouble, and to refer me back to my own physician when deemed necessary. It truly can't be too much to ask.

When I look back at this article a dozen years from now, I hope to report on a great deal more progress in protecting the health of family caregivers. I'd like to say that the health of America's family caregivers has improved significantly and, because of that, so has the health of those for whom we care. ■

*Editor's Note: For complete source information for the statistics mentioned in this article, go to [www.thefamily-caregiver.org](http://www.thefamily-caregiver.org), click on "Who Are Family Caregivers?" and "Caregiving Statistics."*

**N F C A**®

## NATIONAL FAMILY CAREGIVERS ASSOCIATION

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### A CAREGIVER'S EYES

*By Rose M. Trosper, July 2007, inspired by and dedicated to all caregivers.*

A caregiver's eyes tell me everything I need to know.  
Their sadness, their fatigue,  
the overwhelming feelings that consume them.  
How do I tell them how much I care,  
how much I would do ... if I could?  
These precious souls with hearts of gold,  
forgotten by those who should be so close,  
and, yet, they are so distant.

Do they know how often I feel the burning questions,  
those that haunt their every waking moment?  
The ones that ask ... why me,  
how much longer ... how much more?  
I would change their world if only I could,  
if only miracles were mine to give,  
if only I held the power,  
if only I had wings.

Don't they know they already have their own wings,  
and that they teach me so much?  
More than I could ever offer to them in return.  
Do they know I watch over them  
as best I can with the watchful eyes  
of a mother, a friend?  
Or, that they are in my heart,  
each one so cherished, so unique.

A caregiver's eyes tell me everything I need to know.  
But every now and again,  
I see a faint smile, a knowing look  
that says ... thank you, my friend.  
It is in those moments that I know  
I am where I should be.  
And, for as long as they need me ...  
this is where I can be found.