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Adult Foster Care of the North Shore provides financial and emotional solutions to families

Adult Foster Care of the North Shore is a one of a kind organization. For the last 15 years they have been providing financial and emotional solutions to families in need of care for a disabled or chronically ill loved one (clients). Many Adult Foster Care clients are already living with a parent, child or other family member who qualifies as a caregiver. Others are placed in homes with compassionate and diligent caregivers.

In 2000, Dr. Cynthia Bjorlie left her private practice of 17 years and opened Adult Foster Care of the North Shore after reading an article in the NY Times about “Foster Seniors,” a program in New Jersey. Having always been interested in the care of people who cannot manage alone, she decided to

develop her own program in Massachusetts. With a grant from the Robert Wood Johnson Foundation, she started Adult Foster Care of the North Shore.

Since 2001, Adult Foster Care of the North Shore has grown to a staff of 30 and now serves over 400 clients. The difference between AFCNS and other similar companies is that, even though they share the same mission, the staff at Adult Foster Care of the North Shore actually lives the mission. They believe in a more compassionate and people-focused approach that produces great results.

If you are interested in becoming a paid caregiver for a disabled family member or qualified disabled adult, visit AdultFosterCareNS.com or call today at 978-281-2612.

About the Program:

This innovative program provides caregivers with a monthly payment for taking care of a disabled or ill adult. Caregivers are special, dedicated people who may take care of a family member or a new friend and welcome them into their own home.

Caregivers are reimbursed up to \$1,500 monthly, tax-free, for personal care services. Each and every caregiver is supported by Adult Foster Care’s professional staff that helps train the individual regarding the personal care needs of their clients. Adult Foster Care carefully and selectively matches clients with caregivers to ensure compatibility.

Adult Foster Care of the North Shore provides the following financial and emotional support:

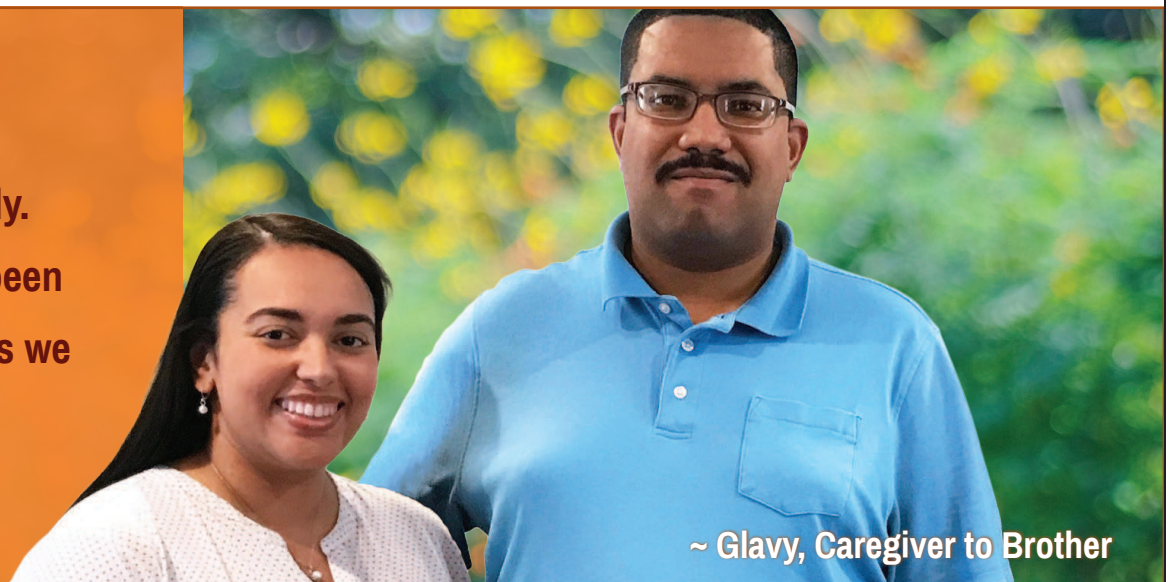
Financial Support: Through MassHealth, a monthly, tax-free stipend is given to the caregiver.

Health & Social Support: Clients and caregivers are assigned a nurse and care manager who visit the homes regularly. Staff members can answer questions about health issues and serve as a resource for medical training, education and needed interventions. On call support is available 24 hours a day, 7 days a week.

General Resource Support: Seasoned nurses and care managers can identify vital resources including:

- Adult Day Health Programs
- Specialized work and community support programs
- Mental health counseling
- Guardianship and health care proxy information
- Transportation services

“My brother’s stability is really important. Keeping him home is essential to our family. Adult Foster Care of the North Shore has been instrumental in facilitating all the resources we need for him to thrive in our family home.”



~ Glavy, Caregiver to Brother

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The perks of growing older — from discounts to perspective

Growing older does come with its challenges. But there are many positive things associated with aging.

Seniors are a rapidly growing segment of the population. In the United States, the Administration on Aging states that the older population — persons 65 years or older — numbered 46.2 million in 2014 (the latest year for which data is available).

With so many people living longer, it's time to celebrate the perks of getting older rather than the drawbacks. Here are some great benefits to growing old.

Higher self-esteem: The insecurities of youth give way as one ages, and older people have less negativity and higher self-esteem. A Swiss study of people ranging in age from 18 to 89 found that regardless of demographic and social status, the older one gets, the higher self-esteem climbs. Qualities like self-control and altruism can contribute to happiness.

Financial perks: Seniors are entitled to discounts on meals, museum entry fees, movies and other entertainment if they're willing to disclose their ages. Discounts are available through an array of venues if one

speaks up. Seniors also can enjoy travel perks, with slashed prices on resorts, plane tickets and more. The U.S. National Park Service offers citizens age 62 and older lifetime passes to more than 2,000 federal recreation sites for \$80.

Reasoning and problem-solving skills: Brain scans reveal that older adults are more likely to use both hemispheres of their brains simultaneously — something called bilateralization. This can sharpen reasoning skills. For example, in a University of Illinois study, older air traffic controllers excelled at their cognitively taxing jobs, despite some losses in short-term memory and visual spatial processing. Older controllers proved to be experts at navigating, juggling multiple aircrafts simultaneously and avoiding collisions.

Less stress: As people grow older, they are able to differentiate their needs from wants and focus on more important goals. This can alleviate worry over things that are beyond one's control. Seniors may realize how little the opinions of others truly mean in the larger picture, thereby feeling less stress about what others think of them.



Courtesy photo

Studies find that people experience less stress and have more desire to embrace life's opportunities as they age.



Courtesy photo

Enjoying an activity while spending time with others is a good way to stay physically and mentally engaged.

Staying engaged at any age has its rewards

You are never too old or young to take part in activities that enrich your physical, mental and emotional well-being. No matter your age, there is no better time than now to start.

To help do just that, consider these tips from the Administration for Community Living:

Be well

If you don't usually exercise, choose a low-impact activity that you can do a little at a time. Walk for 10 minutes in the morning, sign up for a tai chi class or learn gentle stretches, for example. Remember, it is wise to consult a health care provider before beginning an exercise routine.

Exercising is less of a chore when you do it with people you enjoy. Gather a group of friends or join a class. Some senior and

community centers even offer free or low-cost options.

Good nutrition is vital. Keep an honest record of what you eat. If you have a condition like diabetes, consult your doctor before changing your diet. Nutritionists can be excellent resources, whether you have special dietary needs or not.

Eating healthy foods and staying active may reduce physical health risks, and you also can exercise your mind by reading, playing games, taking a class or simply being social.

Reinvent yourself

Second or even third careers can be personally and financially rewarding. Determine whether you have the skills needed for something new. If not, seek out classes or training, and remember to ask whether financial

assistance is available.

Express yourself through the arts. Learn to paint or draw, dust off those dancing shoes, take an acting class or finally write that novel. As a bonus, studies show the arts can improve brain health.

Keep expanding your knowledge and growing by learning a new language or taking a computer class. Or, if you're more of an adventurous type, maybe you've always wanted to travel and discover other cultures.

Give back

Consider using your experience to serve others. Volunteers meet a range of community needs, from mentoring at-risk youth and providing job training to helping families recover from disasters. Find opportunities by visiting local organizations or charities.

Pick and schedule service

activities that match your skills and interests. If you are handy, assisting with a nonprofit housing organization may be most rewarding. If you enjoy working with kids, contact a local school to talk about ways you can help.

If you want to help others in a less formal manner, consider helpful tasks like driving neighbors to appointments, babysitting for working parents or tutoring kids in your neighborhood. If you are a member of a spiritual community or club, ask if there are outreach programs that need assistance.

Increasing your well-being — physically, mentally and emotionally — can be made simpler by finding activities that fit your personality and interests. Visit oam.acl.gov to find more information and resources to engage at every age.

Sharing knowledge, insight across the generations

In the not-so-distant past, extended families frequently lived in close proximity to one another. These families shared meals and experiences and essentially grew up together.

Nowadays, families separate for various reasons, such as job opportunities and cost-of-living concerns.

While there are advantages to spreading out, there are also some disadvantages, namely that grandparents and grandchildren may not see each other frequently enough. Even though people of different age groups may not have the same interests, the interactions between generations can benefit both young people and their aging relatives.

Finding renewed vigor

Senior living and active lifestyle communities provide invaluable care and amenities for seniors. While

being around like-minded individuals can be handy, it's also limiting. Seniors who continue to age in place in mixed-age communities can extract joy from watching youthful children and young adults growing up, playing and socializing. Being around multiple generations also can spark interesting conversation, and all those involved can learn something from one another.

Planning for the future

Younger generations may not understand the concept of "hard times" or "doing without" like a person who has lived through various ups and downs. Many seniors excel at passing along advice about economic cycles, saving for the future and maintaining stability that can benefit those just reaching adulthood.

Practicing interpersonal skills

All the technological savviness in the world cannot compensate for the power of strong interpersonal skills. Being able to address a group of people or speak one-on-one is essential in the workplace and in life. When younger generations speak to older adults, they may become stronger at verbal discourse and have greater perspective of different points of view.

Learning new technology

Younger generations can impart knowledge of electronic and tech devices to older adults. People with skills are usually happy to share their knowledge. Even if seniors aren't ready to purchase tablets or smartphones, they may be excited to have their grandchildren teach them about the latest gadgets.



Interactions between the generations can bring rewards for both the young and the more mature.

Courtesy photo

Providing a sense of purpose

Both seniors and younger generations can realize a greater sense of purpose when interacting with one another. One individual may be the reason another person greets the day with a

smile. Visits from grandchildren can reduce the likelihood of isolation and depression in older adults.

And younger generations can discover the benefits of personal social interaction rather than communicating

exclusively through social media apps.

Fostering intergenerational connections is a great way to broaden social circles, improve communication and learn new things.



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Remember these tips to stay sharp and alert



Courtesy photo

A diet that includes lots of vegetables can help men and women reduce their risk for cognitive decline.

Forgetfulness can affect anyone. For example, few, if any, adults can say they have not experienced moments when they could not find their keys. And once the keys are found, people move on without giving much thought to why they did not immediately remember where they left their keys.

Isolated incidents where people cannot recall where they placed their car keys or other minor bouts with forgetfulness do not occur by accident. In fact, the Harvard Medical School notes that they are likely byproducts of age-related changes in thinking skills. When people reach their 50s, chemical and structural changes in the brain may begin to occur, and these changes can affect a person's ability to process memories.

Father Time may be a

formidable foe, but people can take steps to give their memories a boost as they get older.

■ **Embrace recognition instead of trusting recall.** Dr. Joel Salinas, a neurologist who specializes in behavioral neurology and neuropsychiatry at Massachusetts General Hospital, notes that human beings are better at recognition than recall. That means people are more likely to remember something they read, such as a note or a list, than something they're simply told.

■ **Recognize the value of repetition.** The Harvard Medical School notes that people might be more inclined to remember what they hear if they repeat it out loud. Names and addresses might be more easily remembered after they're repeated out loud because repetition increases the likelihood

that the brain will record the information and be capable of retrieving it later. When studying for exams, many students repeat important points to themselves time and again, and that same approach can be applied by adults who are trying to improve their memories.

■ **Eat a healthy diet.** A study published in 2015 in the journal *Neurology* found that people who eat healthy diets with lots of fruits, vegetables, nuts and fish and little alcohol and red meat may be less likely to experience declines in their memory and thinking skills. Authored by Andrew Smyth of McMaster University in Ontario and the National University of Ireland in Galway, the study following more than 27,000 people in 40 countries for an average of roughly five years. All

participants were 55 and older and had diabetes or a history of heart disease, stroke or peripheral artery disease. Those who ate the healthiest diets were 24 percent less likely to experience cognitive decline than people with the least healthy diets.

■ **Break things down.** Breaking things down into small chunks also can help improve memory. If tasked with remembering something extensive, such as a speech, focus on a single sentence at a time, only moving on to the next sentence when you're confident you have successfully committed the preceding sentence to memory.

Periodic memory lapses are often nothing to worry about. But men and women concerned about maintaining their memories can employ various strategies to do just that.



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Take time to smell the roses to keep senses engaged



Courtesy photo

Loss of hearing or diminishing vision are widely associated with aging. But sense of smell and taste may diminish with aging as well.

Aging comes with several sensory changes, many of which people expect. Loss of hearing or diminishing vision are widely associated with aging. But one's senses of smell and taste may diminish with aging as well.

The senses of taste and smell work in concert. The sense of smell is vital to personal health, not only because inhaling pleasant aromas can provide comfort and stress relief through aromatherapy and help trigger important memories, but also because smell enables a person to detect the dangers of smoke, gas, spoiled food and more.

The National Institute on Aging says that as a person gets older, his or her sense of smell may fade, and that will also affect taste. The Mayo Clinic says some loss of taste and smell is natural and can begin as early as age 60.

Adults have about 9,000 taste buds sensing sweet, salty, sour, bitter and umami flavors, or those corresponding to the flavor of glutamates. Many tastes

are linked to odors that begin at the nerve endings in the lining of the nose. Medline says the number of tastebuds decreases as one ages, and that remaining tastebuds may begin to shrink. Sensitivity to the five tastes also begins to decline. This can make it more difficult to distinguish between flavors.

Similarly, especially after age 70, smell can diminish due to a loss of nerve endings and less mucus in the nose. With the combination of the reduction of these important sensory nerves in the nose and on the tongue, loss of smell and taste can greatly affect daily life.

Changes in these senses can contribute to feelings of depression, diminish one's enjoyment of food and cause harmful conditions, such as extreme weight loss from disinterest in food to problems associated with over-using salt or sugar.

Although aging is often to blame, loss of smell and taste also may be tied to early

symptoms of Parkinson's disease or Alzheimer's disease. Cancer treatments, medications, lack of saliva, colds, flu, and other factors may contribute to sensory loss. Changing medications or treatments may help.

It's important to bring up diminished flavors or smells with a doctor to rule out something more serious and to determine what might help restore pleasure from smells and flavors. An otolaryngologist, or a doctor who specializes in diseases of the ears, nose and throat, may be able to help fix the problem, though some people may be referred to a neurologist or another specialist.

Continuing to use one's sense of smell and taste by cooking, gardening, trying new flavors and experimenting with different aromas may help slow down the decline of these senses. Although age-related loss of taste and smell cannot be reversed, some such cases may be treatable.

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~ Cindy



Preserving their stories

New app creates video memories before 'they're gone forever'

BY BRENDAN MEYER
TRIBUNE NEWS SERVICE

Patti Fitch never thought to record videos of her mother.

Of course, she knew the stories, about her mother's Polish heritage or job at AT&T. But she never captured them on camera — to preserve her voice, mannerisms and tales for future generations.

Today, Patti's mother, Irene Skurla, lives at an assisted living center in Texas. She's 85 years old with short white hair and purple glasses.

Her days are a routine of meals, activities and TV on a couch. But thanks to an app created in Dallas, on some afternoons, Irene will tell a story.

The app is called OneDay. It's a prompted question-and-answer app — with topics such as childhood, wartime and romantic experiences — that records a video, which is then shared with family members via text or email.

"Let's talk about your ancestors today," said Lynn Brink, the vibrant life director at The Village at Mapleshade, who sat across from Irene on a recent afternoon with the app open on her iPad.

She asked the first question that popped up on the screen, and pressed record.

"Where did your ancestors originate?"

Irene smiled and began talking about a mother from Poland and a father from New York City, in a way

only Irene could tell it, a five-minute story that would be captured and emailed to Patti and other loved ones.

It's exactly what the creator of OneDay intended.

'Gone forever'

As a teenager, Clint Lee spent after-school days and holidays helping seniors. His parents owned an assisted living home. He'd dress up like the Easter Bunny, buy groceries or mow the front lawn. But many days, he'd just sit and listen, to stories about war, life back in the day or the ones that got away.

He realized then that these uncaptured stories were important. But it didn't hit him personally until he was 23. That's when his grandfather died, and he

and his father, John Boaz, realized they had little video or audio to remember him by.

"We had lost his voice," Lee said. "The way he would say things."

So the University of North Texas graduate set out to find a solution for other families. Six years ago, he created and co-founded a technology company with his father called OneDay with a goal to preserve stories. Since then, there have been multiple incarnations of the company, but last January, OneDay rebranded to focus solely on older generations.

The app is exclusively licensed to senior living communities. Today, OneDay is in 1,000 locations

See MEMORIES, PAGE S9



ASHLEY LANDIS/Tribune News Service

Irene Skurla, 85, talks about her mother's arrival to Ellis Island from Poland at the age of 15 and how she went on to work for the Ziegfeld Follies. A new OneDay app exclusively licensed to senior living communities allows residents to record their stories and share them electronically with family members.



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MEMORIES

■ Continued from Page S8

across the U.S., Canada and the United Kingdom. For now, individuals can't buy the app.

"The senior citizen population is growing every day, and their stories are disappearing at an alarming rate," Lee, 32, said. "We've got to have a sense of urgency, because once these stories are gone, they're gone forever."

The app, which is compatible with iOS platforms and will soon be on Android, is easy to use. Senior living facility members simply need to select a topic, ask the questions that pop up on the screen and press record. When finished, an automated video is created, with high-quality audio and music.

The video is sent via a private link by text or email to relatives and loved ones. Family members can also view the resident's videos on their personal OneDay life story page, and even

submit questions or topics of their own.

The app costs \$150 to \$250 per month depending on the size of the senior living community. Lee said there are plans for expansion to different markets, as well as possible consumer use in the near future.

"The meaning behind OneDay is we tell your story, one day at a time, for your kids to one day have," Lee said.

"I feel like if I knew my grandpa and great-grandpa's story, and the ins and outs of them as men and what made them great husbands and what their struggles were, I would have a better connection to them. Overall, I'd be a better son. A better husband. A better father. These stories are so rich and experienced that we can all learn from them."

Priceless keepsake

Irene sat on the couch across from Brink with a microphone hooked to the lapel of her shirt. She stared at the iPad as it recorded



ASHLEY LANDIS/Tribune News Service

Bob Stiegler reminisces about his childhood as Vibrant Life Director Lynn Brink records him using the OneDay app at The Village at Mapleshade in Texas.

a story about her heritage. Her story started with her mother, who arrived at Ellis Island in the lower deck of a ship from Poland.

"She was 15 years old," Irene said, as Brink nodded along. "She landed in New York City. She worked for the Ziegfeld Follies."

Mapleshade has been using the app for seven months now. Every week, Brink tries to find a different resident to record.

She finds it improves the relationships she has with the seniors, as she's able to get to know them on a more personal level.

Some videos have already proved priceless. In June, a resident died, and the family featured a OneDay video on the online obituary.

Irene, who's been at Mapleshade almost a year, continued on. She talked about her father working in real estate and his time during the Great Depression. After a handful of questions, Brink pressed create video.

The video was emailed to Patti. The following day, she clicked the link as she sat in her office.

There was her mother, miles away at Mapleshade, talking about her ancestry. She looked happy. She was laughing. She was relaxed.

Patti couldn't help but smile along. Of course, she'd heard the story about her grandmother many, many times, from Poland to Ellis Island to Ziegfeld Follies.

But now, it was preserved forever.



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Managing debt in retirement takes some planning

BY LIZ WESTON
NERDWALLET



Liz Weston

Owing money in retirement isn't ideal — but most people do.

Seventy percent of U.S. households

headed by people ages 65 to 74 had at least some debt in 2016, according to the Federal Reserve's latest Survey of Consumer Finances. So did half of those 75 and older.

Paying debt usually gets more difficult on a fixed income. Mortgage debt, especially, can be a huge burden in retirement. Retirees may have to withdraw larger amounts from their retirement funds to cover payments on debt, which can trigger higher tax bills and increase the chances they'll run short of money.

People have the most options to deal with debt if they create a plan before they retire, financial planners say. Refinancing a mortgage, for example, is usually less of a hassle while people are still employed. It's also typically easier to generate the extra income that may be needed to pay off debt.

"It is much easier to keep working for another year or two than to try and come back into the workforce when they are older and the employer needs have changed," certified financial planner Linda Farinola said.

Here are three loans to consider before you stop working:

Refinance (or recast) your mortgage

Certified financial planner Rebecca L. Kennedy would prefer that clients pay off their mortgages before they retire. But paying off a mortgage may not be feasible

or advisable, especially if it would mean taking a lot of money from a 401(k), IRA or other account.

"Often the majority of the assets are pretax so it would require a much larger withdrawal to net the after-tax amount needed," Kennedy said.

People also could consider downsizing to eliminate or reduce mortgage debt, Farinola said.

For retirees determined to stay put, refinancing or "recasting" the loan can lower payments, said Serina Shyu, a certified financial planner. While refinancing requires taking out a new loan, with substantial fees, recasting means keeping the same loan, but using a lump sum to pay down the balance and lower the payments. Recasting is offered by some, but not all lenders and may not be a good idea if the lump sum would come from retirement accounts.

Another option, if the mortgage balance is less than half of the home's market value, is using a reverse mortgage to pay it off.

Reverse mortgages allow people 62 and older to tap their home equity without having to pay the money back until they move out, sell the house or die.

"For many, that is a very viable way to increase cash flow," said Chris Chen, a certified financial planner in Waltham.

Consolidate your debt

Credit card debt indicates people may be living above their means. That's not something that tends to get better when incomes drop in retirement, Farinola said.

"I find that if people cannot pay off debt when they are working, they certainly cannot when they retire and the cycle just continues," she said.

People with good credit

scores, and sufficient discipline, can use zero-percent balance transfer offers to consolidate and pay off their credit card debt. Those who need more time to pay off debt might consider a personal loan with a fixed interest rate and fixed payments. If it would take over five years to pay off the debt, however, their debt load may be unmanageable. In that case, they should talk to a credit counselor and a bankruptcy attorney to better understand their options.

Open a home equity line of credit

A home equity line of credit is like a credit card that allows you to borrow against the value of your home. If that sounds dangerous — good. It should.

HELOCs shouldn't be used for frivolous spending, but they can be a good backup to an emergency fund. HELOCs also can fund home

repairs or long-term care.

A HELOC probably isn't a good option for people who aren't disciplined about their spending. HELOCs have another big pitfall: Payments on any borrowed money can spike after an initial interest-only "draw period" ends, usually after 10 years.

Another product, a reverse mortgage HELOC, costs more to set up, but payments are optional. Some financial planners recommend reverse mortgage HELOCs as a potential source of cash in market downturns. The retiree can draw on the HELOC rather than selling stocks in a bad market, and pay the money back — or not — in good markets.

"The key advantage is ability to choose if and when to make payments, and ability to access a growing line of credit," certified financial planner Tom C.B. Davison said.



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Taking care in discharging a patient is vital to their well-being

By JUDITH GRAHAM
KAISER HEALTH NEWS

The kidney doctor sat next to Judy Garrett's father, looking into his face, her hand on his arm. "There are things I can do for you," she told the 87-year-old man, "but if I do them, I'm not sure you will like me very much." The word "death" wasn't mentioned, but the doctor's meaning was clear: There was no hope of recovery from kidney failure. Garrett's father listened quietly. "I want to go home," he said. It was a turning point for the man and his family. "This doctor showed us the reality of my father's condition," Garrett said, gratefully recalling the physician's compassion. A month later, her father passed away peacefully at home.

This kind of caring is what older adults want when they become seriously ill and move back and forth between the hospital and other settings, according to the largest study ever of patients' and caregivers' experiences with care transitions.

Two other priorities are also crucially important, according to recently published research: Patients and caregivers want to feel prepared to look after themselves or loved ones when they leave the hospital, and they want to know that their needs will be attended to until they stabilize or recover, however long that takes.

What's striking is how often hospitals fail to fulfill these expectations, even though it's been known for decades that care transitions are problematic and strategies to reduce preventable hospital re-admissions have been widely adopted.

"Despite millions of



Courtesy photos

Without a sense of caring, patients and caregivers say they often feel abandoned and lose trust in health care professionals.

dollars of investment and thousands of hours of effort, the health care system still feels very hazardous, unsafe and stressful from the perspective of patients and caregivers," said Dr. Suzanne Mitchell, assistant professor of family medicine at Boston University School of Medicine and lead author of the new report.

She's part of a team of experts spearheading Project ACHIEVE, a five-year, \$15 million study investigating the effectiveness of interventions designed to improve care transitions. The focus is on what Medicare patients and caregivers need and want when a hospital stay ends and they return home.

One part of the project involves asking people who undergo these transitions, mostly older adults, about their experiences, including what went well and what didn't. In addition to the new report, a survey of more than 9,000 patients and 3,000 caregivers is close

to completion. Results will be published this fall.

Another part involves looking at what hospitals are doing to try to improve transitions, such as teaching patients and caregivers how to care for wounds or arranging follow-up phone calls with a nurse, among other strategies. A preliminary research report published last year found common problems with transition programs, including haphazard, uncoordinated approaches and a lack of teamwork and leadership.

Several areas deserve special attention, according to people who participated in focus groups and in-depth interviews for Project ACHIEVE:

Getting actionable information

Too often, doctors speak to patients and caregivers in "medicalese" and fail to address what patients really want to know, such as "What do I need to do to feel better?" said Dr.



Experts say hospital staff should inquire about older patients' living circumstances, social support and the help they think they'll need before they release a patient back home.

Mark Williams, Project ACHIEVE's principal investigator and chief transformation and learning officer at the University of Kentucky HealthCare system.

"You really need someone to walk you through what you're going to need, step by step," Williams said.

Nothing of the sort occurred when Anita Brazill's parents, ages 86 and 87, were hospitalized seven times between Dec. 25, 2016, and Feb. 13, 2017.

First, her mother needed emergency gastrointestinal surgery, then her father became ill with pneumonia. Both went to an understaffed rehabilitation facility after leaving the hospital, and both bounced right back to the hospital, five

times altogether, because of complications.

Each time her parents left the hospital, Brazill felt unprepared.

"You're out on the concrete of the discharge pavilion and they send you off by ambulance or car without a guidebook, without any sense of what to expect or who to call," she said.

Planning collaboratively

Ideally, when preparing to release a patient, hospital staff should inquire about older patients' living circumstances, social support and the help they think they'll need, and discharge plans should be crafted collaboratively with caregivers.

In practice, this doesn't happen very often.

In May, Art Greenfield, 81, was admitted at 3 a.m. to a hospital near his home in California, with severe food poisoning and dehydration. Less than six hours later, after a sleepless night, a hospitalist he had never met walked into his room and told him she was sending him home because his situation had stabilized. (Hospitalists are physicians who specialize in caring for people in the hospital.)

"She had no idea if he could get out of bed on his own," said his wife, Hedy Greenfield, 76. "I wasn't there, and no one asked him if there was somebody who could take care of him at home when he got there. Fortunately, he had the presence of mind to say I'm not ready, I need to stay another day."

Expressing caring

Over and over again, patients and caregivers told Project ACHIEVE researchers how important it was to feel that health professionals care about their well-being.

Simple gestures can make a difference. "It's looking at you, rather than the computer," said Carol Levine, director of the families and health care project at United Hospital Fund in New York. "It's knowing your name and giving you a sense of 'I'm here for you and on your side.'"

Without this sense of caring, patients and caregivers often feel abandoned and lose trust in health care professionals. With it, they feel better able to handle concerns and act on their doctors' recommendations.

Kathy Rust remembers walking into a room at an outpatient clinic and seeing a doctor stroking her mother's hair and calming her before reinserting a feeding tube that the 93-year-old

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TOUCH

■ Continued from Page S12

woman had pulled out.

"He was making sure she was comfortable," Rust said, recalling how moved she was by this doctor's sensitivity.

Anticipating needs

Few people know what they'll need in the aftermath of a medical crisis: They want doctors, nurses, pharmacists, social workers or care managers to help them figure that out and devise a practical plan.

Under the CARE Act, now enacted in 36 states, the District of Columbia and Puerto Rico, hospital staff are required to ask patients if they want to identify a caregiver (some choose not to do so) and to educate that caregiver about medical responsibilities they'll face at home. But implementation has been inconsistent, Levine and other experts said.

Rust panicked the first



Courtesy photos

Studies are finding patients, especially seniors, want to be treated with compassion when it comes to facing transitions in care from the hospital to home or another medical facility.

time her mother's feeding tube came out, by accident. "I called the transition service at my hospital's outpatient clinic, and they sent someone over in 30 minutes," she said. "They were very reassuring that I had done the right thing in calling them, very calming. It was such a positive experience that I wasn't afraid to contact them with all kinds

of questions that came up."

Too often, however, discharges are hurried and caregivers are unaware of what they'll face at home. Levine tells of an older woman who was handed a pile of paperwork when her husband was being released from the hospital.

"She couldn't read it because she had macular degeneration and no one



Patients and caregivers involved in a recent study told researchers it was vitally important that they felt their health professionals cared about their well-being.

had thought to ask, 'Do you understand this and do you have any questions?'"

Ensuring continuity of care

"Patients and families tell us that once they leave the hospital, they don't know who's responsible for their care," said Karen

Hirschman, an associate professor and NewCourtland Chairwoman in Health Transitions Research at the University of Pennsylvania School of Nursing.

The name of a person to call with questions would be helpful as would

around-the-clock access to emergency assistance, for months, if needed.

"It's not just, 'Now you're home and we called you a few times to follow up,'" Hirschman said. "It can take much longer for some patients to recover, and they want to know that someone is accountable for their well-being all the way through."

Garrett found that having cellphone numbers for a home health care nurse and a doctor who made house calls was essential, until hospice took over shortly before her father's death.

"My advice to families is be physically present as much as possible, although I know that's not always easy," she said. "Appoint one person in the family to be the point person for medical professionals to reach out to. Request cellphone numbers, but use them only when you have to. And if you don't understand what professionals are telling you, ask until you do."

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Family caregivers share stories, tips to ease Alzheimer's toll

BY BLAKE FARMER
KAISER HEALTH NEWS

Vicki Bartholomew started a support group for wives who are caring for a husband with Alzheimer's disease because she needed that sort of group herself.

They meet every month in a conference room at a new memory-care facility in Nashville called Abe's Garden, where Bartholomew's husband, a Vietnam veteran and prominent attorney, was one of the first residents.

"My husband's still living, and now I'm in an even more difficult situation. I'm married, but I'm a widow," she tells the group one day.

These women draw the shades and open up to each other in ways they can't with their lifelong friends.

"They're still wonderful friends, but they didn't know how to handle this. It was hard for them, and as you all know, your friends don't come around as much as they used to," Bartholomew said. "I was in bad shape. I didn't think I was, I did have health problems, and (now) I know I was depressed."

As the number of Americans afflicted with Alzheimer's disease continues to swell to an estimated 5.7 million, so do the legions of loved ones caring for friends and family members. The toll on Bartholomew's own mental health is one of the reasons the Alzheimer's Foundation of America focuses on the nation's estimated 16 million unpaid caregivers.

With no cure on the horizon, the foundation has been highlighting the necessity of better support for those caregivers through a national tour.

At the live events, Alzheimer's researchers and clinicians offer guidance on a number of topics, including how to ensure safety for patients at home, care planning and even how to entertain someone with memory loss.

The organization



BLAKE FARMER/WPLN

April Simpkins supports her husband, Joe, during lunch at the memory-care facility where he moved as his Alzheimer's advanced. She says caring for her husband at home became all-consuming. She tries to visit him every day at the facility.

promotes in-person and telephone support groups, since being a caregiver is often a barrier to getting out of the house alone. Virtual support systems showed effectiveness at reducing loneliness, stress and depression in a small 2014 study.

"We have to do everything we can to educate a caregiver, to provide them with the best practices on caring for somebody," said Charles Fuschillo Jr., the AFA's CEO.

For example, the AFA recommends that family members:

- Feed Alzheimer's patients one food at a time. "A busy plate can be confusing," the group says.

- Mark rooms in the house with signs to avoid unnecessary confusion.

- Remind a person with Alzheimer's to use the toilet; don't wait for them to ask.

- When traveling, stick with familiar destinations.

- Watch for a cough while eating; it can signal a swallowing disorder in people with dementia.

- Schedule overnight stays at a memory-care facility so the caregiver gets some respite.

- Just as important, Fuschillo said, "We want to do everything we can to avoid caregiver burnout."

The breaking point sneaks up on even the most committed caregiver, say Alzheimer's advocates, especially as the nights grow more sleepless. Alzheimer's patients can tend to pace, or wake up their partner every few minutes. They can become violent. Or, perhaps worse, they can leave the house.

"And I've had some issues at night that I had to take care of alone," Pam Hawkins, who cares for her husband with Alzheimer's, said during a support session. "But I'm not ready to have anyone there at night."

For now, she said, her husband usually sleeps all night. And if there's a problem, her son-in-law is 15 minutes away.

She's had to hire caregivers during the day. Knowing

how to find and hire the right person is a shared concern by Alzheimer's family members that inspired a checklist for navigating the process. Tips include these: Interview the aide in the home. Over-share information about the patient. Ask what kind of quality control a supervisor would provide.

Hawkins is adamant about keeping her husband at home, whatever the cost.

"He's not going anywhere," she said. "He's staying at our home until he moves to heaven. We made that decision a long time ago."

But many caregivers have no choice.

April Simpkins said tending to her husband became all-consuming, and she's young enough that she still needs to keep her job; she works at a local university.

"It was not possible for us to keep Joe at home," she said.

Simpkins found she'd often have to call her husband's siblings to settle him down over the phone. One night,



VICKI BARTHOLOMEW/Courtesy photo

Vicki Bartholomew founded a caregiver support group to gain advice and get help with depression after her husband entered a memory-care facility in 2015.

she had to dial 911 when he kept yelling in the hallways of their condo building.

And yet she felt some societal pressure that she wasn't doing enough.

"There's a lot of ... glory given to the whole idea of someone being long-suffering and staying at home and giving up their life, basically, to care for their loved one," Simpkins said. "It makes it harder for people who can't do that."

Everyone around the table nodded in agreement. Whatever stage of illness their loved one is experiencing, these caregivers understand the complicated existence that many have dubbed "the long goodbye."

Along with sharing the sorrow, they find a way to share in the humor of it all; one woman said her husband wears a laundry basket's worth of shirts and pants because he forgets he's already gotten dressed.

Even tips on how to reduce the odor from incontinence are offered with a loving laugh.

The support group ends with hugs. Some women head for the parking lot. Others buzz through the locked doors to see their husbands.

Simpkins sits down for lunch at the memory-care facility in Nashville, Tennessee, with her husband, who is a former state employee and a youthful-looking 66 years old. She drapes an arm around his slumping shoulders and assists him as he spears a cold strawberry with his fork.

"You know, there are some days," she said, interrupted by a random reflection from Joe. "Yeah, some days are clearer than others."

Simpkins tries to stop by to see her husband every day. But it's a wicked kind of blessing, she said, that when she misses a visit, her husband no longer notices.

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Nancy Ellen Moore with her mother Theresa Downey (circa 1961)



Nancy Ellen Moore, Executive Director of The Herrick House, with her mother and resident Theresa Downey (2018)

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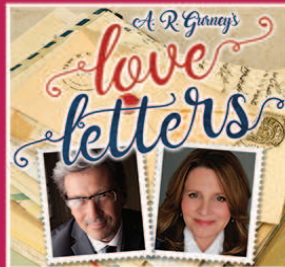
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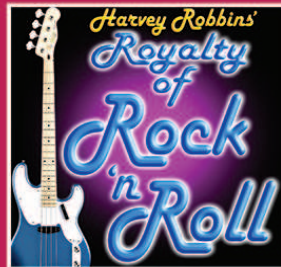
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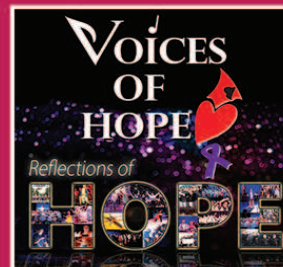
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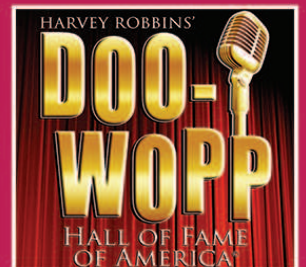
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