

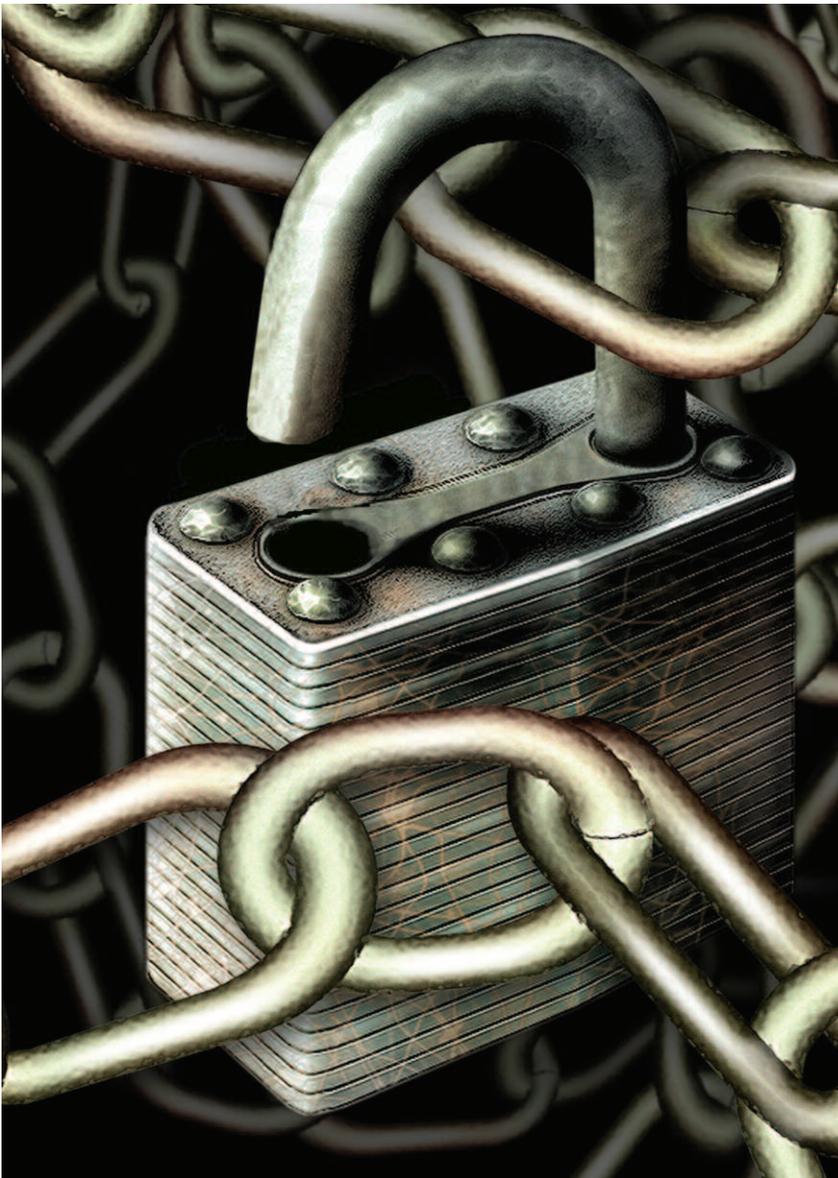
# Caregiver's

## HOME COMPANION

Volume 4 Issue 11 | June, 2006

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

H E L P I N G T H O S E W H O H E L P O T H E R S



## Managing Caregiver Guilt

# 8 Steps for Guilt to Serve You, Not Imprison You

By Dr. Vicki Rackner, MD

**G**uilt is a common feeling in the slippery landscape of caregiving. Guilt can immobilize you...or it can propel you to be the best you can be.

For caregivers, painful feelings—such as guilt, sadness and anger—are like any other pain. It's your body's way of saying, "Pay attention!" Just as the pain of a burned finger instinctively pulls your hand from the stove, so, too, guilt guides your actions and optimizes your health. Yes, guilt can be a *positive* influence in our lives.

You have a picture of the "Ideal You" with values you hold and how you relate to yourself and others. Guilt often arises when there's a mismatch between your day-to-day choices and the choices the "Ideal You" would have made. The "Ideal You" may be a parent who attends all of the kids' soccer games. Miss a game to take your dad to the doctor, and you think you're falling short. ▶

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Online: \$19.95 per year (U.S.)

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Caregiver's Home Companion  
is published monthly by:  
**Pederson Publishing, Inc.**  
P.O. Box 693,  
Southport, CT 06890-0693

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## Unrecognized guilt eats at your soul. Name it; look at the monster under the bed.

### Managing Caregiver Guilt *Continued from page 1*

But in fact, you may have needs out of line with this "Ideal You." You may believe that your own needs are insignificant, compared to the needs of your loved one. You then feel guilty when you even recognize your needs, much less act upon them. A mother may ask herself, "How can I go out for a walk with my kids when my mother is at home in pain?" (A hint: she can give more to her mother with an open heart when she takes good care of herself.)

You may have feelings misaligned with the "Ideal You." Feeling angry about the injustice of your loved one's illness? You might even feel angry at your loved one for getting sick! Recognizing those feelings can produce a healthy dose of guilt. Yes, you may even feel guilty about feeling guilty.

"Why did my loved one get sick?" you may ask. Perhaps, if the "Ideal You" acted more often, your loved one would be healthy. What if you served more healthful meals? What if you called 911, instead of believing your husband or father when he said his chest pain was just "a little heartburn?"

If you're the kind of person prone to guilt—and many elder-caregivers are—learn to manage guilt so that guilt serves you rather than imprisons you. That may sound strange, but here are 8 tips for managing your caregiver guilt:

**1. Recognize the feeling of guilt:** Unrecognized guilt eats at your soul. Name it; look at the monster under the bed.

**2. Identify other feelings:** Often, there are feelings beneath the guilty feeling. Name those, too. For example, say to yourself: "I hate to admit this to myself, but I'm resentful that dad's illness changed all of our lives." Once you put it into words, you will have a new perspective. You will also be reminding yourself of how fortunate you are to have what it takes to take care of your loved one.

**3. Be compassionate with yourself:** Cloudy moods, like cloudy days, come and go. There's no one way a caregiver should feel. When you give yourself permission to have any feeling, and recognize that your feelings don't control your actions, your guilt will subside.

**4. Look for the cause of the guilt:** What is

the mismatch between this "Ideal You" and the real you? Do you have an unmet need? Do you need to change your actions so they align with your values?

**5. Take action:** Meet your needs. Needs are not bad or good; they just are. If you need some time alone, find someone to be with your loved one. This is called respite, and every caregiver needs and deserves it to stay energized.

**6. Change your behavior to fit your values:** For example, Clara felt guilty because her elderly aunt living some distance away was in the hospital and she didn't send a card. Her guilt propelled her to buy some beautiful blank cards to make it easier for her to drop a note the next time.

**7. Ask for help:** Call a friend and say, "I'm going through a hard time. Do you have a few minutes just to listen?" Have a family meeting and say, "Our lives have been a lot different since grandma broke her hip. I'm spending more time with her. Let's figure out together how we'll get everything done."

**8. Revisit and reinvent the "Ideal You.:"** You made the best choices based on your resources and knowledge at the time. As you look to the future, you can create a refined vision of the "Ideal You." What legacy do you want to leave? What values do you hold dear? Then, when you wake up in the morning and put on your clothes, imagine dressing the "Ideal You." Let this reinvented "Ideal You" make those moment-to-moment choices that create your legacy.

And finally, understand that you will be a more effective caregiver when you care for the caregiver first. Loved ones neither want nor expect selfless servants—no matter how they may act towards you at times. As a caregiver, when you care for yourself, you increase and improve your own caring. Yes, guilt is part of caregiving, but this guilt can help you become the caregiver you and your loved one want you to be. ■

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**Dr. Vicki Rackner** is a board-certified surgeon and clinical instructor at the University of Washington School of Medicine who left the operating room to help caregivers and patients take the most direct path from illness to optimal health. Want more caregiving tips? Get your free report "Caring for the Caregiver" by emailing her at [DrVicki@DrVicki.org](mailto:DrVicki@DrVicki.org).

## No More Yelling in the Ear

# How to Communicate with a Hard-of-Hearing Loved One

By Marion Karpinski, RN

Everyone knows how frustrating it can be to talk to an elder who can't hear well. Too often, we find ourselves yelling in their ear. Sometimes we even quit trying and pass it off as hopeless. But as a conscientious caregiver, you know there must be more you can do to bring your loved one back into the loop of meaningful two-way communication. After all, their quality of life depends on it!

As the old adage goes, "put yourself in their shoes." Imagine how isolated you would feel if you were in the midst of a family gathering where everyone is talking but you are left out of the conversation because you can't hear well enough to join in. Day after day, people speak or yell into your ear but you only comprehend pieces of what they say. Most of their speech comes across as incomprehensible mumbles or overly loud bursts of sound. After a while, people stop trying to talk to you, and you begin to doubt your own self worth, withdraw and sink into a debilitating depression.

As a caregiver, what you do to help the hearing impaired person communicate will greatly contribute to their ability to thrive.

### Evaluation Sheds New 'Sound' on Life

Though your elderly loved one has likely seen a doctor, it is still important to have a professionally trained audiologist evaluate the type and extent of their hearing loss. This will pinpoint the types of sounds the person has most difficulty hearing and will provide insight into how to alter your environment, your approach or even your speech.

For example, the inability to hear upper frequency sounds may make it difficult to hear a high-pitched voice or certain consonant sounds. The letter "s" is often difficult to hear because it occurs at a high frequency. Instead of hearing the word "slide," the elderly may hear "lied" or "I'd." In the context of a whole sentence, they lose a lot of critical information when all of the high frequency sounds are blurred or missing.

If you sense that your loved one doesn't understand the message, you can try to speak in a lower pitch. If that doesn't help, you can ask the hearing impaired person to repeat what has just been said

so you will know what part of the conversation needs to be clarified.

Another common problem to be diagnosed by an audiologist is tinnitus, a constant or periodic ringing in the ears. It may sound like a whistle, a ringing or a foghorn. Certain medications can irritate nerve endings, causing tinnitus. An audiologist or doctor may be able to identify the problem medication and the drug may be changed or adjusted.

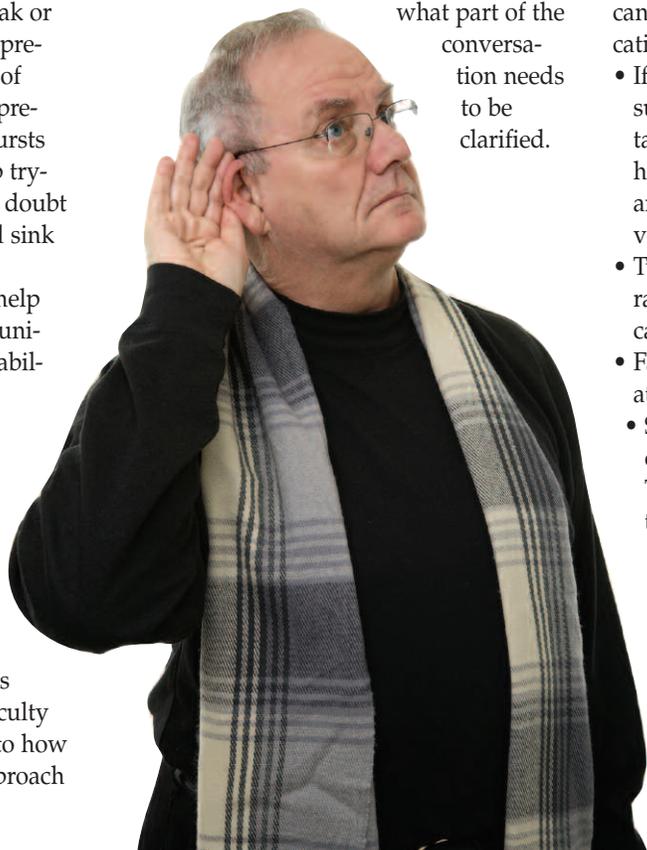
Caffeine and nicotine are known causes of tinnitus. Reducing or eliminating these substances from the senior's diet can significantly improve his or her hearing.

### Finding New Ways to Be Heard

For anyone with hearing loss, there are a variety of communication techniques that can be used to improve overall communication:

- If he or she wears a hearing aid, make sure it is in place before you begin to talk or provide care. Make sure the hearing aid is clean, placed properly, and that its battery is charged and the volume adjusted.
- Turn off the television, dishwasher, radio or other surrounding noises that cause distraction.
- Face the elderly person or get his or her attention with a gentle touch.
- Speak to him or her at eye level from a distance of between 3 to 6 feet away. Try not to sit or stand with your back to a window or light because it causes your face to be dark and hard to see. Adjust the lighting so your face and body are easy to see. This enables the hearing impaired person to "read" your body language and facial expressions for nonverbal cues that help the person better understand what you are saying.

*continues on page 7*



# TOP 10 TIPS

# SURVIVAL SKILLS FOR CAREGIVER BOOT CAMP

By Paula S. McCarron

I never really wondered *if* I'd become a family caregiver but only *when*.

It was 2003 when my mother was diagnosed with vascular dementia. She was living independently and managing with minimal assistance. But in February of this year, she spiraled into a health crisis. That's when I found myself thrust into the ranks of family caregivers and discovered that no matter how much training or knowledge one might seem to have, one can never have enough.

What follows is a list of "survival skills" that I hope will prove beneficial to all elder-caregivers who find themselves as enlistees of what I affectionately refer to as Caregiver Boot Camp.

## 1. CONVENE A SUMMIT

Arrange for a family meeting to share concerns, evaluate options and identify resources. Inviting other family members to be part of the decision-making process sends the message that caring for a loved one is a family affair. If you anticipate that a family meeting might disintegrate into a "gripe and blame" session, consider hiring a mediator, counselor or geriatric care manager to act as facilitator.

If a family meeting is not possible because of distance or other considerations, you may wish to try group email, online chat forums, instant messaging or phone conferencing as a means of communication.

## 2. OBTAIN LEGAL AUTHORITY

Encourage your loved one to set up the legal documents that will allow for a designated person to make medical and financial decisions on their behalf in the event they can no longer do so.

Other documents to ensure that your loved one's wishes will be carried include a living will. In some situations, do-not-resuscitate orders, or what are commonly known as "comfort care" orders, may be appropriate.

Note that in some states, these documents may require the involvement of an attorney or physician. Be sure to research requirements for the state in which your loved one resides.

## 3. GET EDUCATED

Being an informed consumer takes time and considerable research. It's also a never ending process, as your loved one's healthcare needs will change over time.

How, then, can one expect to become a savvy caregiver? "First, get a copy of *Circles of Care* by Ann Cason (Shambhala Publications 2001). Second, contact your council on aging as they know what's available in your community. And then, join a caregiver's support group," says Karen Pollack, a geriatric care manager working in the Boston area.

## 4. DIG DEEP

To get the best answers, you need to dig beneath the surface. If you ask questions in a manner that invites others to share their insights and expertise, you may get not only answers but more creative solutions.

Here are some suggested questions: What would you do if your loved one were facing a similar situation? What options do you feel we may have? What kinds of problems have others encountered? What might be the consequences of taking this step?

Before ending a conversation, ask if the person you are speaking with has suggestions as to where you might call next or if there is someone else who may have information or expertise you need. When asked, most people will gladly share this information, but it's surprising how rarely they do unless specifically asked.

## 5. CREATE A PAPER TRAIL

Keep a notebook containing the following information: Your loved one's insurance coverage information, Social Security number, a current list of medications and the names and phone numbers of the primary physician as well as other healthcare providers. Sometimes, rather than a notebook, caregivers find online "personal health record" services convenient, especially for sharing information with



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**“It takes time, effort and a real willingness to step aside from the emotions and get your hands dirty. Being a caregiver often means stepping into a new and uncomfortable role with your parents.”**  
—Jane Hart, founder of Hart Felt Ministries.

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far-flung siblings. Check out [www.myphr.com](http://www.myphr.com) for available options.

If you are providing “hands-on” care, especially during time of health crisis, keep a daily log of symptoms, medication administration, sleep patterns, frequency of bowel and bladder function, food and fluid intake, as well as any problems or questions that arise.

This log can be especially helpful if you summarize major concerns based on your notes and then fax them to the physician’s office prior to a visit. It can also prove invaluable in the event your loved one requires hospitalization.

## **6. CALL FOR REINFORCEMENTS**

Determine what is needed and who can help. Be specific with your request. Asking a friend to “please come stay with Mom for two hours on Tuesday afternoon” is more likely to yield the help you need than vaguely asking that same friend to “please lend some help when you can.”

If family or friends are not available, consider using paid or volunteer caregiver services at least occasionally.

It’s trite but true that you must first care for yourself in order to care for others. As a good friend has reminded me more than once, “Follow the advice given by flight attendants prior to take-off: In the event of a crisis, apply your own oxygen first and then lend assistance to other passengers.”

## **7. DRAFT AN ALLY**

“The most successful caregivers I’ve known are the ones who have built a package of services for their loved one. They’ve arranged for home-delivered meals, specialized equipment, hired aide services and made arrangements for respite,” says Jane Hart, founder and director of Hart Felt Ministries, a faith-based volunteer caregiver program in Jacksonville, Florida.

Hart acknowledges that it takes considerable time to locate, hire and coordinate services, so she suggests that caregivers hire a geriatric care manager, if at all possible. “I know it can seem expensive, but I think they save people money and headaches in the long run,” she says. “It’s like telling someone where you want to go and then allowing them to fly the plane.”

## **8. BE WILLING TO STEP INTO A NEW ROLE**

“It takes time, effort and a real willingness to step aside from the emotions and get your hands dirty,” says Hart. “Being a caregiver often means stepping into a new and uncomfortable role with your parents.”

Keep in mind that a new role doesn’t mean that you must become the “parent,” but it might require that a new type of partnership needs to develop between you and your loved one.

## **9. STRATEGIZE**

Take time to gain some understanding of what your loved one is facing, what he or she needs and what options are available. Don’t attempt to chase down every possible care option. Instead, determine the greatest needs and what resources are available, both in terms of services and payment sources. Then proceed to work from the most critical needs down to the less vital needs. For example, my mother’s greatest need upon leaving the hospital was a safe, stable, and supervised environment. So that is where my family and I focused 90% of our energy.

## **10. BE GENTLE WITH YOURSELF**

During the time my mother was in highest need, I was in highest need myself. I was fortunate to have had the help of many people including siblings, cousins, co-workers, and friends. But even with all of that support, I came to accept that during the time of my mother’s crisis, I was in crisis myself.

Oddly enough, this realization proved to be very helpful. It allowed me to accept the help of others, and in the process the support given to me became the emotional strength I needed to help my mother. ■

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*Aside from caring for her mother, Paula McCarron has more than 20 years of experience in healthcare, including nursing homes and hospice. She lives in Chelmsford, Massachusetts, and can be reached at [paulamccarron@gmail.com](mailto:paulamccarron@gmail.com).*

## Caregiver Checklist

# Helping Seniors Weather the Storm

The nation's elderly become the most vulnerable part of the population in the midst of a catastrophe. The eldercare group Visiting Angels has compiled the following list to help seniors and their families arm themselves with the best resources and supplies before disaster strikes.

**Keep copies of all relevant medical records.** In an emergency, up-to-date medical records will help first responders provide proper care with the least amount of delay. This is especially important for those with diseases, drug



allergies, or other medical conditions.

**Refill all necessary prescriptions.** Be sure to have an ample supply of all daily medications. These refills may save lives, or buy enough time to find treatment at a healthcare facility.



**Have extra food and water on hand.** Stock up on canned goods, non-perishable food, and—most importantly bottled water in case the senior's home is inaccessible to first responders, or stores are closed or have empty shelves.

**Work with a reliable caregiver.** Families with elderly relatives should arrange for a professional or volunteer caregiver to check them in the event of an emergency. Choose an agency or individual who can assist seniors in a timely and responsible fashion. Seniors who have assistance are more likely to avoid a disaster completely or have help after the emergency hits.

**Pocket spare cash.** Keep a moderate amount of cash on hand in case banks close, ATMs become inoperable, or travel is hindered. Spare cash will help seniors and their caregivers evacuate or act

quickly in case of an emergency. An absence of cash or other funds may prohibit them from buying food, gas, medicine, or other vital items.

**Collect cherished possessions.** In a time of panic, it is comforting to know that important items, such as family heirlooms and treasured photographs, are in a safe place. Seniors should keep a small box of these keepsakes ready to grab in case of an evacuation.

**Maintain open communications.** Cell phones, a working land line, and radios are important means of contacting emergency personnel, caregivers, family, and learning about the status of first responders or important safety information. Keep these items handy, operable, and in a safe place to ensure that seniors are taken care of and informed.

**Stockpile flashlights and**

**batteries.** Store a reliable flashlight and extra batteries for possible nighttime emergencies or for vision during a power outage. A working flashlight is a crucial navigation tool, and can help those at risk identify their location for emergency crews.

**Keep a supply of blankets and dry clothes.** To prevent hypothermia or other illnesses during a natural disaster, seniors need to stay warm and dry. Items such as blankets and dry clothes are essential during a flood or extreme cold. Seniors should keep several days' worth in their home and car.

**Mobilize disabled seniors.** Those who are already disabled, or those with limited mobility, should consider keeping a wheelchair or other mobilization device on hand. This will allow for fast and safe transportation of seniors dur-





ing a last-minute evacuation.

**Establish a meeting place with family and friends.**

During an evacuation or chaotic event, families may be split up. Try to establish a few meeting places, depending on the emergency. If family members must leave from different locations, agree on a shelter or other public area for everyone to convene. If a natural disaster forces statewide evacuation, designate a recognizable landmark or another family member's house as a contact point. Family members should also be sure to have an updated photo of their elderly relative.

**Clear obstacles for a smooth exit path.** Obstacles



around the house may slow a hasty evacuation or cause injury. Clear sticks and branches from the yard to make sure a car or ambulance can pull up to the house. In addition, formulate an evacuation plan before disaster strikes. This includes safely exiting the home, and knowing how to get to major evacuation routes. ■

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## Your effort to draw your loved one into daily activities keeps them from feeling lonely and isolated.

### How to Communicate with a Hard-of-Hearing Loved One *Continued from page 3*

- Do not cover your mouth, chew gum or talk with your mouth full. This distorts speech and facial cues that support what you are saying.
- Try stating the topic before beginning a conversation. This gives the person with hearing loss a point of reference or a helpful context for the words you use.
- Avoid speaking or yelling into a person's ear. It may be helpful to speak louder, but rarely does yelling do more than cause distortion, especially if that person is wearing a hearing aid. When a person yells, the listener will likely interpret the communication as angry.
- If a person hears better with one ear, sit or stand angled toward that ear, but stay far enough away so the person can read the other helpful facial and body cues.
- Speak clearly without exaggerating your lip movements. This sends the most accurate facial clues to what's being said. If you are a fast speaker, slow down.
- Try rephrasing your words by using short, simple sentences. Avoid repeating the same thing over and over.

### Outside the Home

We are surrounded by distracting sounds when riding in a car, eating in a restaurant or outside our controlled home environment. As much as possible, try to minimize the noise by keeping car windows up and turning the radio or fan off before you begin to talk.

In a restaurant, ask for a table near a corner or wall or as far removed from the middle of a crowded room as possible. Have the person sit with his or her back to the wall and sit across from him or her, keeping your face visible.

In a group setting, remind others to allow only one person to talk at one time.

### Success Takes Two

It takes patience from both parties when one person has hearing loss. Give the person plenty of time to process what's been said and time to respond. Remember that for

someone who has limited hearing, there is more work involved in communicating, and this process can be tiring. When a person isn't feeling well or is very tired, they may simply need time to rest.

Even when it seems there is nothing new to talk about, reading a newspaper headline or commenting on the weather shows that you are attentive, receptive and responsive. Your effort to draw your loved one into daily activities keeps them from feeling lonely and isolated. Share what you have learned about communicating with your loved one and other significant people in their life so they too can share meaningful conversation.

As a caregiver—family or friend—a person with hearing loss will appreciate that you recognize them as a functional person with the need to express thoughts, feelings, desires and dreams. ■

*Marion Karpinski is president of Health Care Training Systems Inc. and founder of Healing Arts Communications based in Medford, Oregon. For 11 years, her company has provided educational resources in the form of DVD/video programs, books and online education to caregivers and those who support and train care providers. Marion can be reached at [marion@homecarecompanion.com](mailto:marion@homecarecompanion.com).*

## COMING UP IN JULY

■ Using **personal health records** to streamline your caregiving. What are they, and how can they help you and your loved one?

■ **Senior-proofing your elderly's home** can result in greater safety for them and peace of mind for you. We'll give you a dozen tips you can implement right away.

■ **Laxatives and the elderly.** They are sometimes necessary, but can also be abused. We'll tell you about proper use as well as possible overdosing risks.

■ **Seasonal allergies** bedevil many of us, caregiver and elderly alike. Understanding what makes allergies—and their treatment—different for aging loved ones.

# When Is a Coma Not a Coma? Ask Hollywood

**W**atch some of the movies churned out by Hollywood these days and you might think the director was comatose. Well, not exactly. But the way comatose characters are portrayed in movies has come under scrutiny—and most receive a failing grade.

Newly published research shows that coma is often misrepresented in movies, which could skew public perception of coma and impact real-life decisions. This last point is the real concern, according to a study published in *Neurology*.

In a review of U.S. and foreign movies, only 2 of 30 movies with characters in prolonged comas showed a reasonably accurate representation of coma, according to study author and coma expert Dr. Eelco Wijdicks, a neurologist with the Mayo Clinic in Rochester, Minnesota.

Problems included showing a comatose person suddenly awakening with no physical or mental problems after years in a coma and portraying the comatose person as a sort of “Sleeping Beauty” with no

loss of muscle tone or feeding tubes and with perfect grooming and tanned complexions. All but one of the movies showed the comatose person only with closed eyes, when in reality people in prolonged comas often have their eyes open.

Wijdicks reviewed comedy, drama and thriller films made between 1970 and 2004 to identify 30 movies for the study. He then showed clips of 22 scenes from 17 of the movies to 72 people with no medical training and surveyed them on the accuracy of the portrayal of coma.

“More than a third of the time, the viewers weren’t able to identify important inaccuracies in these scenes,” Wijdicks said. “We are concerned that these movies can often be misinterpreted as realistic representations, especially in the wake of the Terri Schiavo tragedy and public debate.”

One comedy showed a comatose person tapping out a message in Morse code with his finger. Thirty-one percent of those surveyed thought that this behavior was possible. (Clue: it’s not.)

Wijdicks also sought to determine how much impact these movies may have on the public’s decision-making. Study participants were asked how strongly they agreed with this statement: “If my family member would be in the same situation, it is possible that I would remember what happened in the scene and allow it to influence any decisions that I would make.”

More than a third of the viewers—39%—said that they would allow the scenes to influence their decisions.

“We understand that making motion pictures is an art form and that entertainment is a very important component of that art form,” Wijdicks said. “But this misrepresentation in both U.S. and foreign movies is problematic.”

Which two movies passed Wijdicks’ test? “Reversal of Fortune” and “The Dreamlife of Angels” received passing grades for accurately portraying the agony of waiting for a comatose patient to awaken and depicting the patient and complexity of care. ■

# Give the Lasting Gift of Care

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