

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



QUICK TIPS FOR SINGLE CAREGIVERS

These tips will help jump-start your efforts to build a social life while caregiving:

- Check your loved one's health insurance policies to see if home health care services are covered
- Hire part-time help to stay with the care recipient so you can go out
- Take advantage of programs that offer respite for caregivers
- Ask friends and family to stay with your loved one occasionally
- When dating, be upfront about your caregiving situation
- Don't waste time trying to develop a relationship with someone who is not understanding and supportive of your caregiving
- Find out if you are eligible for rights and benefits under the Family Medical Leave Act

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Getting a Life

Finding a Social Life as a Single Caregiver

By Melissa A. Goodwin

Just what's a poor girl, or guy, to do? In what can seem like an impossible situation for single elder-caregivers, finding or maintaining a social life, especially a romantic relationship, while balancing caregiving and work is a daunting task, leading some to think it's simply not worth the effort.

That finding was confirmed in a 2004 family caregiving survey that validated indications from previous studies—that caregivers rate finding time for a social life as the most significant challenge they face. It comes as no surprise, then, that many divorced or never-married caregivers simply forgo trying to date at all because they feel as though they just don't have the time or energy.

Single caregivers also face unique concerns in the workplace, because they typically have no one else to call on the home front to help out when caregiving demands conflict with work schedules. As the sole source of their own financial support, they carry an extra layer of worry about taking time out from work, as well as concern over the impact the situation may have on career advancement and earning potential. ►

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Editor and Publisher
Chris Pederson

Marketing Director
Shelly Harvey

Strategic Business Development
Director
Karen B. Knowles

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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"You need to recognize that you only have so much emotional energy available to you, and dealing with an unsupportive partner will just drain you all the more."

Gail Simmons, single caregiver, on the perspective needed for dating while caregiving.

Finding a Social Life as a Single Caregiver

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Take Elizabeth, a single woman living in Scottsdale, Arizona, for example. She had a full-time job that enabled her to be financially self-sufficient and which she enjoyed. At age 58, she was in the prime of her life when her 83-year-old mother's health began to deteriorate. Mom moved from New Jersey to Scottsdale to be near Elizabeth, who took on the responsibility for most of her mother's needs.

Managing time off to care for her mother wasn't easy. As Elizabeth puts it, "I don't think my bosses liked all the time I took off from work, but because of the Family Medical Leave Act (FMLA), my job was protected. Still, I needed to get all my work done whether I was in the office a full 40 hours a week or not. That increased my stress, along with the fact that the attitudes of co-workers were not always kind. Believe me, the time I took off from work was no vacation."

No Energy for Romance

With regard to dating, Elizabeth says, "I dated a bit before my mother moved here, but since then my focus has been entirely on her. I have a social life with my friends occasionally, which is easier than a romantic relationship. My friends know the situation, and I don't have to worry that they will be offended when I can't be with them. While I've been caring for Mom, I just haven't felt as though I have the time or the energy left over for a romantic relationship."

Gail Simmons, also of Scottsdale, knows exactly how Elizabeth feels. As director of a volunteer caregiving program for seven years, she helped many single caregivers with their struggle to balance caregiving with work and a social life. A single woman herself, Gail experienced this same situation when she became caregiver for her 90-year-old uncle who lived nearby. Her experiences gave her valuable insight into how the single caregiver can cope and find some life balance.

Gail explains, "You can't be there for someone else if you are 'spent.' The guilt can be hard sometimes, but if you establish a routine for taking time off from caregiving, and stick to your

guns, your loved one will adapt. If you allow yourself some time off for fun, you'll be much better able to cope with the stressful times."

One option is to take advantage of free respite programs offered by volunteer caregiving programs like the one Gail ran. "These programs provide volunteers who will stay with a loved one for several hours so you can get out on your own," she said. "We had a situation with a single woman in her forties, who ran her own business and also was the sole caregiver for her ailing mother. We found a volunteer to stay with the mother one evening a week so the daughter could go dancing."

Gail also recommends asking other family or friends to give you a full night off by staying overnight occasionally with the care recipient. "One overnight getaway works wonders for the mind, body and spirit," she says. Another option is to hire someone to stay with your loved one for a few hours in the evening, so that you can get out and socialize – almost like an "adult babysitter."

Building Support Groups

Over time, Elizabeth expanded her support system to include a caregiver support group, church groups, friends and family. "Today, I have so much support I don't know where to begin," she says. "I finally realized that just because other family members live far away doesn't mean that they can't help. The key is that you have to ask! My brother and his family from New Jersey have come here to stay with Mom, and I've taken her to New Jersey to stay with them. My friends now force me to come out and play, and they remind to laugh and have fun again. Not only that, but at times they have taken Mom to doctor appointments, checked on her when I've been away, and visited her in the hospital."

Still, trying to develop or maintain a romantic relationship remains a significant challenge. Says Elizabeth, "When I do have some free time, I find that I really just want to be alone, read a book, or play with my animals."

Gail agrees that it's difficult, but not impossible, to have a romantic relationship while caring for a loved one. In this situation, she explains,

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Helping Mom and Dad—and Yourself

5 Steps to Choosing the Best Adult Day Program

By Molly Shomer, MSSW, LMSW



As family elder-caregivers, we should be great fans of good adult day activity programs.

A good day program offers benefits that no amount of loving care at home can provide: a combination of stimulating activities and soothing time to regroup, carefully programmed throughout the day; experienced staff who rotate so no one becomes frustrated or exhausted; opportunities for every participant to be successful at something

every single day; and friends and experiences that belong solely to the participant.

For the caregiver, the benefits are also clear: a chance to spend some guilt-free time away from caregiving responsibilities; the opportunity to watch their loved one grow and flourish; and a supportive professional group who come to know their attendees well and who can give guidance and support.

There are literally thousands of adult

day centers across the country. Some are excellent (like the ideal described above). But some are not so good. So, the question becomes: How do you tell the difference between an adult day center you would be thrilled for your elder to attend and one you should avoid?

There are several steps you should take to find the best day care program for meeting the needs of your individual senior. Here's a checklist:

1. Determine what you need from an adult day program

- a. How much time will you need? Do you need an occasional break; i.e., one or two afternoons a week, from one to three full days each week, or five full days to accommodate your work schedule or other responsibilities?
- b. Do you need transportation assistance?
- c. Do you need a day care program that participates in Medicaid or where there is a sliding fee scale?

2. Determine what your elder needs from a day care program in addition to supervision and social stimulation

- a. A special diet
- b. Help with personal care: bathing, shaving, hair care
- c. Help with using the toilet
- d. Help with walking or eating
- e. Health status monitoring: blood pressure, blood sugar, weight, etc.
- f. Medical therapies: physical, occupational or speech therapy

If you answered "yes" to "e" or "f," you will want to find a day program with a nurse on staff.

3. Use the telephone first

Locate local adult day care centers through the Area Agency on Aging (800-677-1116) or your local senior center. When you call, ask about days and hours of operation, the application process and fees.

Then you can decide whether it's worth your while to make a visit. Ask whether they have a brochure they can send you or a website you can visit.

4. Pay an initial visit (on your own, if you can). Make note of the following:

- a. Is the facility clean, bright, well furnished and without odor?
- b. Is every part of the building wheelchair accessible?
- c. Does the furniture look comfortable? Are there recliners available for those who need to rest? Do chairs have arms to assist with standing?
- d. Is there a "sick" room where participants can be isolated?
- e. Is there a spacious bathing room for anyone who may have had an accident or who participates in a bathing program?
- f. Is there a quiet room for those who may need down time?
- g. Do participants help plan activities?
- h. Does everyone—staff and participants—appear to be cheerful and happy to be there?
- i. Is there a volunteer program? A pet program? Do children visit?
- j. If the facility looks like a place you might consider, ask the following questions:

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Caring Conversations

10 Tips for Tackling Tough Topics with Parents

By Roberta Cole

“We cannot do great things.
We can only do small things with great love.”
Mother Teresa

“Mom and Dad, we need to talk!” I’ll bet those are seven of the most difficult words you’ve had to say. I know for me they were. Considering that over 59% of the adult population is currently or expects to be a family caregiver, we do need to talk—about how best to talk to our aging parents.

When we were young, our parents seemed all-knowing. We saw them as pillars of wisdom and strength, larger than life. Even in strained relationships, it was our parents who helped us navigate the back roads of childhood. For better or worse, that was their job.

But fast forward several decades and suddenly it is our job to parent them. How can this possibly be easy? To further complicate things, in many cases our parents have suffered physical and mental losses, such as hearing impairment, poor vision or even dementia, which makes a difficult situation even more difficult. For our parents, it feels as if their worlds have been rocked and everything is out of place because of our deep involvement. They think they are managing just fine, but at the same time they are finding themselves at the mercy of their children.

No wonder this awkward dance has everyone stepping on everyone else’s toes. But that doesn’t change the fact that addressing topics such as relinquishing keys to the car, no longer living alone, managing finances or medications, and providing wills and power of attorney



can be essential for survival. Why is it that our elders resist assistance when it seems so natural to embrace it?

Certainly, young, even middle-aged people welcome all the help they can get! That is one reason why it confounds us that our parents are not doing the same. But, of course, for them, the idea of relying on their children for assistance is emotionally laden and is to be avoided at all cost. Often, they feel so strongly that they attempt to shield their children from little daily disasters, simply so they can hold on to their independence. One assisted living facility told me about a resident who decided that she did not need any help taking her eye drops for a glaucoma condition. That was until the day she held a bottle of nail polish remover to her eyes and was about to drop the fluid in when her daughter rang the bell and intercepted the situation.

Isn’t it unfortunate that “dependent” cannot be seen as “interdependent” and as a natural part of the life cycle? If we could only get our parents to accept help as a great payback or gift of kindness—a reciprocal gesture, designed to give, not to take away—wouldn’t that be wonderful?

Psychologist and author Mary Pipher suggests that as we became a therapy-crazed society, dependency became equated with weakness, shame and pathology. And now we are a “dependent phobic” culture. I remember hearing about a friend’s mother who accompanied her husband to a care facility and was mistaken for the patient and asked if she needed help. Without missing a beat, she responded indignantly— “No, I am not a patient. I am only impatient!”

So how do we engage in sensitive conversations that are also effective? Are there specific techniques? Absolutely. What follows are 10 suggestions:

1. Do not say “We need to talk.” Those words set an agenda which is threatening and appears controlling. Your loved one does not want or “need” to talk; you need to talk! Simply wait for the right moment and talk.
2. The right moment to talk is when there is ample time to let the conversation meander where it needs to go and not when anyone is hungry, tired or uncomfortable. Be sure to choose a

*Roberta Cole is a writer, teacher and TV documentary and radio programming producer. Her past credits include producing and hosting the award-winning program Healthline on National Public Radio. She is the co-author of *Caregiving from the Heart: takes of inspiration* and has taught for nearly 20 years at New York University. She lives in New York and Connecticut and can be reached at rjcole24@yahoo.com.*

comfortable setting. Be alone. Do not risk embarrassment because others are present and it seems as if you are all ganging up.

3. Be aware of physical challenges your parent may have. For example, if there is hearing impairment you might want to jot down some things on paper, or if dementia is an issue, speak slowly, using simple words and repeat them often.
4. Respect your loved one's values and ways of doing things. If your parent has a strong investment in a way of doing something or a particular belief, try to honor it and still carve out a viable way to change whatever needs changing.
5. Do not deal with multiple issues at one time. It's too overwhelming. Save some for later.
6. Emphasize collaboration whenever possible. Speak about what can be done together.
7. Make careful verbal and nonverbal choices when you speak. Use "I" words such as "I would like" instead of "you should" or "you need." Never talk down to the person.
8. Remember, your issues are not their problem. You cannot demand that someone change his or her way of life because it is what you want. It is always an advantage to make a person feel it is what he or she wants. Never threaten to take away care or affection if they do not comply.
9. Think carefully about what you want to accomplish, then act.
10. Be patient. Don't press for an answer or action immediately.

While this does not fall under the heading of a communication technique, I know several people who have alerted their family physician to a parent's resistance to comply with health and safety modifications, and the physician gladly turned the suggestion into a prescription. Similarly, if your parent lives in a facility, the professionals at that facility can be called upon to help support your concerns.

No one is suggesting that these conversations are easy or stress-free. But using these techniques can certainly help. Keep in mind that there are situations in which you might want to consult a geriatric psychiatrist or care manager, and always remember, this is a process. It won't happen all at once. ■

Finding a Social Life as a Single Caregiver *Continued from page 2*

the whole nature of what constitutes a "date" may have to change. Having a quick dinner together may have to take the place of a whole evening out. Dining at home and watching DVDs in lieu of going out is another option.

Be Honest with Your Romantic Interest

The key to finding and maintaining a relationship during this period is total honesty—and allowing yourself to be very choosy about partners. "You have to be totally upfront about the situation," Gail says. "Don't sugarcoat it because you want to be in a relationship. You know how challenging the situation can be, and it's only fair that your friend knows it too. You need to recognize that you only have so much emotional energy available to you, and dealing with an unsupportive partner will just drain you all the more."

In spite of the challenges, there are major positive aspects to having a special relationship during stressful times. Gail explains, "Supportive phone calls, cards, and flowers from a special friend on a really bad day can mean so much. You can learn a lot about a person by how they act when you really need their love and support. The best discovery is that the person who is willing to stick with

KNOW YOUR RIGHTS AND BENEFITS

In balancing caregiving with a social life and working commitments, the Family Medical Leave Act (FMLA) can help. Here are highlights:

- 12 weeks unpaid leave in a 12-month period
- Continuation of group health benefits during FMLA leave
- Restoration to the same or an equivalent job upon return to work
- Retention of accrued benefits
- Protection from discrimination as a result of taking FMLA leave

Check the Department of Labor website at www.dol.gov to determine your eligibility for FMLA.

you and help you through challenging circumstances is a rare treasure, and you can certainly feel confident that their interest in you is sincere." ■

RESOURCES:

2004 Family Caregiver Survey Results
www.caregiving.com/yourcare/html/survey2004.htm

Faith in Action Volunteer Caregiving Programs
www.fiavolunteers.org

"Caregiving or Your Career?"
www.caregiving.com/Focus/html/0903focus_1.htm

"Maintaining Independence for the Care Recipient and Yourself"
www.caregivers.com/DBArticles/pages/viewarticle.php?id=220

Melissa A. Goodwin is a freelance writer and photographer living in Santa Fe, New Mexico. She has years of experience working with volunteer caregiving programs that help seniors and family caregivers. She can be reached at meesarj@msn.com.

COMING UP IN AUGUST

- Caregiving extracts a heavy toll from all involved, including employers. When caregivers feel under the gun at work from their eldercare pressures, it's best to be upfront with employers and gain their understanding and buy in. We'll tell you why.
- Denial. Everyone has it at some points in their life, but it can impede the very process of life. A look at how caregivers can help loved ones cope with denial of their own aging, illness or frailty.
- The scourge of osteoporosis: 7 common myths about this brittle-bone disease. Hint— it's not just found in women.
- Caregiving Gadgets and Gizmos. A new quarterly look at the latest in products developed to make life easier for caregivers and their seniors alike.

Deciphering the Code

Making Sense of Medical and Hospital Bills

By Ursula Furi-Perry, J.D.

You open your loved one's mailbox, only to find yourself confused by a barrage of medical and hospital bills, many of them dotted with unfamiliar codes and service descriptions in jargon you don't understand. How can you read—much less interpret or make sense of—those bills? More importantly, how can you help your loved one ensure the charges are legitimate and proper?

It's a true caregiver's dilemma, but according to Dr. Randy Card, a family physician at Marquette General Health System in Marquette, Michigan, you can take comfort in knowing you're not alone with this head-scratching.

"Medical bills are very complex because usually there are multiple billing sources," Card explains, "especially if the patient has a long or severe illness where you have several people involved in the care."

For example, if your loved one needed radiology services, you may see one bill for the actual service, and a separate one for its reading and interpretation. Hospital services are no different: for a routine operation, you may receive separate bills from the hospital, the provider, and the anesthesiologist, as an example. "There are lots of different places things come from, and they tend to come at different times," Card says. "It becomes difficult to keep track of which [bill] is which."

To help make sense of the mountain of your loved one's medical bills, consider the following tips:

- **Separate bills by provider**, and keep copies of bills—paid and unpaid—in distinct file folders. Organize bills by dates of services rendered, and make sure you keep them in order. "Ask for business cards from any doctor [your loved one] sees, and keep them

with the file," Card recommends; that way, you will have easy access to the provider's contact information if you don't understand a bill or need to dispute it.

Also keep track of any paperwork sent to your loved one that isn't an actual bill and file accordingly. For instance, your loved one's insurance company may send out an "Explanation of Benefits," which shows you what insurance will cover and what your out-of-pocket expenses will be. Though this is not a bill, it may be instrumental if a dispute should arise about an actual bill.

- Before the bill even comes, **keep track of medical and hospital services rendered** as accurately as possible. "Ask questions about different treatments, and track who was in the room or where the

patient went," says Card, who also is associate director of the Family Medicine Residency Program at Marquette General Hospital.

Sure, asking too many questions might make some doctors uneasy, but there is no need to feel like you are a burden or a snooper: be open and honest about your reasons for keeping track, Card advises, and any reputable provider should be happy to respond to your questions.

- **Read the bill thoroughly.** If there are portions you don't recognize or understand, call the provider's billing department for guidance first. Most hospitals and medical offices have a billing system in place to keep track of billing codes and services rendered, Card says, and they can help you decipher some of the medical language on your loved one's bills. If you don't understand a code abbreviation, for example, you may want to try the billing department first and ask them to explain it to you.

Keep written and detailed records of any contact you make with your loved one's providers: Save copies of letters or emails, and keep a call log of every phone conversation, including the name of the person you spoke with, the date of the call, the contents of the conversation, and any follow-up actions.

- **Dot your "i's" and cross your "t's"—legally speaking.** "Make sure you have legal power of attorney so you can communicate on behalf of your loved ones," Card stresses. Because of tougher health care laws and regulations, including HIPAA, your loved one's medical and hospital providers won't give out information or let you lobby on behalf of your loved one without signed



“Make sure you have legal power of attorney so you can communicate on behalf of your loved ones,”
advises Dr. Randy Card, on sorting out medical billing questions.

legal documents authorizing you to take charge.

- If you need to dispute a bill, *use your insurance or Medicare provider to your advantage*. Most companies have a communications mechanism already in place, Card says, and can help you resolve issues or disputes by dealing directly with your loved one’s provider. It might still be prudent to let the provider know—preferably in writing, and as soon as possible—that you wish to dispute the bill; doing so can sometimes resolve the underlying dispute more quickly, particularly if the bill was sent in simple error.
- *Turn to the authorities if necessary*. For example, most states have an agency that regulates insurance companies’ conduct, so if you have a dispute with your loved one’s insurance company over a medical

or hospital bill, or if you need to file an appeal on a claim that was denied, you may seek out help from your state’s agency. Consumer protection agencies and health law organizations may also be helpful. If you suspect Medicare fraud, consult the CMS website listed below to determine your next steps.

- However, *don’t automatically assume fraudulent practices* if you find mistakes in your loved one’s bills. “The whole process of billing and following up is very complex and challenging,” even for medical and hospital providers, Card says. Usually, providers have a tracking system in place to ensure bills are correct, and they are sending bills out in good faith; furthermore, insurance companies and Medicare conduct periodic fraud audits to ensure compliance. “Do mistakes happen? Yes, but most places

are monitoring very closely and have compliance programs...to make sure they’re not making too many mistakes,” says Card. ■

RESOURCES:

American Academy of Family Physicians on Understanding Your Medical Bills: <http://familydoctor.org/online/famdocen/home/pat-advocacy/healthcare/888.html>

Health Consumerism Tips on Medical Billing: www.healthconsumer.com/bills/index.htm

How to Recognize Medicare Billing Fraud: www.medicare.gov/FraudAbuse/Overview.asp

Ursula Furi-Perry, J.D., is a nationally published writer and adjunct professor living in Haverhill, Massachusetts. She can be reached at furiperry@verizon.net.

5 Steps to Choosing the Best Adult Day Program

Continued from page 3

- _____ k. Who owns the facility, and how long has it been in operation?
- _____ l. Is the center licensed?
- _____ m. What is the enrollment?
- _____ n. How many staff does the facility have, and what is the staff-to-participant ratio?
- _____ o. What are the staff credentials, and what additional training is provided?
- _____ p. What medical or cognitive conditions does the facility accept? Are wheelchairs allowed? Is incontinence accepted?
- _____ q. What are the days and hours of operation?
- _____ r. Is transportation available?
- _____ s. Is there financial assistance available?
- _____ t. What are typical activities, and can participants choose whether they wish to participate? What arrangements are available for those who do not want to participate in a particular activity?

- _____ u. What are the costs for part- and full-day? Is there a discount for attending several days per week or per month?
- _____ v. At what stage will the center suggest that it is time for your senior to withdraw from the program?
- _____ w. Are there support services or programs for families and caregivers?

5. Give any new adult day center a real try

Once you’ve narrowed your search, take a trial run at the center that appears to meet your needs best. Expect that your elder may be reluctant to attend; it often takes several visits before an elderly individual feels comfortable in new surroundings. Those with dementia are often frightened until new places become familiar. Experienced staff will anticipate reluctance and will know how to overcome these initial fears, so don’t be too quick to conclude that a good day program won’t work because of your loved one’s initial reaction.

*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.*

Clues: When It's Time to Consider Assisted Living



When is the right time to suggest that aging parents or loved ones can no longer live safely on their own? Sometimes, the decision is forced by illness, an accident or other circumstances related to aging.

For other elders, changes are subtle—but still conclusive. In a special report on assisted living, the *Mayo Clinic*

Women's HealthSource lists warning signs to help gauge when seniors need assistance in the home or alternative living arrangements. These signs may also indicate that a call or visit to a primary care doctor is in order.

Weight loss. Losing weight without trying is a signal that something is wrong. It can indicate a significant health problem, such as cancer, dementia, depression or heart failure. Weight loss can also be related to difficulty finding the energy to cook or problems with grasping cooking tools. Changes in the ability to taste and smell can make food less appealing.

Poor home maintenance. Piled up dirty dishes or clutter,

overgrown grass or any big negative changes in home upkeep are clues that seniors may be having health problems or age-related changes that hinder them from keeping up with household chores.

Lack of personal hygiene. Failure to keep up with daily routines—teeth brushing, bathing and basic grooming—can be signs of trouble.

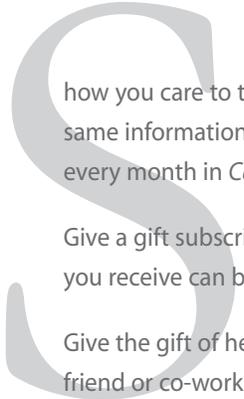
Mood changes. Everyone has good and bad days, but a different mood or outlook on life could be a sign of depression or another health concern. Losing interest in hobbies or daily activities is not a natural sign of aging.

Memory loss. Forgetfulness tends to increase with age, but there's a big differ-

ence between normal absent-mindedness and the type of memory loss associated with conditions such as Alzheimer's disease or other forms of dementia. Early warning signs can include repeatedly asking the same questions; having difficulty finding words; using inappropriate words; and being unable to complete familiar tasks.

Mobility problems. Muscle weakness, joint problems and other age-related changes can make it difficult to move around and perform basic tasks or chores. Unsteadiness increases the risk of falling. And falls can cause major injuries and even death in older adults. ■

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