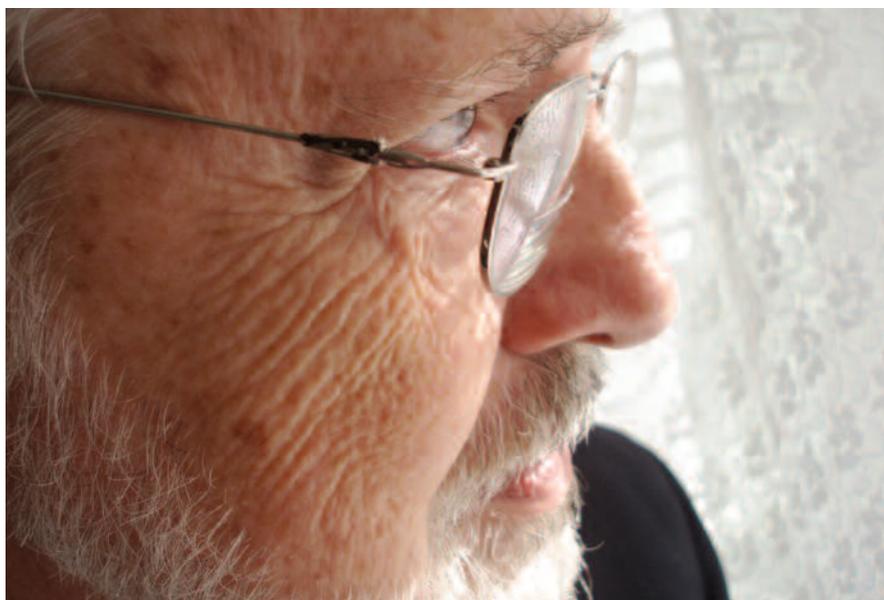


I Am the Face of Alzheimer's

Alzheimer's from the Inside Out



By Richard Taylor

MY LIFE HAS BECOME A PARADOX: Why is it that sex is over quicker than I want, while the rest of my life happens slower than I want?

I won't detail my sexual issues. Suffice it to say, I enjoy it just as much as I did when I was 23, but for a much briefer period now that I am 63. As for life, most times it seems to drag. I wait, always wait.

I wait for someone to find time to give me a ride. I wait.

I wait for someone to help me cut my lawn. I wait.

I wait for someone to fix my computer after I have screwed it up for the third time this month. I wait.

I wait for someone to be home so I can take the briefest of walks by myself to the end of the block and back. I wait.

I wait for someone to come and tell me if I have my shirt buttoned correctly (Looking in the mirror is no longer enough input for me to decide by myself if I am buttoned correctly). I wait. ▶

Editor's Note: For the past five years, Richard Taylor has been living with a diagnosis of early-onset Alzheimer's disease. A former psychologist living in Houston, Taylor has become a champion for those living in the early stage of the notorious disease, promoting a belief that people with dementia should not be labeled as disabled, and instead should be enabled to live as long and full a life as possible. In his travels, he speaks with caregivers and those living with a dementia diagnosis, encouraging them to share their insight into the disease. Here, Taylor shares his view of Alzheimer's from the inside out.

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"I have reached the point where I can't even remember all the things I can't do. Thank heavens there are those around me who remind me!"

—Richard Taylor, diagnosed 5 years ago with Alzheimer's disease.

Alzheimer's from the Inside Out

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MOST TIMES, I DON'T CARE. Honestly, I generally don't mind waiting. I forget I am waiting and start to do something else! But sometimes I do care and get frustrated and feel sorry for myself. I get upset with those I perceive are the cause of my waiting.

I recall times when I didn't keep them waiting, when I went out of my way to respond quickly to their request, times when I put aside my own activities in order to not keep them waiting. "Why do they make me wait?" I now sometimes ask. It's odd.

My caregivers don't intentionally mean to keep me waiting. They try their best to work me into their already overcrowded lives. Sometimes they give me first priority, but I must still wait while other first priorities are addressed. They are mostly right: I shouldn't—and sadly can't—do many of the tasks I formerly never gave a second thought to attempting by myself. Cook on the stove? Now I don't even remember when I put things in the microwave! Turn off and on the Christmas lights?

When I do remember to start to do it, I almost never complete the task before I distract myself with other tasks. I have reached the point where I can't even remember all the things I can't do. Thank heavens there are those around me who remind me!

Sometimes I make myself wait. I waited half an hour the other day before I could continue cutting the grass. I ran out of gas and couldn't find the gas cap on the lawn mower. I made myself wait 30 minutes because I was too proud to go next door and ask my neighbor to find the gas tank on my own lawn mower.

Sometimes I make myself wait because I can't find my shoes, or my watch, or my glasses, or my pants. I have to wait until my wife comes home to find them for me. I could simply wear different shoes, not wear my watch, skip wearing my glasses, and wear a different pair of pants—but I get fixated on something and can't seem to let go.

Well, if I know all this stuff, if I'm so smart, why don't I just stop waiting and get on with my life?

I don't know. Ask Dr. Alzheimer.

I can still understand what has happened to me. I can figure it out most of the time. But increasingly, the fact that I understand it seems to have less and less impact on my behavior.

I learn less and less from my own mistakes. In fact, as more time passes, I have less and less awareness of my mistakes while they are happening. I don't much care when someone explains them to me after the fact. And when I write about them, I better understand what went on but it has little to no impact on me and I repeat them over and over again. That's the disease at work.

I just can't seem to let go of seeing all of this as "mistakes." Others around me seem to have adjusted. It's no big deal to them when I forget, misunderstand, or can't figure something out. "That's just the way Dad is now," they say. But to me, I'm still making "mistakes."

Ironically, it is probably a "mistake" to expect everyone to adjust their lives to meet my needs according to my timeline. It is probably a mistake to expect everyone to change based on when, where, and how I and my needs are changing.

But is it a mistake to expect life to move faster for me, because I believe I have less life to live than I did previous to the day of my diagnosis? I would like to squeeze more in, in less time. As the means for me to live life are systematically being restricted (can't drive, can't be alone, can't manage my own money, can't, can't, can't), is it little wonder that it feels as if my life is slowing down? More energy is required to accomplish less. More time is required to do less. More patience is needed to succeed at fewer and fewer responsibilities and activities.

Perhaps I should work on being satisfied with doing the things I can still do well, and I still most enjoy, even if it consumes less time than in the past. Perhaps "quickies" aren't that bad, at least from my perspective. Time will tell. ■

Richard Taylor can be reached at richardtaylorphd@gmail.com. He is the author of a recently-published book on his experience, Alzheimer's from the Inside Out (Health Professions Press, 2006).

Did Mom Take Her Medicine?

Missing Meds is Risky Business

By Kelly D. Morris

Medication compliance is a serious issue among the elderly.

Compliance refers to taking medication as it is prescribed by the doctor, and that means taking it on time, taking the right amount, and taking it for as long as prescribed. In practice, however, that too often is not the case, sometimes with tragic consequences.

In many cases, the elderly simply may not understand the seriousness of taking medication as directed by their doctor. When Nicole Calloway's grandmother failed to take her medication and eat properly, she suffered severe complications from diabetes and finally had to be placed in a nursing home. Nicole, a resident of Charleston, South Carolina, says, "She never fully understood the disease and how important taking her medicine was, no matter how hard we tried to explain it to her."

An article in the January issue of *Drugs & Aging* reports that nearly a third (30%) of osteoporosis patients stopped taking their medication after just six months. Osteoporosis causes bones to be more brittle and increases the risk of fractures, such as broken hips, among the elderly. Calcium supplements and weight-bearing exercise are helpful in preventing the condition, but if medication is prescribed, it needs to be taken as directed in



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

order to lower the risk of serious injury.

Another study, conducted in Ireland, found that 22% of breast cancer patients on medication to prevent a recurrence of cancer stopped taking the medicine after one year, even though their doctors told them take it for five years. Many of the patients who stopped taking their medication were elderly.

Even antibiotics should be taken until the prescription is completely gone. Taking only a partial course of antibiotics may not cure the infection completely, but it can lead to the build up of resistance to the drug. However, people often stop taking antibiotics as soon as they begin to feel better.

Why else do people stop taking their medications? There can be many reasons.

"Forgetfulness is one reason," says Linda Andrews, case manager for the Ohio Area Agency on Aging in Richland County, Ohio. "They may forget to take the pills. They may forget to fill their prescriptions."

Stan Andrews, age 65, is Linda's husband. He is on medication for diabetes and heart problems. "Sometimes I'm already in bed when I remember that I forgot to take my pills," he says. "I don't want to get up to get them. I figure missing one dose won't hurt me." But missing one dose can be a risky decision, especially with medication for diabetes.

Sometimes people stop taking medication because of side effects. If this is the case with your loved one, talk to their doctor. They may be able to use a different drug, or there may be a way to treat the side effect. For example, if a drug causes

nausea, another medication might be prescribed to treat the nausea.

For instance, Dr. Gbenga Ogedegbe, an internist at Columbia University in New York, says that many patients on diuretics (water pills) for high blood pressure don't like to take them because they "keep them running to the bathroom." But high blood pressure can be a serious condition, increasing your risk of having a stroke as well as other health problems.

There can be other reasons the elderly stop taking medication as well. "The main reason I see is the cost," says Kathy Bowman, a home health aide in Greensboro, North Carolina, when asked about her patients who are not compliant with medications.

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Exclusively Caring for the Elderly

When and Why to Seek Care from a Geriatrician

By Paula Sanders McCarron

“With many of the health problems faced by the elderly, cure is not an option. It’s all about care—and it’s more than just medical care,” says Dr. Patricia Borman, a board-certified geriatrician and director of the Swedish Medical Center in Seattle.

Geriatricians delve not only into the patient’s medical concerns but also assess their functional abilities, concerns that impact the quality of life, the presence of or lack of social supports, and they extend their work into helping patients plan for a “good death” as defined by the patient.

While many physicians may treat elderly patients, the term “geriatrician” is reserved specifically for medical doctors who are board-certified in either family practice or internal medicine and have also acquired the additional training necessary for certification in accordance with the American Geriatrics Society.

Does this mean that everyone over age 65 would benefit from the specialized care offered by geriatricians?

“Not necessarily,” says Borman. She believes, as do many of her colleagues, that it is possible to get good geriatric care from family practice and internal medicine physicians who are trained in the principles of geriatric care.

And that’s a good thing because there is a serious shortage of geriatricians and it can be difficult to locate one, depending on where you live. Here are the cold, hard facts: From 1998 to 2004, the number of certified geriatricians fell by about one

third. Currently, only about 300 new practitioners complete a fellowship within geriatric programs each year.

Who, then, is most in need of a geriatrician? Here are some broad categories of those who might most benefit from the services of a geriatrician:

- Older adults with multiple medical problems and limited caregiver support.
- Older adults who are at high risk due to dementia, depression, and delirium.
- Older adults with untreated or unresolved pain.
- Older adults who are on multiple medications or who may need a re-evaluation of their medications or a change or reduction in their medications.

So, adequately matching need with the available supply of geriatricians can be something of a scramble. Many geriatricians say part of the problem rests in the nature of geriatrics itself. In contrast to younger patients who tend to seek medical care for acute and solo health issues, the elderly turn to physicians for help with what are often chronic and multiple health concerns such as arthritis, diabetes, high blood pressure, depression, and dementia. The elderly patient is also likely to suffer from unresolved or untreated pain, have other functional difficulties

such as poor vision or limited mobility and lack a social support system.

As a result, physicians who do serve the elderly spend large blocks of time in assessment, education, office visits, communicating with family members, and in attempting to address problems that can be very difficult or impossible to fully resolve.

There is also the problem of getting paid adequately for one’s services. Because of Medicare’s lower-than-normal reimbursement level, physicians have no financial incentive to spend great amounts of time addressing the concerns of their elderly patients. Some physicians deal with this problem by limiting the number of elderly they serve while others refuse to accept Medicare at all, thereby eliminating the need to serve the elderly. Even those physicians who want to serve the elderly find it virtually impossible to financially sustain a practice built solely on serving Medicare beneficiaries.

Such issues are causing geriatricians and others to develop an “across the board” approach. The goal is not to train more geriatricians per se but to increase knowledge of geriatric care principles among healthcare professionals and lay people alike. Programs like these are examples of what is being currently offered:

At the John Hopkins Bloomberg School of Public Health in Baltimore, a three-week training course is helping nurses learn how to identify some of the most common problems experienced by older adults, including depression, risk of falling, malnutrition, and isolation, as well as how to create care plans to address those issues.

In another program, an intensive, retreat-style training course developed by



Missing Meds is Risky Business

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This may not be a concern if your loved one qualifies for Medicare or has another prescription drug plan. If not, though, medication can be very expensive. If cost is an issue, there are several things you can do. Your loved one's doctor may be able to give you free drug samples. The pharmaceutical company may offer a program to provide low-cost medication to low-income patients. Shop around, because prices can vary from pharmacy to pharmacy.

Another reason people may stop taking medications is difficulty swallowing. Lynne Gardenia from British Columbia, Canada, says, "My mom took care of my grandma at home. She had trouble swallowing the pills. Mom started crushing them up and putting them in her tea. That worked great." It may not work great for everyone, though, because the pills may cause the drink to become bitter. Crushed pills could be mixed with pudding or applesauce, which may help to disguise the taste.

Make sure to speak with your loved one's doctor before crushing pills, though. Some pills are designed to dissolve slowly in the stomach and crushing them releases too much medication too quickly. If pills cannot be crushed, a liquid form of the medication may be available. Increasingly, timed meds may be available through a patch that does the trick. You can also try giving the whole pill in a spoonful of applesauce or yogurt. They are often easier to swallow this way than with liquid.

So, how can you help ensure your love one takes their medication?

With their doctor's help, educate your loved one about the importance of taking meds as prescribed. Explain why the medication must be taken for the length of time ordered by the doctor.

Sometimes a gentle reminder is all it takes. Using a medi-set, one of those little boxes with a section for each day of the week, can help a lot. You can also set an alarm to go off when it is time to take their medication. Make sure medicines

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Boston University Medical Center provides education about the unique needs and treatment of geriatric patients and is targeted to chief residents and medical faculty. This program is particularly promising, as organizers expect it will be offered nation-wide with the support of grant funds beginning this summer.

A completely different approach is being taken by Robert Stall, a geriatrician based in New York who describes his effort to educate older adults and family caregivers as an effort to promote "grass-roots geriatrics."

By turning the oft-quoted statement of President John F. Kennedy, Stall says he advises older adults: "Ask not what your doctor can do for you, but what you can do for your doctor—and yourself."

Toward this end, Stall maintains a website (www.geridoc.net) where individuals can find a wealth of information and resources including a free self-assessment. Once the self assessment is completed, a personalized summary is generated. The summary can be used to help older adults and their family caregivers identify care issues and options as well as serve as a tool in communicating their needs and concerns to healthcare professionals.

"It takes about an hour and a half to complete the assessment," says Stall. "Some people do tell me that the assessment takes too much time to complete." But as Stall points out, the value of the assessment is in its encompassing view of

health, just as is true of a visit with a geriatrician. And he says, "The investment of time in completing the assessment is an investment in one's own health and life."

Dr. Borman also advises older adults and their family members to always ask their primary physician to make a referral to a geriatrician for a consultation visit. The geriatrician can conduct an assessment and give recommendations that can then be carried out through the patient's primary physician. This can be an attractive alternative for many older adults who often do not want to transfer from one physician to another.

In addition to obtaining a primary doctor's referral, the American Geriatrics Society provides a physician referral service at no cost. All physicians participating in the referral service are members of AGS. To reach the referral line, phone (800) 563-4916 or submit a request via the AGS website at www.americangeriatrics.org.

For anyone who isn't sure now is the "right time" to look for a geriatrician, Stall says there is one simple and sure-fire way to know it is the right time to do so: "It's time to go looking if your own doctor ever says these words: What would you expect at your age? After all, you're not getting any younger." ■

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.

Are You Among the Worried Well?

Seeking a Cure When There is No Ailment

By Dr. Vicki Rackner, MD

“Let our advance worrying become advance thinking and planning.”

—Winston Churchill

MARY LOST ALL OF THE WEIGHT she gained in her pregnancies. Her late-night worries about obesity-related illnesses were then replaced with worries about cancer. She paid out-of-pocket for a full-body screening CT scan. The good news: no cancer. The bad news: gallstones. She was surprised, as she had never had any abdominal pain in her life.

Mary saw her primary care doctor who referred her to a surgeon. The surgeon said that although the gallstones may never cause any problems, a gallbladder attack could be as painful as birthing labor. Mary scheduled the gallbladder removal before she left the surgeon's office.

The operation went well; Mary's recovery did not. She developed a post-operative infection. Her busy nurse made a human error and gave Mary the antibiotic intended for her roommate. She spent a few days in the ICU recovering from the allergic reaction to the wrong medication. She finally went home a week later, and visiting nurses packed her open wounds for another two weeks.

Mary reflected that the whole gallbladder nightmare started with a worry.

Some people are worriers. It's part of their temperament. I know because I'm one of them. As a medical student studying for the boards, I read about a rare pancreatic tumor I was sure I had. I had been through this self-diagnosis drill



many times, and I saw how much anguish each of these imagined diseases had brought me. Sometimes I wished I could perform a surgical excision of the part of my brain that generated the worried thoughts.

I am in good company. If you look at the patients in the waiting room of a primary care doctor's office, one in three will be there for symptoms that are never diagnosed. The “worried well” is a class that grows by the day. And it knows no bounds—elderly, caregiver, physician, etc., are affected.

Here are some steps that might help if you worry about your health:

Recognize that you're a worrier.

Samuel Johnson described worry as fear and imagination. The ready access to online medical information fuels the imagination. More and more people have enough information to be dangerous.

Al had a headache, and his “worrier

within” (whom he calls Hal) sprang into action. He searched the Internet for the causes of headaches. His heart started pounding when he read the words *brain tumor*. He immediately imagined himself with a shaved head and a big surgical scar over his right ear. Al took a breath and said to himself, “This is the imaginative worried voice of Hal that's telling me I have a brain tumor.”

Let your doctor be your doctor. Al's next step was to implement the plan he and his doctor had agreed upon: let the doctor be the diagnostician. He picked up the phone and called the doctor's office. Sally, the receptionist, answered and Al said, “Hi Sally. I have a headache and today's diagnosis is a brain tumor. Help!” Usually the nurse would talk with Al, collect his symptoms and feared diagnoses, run them by the doctor and get the reassurance that squelches Al's imagination. Sometimes it meant an office visit.

Remember, even doctors don't treat themselves or family members. They know that they do not have the objective perspective that is required for good medical care. You can follow your doctors' lead and let your doctor be the diagnostician.

Remember, even doctors don't treat themselves or family members. They know that they do not have the objective perspective that is required for good medical care. You can follow your doctors' lead and let your doctor be the diagnostician.

Find the right doctor partner. It took Al a while to find this doctor. I encouraged him to do so after I heard Al say that it seemed his doctor judged him and wrote him off as a "hypochondriac."

Doctors like solving puzzles and fixing problems, and the more dramatic the intervention the better. The other side of this coin is that some doctors feel like failures when they cannot make a diagnosis or offer a cure. I'm convinced that many patients who sue their doctors observe the doctor avoiding them after the bad outcome occurs and interpret the distance as an admission of guilt. In most cases, this is a doctor acting human by averting attention from failures, and it leaves patients feeling abandoned at a time that they most need the support of their doctors.

It takes a special doctor to work with patients who cannot be fixed, be it those with chronic medical conditions, the elderly or patients plagued with imagined illnesses. Your life will be better when you find that right doctor partner who works with you to manage medical worries. Here are some qualities to look for:

- The doctor listens.
- The doctor believes you.
- The doctor does not judge you.
- The doctor is willing to look at the clinical picture with a fresh set of eyes.

"Out" your feared diagnosis. Most patients go to the doctor with a possible diagnosis in mind. While it's reassuring when the doctor never broaches the feared medical condition, the comfort is quickly replaced by a worry that the doctor wasn't being thorough and had just not considered the rare medical condition you found on the Internet. Better to ask directly, "Could this breast pain mean breast cancer?" Then you know your doc-

tor has considered the possibility and has taken the appropriate action.

Write your symptoms down. Keep a journal with things you notice about your body. Try to make it as specific as possible, and use numbers when you can, such as the level of pain on a scale of one to ten, the duration of the pain in minutes.

Step back to see the big picture from time to time. Lisa had mild, vague symptoms that would come and go — a rash, joint pain, a mild fever. After several years, the doctor finally made the diagnosis of lupus. A journal, had she kept one, would have been useful in this situation.

Know the difference between worry and your intuition. Lisa, a known worrier, imagined all sorts of fatal illnesses before her medical condition was finally diagnosed. She said, "Worry feels like someone shouting in your head. In calmer moments, there was another whispering voice that told me to keep trying to find the answer; I had a hunch that this was more than my imagination." Start to listen more carefully to the small still voice of your intuition. You'll hear it better when you calm the worry.

As Mary recovered from her gallbladder removal, she decided to treat the underlying problem: her worrying. She took many of these steps. She said, "Before the gallbladder operation, the medical tests and doctor appointments make me feel better for a little bit, but then there was another new worry. Now, when I catch myself worrying, I imagine a little devil standing on my shoulder shouting worries into my ear. I just say, 'Thanks for the information' and flick the grump away. My life is SO much better." ■

Dr. Vicki Rackner is a board-certified surgeon and clinical instructor at the University of Washington School of Medicine who left the operating room to help caregivers and patients take the most direct path from illness to optimal health. Get your free tips "Caring for the Caregiver" by contacting her at DrVicki@DrVicki.org.

Missing Meds is Risky Business

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are kept in a prominent, easy to reach place.

Keep track of when prescriptions need to be refilled, and make sure you or your loved one gets to the pharmacy.

Monitor your loved one for side effects. If side effects occur, talk to the doctor about alternatives.

Make sure your loved one can afford their medication. If not, investigate options. Ask their doctor for samples. Contact the pharmaceutical company. Shop around at different pharmacies to see which is cheaper.

Make sure your love one is able to swallow their pills. If not, talk with the doctor about alternatives.

Helping your loved one take their medication as prescribed is one of the most important things you can do to ensure their good health. Fortunately, there are many simple steps you can take in order to accomplish this. Remember to talk with your loved one's doctor as well as trying the tips listed here. He or she will likely be able to help you come up with a solution. ■

COMING UP IN JUNE

- Men are changing the face of elder-caregiving as more sons and nephews take on the primary care role. What's different about male caregivers?
- The pros and cons on nutritional supplements swirl like a storm around elderly and caregiver alike. We'll help you separate fact from fiction.
- Medicare Medical Savings Accounts are one of the newest Medicare Advantage Plan options. Are they right for your loved one?
- Aging gracefully with a chronic disease. It's a knack, and we'll tell you what the experts recommend as the way to do it.

Is Mom's In-Home Caregiver Trained? Or Not?



While the United States has no formal training requirement for in-home elder-caregivers, most Americans surveyed recently thought the caregiver they hired had received at least some formal training.

Calling caregiver training “usually haphazard and spotty at best,” The Caregiving Project for Older Americans found that more than three quarters of all the people it surveyed assumed their caregiver had been trained.

“The public has a dangerous misperception about the amount of training these in-home caregivers are receiving,” said Dr. Larry Wright, co-director of The Caregiving Project and director of the Schmieding Center for Senior Health and Education. “The truth is that professional

caregivers today are often unskilled or poorly trained.”

The survey, conducted by Harris Interactive, found that among adults who have used or paid for an in-home caregiver for someone age 65 or older, more than three quarters (78%) said they believed their caregiver had formal training, 14% didn't know, and 8% felt their caregiver had received no training.

The Project also examined how common in-home care has become in our society. Of 1,030 adults, 8% of respondents said they have used and/or paid for the services of a paid in-home elder-caregiver in the last 12 months. Among those who used or paid for caregiving, 44% paid out-of-pocket for at least some of the costs.

“With the increase of life expectancy [77.9 years in the United States], large numbers of older adults are living with increased chronic disease, frailty and

dementia,” explained Dr. Robert Butler, co-director of The Caregiving Project and president and CEO of the International Longevity Center-USA. “In-home caregivers need special training to care for the complex issues associated with caring for older adults.”

The overall problem, according to Schmieding's Wright, is that whether the professional caregiver is hired independently or receives some degree of caregiving training through a for-profit agency or community program, there is no national standard of training they are required to meet. That, he said, needs to change.

The Caregiving Project for Older Americans describes itself as “an action-oriented collaboration that aims to improve the nation's caregiving workforce through training, the establishment of standards, and the creation of a career ladder.” ■

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