

Caregiver's

HOME COMPANION

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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

DANCING with Dementia

Learning to Cope with a Life-Altering Disease



By Susan M. McCurry, Ph.D.

Without a doubt, caring for someone with dementia presents many unique caregiving challenges. In addition to the physical assistance many older adults need, dementia patients also can experience a range of mood and behavioral changes that leave caregivers scratching their heads on how best to manage.

Dementia symptoms continually change and evolve. No sooner is one problem resolved than a new one appears. One day the demented individual responds easily to reason, and the next day they are resistant to any attempt to influence their behavior. Predictability goes out the window, and caregivers are often divided over the best way to handle the dementia patient because they act differently in each case. Such behavioral inconsistencies in a person who looks perfectly healthy are common in dementia, but they can make dementia caregiving extremely difficult.

Dementia caregivers need a set of skills that can help them be more resilient, to develop creative solutions to the infinitely varied and continually surprising situations they encounter. In my research and clinical practice, I have found that the acronym D.A.N.C.E. is a useful tool for discussing these skills. The acronym stands for:

- D** = Don't argue;
- A** = Accept the disease;
- N** = Nurture yourself;
- C** = use Creative problem-solving; and
- E** = Enjoy the moment.

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Webmaster
NOW Interactive Solutions
webmaster@caregivershome.com

Mail
Caregiver's Home Companion
P.O. Box 693
Southport, CT 06890-0693

Phones
Subscriptions & Customer Service:
(877) 259-1977

Advertising & Sales: (203) 257-6684
or (203) 254-0380 ext. 2

Administration & Editorial:
(203) 254-3538

Custom Publishing: (203) 438-0810

e-mail Inquiries:
editor@caregivershome.com

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'Dancing' with Dementia

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The following scenario illustrates how each of these principles work.

Margie was an 87-year-old woman with Alzheimer's disease. In addition to memory problems, she was preoccupied with her health and called her daughter, Madeline, every day asking to go to the doctor to find out what was wrong. Although Margie couldn't remember that she had already been to the doctor and talked to Madeline several times in the past hour, she could recall old accidents, hospitalizations, and past illnesses in vivid but incorrect detail. She was convinced that she had an undetected cancer and that her daughter and doctors were conspiring against her. Never a very happy person, Margie was now tortured by pain, fear, loneliness, and confusion.

Madeline, who was caring but exhausted, desperately wanted to help but was also furious that all of her attempts to do so were forgotten and unappreciated. How might use of D.A.N.C.E. make this situation better?

For Madeline, the first step was to accept her mother's disease. Margie had always been a worrier, and her repeated requests to see her doctor for nonexistent maladies had been going on for years. It was hard for Madeline to believe that her mother wasn't being deliberately difficult and controlling. Like Madeline, every caregiver should talk with his or her healthcare provider about the typical and atypical signs and symptoms of dementia, its progression, and available treatment options. It helps to have these conversations in private, where you can feel free to voice your concerns without embarrassing or upsetting your loved one.

I also recommend scheduling a family conference with the physician or nurse so that other relatives who may not be involved in your loved one's day-to-day care can have their questions and concerns addressed, particularly if there are differences in opinion about the diagnosis or appropriate level of care. Accessing educational resources such as the Alzheimer's Disease Education and Referral Center (ADEAR; www.alzheimers.org) and the Alzheimer's Association (www.alz.org) provide up-to-date information about the latest breakthroughs in treating and managing dementing illnesses, and will address many typical caregiving questions about common behavioral symptoms associated with such conditions.

Talking to her mother's doctor helped Madeline recognize that Margie truly didn't remember her repeated phone calls and

demands. Margie was not capable of understanding the reassuring feedback her doctors repeatedly gave her. She was frightened and confused, and Madeline's frustrated tone and explanations only made her mother's emotional upset worse. As Madeline became better able to accept her mother's diagnosis, to see that this seemingly impossible situation was dominated more by her mother's brain disease than by her personality, Madeline stopped arguing. She no longer assumed that her mother could just "stop acting this way."

Madeline also realized that although Margie wanted to remain in her own home, it was time to look around for residential alternatives. She located a nearby assisted living facility that offered a range of services, including on-site 24-hour medical staffing and a specialized Alzheimer's care building. When it became clear that trying to convince Margie to move wasn't going to work, Madeline looked for a different, more creative way to introduce the idea. She discovered a comprehensive adult day program at the facility and, after visiting their music and exercise classes, liked them well enough to go back. After attending for a couple of months, Margie was familiar with the staff and felt comfortable when she walked in the door. At that point it was less difficult for Madeline to get Margie to tour the available apartments in the facility, one of which was a sunny room with a park view very similar to her bedroom at home. The move transitioned fairly smoothly thereafter.

Accepting her mom's disease also helped Madeline refocus her own caregiving values and goals. Armed with information and more realistic expectations, she became more compassionate and patient. It was still hard to listen to her mom's repeated complaints, but knowing that Margie was in a safe place and that she didn't remember telling the same story over and over made it easier to bear. The medical director at the assisted living facility suggested treating Margie with a low-dose medication for depression and anxiety, and after a few weeks of frequent reassuring visits to the clinic, Margie's insistent demands to see a doctor began to diminish.

Madeline had more time for herself and her husband and children, and took a much-needed vacation out of town for the first time in many years. While away, to her surprise Madeline realized she missed her mom. She returned happy to see Margie again, and took pleasure in her regular visits despite Margie's difficult moods and preoccupations.

Caring for a person with dementia takes resilience and flexibility. As one caregiver told

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Curbing a Silent Killer

By Ursula Furi-Perry

It's dangerous. It may even turn deadly. And it affects millions of Americans, many of them without being aware of their condition. This is a silent killer—this is hypertension, better known as high blood pressure.

The National Heart, Lung and Blood Institute estimates that one in four Americans has hypertension, while the American Heart Association says the number may be as high as one in three. Regardless of the exact statistic, high blood pressure is a deep-rooted condition in our society and an especially insidious condition for our elderly loved ones.

As a caregiver, your assignment is clear: if your loved one is one of the many millions of Americans with this disease, you must be vigilant on their behalf by learning to monitor and manage their blood pressure.

Hypertension is "currently defined by measurement of the blood pressure in an individual," explains Dr. Daniel W. Jones, spokesperson for the American Heart Association and Dean of the School of Medicine at the University of Mississippi Medical Center in Jackson. "Consistently elevated blood pressure at or above 140/90 mmHg is considered high blood pressure in any patient, regardless of age."

The disease is often called "the silent killer," and with good reason: this symptom-less disease can cause serious health problems, many of which can prove deadly. "Consequences of high blood pressure that's not controlled are heart problems, including heart attacks, stroke, decrease in kidney function, and also problems with the blood vessels," says Dr. Jeffrey Cutler, senior advisor at the National Heart, Lung and Blood Institute, an entity of the National Institute of Health. "It can convert a functional old age into a disabled old age if not prevented."

And chances are your loved one will experience hypertension, Dr. Cutler says. "By and large, when you reach old age, most people will have hypertension if they haven't attended to these things early on," he says.

Not only is high blood pressure a killer, it's easily over-

Monitoring and Managing Your Loved One's Blood Pressure



looked: a big problem for caregivers is that hypertension usually shows no symptoms until a major problem like heart disease or a stroke presents itself. In fact, the American Heart Association says nearly a third of people affected by hypertension have no idea about their condition. "It is only through regular measurement of the blood pressure that high blood pressure can be detected," says Dr. Jones. "Rather than waiting for troubling finds, it is important to have regular management of high blood pressure, including regular measurement of the blood pressure."

Where and how that measurement takes place can be critical. "For the initial diagnosis, it's important to see a doctor," says Dr. Cutler. Later, a nurse can take your loved one's blood pressure—at a local health clinic or your loved one's practitioner's office, for example. "It's also good to have a device at home and measure blood pressure periodically," Dr. Cutler advises.

As for those casual offers to measure blood pressure at the drug or grocery store or other non-medical places, Dr. Cutler warns caregivers to stay away from devices that aren't made according to medical standards or knowingly well-maintained. If you do opt for such a measurement and your loved one's numbers are above normal levels, do follow up with a professional—but don't rely on the initial measurement if your loved one's pressure check comes back normal.

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Ursula Furi-Perry is a writer based in Haverhill, Massachusetts. She can be reached at furiperry@verizon.net.

Nutritional Supplements: A Boost for the Elderly *and we add zip!*

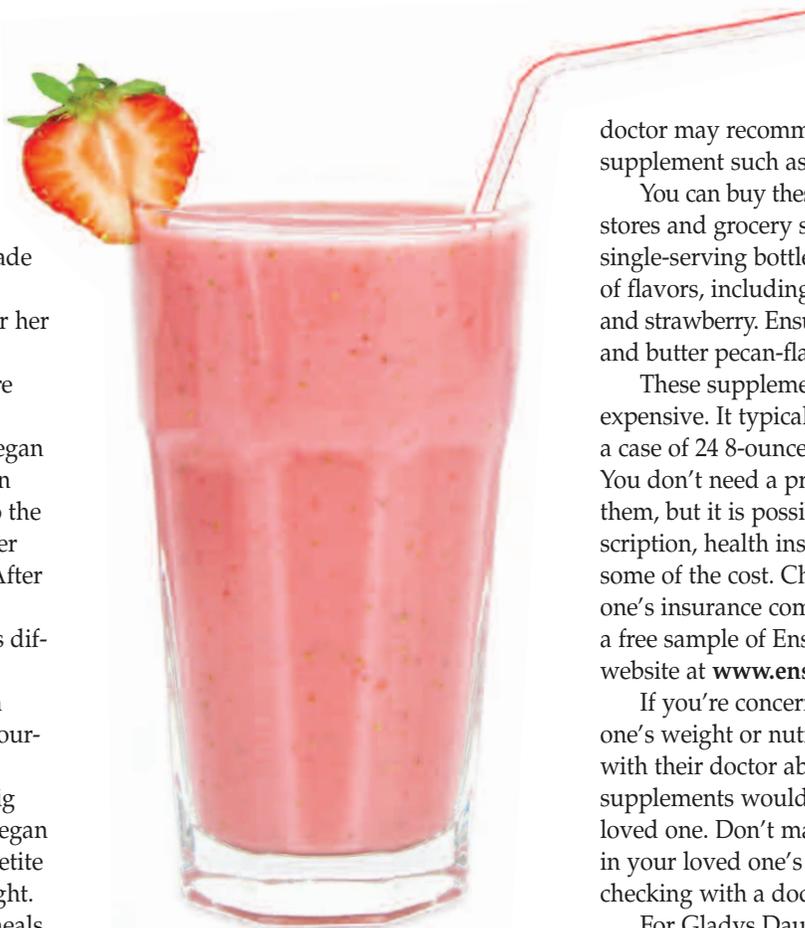
By Kelly D. Morris

Gladys Daugherty always loved to cook. She baked from scratch, even supplementing her family income by selling homemade pies made with fruit from her own garden in Cincinnati. She prepared breakfast for her husband every morning, and dinner every night. Visitors to her home were always offered something to eat.

As she grew older, though, she began to have difficulty cooking. Poor vision made it impossible for her to drive to the grocery store, so she had to rely on her grown children to do the shopping. After she fell and broke a hip, she was no longer able to tend her garden. It was difficult for her to stand at the stove for long. When she once left the stove on overnight, her children began to discourage her from cooking at all.

Gladys had never really been a big eater, but after her health problems began to prevent her from cooking, her appetite declined greatly. She lost a lot of weight. Her children brought her prepared meals, microwave dinners and the like, but these weren't to her taste. She was used to eating fresh food from her garden. Depression further dampened her appetite. In short, Gladys simply lost interest in eating.

There are many benefits for seniors who eat a healthy diet. They include increased energy, a stronger immune system, faster recuperation from illness or injury, and even being more mentally alert. Seniors need a diet high in fiber to prevent constipation, a common side effect of many medications and a result of decreased physical activity. Seniors need added calcium and vitamin D to strengthen fragile bones. Many seniors require special diets to help manage diabetes, heart disease, high blood pressure, kidney disease, or other health problems.



The elderly are at risk for poor nutrition and weight loss for a number of reasons. It's common for the appetite to decrease as one grows older. The senses of taste and smell diminish with age, so food becomes less appetizing. Many medications have a side effect of decreasing the appetite. Sometimes simple things like ill-fitting dentures make eating difficult.

Beyond that, some seniors may find it difficult to shop for groceries and prepare meals by themselves. If they live alone, well, it's not very enjoyable to cook for one and eat alone. Depression, common in many elderly people, can suppress appetite.

If your loved one is underweight or has difficulty eating enough healthy food to maintain proper nutrition, his or her

doctor may recommend a nutritional supplement such as Ensure or Sustacal.

You can buy these drinks in most drug stores and grocery stores. They come in single-serving bottles or cans in a variety of flavors, including chocolate, vanilla, and strawberry. Ensure even offers eggnog and butter pecan-flavored drinks.

These supplements can be rather expensive. It typically costs about \$30 for a case of 24 8-ounce bottles of Ensure. You don't need a prescription to buy them, but it is possible that with a prescription, health insurance may cover some of the cost. Check with your loved one's insurance company. You can order a free sample of Ensure by visiting their website at www.ensure.com.

If you're concerned about your loved one's weight or nutritional intake, talk with their doctor about whether these supplements would be helpful for your loved one. Don't make any big changes in your loved one's diet, though, before checking with a doctor.

For Gladys Daugherty, strawberry-flavored drinks did the trick. Her children mixed them with strawberry ice cream to make milk shakes for her. It wasn't as good as the food she used to cook, but she liked them well enough. She regained some of the weight she lost, and her overall health began to improve.

Despite what the advertisements might tell you, these supplements don't always taste great. Here are some simple-to-prepare recipes for flavorful drinks and shakes that will be more palatable to your loved one and provide a bit more variety in their diet. Feel free to experiment and come up with your own recipes, as well. ■

Kelly Morris is a former social worker and home health and hospice worker whose writing has appeared in a number of journals. She lives in Mansfield, Ohio, and can be reached at multihearts@hotmail.com.

CHOCOLATE MOCHA TREAT

- 1 can chocolate-flavored nutritional supplement
- 2 cups coffee ice cream
- whipped topping (optional)

Combine supplement and ice cream in blender and blend well. Top with whipped topping, if desired. Makes about two servings. Store leftovers in refrigerator.

CHOCOLATE PEANUT BUTTER DELIGHT

- 1 can chocolate-flavored nutritional supplement
- 1-3/4 cups chocolate ice cream
- 1/4 cup peanut butter (smooth, not chunky)

Combine ingredients in blender and blend well. Makes about two servings. Store leftovers in refrigerator.

EGGNOG SHAKE

- 1 can eggnog-flavored nutritional supplement
- 2 cups vanilla or eggnog-flavored ice cream (eggnog-flavored ice cream is often available during the winter holiday season)
- nutmeg (optional)

Combine nutritional supplement and ice cream in blender and blend well. Sprinkle with a small amount of nutmeg before serving, if desired. Makes about two servings. Store leftovers in refrigerator.

PEACHES AND CREAM SHAKE

- 1 can vanilla-flavored nutritional supplement
- 1 cup vanilla or peach ice cream
- 1 cup diced canned peaches (drained)

Combine ingredients in blender and blend well. Makes about two servings. Store leftovers in refrigerator.

PINEAPPLE SHAKE

- 1 can vanilla-flavored nutritional supplement
- 1-1/2 cups pineapple sherbet
- 1/2 cup crushed pineapple (drained)

Combine ingredients in blender and blend well. Makes about two servings. Store leftovers in refrigerator.

STRAWBERRY BANANA SMOOTHIE

- 1 can strawberry-flavored nutritional supplement
- 1 cup vanilla or strawberry yogurt
- 1/2 cup strawberries
- 1 banana, sliced

Combine ingredients in blender and blend well. Makes about two servings. Store leftovers in refrigerator.

TRIPLE CHOCOLATE SHAKE

- 1 can chocolate-flavored nutritional supplement
- 2 cups chocolate ice cream
- 2 tablespoons chocolate syrup
- whipped topping (optional)
- chocolate chips (optional)

Combine supplement, ice cream, and chocolate syrup in blender and blend well. Garnish with whipped topping and chocolate chips, if desired. Makes about two servings. Store leftovers in refrigerator.

VERY BERRY SHAKE

- 1 can strawberry-flavored nutritional supplement
- 1 cup vanilla or strawberry ice cream
- 1 cup fresh strawberries

Combine ingredients in blender and blend well. Makes about two servings. Store leftovers in refrigerator.

Curbing a Silent Killer *Continued from page 3*

Once your loved one is diagnosed with hypertension by a doctor, you can take steps to control the disease. "The combination of lifestyle management, including attention to dietary salt intake, along with appropriate medications can control high blood pressure," says Dr. Jones. "Though it may be difficult, it's important to cut down on excess salt. You have to do a lot of label-reading," warns Dr. Cutler.

Maintaining a healthy weight and performing a reasonable level of physical activity are likewise essential, as is avoiding excessive alcohol use. "It's also important to eat quite a few servings of fresh fruits and vegetables; those get you a lot of potassium, which helps control blood pressure," Dr. Cutler explains. Foods that are particularly rich in potassium include soy, bananas, figs, raisins, potatoes and sweet potatoes; you may also consider a supplement with the approval of your loved one's doctor.

Caregivers should be aware that certain medications, including anti-inflammatory pills for arthritis, may likewise increase blood pressure. Check with your loved one's doctor about any medications taken and whether you should be concerned about high blood pressure with those pills.

Your loved one's practitioner may also prescribe medication to lower their blood pressure. As with any other medicine, regularly taking blood pressure pills is essential, says Dr. Cutler. "Many of them are long-lasting and do control blood pressure even if you miss a few days, but the problem is that you get out of your routine," he states. And if your loved one misses more than just a few days' worth of pills, he or she may again be at risk for the serious illnesses that can accompany hypertension.

Most importantly, caregivers must monitor their loved one's blood pressure vigilantly and keep to a regular maintenance plan prescribed by their elderly's doctor. "The critical issue here is to listen and follow carefully the advice given by your health professional for management of the high blood pressure," says Dr. Jones. "Assuring compliance with the advice of your health professional in managing high blood pressure is the best thing that a caregiver might do to assist with high blood pressure management." With regular management and monitoring, caregivers can help curb this dangerous silent killer. ■

RESOURCES:

National Heart, Lung and Blood Institute's Guide to Lowering High Blood Pressure, www.nhlbi.nih.gov/hbp/

American Heart Association's high blood pressure section, www.americanheart.org/presenter.jhtml?identifier=2114

Cardiology Channel, high blood pressure pages, www.cardiologychannel.com/hypertension/

About High Blood Pressure, patient-oriented website, www.high-blood-pressure.org/



Understanding the Ins and Outs

Adult Day Care Becomes a Basic Senior Service

By Kelly D. Morris

When Frank Eisele was diagnosed with Alzheimer's disease, his children wanted to care for him at home instead of placing him in a nursing home. As his illness progressed, however, it became more and more difficult to manage. Frank's children all work during the day, but he could no longer be left alone. Not only that, but Frank, who had been very active his whole life, was getting depressed just sitting around the house all day.

Adult day care proved to be the answer. Frank now attends day care twice a week in Cincinnati. The day care center even provides transportation. Despite his growing confusion and disorientation, Frank knows what days he goes to the center. He gets up early on those mornings to dress and shave before the bus comes. He enjoys having someplace to go and likes participating in the activities.

Meanwhile, his children are relieved to know he is getting the care he needs while they go to work, and they are happy to know he is enjoying his time there.

For elderly people who need some supervision and support during the day, day care can be the perfect solution. Adult day care centers (some prefer to call them day centers or day health centers because day care sounds like care for children, not seniors) serve the elderly with dementia, Alzheimer's disease, and other cognitive and physical disabilities.

There are currently about 3,500 such centers in the United States. Many more centers are needed, according to Nancy Cox, MSW, national director of Partners in Caregiving and instructor at Wake Forest University Baptist Medical Center in Winston-Salem, North Carolina. Adult day care centers are valuable, she says, because "they help keep individuals who are in need of chronic care at home, in the community, with family and friends as long as possible."

Adult centers provide a variety of services. Some are open only a few hours a day during the week, while others are open for a full day, seven days a week. Most provide social and recreational activities, such as games, music, and arts and crafts. These activities provide mental stimulation and encourage social interaction. Most centers offer some type of exercise program or physical activities. Meals and snacks are usually provided. Door to door transportation is often offered, as well.

Some centers also offer assistance with personal care, such as showering and shaving. Some offer physical, occupational, and speech therapies. Some offer medical monitoring and other healthcare services. At many centers, social workers, counselors, and health educators offer services to caregiving family members, as well.

Available services may vary widely from center to center. In addition to the usual services and activities described above, the monthly calendar for the Jewish Home and Hospital Day Health Care Program in The Bronx, New York, offers outings to local shopping centers, movies, tai chi classes, Bible study groups, and classes on a variety of health-related topics. The McLean Day Care Center in Simsbury, Connecticut, offers gardening activities, dancing, pet therapy, and visits from local children's groups.

David Kuhn, MSW, and author of *Alzheimer's Early Stages: First Steps in Caring and Treatment*, says family caregivers should consider day care when their loved one is isolated for much of the day and misses companionship, when they can no longer be left alone safely during the day, or when they become unable to provide themselves with structure for daily activities.

Kelly Morris is a former social worker and home health and hospice worker whose writing has appeared in a number of journals. She lives in Mansfield, Ohio, and can be reached at multihearts@hotmail.com.

To find day care centers in your area, look up “Day Care” in the Yellow Pages of your local telephone book. If you don’t find what you’re looking for there, try looking under Social Services for an Area Agency on Aging or similar organization. You can also contact local nursing homes, senior citizens centers, hospitals, Alzheimer’s support groups, or your local United Way agency. Local churches are always a good source for such information.

Donna Albright, an aide at the Riverside Day Care in Newport News, Virginia, recommends that family members and their loved one go together for a tour of any day care center they are considering.

Paying for day center services can be expensive. The cost is generally about \$50 to \$60 per day, but it can be higher depending on your location and the exact services needed by your loved one. Medicare does not currently cover these services (you may wish to write your elected representatives and share your opinion about that). Veteran’s Administration benefits, private health insurance plans, and long-term care insurance may help with the costs; check with your loved one’s plan to find out. Medicaid may help with expenses for low-income residents. Most families end up covering a significant portion of the costs themselves.

For many elderly and their families, though, the cost is well worth it. “Day care has been like an oasis in the desert for Hughes and for me,” says Lela Knox Shanks, whose husband has Alzheimer’s. “The costs are now a necessary and integral part of our household budget.” Shanks is the author of a book about her experience with her husband’s illness, entitled *Your Name is Hughes Hannibal Shanks: A Caregiver’s Guide to Alzheimer’s*. ■

EXPLORING ADULT DAY CARE

Finding the right day care facility for your elderly loved one can be a daunting task. Sure, you want a strong staff, clean and safe facility, and a warm atmosphere for your elderly, but how can you really know what’s in store?

Experts say a facility tour for you and your loved one is essential, and they recommend asking a series of questions to help you gain comfort that your decision is the right one.

Here are some questions to ask when selecting a day care facility:

- **What kinds of services are provided?**
- **What kinds of activities are offered?**
- **Is transportation provided?**
- **What about meals?**
- **What are the qualifications of the caregivers? Do they have experience with your loved one’s condition?**
- **What is the ratio of caregivers to clients? (One caregiver to three or four clients is a good number.)**
- **What are the hours of operation?**
- **What is the cost?**
- **Are they licensed or accredited by the state or any other organizations?**
- **Can they provide references? Can you talk to some clients and their families?**

‘Dancing’ with Dementia *Continued from page 2*

me, it requires us to “listen from your heart, not your head.” Providing resilient care is an artful skill that can be learned and practiced, but like any skill we never do it perfectly and there will always be new challenges to overcome.

Still, I knew Madeline had changed when I saw them both about six months later. When I walked into Margie’s room, she was agitated and crying that she was sick and didn’t understand why no one was helping her. Madeline sat down and put her arms around her mom, not saying a word but offering her comfort and reassurance. As Margie’s tears began to subside, Madeline pointed to the tulips blooming in the sunlight below and offered to take her mom for a stroll and some ice cream. Margie visibly relaxed, and when I left, she and Madeline were still sitting quietly together, enjoying the spring view. ■

Susan M. McCurry, Ph.D., Research Associate Professor at the University of Washington, School of Nursing, and a licensed clinical psychologist. She is a fellow in the Gerontological Society of America and an expert in the development of behavioral interventions for the treatment of mood and behavior disturbances in persons with dementia and family caregivers. Her publications include the recent book, “When A Family Member Has Dementia: Steps to Becoming a Resilient Caregiver” (Greenwood Press). She can be reached at smccurry@u.washington.edu.

COMING UP IN APRIL

- Is it really possible for our nation’s assisted care facilities to become a most-inviting destination for our elderly? Backers of **the Green House project** think so, and they’re putting their money where their mouth is to prove it. The second installment in our series *The Changing Face of Long-Term Care in America*.
- For many elderly, **investing in annuities has meant a chance to financially secure their last years**, but are these instruments really a no-lose proposition. We’ll help you sort it out.
- Mom needs my help, and what on earth am I going to do? A common cry we’ll help you answer with **practical advice and inspiration from an expert** who’s been there and can tell you about the financial, logistical and physical planning as well as keeping a strong mental and emotional outlook.
- **Arthritis creates pain on a good day and can cripple over time.** What do caregivers need to know about this bone-aching condition and how can they help prevent and treat it in their elderly?

Hearing Problems Plague Half of Our Elderly —We Have Tips for You

DID YOU KNOW THAT AN ESTIMATED 50% of all Americans over age 65 suffer from hearing loss?

That's the startling statistic half of the nation's caregivers are dealing with every day of their elder-caregiving lives. Mom can't hear clearly. She missed what was said. Why doesn't dad answer the phone when I call? That bloody TV is so loud it is driving me crazy.

Any of that sound familiar? Probably.

Dr. Jane Potter, president-elect of the American Geriatrics Society, says age, family history and environmental exposure to noise are the primary risk factors for age-related hearing loss. While there is not much one can do about the first two factors, limiting exposure to loud noises throughout youth and adulthood helps reduce the risk of hearing loss in the sen-

ior years. While it is a little late for some precautions to be taken "in the early years" to avoid hearing loss as we age, there are tips for elder-caregivers that can ease the situation for their loved ones and themselves.

Dr. Potter offers the following tips on recognizing hearing loss and seeking treatment for the condition:

Signs that you or a loved one may be experiencing hearing loss:

- Difficulty hearing or understanding another person when the person's face is not in view
- Difficulty hearing in crowds of people
- Sounds reverberating in the ear
- Frequently needing others to repeat themselves

If you think you or a loved one may be experiencing hearing loss:

- Make an appointment with the geriatrician. He or she can check the ears to rule out other problems like earwax buildup and provide a referral to an audiologist.
- Visit a licensed audiologist who is specially trained to evaluate and treat hearing loss. He or she will be able to provide information about hearing aids and other treatment options.
- Do not order a hearing aid through the mail. You will need the help of an audiologist to find out what treatment is right for you or your loved one.

For more information on geriatric hearing loss, check out *Geriatrics Advisor: Understanding the Causes of Geriatric Hearing Loss and Providing Appropriate Treatment* (www.geri.com/geriatrics/data/articlestandard/geriatrics/152002/15158/article.pdf) ■

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