Love and Loss
When You Can’t Be There

TELEHEALTH
for Alzheimer’s

Do You Need
Long-Term Care Insurance?

ASKING FAMILY
for Help

GENE WILDER
THE ACTOR'S WIDOW SHARES THEIR STORY OF LOVE AND LOSS
The Courage to Take Action campaign was created to highlight the courage it takes to live with Alzheimer’s and to be an advocate in the fight against the disease.

To create a virtual or in-person fundraiser with physical distancing guidelines in mind, go to: ALZINFO.ORG/FUNDRAISING
ON THE COVER

Gene Wilder

The late actor is remembered by his widow and an upcoming documentary. Page 16

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Preserving Your Memory

is a product of
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Cover photo: Daniel Smith / Getty Images

Snap a photo of this QR code* to get more information about Alzheimer’s disease!

*Download a free code reader app for your smartphone at your phone’s marketplace

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Reflecting on Matters of the Heart

No doubt this year will go down as one of the most volatile in recent history. The COVID-19 pandemic forced us to slow down because our existence depended upon it. We acknowledged the essential workers putting their lives on the line for us. We witnessed the best of humanity as volunteers emerged to help deliver food and aid to senior citizens, and folks found creative ways to get things done while navigating their new normal.

Meanwhile, life and loss continued, but saying goodbye to loved ones was more devastating when it couldn’t be done in person. This issue of Preserving Your Memory offers insights from Lisa Henry on what to do when you cannot be there (page 8), Valarie Benning Thompson on the importance of long-term planning (page 24) and advice about asking family members for help from Gary Joseph LeBlanc (page 26).

On the heels of the pandemic, we saw a brutal history of racism repeat itself. Communities acted and recorded what was not being covered on the news, while others took to the streets to protest inequality and injustice.

Against this backdrop of chaos, however, we’ve found reasons to celebrate, such as the retirement of Fisher Center lab assistant Elaine Markland after 41 years of service (page 13). With a sharp mind and a beautiful smile, Elaine does not look old enough to be retiring from anywhere! We recognize, too, the lab’s latest scientific breakthroughs (page 14) and spotlight Senior Research Associate Jean-Pierre “JP” Roussarie (page 27).

We also honor actor Gene Wilder. I remember the first time I saw Willy Wonka & the Chocolate Factory and the effect it had on me as a child. As the strange and magical owner of a candy factory, Gene was a comedic genius; many of his characters shared a tender vulnerability. In August 2016, Gene died from complications of Alzheimer’s disease at age 83. His wife and caregiver, Karen, graciously shared some of her memories of Gene with us, including unexpected challenges and lessons learned (page 16).

We hope the rest of 2020 is a little gentler to you. As always, thank you for your continued support of our mission. Your generosity is making a difference in our research and the quality of our online Information Program. I encourage you to spread the word about our Courage to Take Action campaign (page 2).

Be kind to yourself and others and stay safe.

Warmest regards,

Lucretia Holden, SHRM-CP
Executive Director
Exposure to bright light may improve sleep and ease depression and agitation in people with Alzheimer’s disease, according to a new report.

Bright light therapy has been used for decades to treat “winter blues” and other mood disorders. A new study suggests that light therapy, or even spending more time outdoors in sunlight, may have benefits for people with Alzheimer’s disease as well.

Researchers studied 46 women and men with Alzheimer’s disease who were living in Alzheimer’s care facilities in New York and Vermont. For four weeks, the subjects were exposed to bright light that simulated sunshine via specially designed floor lamps or light boxes. The bright lights were placed in bedrooms, dining rooms and other common areas, so they were exposed to bright light for much of the day.

The researchers found that exposure to the bright daytime light significantly improved sleep quality. During the light period, subjects also showed fewer symptoms of depression and agitation. The findings were published in the Journal of Clinical Sleep Medicine.

No one is sure how light therapy works. But light is known to help reset the body’s biological clock. Light also stimulates melatonin and other hormones involved in mood and sleep regulation.

Light therapy is far safer than antipsychotic drugs, which are often prescribed to people with Alzheimer’s to ease agitation and aggression, but which can have dangerous, and even fatal, side effects.

Other research has found that massage, touch therapy, exercise, music therapy and other nondrug treatments can be an effective way to reduce aggression and agitation in people with Alzheimer’s disease. In many cases, they should be given priority in treating disruptive behaviors in people with dementia, before drugs are tried.

The study authors recommend that people with Alzheimer’s disease have regular exposure to natural light in their homes during the day and go outside whenever possible, including for walks.
A Daily Toast to Brain Health

Moderate drinking may be good for the brain. Korean researchers report that older women and men who drank moderately for much of their lives had fewer brain deposits of beta-amyloid, the toxic protein that clumps together to form the telltale brain plaques of Alzheimer’s disease. The findings appeared in PLOS Medicine.

Moderate alcohol consumption is typically defined as no more than one drink a day for women and one to two drinks daily for men, and no more than 14 drinks per week. A drink is defined as 5 ounces of wine, a 12-ounce beer or 1.5 ounces of 40-proof vodka or spirits with a similar alcohol content.

The traditional Mediterranean diet, which includes moderate amounts of red wine along with heart-healthy foods like fish, fruits, vegetables and whole grains, has also been linked to better brain health.

Stay Social!

In this time of social distancing, a growing number of people find themselves wary of social interaction. But social isolation has been linked to a 50% increased risk for Alzheimer’s disease.

A recent study of 260 older women and men, published in JAMA Network Open, found that those who lost a spouse were at increased risk for cognitive decline. Declines in memory and thinking skills were particularly prominent in those who had higher brain levels of the toxic protein known as beta-amyloid, which increases the risk of developing Alzheimer’s.

Experts say we all can take measures to counter the negative consequences of social isolation:

- Reach out to friends and neighbors and ask how they’re doing. Helping others, even if it’s a small gesture, can be incredibly powerful and rewarding and a good reminder of purpose.
- Pick up the phone and give someone a call. Hearing a person’s voice offers a level of closeness that you can’t get with texts or emails.
- Many tools, like Zoom and FaceTime, are now available for videoconferencing with friends and family. A short five-minute check-in, free of other distractions, can be rewarding for everyone involved.

People who never learned to read or write have nearly three times greater risk of developing dementia than people who can read and write, according to a study of 983 older women and men living in northern Manhattan. The findings add to a growing body of evidence that reading, writing and other intellectual stimulation may help to bolster the brain and perhaps even help to protect it against Alzheimer’s disease and other forms of dementia in old age.

“Being able to read and write allows people to engage in more activities that use the brain, like reading newspapers,” says study author Jennifer J. Manly of Columbia University. Earlier studies have linked activities like reading books, doing crossword puzzles, speaking a second language or playing a musical instrument to a lower risk for dementia.

Cognitively stimulating activities, like reading and writing, may help the brain to build up a more robust network of connections. These connections may help to compensate for those lost in illnesses like Alzheimer’s disease. The findings were published in Neurology.

Reading Is Good for the Brain

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S
o many of the ways we express affection involve touch, or at the very least, face-to-face contact. Physical distancing has slowed the spread of COVID-19. However, it’s also taken a toll on relationships and mental well-being.

Right now, we can’t always be near loved ones, even at the end of their lives. And mourning our losses looks completely different from anything we’ve experienced.

CARING FROM AFAR
A crisis like a pandemic brings a wide range of emotions, especially if you have loved ones at risk for severe illness. You may feel fear and worry, loneliness, guilt about not doing more and anger at others or at the virus itself.

Knowing that all these feelings are normal may provide some relief. In addition, there are active steps you can take to improve both the situation and your ability to cope.

CONNECTING AS YOU CAN
If you can’t visit someone in person, you can try video chat apps or the phone, if possible. However, keep in mind that, depending on your loved one’s condition, some types of visits can be challenging.

Before the pandemic, Lisa Henry paid weekly visits to her father, Lauchland, in the nursing home where he began living after a stroke and Alzheimer’s disease diagnosis.

But two weeks before New York City’s shelter-in-place order began, the home notified families that visitation would be restricted due to the COVID-19 outbreak. Telephone calls to her dad were already a difficult proposition—he didn’t have a phone in his room—but Lisa managed a few with the help of nursing staff.

They also had a couple of FaceTime sessions, the first of which Lisa describes as “terrifying for both of us.” Lauchland was disoriented and had lost weight. “It was heartbreaking,” Lisa recalls. Thankfully, they had one last video session prior to his passing in which he seemed more like himself.

If phone calls or video chats prove too difficult, consider sending letters, care packages or postcards. If you’re nearby, visit through a door or window.

Here are a few other ways to care for your loved one from afar:

• **Center on your purpose.** You don’t have to be with a person to impact their lives. Focus on what you can do, such as coordinating information or assisting with finances.

• **Educate yourself.** The website for the Centers for Disease Control and Prevention (cdc.gov) offers guidance for nursing home operators on infection control. Read up on protocols for staff, residents and visitors. Ask questions about how facilities are implementing them.
• **Recognize your grief.** Even if no one has died, you may still be feeling profound loss. You’re missing valuable time, and your own sense of security and control. Viewing it in this light can help you understand and process difficult emotions.

• **Nourish your body.** Paying attention to your own physical needs relieves stress and anxiety, and also ensures you can be there for others. Eat a nutritious diet; get plenty of sleep and exercise; and take time to unwind with books, music or other activities you enjoy.

• **Share your feelings.** Confide in your family and friends, even if you must do it by phone or web conference. If you don’t have anyone to turn to, try a mental health professional. Many are now offering telehealth sessions.

**GRIEVING YOUR LOSSES**

When a loved one passes away, mourning is never easy. The pandemic has made things even more complex and challenging than usual.

For one thing, there’s added emotions—guilt at surviving or not visiting, and anger at individuals or institutions. In addition, the rituals and rites we take comfort in have been disrupted. Religious services, funerals, wakes and other memorial gatherings are limited. We can’t offer each other literal hands of support or shoulders to cry on.

As Lisa says, “I realized there’s such an importance to these rituals we have of gathering together. I didn’t realize how important going through that process was until I couldn’t have it.”

Anticipating these emotions may make them easier to handle. Here are some other things you can do:

- Livestream memorial events, if those involved agree.
- Hold online group remembrances.
- Check in with loved ones by text, phone or video chat.
- Plan to hold an in-person service later on, when more restrictions have lifted.
- Look to faith leaders for guidance on ways to seek closure.

Lisa made a small altar to honor her dad and lights candles in his memory. But she’s anticipating an in-person memorial once gatherings are allowed again. “Dad’s request was a huge party with lots of jazz, food, wine and stories,” she says.

You can also honor a person’s memory by sharing their story online. The Fisher Center for Alzheimer’s Research Foundation’s Memory Wall offers an opportunity to upload a photo, bio and audio. You can revisit it anytime, and share it with others, to keep your loved one’s memory alive. Visit ALZinfo.org/memory-wall.
Virtual House Calls: TELEHEALTH FOR ALZHEIMER’S

By Linda Wasmer Andrews

Telehealth—receiving health care from a doctor or other provider over video chat or phone—is having a breakout moment. It's not a new idea. But as COVID-19 took hold, telehealth took off. Suddenly, more people were able to consult their providers while staying safely at home. And we're starting to see the benefits for those with Alzheimer’s.

EASIER ACCESS TO CARE
Telehealth visits take place on a smartphone, tablet or computer. Providers who treat Alzheimer’s may use these visits to:

• Detect mild cognitive impairment (MCI) before dementia starts

• Help diagnose and manage Alzheimer’s
• Monitor how a person with Alzheimer’s is doing
• Prescribe and make changes to medication
• Care for other health problems that may coexist with Alzheimer’s

More research is needed on the use of telehealth in these situations. But results so far are promising. For example, studies have shown that providers can diagnose MCI and Alzheimer’s about as accurately by telehealth as in person. For someone who lives far from the nearest medical center, connecting with a provider remotely could lead to an earlier diagnosis.

Distance isn’t the only barrier to in-person care. Alzheimer’s impairs the ability to carry out day-to-day
activities, such as getting to a provider’s office or medical clinic. Once in the exam room, a person with dementia may be thrown off by the unfamiliar environment. Talking with a provider from home is often easier and less stressful.

FEWER EMERGENCY TRIPS
When people with Alzheimer’s get sick with other illnesses, they may be more likely to end up in the emergency department than those without Alzheimer’s. Often, the illness doesn’t require emergency care. But getting in to see their own providers may be complicated.

Telehealth offers an alternative. One study looked at residents from 22 senior living communities who had dementia. Residents with access to a telehealth program went to the emergency department less often than those without that option. The telehealth program used in the study was more comprehensive than is typical. Still, the findings add to the growing evidence that virtual health care visits can have real-world benefits for people with dementia.

WHAT YOU’LL NEED
How do you get started? Let’s say you want to set up a live telehealth chat between your family member with Alzheimer’s and a provider. The first step is to call the provider’s office and ask whether they offer this option. Although telehealth is on the rise, not all providers use it yet.

For a video chat appointment, you will need a device with video capabilities and an internet connection. If you don’t already have the app that the provider uses on your device, you will need to download that, too. If you have ever talked with friends over FaceTime or met with coworkers on Zoom, you may already have what you need. Federal policy changes during COVID-19 allow providers to use these popular apps for telehealth. Other apps with video options that may be used include Facebook Messenger, Google Hangouts and Skype.

Check with your family member’s health insurance to find out whether telehealth visits are covered. During COVID-19, Medicare expanded its coverage of telehealth services, and some private insurance companies have done the same.

HOW YOU CAN HELP
Plan to be there for your family member’s telehealth appointment. Most people with Alzheimer’s will need a caregiver’s help to ensure that things go smoothly. However, ask your family member whether it’s OK for you to be present.

If you’re unfamiliar with video chat technology, try it out first. Give one of the popular apps mentioned above a test run with a friend. Or call the provider’s office and ask whether someone there can walk you through the process.

Find a place for the telehealth visit that offers privacy and limits distractions. Anticipate ways to reduce background noise. You might put your barking dog in another room, for example, or give your children quiet activities to do.

On the day of the appointment, set up the device you’ll be using. Close other apps that are open on the device to avoid slowing down the connection speed. To keep the camera steady, put the device on a table for hands-free use. If you’re using a smartphone or tablet, you can buy an inexpensive stand to hold it upright, or simply prop it up.

When it’s time for the appointment, make sure your family member is seated comfortably in front of the device. Then be supportive just as you would if you went along for an in-person appointment. If you have concerns or questions, you can still discuss them with the doctor face-to-face. The only difference is the screen in between.
TELEHEALTH: A Remote Care Solution During COVID-19

Telehealth means using video or phone calls for real-time conversations with a health care provider from your own home. You can see and talk with your provider using your computer, tablet or smartphone.

TELEHEALTH IS A GREAT OPTION FOR:

- Managing a chronic condition that's under control, like diabetes or heart problems
- Mild symptoms of an illness, such as a rash
- A minor injury
- Questions about medicines or ongoing treatment

TELEHEALTH ISN'T FOR SERIOUS PROBLEMS.

You may need an in-person visit if you have:
- Sudden changes in a chronic health condition
- Reactions to medicines
- Severe symptoms of illness

GO TO THE EMERGENCY ROOM IF YOU HAVE ANY OF THESE SYMPTOMS:

- Chest pain and pressure
- Trouble breathing
- Symptoms of stroke or heart attack
- Severe injury
- Sudden, severe pain

HOW TO PREPARE FOR YOUR VIDEO VISIT

- Write down the issues you want to discuss with your provider.
- Download and set up the video application your provider’s office uses. Follow all instructions they give you.
- Plan to do your video visit in a quiet, private, well-lit place.
- Have a pad and pen handy to take notes.
- Have your phone nearby in case the video doesn’t work and your provider needs to call you.

Call your health care provider’s office to ask about making a telehealth appointment.
For more than four decades, Elaine Markland played a vital role at The Rockefeller University. Elaine, who recently retired from her position as a skilled laboratory helper at the Fisher Center for Alzheimer’s Research Foundation lab, provided support to the late Nobel Laureate Dr. Paul Greengard, founding director of the lab, and his team of scientists, who continue today under the guidance of Dr. Marc Flajolet.

In her role, Elaine made sure the Fisher Center lab ran smoothly every day. She did everything from opening the mail and ordering supplies to ensuring Dr. Greengard’s team of scientists and technicians had the laboratory equipment and other supplies they needed to conduct experiments. But she did far more than keep the laboratory running—she also “helped get everyone laughing and kept them happy,” she says. It was important to her that everyone at the lab loved coming to work.

As the years went by, Elaine took on new responsibilities, always adapting to meet the needs of the scientists and technicians. She describes herself as a “problem-solver.”

“I don’t even think about what I do—it’s so automatic that I can go in there and do it every day,” she says.

She looks back fondly at her role and the professional relationships she formed throughout the decades.

“I loved working with Dr. Greengard,” she says. “The researchers were all very nice, so you looked forward to going to work. Not many people can say that.”

Elaine, who is originally from Jamaica, looks forward to coming back to visit the Fisher Center lab in the future and plans to enjoy her favorite hobby of traveling. She also likes to cook and will continue to devote herself to her extended family.

More than anything, Elaine will miss the people she worked with for so long.

“I’m still not wrapping my head around it,” she says. “I was like the den mother. We bonded together; we talked. I’m going to miss that.”

A FOND FAREWELL TO Elaine Markland

The skilled laboratory helper worked at The Rockefeller University for 41 years.

By Jennie McKee
One unanswered question in Alzheimer’s disease research is why only certain types of neurons and not others degenerate, developing tangles of tau protein, in the early stages of the disease. These neurons are found in a specific part of the brain called the entorhinal cortex layer II, an area that is crucial for memory formation.

A team of researchers at the Fisher Center for Alzheimer’s Research Foundation laboratory are trying to understand what it is about these specific neurons that make them more susceptible to damage. “Since it’s such a specific population that is affected, there has to be something that differentiates them from other neurons,” explains Dr. Jean-Pierre Roussarie, senior research associate at The Rockefeller University and first author on a paper examining this topic.

To answer this question, the team turned to a technology developed by the late Dr. Paul Greengard, founding director of the Fisher Center lab, that allows researchers to inventory all the proteins present within any type of neuron. They used it to inventory all the proteins in the entorhinal cortex layer II neurons in a mouse model of Alzheimer’s, as well as in a set of neurons resistant to degeneration, and then compared the two data sets to see if there are proteins that are expressed at a higher or lower level in vulnerable neurons compared to healthy ones.

The next step was to apply computational analysis to refine the information. “Once you have the inventory of proteins, it’s not very obvious to determine which are most important for the neurons’ vulnerability,” Dr. Roussarie says. Bioinformaticists in the Troyanskaya Lab at Princeton University made computational models using the data that the Fisher Center team collected as well as genetic data from humans to extract a set of proteins thought to be most responsible for the neurons’ vulnerability. This computational software is called NetWAS, or Network-Wide Association Study.

The NetWAS software yielded dozens of proteins that are thought to be significant in the degeneration process. Because the process of testing each of these proteins is time-consuming and expensive, the team focused solely on one promising candidate, PTB, developing a model that can be scaled up to allow researchers to test more proteins at a time. (While many of us are familiar with the protein beta-amyloid as one of the hallmarks of Alzheimer’s disease, it wasn’t one of the proteins identified in this process, says Dr. Roussarie, because the proteins they were looking for occur “downstream” of beta-amyloid accumulation.)

The team discovered that most of the proteins they identified play a role in the plasticity of axons, the part of the neuron that extends to touch other neurons. “They constantly need to remodel themselves and the connection they make with other neurons as we interact in the world and collect new sensory information that we then use to make memories,” says Roussarie. “Perhaps the downside to being so plastic is that they are very fragile as we age.”

PTB determines what particular “flavor” of tau protein is made in neurons. Tau can be made in slightly longer or slightly shorter forms, and PTB determines the length of the tau protein that is formed. The length of the tau protein is crucial in terms of how much it aggregates, forming the neurofibrillary tangles that are associated with neuronal degeneration.

Over the next few years, the team will continue to evaluate more of the proteins they’ve identified to determine what their specific functions are in the vulnerable neurons and how they contribute to Alzheimer’s. With this information, they hope to glean a greater understanding of the processes at work early in the disease and identify therapeutic targets for possible treatment.
To support the Fisher Center’s search for Alzheimer’s treatment options, visit ALZinfo.org/donate.
Gene Wilder: A Life of Laughs and Love Remembered

By Charlotte Robinson

As Willy Wonka, Gene Wilder warned Veruca Salt, “Time is a precious thing. Never waste it.” When Wilder died in 2016 due to complications of Alzheimer’s disease, it became all too apparent how precious life can be. But with years of classic films to his credit, Wilder’s time was far from wasted. Now his life is being honored with a new documentary, due in 2021, that focuses on his career and how Alzheimer’s affected him and his wife and caregiver, Karen Boyer Wilder.

“Come with me and you’ll be in a world of pure imagination,” Gene Wilder sang in one of his most famous film roles, the titular candymaker in Willy Wonka & the Chocolate Factory. While Wonka was arguably the most imaginative of all his creations, Wilder had many memorable turns on-screen, among them the nervous accountant Leo Bloom in The Producers, the scientist who brought a monster to life in Young Frankenstein (his personal favorite) and partner-in-mischief to Richard Pryor in the buddy movies Silver Streak and Stir Crazy.

Next year, fans will once again see Wilder on-screen, this time as the subject of a documentary to air on public television. Wilder: His Life, Legacy and Battle with Alzheimer’s Disease is produced by Julie Nimoy, daughter of the late actor Leonard Nimoy, and her husband, David Knight, with the blessing and participation of Wilder’s last wife, Karen Boyer Wilder. Like the producers’ previous film, Remembering Leonard Nimoy, which chronicled that actor’s life and battle with COPD, Wilder will be part biography and part awareness-raising for a disease that is too often a source of fear and stigma.

As Nimoy and Knight put it, “Our hope is not only to celebrate the legacy of a beloved entertainer’s life but also to create awareness for Alzheimer’s disease, along with providing the latest scientific information, removing some of the associated...
stigma and bringing hope to millions of patients, families and caregivers around the world regarding this serious and progressive disease.”

**MAKING OF A HOLLYWOOD LEGEND**

Born Jerome Silberman on June 11, 1933, in Milwaukee, Wisconsin, Gene Wilder began honing his comedic chops as a child when his mother was ill and her doctor advised the boy to “make her laugh.” At age 13, he followed his older sister into acting lessons with a local instructor. After an unhappy stint at a Hollywood private school, Wilder returned to Wisconsin and began performing in local theater productions while still in his teens.

After graduating from high school, Wilder earned a degree in communication and theater arts at the University of Iowa. His early adulthood consisted of acting classes with giants of the craft, such as Uta Hagen and Lee Strasberg, a stint in the army and working odd jobs, including limo driver and fencing instructor. After joining Strasberg’s Actors Studio, he adopted his stage name (inspired by playwright/novelist Thornton Wilder) and began to gain notice for appearances in several off-Broadway productions.

In 1963, while appearing in the play *Mother Courage and Her Children* with actress Anne Bancroft, Wilder was introduced to Bancroft’s future husband, Mel Brooks. Wilder’s film debut was a small but memorable role in the classic *Bonnie and Clyde* in 1967, but it was his cinematic partnership with Brooks, which began the same year with *The Producers*, that would make him a legend.

As a director, Brooks, who called Wilder “one of the truly great talents of our time,” tapped into Wilder’s gift for comedy and brought forward a memorable on-screen persona. As Wilder once said, “When I first met Mel Brooks, he told me that, in his eyes, I was like a sheep
surrounded by wolves.” In addition to *The Producers*, Brooks directed Wilder in *Blazing Saddles* and *Young Frankenstein*, both released in 1974, the latter cowritten by Brooks and Wilder. Wilder continued working as an actor and director through the decades, appearing in films until the 1990s and last appearing on television in a role on *Will & Grace* in 2003.

**LASTING LOVE**

It was Wilder’s career as an actor that introduced him to his wife of almost 25 years, Karen Boyer Wilder. He was working on the film *See No Evil, Hear No Evil*, in which he played a character who was deaf. Karen, a speech pathologist, helped train him in reading lips for the role. They married in September 1991.

“It really was like a fairy tale,” Karen recalls of their years together. “Gene was a very moral and honest person and a good example of someone whom people would like to have as a friend and a mentor. He was a real partner and that’s not easy to find. He helped me and took care of me from the moment we first met, and encouraged me to do many things to be able to grow and explore.”

But after Gene developed Alzheimer’s, it would be Karen who took care of him.

**UNEXPECTED CHALLENGES**

“The first signs of trouble were small,” Karen recalls. “Always the kindest, most tender man—if a fly landed on him, he waited for the fly to leave—suddenly I saw Gene lashing out at our grandson.” His perception of objects and their distance from him became faulty, and he struggled with his memory. “Once, at a party with friends, when the subject of *Young Frankenstein* came up, he couldn’t think of the name of the movie and had to act it out instead.”

Although Gene wouldn’t be diagnosed with Alzheimer’s until 2013, his symptoms began seven or eight years earlier. “When Gene first started showing symptoms, my life definitely changed. I felt a big responsibility. I wanted to take care of him,” says Karen. Educating herself about the disease, through the internet, books and videos, was a tremendous help. “In addition, I spoke to Gene’s physician, Dr. Michael Raffi, often, along with other experts to get a better understanding on how I could best take care of him,” she says.

Caring for someone with Alzheimer’s is one of the most difficult tasks there is, Karen says, and it was often overwhelming for her. “When I was assisting Gene while he was writing his book, he wanted me to change several phrases. I more or less knew what he wanted, but he would still tell me exactly what to write down. After a while, I’d read it back to him and he’d say, ‘That’s not what I said!’ It’s hard to argue with that when you don’t know what he really wants to say.”

**STAYING AT HOME**

Karen had in-home assistance while she cared for Gene and advises that anyone seeking such help explain their loved one’s personal habits and needs before care starts. “Ideally, I think it should be a combined effort between the family, physician and caregiver to ensure the best results for the patient,” she says.

She also emphasizes the importance of ensuring the home is safe, especially as the disease progresses. “If financially practical, I think that having the loved one home, where he or she is familiar with everything and more or less knows where everything is, is extremely important for making them feel more comfortable.”
“When Gene first started showing symptoms, my life definitely changed. I felt a big responsibility. I wanted to take care of him.”

Through Karen’s efforts and the in-home assistance, Gene was able to remain at home until the end of his life. “I think it was very beneficial for Gene to have me and our housekeepers around because we were the people who really loved him the most,” she says. Gene passed away on August 29, 2016, at age 83.

A DIFFERENT KIND OF LEGACY
Although Karen has been open about the struggles she and Gene experienced with Alzheimer’s, Gene chose not to disclose his diagnosis at the time. “The reason was simple,” she asserts. “He didn’t want his fans to feel sad or sorry for him. Gene said he would much prefer that they would remember him for some of his beloved characters, such as Willy Wonka.”

Still, Karen is confident that Nimoy and Knight’s upcoming documentary would have her late husband’s seal of approval. “Absolutely, I’m certain that Gene would be thrilled knowing that there’s going to be a documentary honoring his life and legacy.”

For her part, Karen was on board with *Wilder* immediately. “I already had watched their film on Leonard Nimoy and was very impressed with not only the high production values but the way they wove Leonard’s health story into his personal life story.”

Plus, there was a personal connection to the filmmakers. “In 1989, my dad was preparing to direct a new film called *Funny About Love* and thought Gene Wilder would be a perfect choice for the lead role,” Julie Nimoy recalls. “He met Gene at his Connecticut house to offer him the part, and this began a very long friendship for the next 25-plus years. Throughout the years, my dad and stepmom, Susan, frequently got together socially with Gene and Karen for dinners, plays, special events and short trips.”

Karen counts Leonard and Susan Nimoy among her and Gene’s closest friends. “Leonard and Susan would always attend special premieres and screenings with us,” she remembers. “One I recall was a play written by Trish Vradenburg called *The Apple Doesn’t Fall…*, which Leonard had directed. The story was a tribute to Trish’s mom, who battled Alzheimer’s disease.”

One of the goals of *Wilder* is to help dispel some of the stigma that continues to surround Alzheimer’s. Reflecting on why this stigma exists, Karen says, “My feeling is that diseases that affect the brain are still a topic that many people are afraid of discussing. In addition, since there are no effective treatments, I think this adds another layer of fear.”

Awareness, she says, is the key to changing that. “The most effective way to get people to start a dialogue is to create more awareness, provide more scientific information, explain strategies to improve the quality of life and, most importantly, give folks hope for the future of a possible cure.”
Pumping iron was once left to bodybuilders with bulging biceps. But now, health experts know that the benefits of strength training extend far beyond looking buff.

Stronger muscles can help you maintain balance, avoid injuries and retain your independence as you age. Everyone—from children to older adults—can benefit from strength training. And while the pandemic has made it harder to hit the gym, you can get a good strength session almost anywhere.

Just ask Wendy Suzuki, PhD, professor of neuroscience and psychology at the New York University Center for Neural Science. During stay-at-home orders, she exercised every day in her New York City home and neighborhood. While many people complained of “quarantine 15” weight gain, she actually lost 5 pounds.

Of course, she’s more motivated than most. After all, her research has shown that exercise is one of the most important things you can do not only for your body but also for your mind. “Simply moving your body has

“Every single time you work out, you are literally giving your brain a wonderful bubble bath of nourishing neurochemicals.”

By Cindy Kuzma
Strong MIND

immediate, long-lasting and protective benefits for your brain,” she says.

SPROUTING NEW BRAIN CELLS
Aerobic exercise that gets your heart pumping has long been known to boost brain health, as Dr. Suzuki’s research has shown. Increasingly, scientists have begun to study the effects of strength training, too. The results so far are encouraging.

When they reviewed the research last year, German experts found evidence that strength training changes the very shape of the brain. People who lifted weights regularly lost less white matter—the “superhighway” of the brain that allows neurons to communicate with each other—and saw improvements in their cognitive performance, the researchers noted.

Some of the same factors may explain why both cardio and weights build better brains. For one thing, exercise boosts blood flow to your brain, nourishing the tissues. Moving your muscles also prompts your body to produce more of a chemical called brain-derived neurotrophic factor, or BDNF.

“That is the growth factor stimulating the birth of brand-new brain cells in your brain,” says Dr. Suzuki. These new neurons mostly appear in the hippocampus, a region of the brain that is key to learning and memory. “The one structure that is affected first, and one could argue most severely, in Alzheimer’s disease is the hippocampus.”

You can’t reverse or completely prevent dementia through exercise alone, but you can offer your brain more resources with which to work. “That means I have something I can do today, in my living room, that will stave off the hippocampal-damaging effects of Alzheimer’s disease,” Dr. Suzuki says.

SHORT- AND LONG-TERM BENEFITS
While some of those changes take time, people in search of instant gratification are in luck. As Dr. Suzuki puts it, “Every single time you work out, you are literally giving your brain a wonderful bubble bath of nourishing neurochemicals.” As a result, your focus, concentration and mood improve.

There’s also some evidence that strength training reduces hormones linked to stress and depression. Plus, it makes you feel more powerful, successful and prepared to handle the challenges ahead.

These perks come on top of a lengthy list of physical rewards. Strength training can:

- Reduce your risk for cardiovascular disease
- Offset the loss of muscle mass that occurs with age
- Decrease your chances of falls and other injuries
- Lower your blood pressure
- Help you sleep better
- Ease arthritis and low back pain
- Keep you breathing easier

The better your overall health, the more you’re able to support others, including those for whom you provide care.

WAYS TO BUILD STRENGTH NOW

Mixing up the types of workouts you do is best for your brain health. More complex movements, like lifting weights, require strategy. This strengthens your prefrontal cortex. Slow, meditative sessions, like yoga and tai chi—a traditional form of Chinese mind/body exercise—improve muscle strength and focus. To reap all these rewards:

- Stream a class. Try an online service like Daily Burn, which has options of many types and levels. Dr. Suzuki even did a research study on participants last year. Though the results aren’t yet published, early analyses found benefits including improved mood, focus and attention, she says.

- Move together, from a distance. If you can’t be with your family members right now, attend a virtual class at the same time. “Even over the phone, you can log in to an age-appropriate yoga class and lead them through it,” Dr. Suzuki says. “They’ll get your company, and you’ll be doing something really valuable for their brain and your brain as well.”

- Hit the street. Gyms may be closed, but most sidewalks and parks are open. Even a walk around the block offers benefits to your body and mind. You can do strength, balance and flexibility exercise almost anywhere. It can look as simple as standing on one foot or doing push-ups against a wall, or as in-depth as taking a tai chi class in the park—socially distanced, of course.
or many of us, a meal just isn’t complete without a sweet, satisfying dessert. Famous chef Julia Child recognized this when she said, “A party without cake is just a meeting.”

Unfortunately, many desserts are full of unhealthy fats and sugars. But with a few adjustments, you can still give in to your sweet tooth from time to time.

SENSIBLE SUBSTITUTIONS
One way to indulge in a more healthful manner is by making a few food swaps. Craving a brownie? Try a square of dark chocolate with 70% cocoa instead. It has much less sugar than milk chocolate and baked goods. Even better, dark chocolate has been associated with a lower risk for heart disease, hypertension and diabetes. When you do opt for a baked treat, try substituting applesauce for oil or butter in your favorite recipe.

Craving a sweet frozen dessert? Skip the ice cream. Frozen yogurt usually has less fat and fewer calories, depending on the amount of sugar and add-ins. Sherbet contains milk solids or powdered milk, but no cream, and has only 1 to 2% fat. Because they are made without milk, cream or egg yolks, Italian ice and sorbet usually have the lowest calorie count of all frozen desserts. You could also try a homemade smoothie made with fresh or frozen fruit.

DON’T FORGET FRUIT
And speaking of fruit, it can make a delightful dessert. Pineapple goes great on a grill. Apples and pears are delicious when baked with cinnamon and nuts. Plus, pears, apples and berries are rich in flavonoids, which have been shown to have brain benefits.

Most recently, a study published in the *American Journal of Clinical Nutrition* found that older adults who consumed only small amounts of flavonoid-rich foods were two to four times more likely to develop Alzheimer’s disease and related dementias over 20 years compared with people whose intake was higher.

CUT BACK
Finally, the simplest way of all to enjoy dessert more healthfully is to simply reduce portion sizes. You can make this easier by baking mini-cupcakes, cutting brownies and sheet cakes into 2-inch squares, and portioning cookie dough using a 1-tablespoon scoop. With this tactic, you can still enjoy your favorite recipes—just a little less of them.
**Red, White and Blue Berry Tarts**

**INGREDIENTS**
- 2 whole graham crackers (4 squares)
- 4 paper muffin cups
- 4 oz. fat-free cream cheese, softened
- 2 tbsp. fat-free sour cream
- ½ tsp. vanilla
- 1 tbsp. powdered (confectioner’s) sugar
- 2 cups mixed berries: raspberries, strawberries, blueberries

**DIRECTIONS**
Finely crush graham crackers and divide crumbs among four muffin cups. A muffin tray will help you shape them correctly. In a small bowl, mix cream cheese, sour cream, vanilla and confectioner’s sugar with a whisk to make no-cook pastry cream. Put mixture on top of graham cracker crumbs. Top with berries. Save some berries to decorate the plate. Refrigerate for at least two hours before serving.

**NUTRITION INFORMATION**
Serves four. Per serving: 105 calories; 1 g fat; 6 mg cholesterol; 250 mg sodium; 18 g carbohydrate

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**Frozen Raspberry Yogurt Pops**

**INGREDIENTS**
- 1½ cups fresh raspberries (one 6-oz. container)
- 1 cup fat-free light vanilla yogurt

**DIRECTIONS**
Mash berries in a small bowl. Stir in yogurt. Divide into four pops and refrigerate. Paper cups work fine. Freeze at least two hours. Serve with a smile.

**NUTRITION INFORMATION**
Serving size is one pop. Per serving: 60 calories; 0 g fat; 0 g cholesterol; 40 mg sodium; 13 g carbohydrate; 3 g fiber; 8 g sugars; 3 g protein
Do You Need Long-Term Care Insurance?

By Linda Wasmer Andrews; Edited by Bernard A. Krooks, JD, CPA, LL.M, CELA

If you are smart about finances, you may not be worried about paying for care in case of an Alzheimer’s disease diagnosis. Between your savings, Medicare and a Medicare supplemental insurance policy, you’ll be fine, right? Maybe not. Medicare and Medicare supplemental plans don’t cover long-term assistance with daily living activities, such as eating, bathing, dressing and getting around—the kind of help that someone with Alzheimer’s is likely to need. Depending on where you live, a room at a memory care unit could cost more than $5,000 per month. At that rate, savings of $100,000 could be gone in less than a year.

Long-term care insurance is one way to plan for this. Unlike traditional health insurance, it covers a wide range of long-term services and support.

WHY CONSIDER COVERAGE?

Television/comedy producer Valarie Benning Thompson understands the importance of this coverage. Her father, Jason Benning, was a veteran, scholar and entrepreneur who founded the Afrocentric clothing boutique New Breed with his wife, Mable, in the late 1960s. After his Alzheimer’s diagnosis in the late 1990s, Mable was his primary caregiver, while Valarie and her sisters assisted on weekends. When Jason transitioned to a live-in facility in 2006, where he’d spend the three remaining years of his life, the family faced financial challenges.

Jason did not have long-term care insurance, and despite having an attorney’s help, they were unable to utilize his veterans benefits.

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Jason did not have long-term care insurance, and despite having an attorney’s help, they were unable to utilize his veterans benefits.
benefits. “A saving grace for us was that we sold my parents’ property, so they qualified for Medicaid,” Valarie says, “but had they still owned their home, they wouldn’t have.” Nonetheless, the family had to help with some expenses that were not covered. “It’s made me think about how I can get long-term care insurance,” she says.

5 Factors to Consider

Although long-term care insurance is a smart buy for some people, it’s not right for everyone. These are five things to keep in mind:

1. **Timing is everything.**
   If you ever develop Alzheimer’s or dementia, you may not be eligible to buy long-term care insurance once you already have the condition.

2. **Benefits don’t kick in immediately.**
   Long-term care policies include an elimination period—the period between the time when you qualify to receive benefits and the time when you start receiving payments. During this period, you’ll have to cover your own costs. Many policies let you choose an elimination period of 30, 60 or 90 days—another factor influencing your premium.

3. **There are limits on the coverage.**
   Most long-term care policies limit how much they pay and how long. In addition, there may be important exclusions in coverage. For example, a policy might pay for room and board at an assisted living facility, but not for supplies and linens. Reading the fine print now could avert some unpleasant surprises later.

4. **Your policy may expire before you do.**
   Only about 20% of people buying this type of insurance opt for pricey lifetime coverage. Most purchase policies with a limit of two to five years of long-term care.

5. **You might never use the benefits.**
   We all wish for a healthy future. But some people worry that money spent on long-term care insurance will be wasted if they stay healthy and independent. A newer type of hybrid policy tries to address this concern by combining long-term care insurance and life insurance. One way or another, the policy always pays out. It’s an appealing idea, but one that’s still evolving.

Sorting through all the different policy options and deciding which one, if any, is right for you can be a daunting task. But the effort is well spent if it buys you peace of mind.

Bernard A. Krooks is a managing partner of the law firm Littman Krooks LLP (littmankrooks.com). A certified elder law attorney, he is a past president of the National Academy of Elder Law Attorneys and past president of the Special Needs Alliance.

UNDERSTANDING THE COVERAGE

Long-term care insurance reimburses you up to a set amount for services that help with daily living activities. Most of these policies are comprehensive, so you can use them in a variety of settings, such as your own home, an adult day service center, a memory care facility or a nursing home.

In a home setting, these kinds of policies may cover:
- Skilled nursing care
- Occupational, physical, speech and rehabilitation therapy
- Personal care services, such as help with bathing and dressing
- Homemaker services, such as cooking and cleaning, in certain cases

The array of coverage options, benefit limits and prices available may seem overwhelming. But take the time to sift through your options and you can find a policy that’s right for your needs.

BALANCING COSTS AND BENEFITS

The cost of long-term care insurance depends on:
- Covered services and settings
- The maximum amount that the policy will pay per day
- The maximum number of days it will pay for
- Optional upgrades, such as benefit amounts that increase along with inflation

The average age of people buying this kind of policy is around 60. Yet it’s never too early to consider it. The younger you are when you buy a policy, the lower the premium will be.
Having been a caregiver for decades, I can tell you with the voice of experience that it is an ever-evolving adventure. For instance, in the beginning, the people you think you will be able to rely upon the most for help have a tendency to somehow disappear. Unfortunately, this can include family members. That’s when it really hurts!

If somehow you find yourself the only family member caring for your loved one, I want you to know that you are not alone. For many years, this has been the number one complaint I have heard from caregivers everywhere.

You may be wondering, “How in the world can my own siblings rarely or never offer to help care for our mother or father? After all, they are their parents, too.”

Well, I can easily answer that. Relatives have a way of dwelling in that frustrating denial stage, sometimes all the way until the end. They simply won’t let go of the belief that you are completely overexaggerating everything. Others may avoid ever spending the time to actually see for themselves the hardships you and your loved one are enduring. They may even get upset or angry at you for asking for help, leaving you scratching your head, wondering, “Weren’t we raised by the same parents? How could we be so different?” The truth of the matter is that siblings are different, even twins. That is most likely why you have become the family caregiver. You are the gifted one. Give yourself a little pat on the back here.

If multiple attempts to get them involved have failed, you may want to explore different tactics. First of all, don’t go into the conversation with your expectations too high. This way the letdown won’t be so full of disappointment and resentment, which is pressure you just don’t need at this point in the caregiving campaign.

However, when you do ask, don’t tiptoe around the issue. Be direct and stay focused. If they straight-out say no, ask them to come up with a plan of assistance that they would consider implementing.

Do not let any disappointment allow the conversation to get sidetracked. Stay on point. Remember what the conversation is about. If you start hearing “I can’t help you right now,” move directly into “When?”

Most of us were brought up to be stoic and taught to get things done on our own. However, this is a totally different situation here. You are caring for another person’s well-being. You have to do what’s best for both of you.

The biggest mistake a caregiver makes is not asking for help. Even early on in this journey, one needs to get in the habit of learning to ask. Waiting to do this until after the disease has advanced will only create another problem you don’t need.

Trust me. Toward the end, you will barely have time to eat. You need to work on this early. Remember: The most successful caregiver is a proactive one.

By Gary Joseph LeBlanc, CDCS
Director of Dementia Education, Dementia Spotlight Foundation

Asking Family Members for HELP

Caregiver’s Corner
HOMETOWN:
Jean-Pierre grew up in Maincourt, a suburban village of 100 people about 45 minutes from Paris. An empty church now serves as Maincourt’s city hall. However, he was born in the U.S. and spent his first few years here while his father was conducting research in particle physics at Stanford University. Many of the Fisher Center’s scientists are from abroad and, despite his French accent, Jean-Pierre is one of the few American citizens at the lab. The Fisher Center’s late leader, Dr. Paul Greengard, would often playfully ask, “Would you guess where this person is from?” and then surprise everyone by answering, “California!”

EDUCATION:
He has an engineering degree from the French École Polytechnique and a PhD in neurovirology from the Pasteur Institute in Paris, where he worked on a viral model of multiple sclerosis.

FUN FACT:
Jean-Pierre loves music and going to the opera. He sings in a choir every week and takes voice lessons every other week. He enjoys singing when he feels overwhelmed by work.

RESEARCH DISCOVERIES:
For years, Jean-Pierre and his Fisher Center colleagues have strived to understand what makes certain neurons more susceptible to degeneration than others in the early stages of Alzheimer’s disease. Dr. Paul Greengard previously developed technology to inventory all proteins present within any type of neuron. The team has since identified several proteins that appear to be key to neuron degeneration; these same proteins play a role in the plasticity of axons, the part of the neuron that extends to touch other neurons.

Focusing on one of these proteins, PTB, the researchers developed a model they’ll use to evaluate the function of different proteins on vulnerable neurons and how that might contribute to Alzheimer’s. The hope is that this information may lead to therapeutic targets.

Thank you, Dr. Jean-Pierre Roussarie, for your hard work every day in the quest to find a cure.

Thanks to the outstanding work of Fisher Center’s world-renowned scientists, we are getting closer to finding a cure!
Brain-Boosting Puzzles

“Use it or lose it.” The message is simple. If you don’t use your muscles, they will no longer be as effective as they should be. Of course, the brain is not a muscle; however, it has recently come to light that “mental workouts,” such as solving crosswords and other puzzles, can help ward off Alzheimer’s. In these pages, we offer a variety of different types of puzzles that will work out your various skills involving memory, deduction, and letter manipulation, and, we hope, also provide you with a ton of fun!

(ANSWERS ON PAGE 31)

MATCH THESE

Can you match each famous TV character to the actor who played the role?

1. _____ Elaine Benes  
2. _____ Murphy Brown  
3. _____ Perry Mason  
4. _____ Remington Steele  
5. _____ Barney Miller  
6. _____ Grace Adler  
7. _____ Gomer Pyle  
8. _____ Doctor Quinn  
9. _____ Lou Grant  
10. _____ Christine Cagney  
11. _____ Niles Crane  
12. _____ Barnaby Jones

DROPLINE

Take the letters in the top half of each column below and distribute them in the blanks of the bottom half so that the letters read from left to right spell out a short witticism. The black squares are the spaces between words. One letter has been dropped in place to start you off.

LEAPFROG

Here’s a list of parts of houses — two terms for every number. The letters of the two words are in the correct order, but they overlap. All you have to do to find the terms is separate the letters.

Example: BREOAOMM — BEAM, ROOM

1. GEAABLVEES  
2. WINDDOOWR  
3. CDHOIMRNMEEYR  
4. HLIALNTLWALY  
5. CLOVASNIETYT  
6. SHETARATIRSH  
7. VEGUTRATENDAR  
8. RAMAFNTE TRELS  
9. BACESILEMINENGT

VISIT US AT KAPPAPUZZLES.COM

28 | Preserving Your Memory | Summer 2020
We have provided two crosswords here to sharpen your puzzle skills. Start with the one on the left, which is the easier puzzle. In this one we have provided solving aids, such as the number of words in multi-word entries. The puzzle on the right is a medium level puzzle and those solving aids are not provided. Have fun testing your knowledge while doing something that’s good for you!

ACROSS
1. "Just as I thought!"
4. Zero
10. Hunter and Holm
12. On land
13. El (weather phenomenon)
14. Decorated anew
15. Difficulty
17. Baby goat
18. Sticky mess
20. Eight, to Eduardo
22. Auction offers
23. -advised
25. Stop dime (2 wds.)
26. Whenever
30. Grate harshly
32. Author Bagnold
33. Taunter
34. Game cubes
35. Give support
36. Prepare leather

DOWN
1. "Am not," slangily
2. Bald man's lack
3. Domini
4. He was married to Sophia
5. "Understood!" (2 wds.)
6. Advanced degree (abbr.)
7. Caught a fish
8. Pyle and Banks
9. Marsh plants
11. Searched for
16. Halloween holler
19. Tipped
20. Pound's 16
22. Journalist Nellie
23. Rica
24. Not active
26. Copies
27. Monogram part (abbr.)
28. Material for Christmas tree snow
29. Genesis site
31. "Take Me ___ Am" (2 wds.)
32. Author Anaïs
34. Rococo
35. Rent
36. Clockwork component
38. Like some fantasies
39. SMART
40. Alphabetic quartet
41. Letterman's onetime rival
42. Setting for an Agatha Christie mystery
43. Triumphant interjection
44. Reggae's kin
45. Not 'neath
All the words in this list, which are about thinking, can be found in the letter grid reading across, up and down, and diagonally. When you have found them all, read the leftover letters to discover an apt quote from Tom Stoppard.

CEREBRATE  MEDITATE  I N R D E L I B E R A T E
COGITATE  PLAN  F A O E F O R M U L A T E
CONCENTRATE  REASON  M R E S D N I T D E A A S
CONSIDER  RECOLLECT  E W E Z A I H O R R E E E
DELIBERATE  REFLECT  D T H C I E S H T E T T N
ENVISION  RUMINATE  I P A V O S R N V I A A V
EVALUATE  SPECULATE  T N L R G L E A O R L N I
FORMULATE  THEORIZE  A O I A N C L H B C U I S
HYPOTHESIZE

SUDOKU

To complete the puzzle below, fill in the squares so that each digit 1 through 9 will appear exactly once in each row, in each column, and in each enclosed nine-unit block.

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**VISIT US AT KAPPAPUZZLES.COM**
Match These
1h, 2e, 3a, 4l, 5i, 6k, 7b, 8j, 9g, 10d, 11c, 12f.

Droplines
There is always a better way to do it when someone else is doing it.

Leapfrog

Hidden Message
If an idea’s worth having once, it’s worth having twice.
TREASURE THE MEMORY

When someone you love becomes a memory, the memory becomes a treasure

Losing someone you love is devastating, however long or well-lived their life was. During this extremely difficult time, the Fisher Center offers you an opportunity to commemorate your loved one through our online Memory Wall. May your loved one’s legacy live on.

To have an online page honoring your loved one created, visit alzinfo.org/memory-wall