

Caregiver's

HOME COMPANION

Volume 7 Issue 6 | February 2009

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

Can They Weather the Storm?

Battered Economy's Big Bite on Seniors

By Maura Keller

For Ryan Malone, the economy has taken an enormous toll on him as a caregiver. With a fixed expense leaving his mother's account every month, the prospect for growth and the amount of time her funds will last has been cut by upwards of 40%.

Malone, author of *By Families, For Families Guide to Assisted Living*, and his mother are not alone. The US economy is experiencing one of its most dismal periods in recent history. Businesses are worried, consumers are cautious, and investors are downright jittery. What does this mean for seniors and their family caregivers?

According to John Buckles, chief executive officer at Caring Transitions, a Cincinnati-based senior relocation firm, a major concern for many older people has long been outliving their assets. "The economic downturn makes that even more realistic for them to foresee," Buckles says. "Older adults often lack the time needed for the market to correct itself so they can make up their losses."

Many older adults are forced to make significant sacrifices, which can be finan-



cial choices that affect their health (e.g., do I buy groceries and eat or do I pay to have a prescription refilled). Recent news stories indicate many older adults are putting

off doctor appointments, surgeries, follow-up care, on-going treatment of health conditions, and more.

"This is significant due to the fact that, ►

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Print: \$34.95 one year (U.S.)
\$58.95 two years (U.S.)

Online: \$22.95 one year (U.S.)
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Editor and Publisher
Chris Pederson

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Director
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Custom Publishing & Operations
Director
Robert G. Whitton

Art Director
Laura D. Campbell

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) 254-3538

Administration & Editorial:
(203) 254-3538

Custom Publishing: (203) 438-0810

e-mail Inquiries:

editor@caregivershome.com

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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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"The economic downturn makes that [outliving assets] even more realistic for them to foresee. Older adults often lack the time needed for the market to correct itself so they can make up their losses."

—John Buckles, CEO, Caring Transitions

Battered Economy's Big Bite on Seniors

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according to the CDC (Centers for Disease Control), over 80% of older adults have one or more chronic health condition that if left untreated, under-treated or not monitored, will hasten the deterioration of their overall health and longevity," Buckles says.

For many older adults, worrying about finances and how they are going to make ends meet is relentless and mentally taxing. In the end, this anxiety may lead to chronic sleeplessness, depression, and substance abuse.

"And don't forget that for those 85 years of age and older, the Great Depression is more than a page from the history books. It is an event that shaped their lives," Buckles says. "Today's economy is like 'déjà vu' to them. They may be reliving their memories and fears, and manifesting their choices and decisions based on what they previously endured."

Signs of the Times

There are obvious signs of distress that caregivers should watch for as it relates to seniors' response to the economy.

"Adult children need to pay attention to how their loved one is coping with the economy by listening to what they're saying and doing," says Mary Rempfer, vice president and general manager at Home Instead Senior Care. "They should check to see if their senior has enough food in the refrigerator and what kind of food they are purchasing."

Rempfer has one client who loves fresh fruit. "She has now turned to canned fruits, because they are cheaper," Rempfer says. "She recently went to see her physician and realized that the canned fruits are cheaper but not as healthy — she gained five pounds from the last time she had seen him."

Adult children should also check to see if their loved one is keeping their house colder than usual in the winter and hotter than usual in the summer. Limiting medication due to expense is also a big problem. "Pay attention to this with your loved one," Rempfer says. "Limiting medication could very well significantly increase the

cost of care to the client because of adverse affects of not taking the prescribed amount."

Other things to look for include:

- Visible signs of stress and anxiety, such as weight loss, inability to concentrate, and physical illness.
- Expressed concerns about finances, fears about the future and frequent discussions about finances, the economy and their current situation. "Discussions that are focused on their concern about 'what will be left for...' someone other themselves are clues that they may be trying to cut corners in their current lifestyles to ensure that a promised inheritance can be honored to other family members," Buckles says.

Take Action

So, what are some concrete ways caregivers can help Mom and Dad weather the storm?

1. **Start the process early.** "Even if the care recipient is not showing any signs of being in financial trouble, start talking to them about their situation," says Dr. Chip Long, an Arkansas psychologist specializing in working with older adults. He recommends that caregivers open the door to discussions about financial matters. "It is difficult, but it can lay the foundation for an open dialogue on this issue and help head off problems down the road," he says.
2. **Don't be afraid to ask for outside help.** Many retirees have fairly complicated portfolios that can involve a variety of financial resources. "Trying to make sense of these issues can be overwhelming for the care recipient, as well as the caregiver," Long says. For that reason, sometimes it is good to involve an expert who is able to tease through the different levels of the finances and provide some concrete recommendations. "I think this can also help to decrease some of the care recipient's defensiveness with regards to this matter," he says. "I have seen some older adults open up to professionals in a way that they cannot with family members."
4. **Help them establish a workable budget.** "Most seniors are accustomed to being on some type of budget—their generation has been through

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Caregiver Primer

Adult Day Care: Another Way to Care

By Rachel Davidson



Adult day care is a caregiver's breath of fresh air. It can free you of your 24/7 caregiving responsibilities, so you have more time for yourself, by offering a win-win program of caregiver respite care as well as socialization and stimulation for aging loved ones.

And sometimes the desperation triggered by a caregiving burden makes adult day care a just-in-time lifesaver. For example:

Tom White's marriage appeared headed for trouble. He and his wife had just retired and were looking forward to long trips around the country when his 85-year-old mother, Eleanor, suddenly moved in with them after suffering a stroke. "We couldn't even go to the movies together anymore. Someone always had to be with mom," says White, who lives in Chicago.

In Springfield, Missouri, single parent Sue Winslow couldn't quit her job when her mother moved in with her. It simply wasn't an option, nor was placing Esther, her 80-year-old mother, in a nursing home.

White and Winslow, like an increasing number of family caregivers, turned to adult day care for help in caring for their loved ones. For some, it's a short-term transition from hospital to home; for others, it's a long-term alternative to institutionalization. Today, there are about 4,000 centers nationwide, caring for 150,000 seniors, typically on a Monday through Friday schedule. The centers are usually

Rachel Davidson is a freelance writer focusing on elderly care. She published a quarterly magazine for nursing home administrators for 15 years, as well as a caregiver newsletter for five years. Rachel lives in Baraboo, Wisconsin and can be reached at families@centurytel.net.

located in hospitals, healthcare facilities, churches, and mental health facilities.

Their goal is the rehabilitation and maintenance of each person's highest level of functioning and independence in a safe, secure environment. This is achieved by offering personalized programs that could include (but are not limited to) arts and crafts, music, mental stimulation games, gentle exercise, and local outings. Many also offer personal care, physical, occupational, and speech therapy as well as other nursing services. They are generally staffed by a registered nurse and other health care professionals.

Types of Adult Day Care

There are three types of adult day care available, depending on need:

- **Adult day social care** emphasizes social activities, along with meals, recreation and some health-related services.
- **Adult day health care** offers more intensive health, therapeutic and social services, as well as meals and recreation.
- **Specialty day centers** for those with Alzheimer's and related dementia provide social and health services specific for seniors with Alzheimer's and other dementias.

Initially, Tom White's mother didn't want to go. "Mom's shy at first," he explains. "We told her to try it for two weeks and if she still didn't like it, we'd drop it. After the first week, we couldn't keep her away." While White and his wife still aren't able to take long trips together, they are going to matinee movies and other nearby activities while Eleanor is at the center.

When faced with the alternative of staying home alone all day or spending

time with others in a day care setting, Esther didn't think twice about it. She wanted to go and meet other people. Daughter Sue Winslow says, "I can concentrate on my job knowing mom is in a secure, caring place that she enjoys."

Cost and Financial Assistance

The cost for adult day care is significantly lower than that of a nursing home. According to the American Association of Homes and Services for the Aging, the average cost nationally is \$61 daily for adult day care, compared to \$213 for nursing home care.

Some day care centers offer need-based scholarships or a payment plan that uses a sliding fee scale. While Medicare does not cover day care costs, a center may be certified for Medicaid or Veteran's Administration benefits. Medicaid will pay most or all of the costs for participants with low income in licensed adult day health care settings and Alzheimer's-focused centers. Long-term care insurance, as well as some private insurance, may also pay for some or all of the costs.

Some county, state, and federal programs may also pick up part of the tab. Your center will be able to tell you if your loved one qualifies for receiving financial assistance from any of these resources.

Be sure you understand the center's payment requirements. Are you billed, or are you expected to pay each day? Do you pay if the center is closed for a holiday or snow day? Can you give notice and not pay when your loved one can't attend? What notice is required to cancel the contract (remember to keep copies of everything you sign)?

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When Grandma is 'Different'

Helping Children and Teens Understand Dementia

By Paula Sanders McCarron

Sarah Miller was 14 years old when her grandmother was admitted to an assisted living home due to advancing dementia.

"I knew Gram forgot things but everyone forgets," Sarah recalls today. "But I didn't realize she wouldn't be able to live alone ever again. And I didn't know things would get worse."

I have to admit that Sarah's lack of understanding shocked me. After all, Sarah is my niece, and I remember thinking how surprised I was by her comments, given the fact that I and other adults in my family had been very open about what was happening at that time as my mother spiraled into crisis because of the dementia diagnosis.

Until talking with Sarah as part of my research for this article, I had no idea that Sarah had felt so alone and confused at the time. "I was out of the loop about everything," says Sarah. "I didn't know anyone with dementia, and I didn't know anyone my age whose grandparent had dementia. I didn't know it would never go away, and I never knew things would get worse."

Sarah remembers adult family members being worried a lot and making lots of plans for her grandmother, but she didn't connect all of that activity with the

depth of our family crisis.

In retrospect, that's not so surprising—and certainly not uncommon. It's happening almost every day in America, as children are confronted in their tender way with the hard-to-explain behavior of an aging family with Alzheimer's disease or another form of dementia.



So, this begs the question: how can a family caregiver help their child understand the changes going on with a demented loved one? Specifically, how do you explain dementia to a young child or teen? What do they need to know? How much should you say?

"I'm always surprised there isn't more demand for help in this area," says Jed Levine, executive vice president at the Alzheimer's Association, New York City Chapter. "You can't always answer all of the questions that a child or teen will raise, but it's important to recognize their

emotions and needs."

Levine points out that a younger family member may not even be aware of their own distress about a grandparent's memory loss, but he says, "What happens is that they act out, their grades drop, they become withdrawn or sullen or angry more often."

Levine suggests that what and how much to share about a grandparent's dementia should be based on three key factors: the age of the child; the child's educational level; and the nature of the relationship between the child and the individual with the dementia diagnosis.

"If a child is in the home with parent or grandparent who has dementia, then that child needs a different level of education and support than the grandchild whose grandparent lives at a distance," says Levine.

"Children and teens—just like adults—need information to be provided on a level they can comprehend and in language they can understand."

Joyce Simard is a Florida social worker who helps children better understand dementia through her appearances at elementary schools and libraries. In those places, Simard takes on her stage persona as "Grandma Joyce," a forgetful grandmother.

"Children do not understand how a grandparent cannot remember their names. They don't understand why their grandparent will ask questions over and over. And many tell me they don't know

Paula S. McCarron has more than 20 years of experience in health care, including nursing homes and hospice. She lives in Chelmsford, Massachusetts, and can be reached at paulamccarron@gmail.com.

what to do when they visit. Some think they may 'catch' Alzheimer's disease," says Simard.

Simard's book, *The Magic Tape Recorder* (Joyce Simard Publishing 2007), compares memory loss to a tape recorder that is shut off. "When they (the children) know that Grandma Joyce's 'tape recorder' is off, she cannot remember their names. So each child who comes on stage to show me something tells me his or her name so that I don't feel sad that I can't remember it."

Simard hears what life is like for children and teens who live in the same household as a grandparent struggling with dementia. "Parents must be very aware of how their children are feeling about sharing time with their grandparent," she says. "It's very hard on teens who like to be part of the crowd and not have anything embarrassing happen when friends visit."

Simard encourages parents to consider options such as asking another family member or hired helper to be the "caregiver" in the home so teens can have uninterrupted time with friends. Another option may be adult day health programs that benefit the individual with dementia and provide a needed "time out" for the family. She also suggests that teen friends could be invited to a pizza party where they learn about dementia and how to relate to someone with memory loss.

Of course, there are situations where the grandparent is residing at a nursing home, assisted living home, or in a dementia care unit within a larger health care facility. In these situations, some parents may be reluctant to bring children and even teens into a setting where they would encounter not just one person but many people who are in varying stages of memory loss.

Karen Froman, social work director at Hollywood Hills, a nursing home in Hollywood, Florida, offers these suggestions to parents who wonder if and how to bring their children and teens into these types of situations:

- Encourage an open dialogue to alleviate any fears that arise.
- Ask about family visiting areas that provide a less stimulating environment for children.
- Time visits for mornings or early afternoons as many residents with dementia

become more confused or agitated as the day passes.

- Allow children to find their own comfortable level of affection toward the older adult.
- Provide parental reassurance of the child's safety.
- Structure visits around mutual sharing.

"It's important for parents to acknowledge their child's feelings by sharing their own feelings of frustration, fear, and anxiety," says Levine. "Children may be feeling guilty about feelings that are normal. Parents might acknowledge that they feel the same way. They can also say they have the same question or concern—and then say: Let's find out the answer together."

I also asked my niece Sarah, who is now a high school senior, what advice she might now give to parents who are faced with trying to explain dementia to other children and teens. Here's what she had to say:

- Tell the truth, but don't share more information than they need to know.
- Let them know that things will not get better, but don't be too specific too far in advance.

Even as she sees her grandmother today in the advanced stages of dementia, Sarah says she still wants to visit her grandmother, who now resides on a specialized dementia care unit within a nursing home.

"Seeing Gram makes me feel better," she says. "After all, she's still Gram and nothing about her is gone really except her memory." ■

RESOURCES

National Institute on Aging has a listing of helpful books and videos for children and teens (www.nia.nih.gov/Alzheimers/Publications/children.htm)

AFA Teens, sponsored by the Alzheimer's Foundation of America, offers online chat groups, message boards and informational articles for teens. (www.afateens.org)

Alzheimer's Association has an online section "Just for Kids and Teens" with a tremendous amount of information written at various levels for kids of all ages, everything from brain health to understanding dementia to 101 ways to spend time with a person who has a dementia illness. (www.alz.org).

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a lot and learned to budget at an early age," says Jerri Scarzella, vice president and chief financial officer for the HealthWell Foundation. "Help them to recognize what things are needed, not needed, and neutral."

5. **Explore benefits.** Many seniors mistakenly think they earn too much money or have savings that disqualify them for programs to cut their costs on home taxes, utilities, telephone bills and much more. Even if you were disqualified in the past, check to see if you are eligible. Guidelines change for many programs on an annual basis. To check for eligibility, go to www.benefitscheckup.org, a screening tool set up by the National Council on Aging.
6. **Think local.** Many suburbs and communities offer independent programs to assist seniors and help keep them in their homes. Services may include low-cost snow plowing, home care or health care workers, chore services and more. Investigate local Meals on Wheels programs to see if loved ones are eligible, research nearby community centers and look for entitlement programs that might allow the senior to apply for financial assistance. Also check out religious organizations that might have day programs. A phone call to your city can put you in touch with your programs. ■

Maura Keller is a Minneapolis-based writer and editor. She has written extensively on elder care, as well as health care and medical-related matters. She can be reached at maurakeller@yahoo.com.

RESOURCES

US Administration on Aging, www.aoa.org

AARP, www.aarp.org

Government benefits, www.govbenefits.gov

National Energy Assistance and Referral (NEAR) project, (866) 674-6327

Energy benefits program, www.focusonenergy.com

National Association of Area Agencies on Aging, www.n4a.org

Online database helping seniors without drug coverage, www.helpingpatients.org

Social Security Administration, www.ssa.gov



Getting a Handle on Wandering

Six Ways to Anticipate and Prevent Danger

By Molly Shomer, MSSW, LMSW

reported. Many families we hear about say their loved one was a first-time wanderer and had not repeatedly walked away.

So, realizing that as a caregiver you cannot constantly monitor your senior, we should anticipate that leaving the house alone and becoming lost is a high probability for our loved ones with dementia who can still easily get around.

Wandering into dangerous areas within the home can also be dangerous. Cellars, garages and attics often contain items that are potentially dangerous, and the opportunity for a serious fall is always present in these areas. It's best to keep them off limits and to discourage exploring in these parts of the house.

While nothing is fool proof, and recognizing that many dementia sufferers are still quite clever at getting around barriers, here are some things we can do to reduce the chance that we will "lose" a loved one:

1. Remove personal items that might suggest "going out" to your loved one. Coats, hats, gloves, boots, umbrellas, and walking sticks should be stored out of sight and always away from outside doors. These items often suggest "going out" to someone who is restless and suggestible. If your loved one never goes out without his hat, you will have a chance to intercept him if he has to rummage for it in another room. The rummaging may even temporarily distract him from the desire to go out.
2. Disguise doors to the outside or to off-limits parts of the house. Paint doors, including the hardware, the same color as the walls. This reduces the attraction of a door that may lead somewhere "interesting." ▶

When a person with dementia is able to get around independently, the potential for getting lost is always present. Never mind that your elder has never wandered before; wandering is something that as many as 60% of all dementia sufferers do at one time or another.

But the potential for wandering need not be a constant caregiving worry. There are relatively simple things we can do to reduce the opportunity for wandering, and thereby avoid the possibly tragic consequences that can result from someone wandering away.

While the Alzheimer's Association and other reputable groups speculate that as many as 60% of dementia sufferers wander, or "elope" as it is sometimes called, the actual number is likely even higher because many wanderers do eventually find their way home or are found and not

CAREGIVER TIP

EASING AN ELDER WITH DEMENTIA INTO BED

As caregivers, we naturally want our loved ones to be comfortable in their surroundings. And while this isn't always simple, it can be especially perplexing when dealing with an elder suffering from Alzheimer's disease or another form of dementia.

However, when it comes to the bedroom, there are ways you can help your loved one with dementia more easily identify where and how to lie in bed:

Sheets are much easier to launder than blankets and spreads. We want to lie between the sheets so that the top and bottom sheets protect the mattress and the blankets from body oils and other things that will soil them.

Sheet sets usually come in the same or coordinated colors. Because their perception is sometimes affected, people with dementia often do not realize that there are two sheets, and that they are to crawl between them.

You can help overcome this common situation by using sharply contrasting colored top and bottom sheets. Be consistent with the colors for top and bottom, always using the same combination to avoid confusion. The different colors will help your loved one recognize that they are to slip between the sheets for sleep. Try to stick to bright, solid colors, as patterns often tend to confuse and agitate those with Alzheimer's or other forms of dementia.

— By Molly Shomer, MSSW, LMSW
molly@eldercareteam.com

3. Attach a sliding bolt to off-limits doors, either near the top or bottom of the door. Paint the bolt the same color as the door. Many dementia sufferers no longer look up or down for clues about why a door won't open.
4. Hang a picture, a mirror, or a mural on a locked off-limits door. Pictures and murals are preferable to mirrors if seeing a stranger in the mirror upsets your elder. Bookshelf and cupboard murals are both good choices that will discourage someone from trying to walk through.
5. Place a thin, dark brown or black mat in front of off-limits doors. People with dementia often lose their depth perception and ability to distinguish surfaces. They will react to a dark mat as if it is a hole in the floor to be avoided. A crisscross design made with black electrical tape will have the same effect.
6. Install window locks on all windows to prevent a determined wanderer from climbing out. This is especially important on the second floor. Your "wanderer" may try to go out a second floor window as if it were on the

ground floor.

If these simple measures are not sufficient, you can purchase inexpensive contact alarms that will sound when an off-limits door or window is opened. Be sure to listen to the alarm before you purchase it, as some are frighteningly loud. You want to be alerted that a door or window is being opened, but you don't want to needlessly terrify your wanderer.

Registering your loved one with the Alzheimer's Association Safe Return program (www.alz.org/we_can_help_medicalert_safereturn.asp) is always a good idea. If your elder does manage to get out without your knowledge, this program will work with your local law enforcement agency to help identify a lost dementia sufferer and help get them back home.

*Molly Shomer is a family caregiving specialist and licensed geriatric care manager. She is a nationally recognized expert on eldercare issues and the author of *The Insider's Guide to Assisted Living*. Her website is www.eldercareteam.com, and she can be reached at molly@eldercareteam.com.*

COMING UP IN MARCH

- Is there an upside for family caregivers in the down economy? We'll look at ways you may be able to bargain for a better deal on assisted living, home care and other products and services of value to Mom and Dad.
- Tinnitus is a nagging condition often caused by age-related hearing loss that sends incessant ringing, whining, hissing and whooshing sounds in the ears of sufferers. There is no cure. A caregiver primer.
- In-home care for an aging loved one fills a caregiver's life with questions, not the least of which is how much they should have to pay for reputable services and how they can be sure their not being taken advantage of. Helping caregivers through the home care maze.
- Dealing with varicose and spider veins: they're dangerous as well as unsightly. Tips on how to prevent them and what to look for and do if you or your loved one develop the condition.

Adult Day Care: Another Way to Care

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Finding a Good Fit

You cannot "change" your loved one to fit the center. The designated center must fit him. If he needs occupational, speech, or physical therapy, is that included? If he needs assistance such as with eating, walking, toileting, or medications, is there adequate staff to provide these services? Is the center located in a safe, secure area? Is it clean, pleasant, and odor-free? Does it have handrails? Is it wheelchair accessible?

Are the social programs and activities offered geared to your senior's interests and abilities? Are they mentally stimulating, interactive, and enjoyable? What is the ratio of staff per senior or activity? Are clients treated with dignity? Will your loved one be able to maintain his maximum level of independence? Will he enjoy going there? Would you like staying there?

Most agencies offer transportation. Evaluate that too. How long will your loved one have to stay on a van? Can it accommodate his physical or mental limi-

tations? What safety equipment is on the van?

Now What About You?

Many caregivers feel guilty when they place their loved one under someone else's care. If that happens to you, it's time to remind yourself that your loved one is receiving the socialization and stimulation he needs in a secure environment staffed with specialists. It's not in your loved one's best interest to become too dependent upon you as his only caregiver. By placing him in a day care situation now, you will enable him to become accustomed to receiving care from other health care providers later.

Take time to also pursue the socialization and stimulation you need to maintain a balance in your life. This means spending time with people who encourage and support you and participating in enjoyable events and creative activities that affirm you. An unknown writer said it best, "Only when one is connected to one's inner core is one connected to others." ■

RESOURCES

Caring.com has two excellent articles on adult day care for a parent with Alzheimer's at www.caring.com/articles/adult-daycare-for-a-parent-with-alzheimers. They are: *Adult Day care for a Parent with Alzheimer's: a Beginner's Guide* and *Using Adult Day Care for a Parent with Alzheimer's: a Step-by-Step Guide*.

About.com Senior Health has additional information on finding and evaluating an adult day care at http://seniorhealth.about.com/od/eldercare/a/day_care.htm.

For a comprehensive checklist when selecting an adult day care center, check out **Assist Guide Information Services** at www.agis.com/Document/1/adult-day-care-center-checklist.aspx.

National Adult Day Services Association provides names, addresses, and contact information for adult day care centers throughout the country at www.nadsa.org/find_members/default.asp.



Show Me the Money

Older Adults Say Cash Might Motivate Them to Walk

It appears that money talks when it comes to motivating older adults to walk as a form of exercise.

That's the conclusion of researchers who set out in 2006 to examine what sorts of walking programs and incentives might induce sedentary people over age 50 to put on their sneakers. They found that small cash payments might just provide that extra push.

A survey asked 501 inactive adults to state their preferences regarding how long they would walk, and whether they would walk alone or in a group, if they had to make a choice.

Participants most often selected three solitary, 20-minute walks per week. In addition, by adding a theoretical offer of \$9 a week, researchers upped the number of enthusiasts by 31%.

"A number of exercise programs are structured around group activity," said Derek Brown, Ph.D., lead study author. "This was not preferred by most. We did find, though, that money would increase participation. Also, people were more receptive to walk-

ing three days a week, rather than more or fewer days. The idea that it takes three days a week to gain sufficient benefits from physical activity seems to be ingrained."

Brown, an economist with the Public Health Economics Program at RTI International in North Carolina, pointed out that one hour of activity per week does not meet government health standards of 30 minutes, five days a week for moderate intensity activity such as walking. In the study, sedentary and inactive adults wanted \$36.30 per week to do this much exercise. If they had to go in a group, they wanted nearly twice as much more.

Brian Martinson, Ph.D., a

senior research investigator with HealthPartners Research Foundation in Minneapolis, had reservations about the study's hypothetical nature.

"No one was paying them," said Martinson, who has no affiliation with the study. "Given the value we Americans place on our autonomy and independence, I was not surprised that people didn't want to walk in structured groups. However, the \$36 a week to meet government goals was discouraging. More nuanced ways of offering incentives, such as having people 'front' their own cash with promise of returns if staying active, have recently been shown to be more cost-effective." ■

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