

TRANSCRIPT

GUIDE—A Comprehensive Dementia Care Model

On July 31, 2023, the Centers for Medicare & Medicaid Services (CMS) announced a new voluntary nationwide model—the Guiding an Improved Dementia Experience (or GUIDE) model—a pilot that aims to support people living with dementia and their unpaid caregivers. In today's podcast, I will share a bit about what to expect with the GUIDE model.

But first, some context. We too often hear about the many families and individuals who struggle to find the affordable, high-quality care they need. For elderly people or those living with dementia, long-term care costs have gone up 40 percent in the past decade. The result has been that many Americans—particularly women—stay out of the workforce to care for their families. Caregiving for people with Alzheimer's or other dementia disorders often includes assistance with bathing and dressing, as well as instrumental activities of daily living, such as paying bills, shopping, and using transportation. Caregivers also provide emotional support to people with dementia, help them manage health conditions, and communicate and coordinate care with other family members and health care providers to ensure safety at home and elsewhere. Then there are the costs of in-home respite care that would allow caregivers to leave the home to go to their own doctors' appointments, tend to errands, or engage in self-care. Or the cost of a supervised adult day center or respite care facility. According to the Alzheimer's Association, in 2022 more than 11 million caregivers provided almost 18 billion hours of unpaid care to people living with dementia, at an estimated value of \$340 billion.

The thing is, the majority of Americans don't know this. In my work with families, countless caregivers have told me that when their loved one declines to the point of needing additional support or care, they'll be able to pay for it through their loved one's insurance. Or they

believe that an assisted living or memory care facility will be covered by Medicare. Not so. Until now, Medicare only covers people for 80 percent of their doctor's visit costs. All other expenses related to dementia caregiving are out of pocket. As you can imagine, this makes paid services for dementia care unaffordable for the majority of families in our country, and the exorbitant costs lead many families to spend down all of their assets in order to qualify for medical assistance to pay for care.

In April 2023, the Biden administration announced the most comprehensive set of executive actions in U.S. history to support family caregivers. The GUIDE model will focus on dementia care management and will be tested to evaluate whether it is an effective way to improve quality of life for people living with dementia, reduce strain on their unpaid caregivers, and enable people living with dementia to remain in their homes and communities. It will achieve these goals through a comprehensive package of care coordination and care management, caregiver education and support, and respite services.

The purpose of GUIDE is, first, to improve quality of life for people living with dementia by addressing their behavioral health and functional needs, coordinating their care for dementia and co-occurring conditions, and improving transitions between community, hospital, and post-acute settings. The second goal is to reduce burden and strain on unpaid caregivers of people living with dementia by providing caregiver skills training, referrals to community-based social services and support, 24/7 access to a support line, and respite services. The final goal is to prevent or delay long-term nursing home care for as long as appropriate by supporting caregivers and enabling people living with dementia to remain safely in their homes for as long as possible.

How will it work? The GUIDE model will establish dementia care programs to provide ongoing care and support to people living with dementia through an interdisciplinary team. Central to this plan is the participant. The participant is an organization that delivers key support services to people with a dementia diagnosis. Under the model, participants will assign people with dementia and their caregivers to a care navigator. The care navigator is the one who will help families access services and support, including clinical services and non-clinical services such as meals and transportation through community-based organizations.

The GUIDE model will also enhance access to the resources that caregivers need. Unpaid caregivers will have opportunities to receive education and support, such as training programs on best practices for caring for a loved one living with dementia. GUIDE participants will also help caregivers access respite services, which will enable them to take breaks from their caregiving responsibilities, and some of the cost of respite care will be covered under GUIDE.

According to CMS, when used over time, respite services have been found to help unpaid caregivers continue to care for their loved one at home, preventing or delaying the need for facility care. Additionally, the model is designed to reduce Medicare and Medicaid expenditures primarily by helping people with dementia to remain at home, and reducing hospitalization, emergency department use, and the need for post-acute care as well as long-term nursing home care.

In order to be eligible to participate in the GUIDE model, provider applicants must be enrolled in Medicare Part B and be eligible to bill for Medicare Physician Fee Schedule services. They must also agree to meet the care delivery requirements of the model.

There are five ways that the GUIDE model aims to improve dementia care:

1. Defining a standardized approach to dementia care

delivery for model participants including staffing, services for beneficiaries and their unpaid caregivers, and quality standards.

2. Providing an alternative payment methodology to model participants. Participants are the organizations providing care, and CMS will provide monthly per-beneficiary payments to support the team-based collaborative care approach.

3. Addressing unpaid caregiver needs by requiring model participants to provide caregiver training and support services, including 24/7 access to a support line, as well as connections to community-based providers.

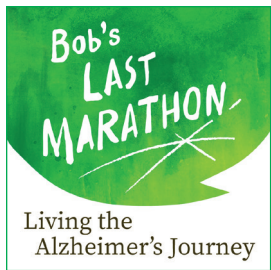
4. Making respite services available to families through the participant, which will partner with local agencies to provide services for in-home care or at adult day centers or facilities that can provide 24-hour care for the purpose of giving unpaid caregivers breaks from their caregiving responsibilities. GUIDE will reimburse families for up to \$2500 a year for respite.

5. Screening for health-related social needs. GUIDE participants will be required to screen beneficiaries for psychosocial needs and health-related social needs and help them navigate to local organizations to address these needs.

Finally, the GUIDE model has a commitment to delivering equitable care and addressing health disparities in dementia. We know that dementia imposes significant financial, emotional, and logistical burdens on families, burdens that are often exacerbated for certain racial and ethnic groups. Black and Hispanic populations have a higher prevalence of dementia, but studies have shown that they also are less likely to receive a timely diagnosis, have more unmet needs, are more likely to experience high caregiving demands, and spend a higher share of their family assets on dementia care. CMS will actively seek out the participation of eligible organizations that provide care to underserved communities for participation in the GUIDE model.

And now, a call to action. If you are an organization that has an established dementia care program or if you are interested in developing one, consider applying to the GUIDE pilot. If you are the family member of a loved one with dementia, talk to your care provider to find out if they know about the GUIDE program and encourage them to apply. If you are a social worker or other allied health professional supporting families living with dementia, consider reaching out to primary care providers or other health care practitioners in your area and appeal to them to apply. The GUIDE initiative has the potential to make a tremendous impact on dementia care, and participating is the right thing for health systems to do. CMS will release a request for applications sometime this fall. The model will launch in July 2024 and run for eight years. For more information, visit <https://www.cms.gov/priorities/innovation/innovation-models/guide>.

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TRANSCRIPT

Reflections: Alzheimer's Association International Conference 2022

AAIC 2022, the Alzheimer's Association International Conference, drew more than 9,000 scientists and featured more than 4,000 presentations in person in San Diego, CA, and online around the world. As Director of Caregiver Support Services for the Massachusetts General Hospital Frontotemporal Disorders Unit, I was attending as a professional in the field. This lens made me feel energized as I scanned the program and saw so many opportunities to connect with leaders around the world. And as I walked into the opening plenary with thousands of attendees, I felt a wave of gratitude wash over me. I am a former caregiver to my late husband, who lived with frontotemporal dementia, and a current caregiver to my father, who has been living with Alzheimer's disease for 13 years. The rush of grateful emotion was for those who do what I can't. They are the scientists who have dedicated their professional lives to uncovering the mysteries of dementia. Many speakers at that first plenary, and throughout the five days of conference activities, shared their own lived experiences as caregivers. They talked about loving and losing people in their own lives. They spoke through deep grief lifted with tenacity and determination. Their fierceness gave me hope that we won't stop until a cure is realized.

My role as a presenter at AAIC was to shine a light on one of the most complex aspects of care and support, advanced care planning. *Courage in Care Planning: Advanced Care Planning Readiness in the Context of COVID-19 for Caregivers of Individuals Living with Dementia* was both a scientific poster and an oral presentation. Through a grant funded by the National Institute on Aging, our team in the MGH FTD Unit is conducting a study about the utility of video decision aids for advanced care planning, and the work we presented at the AAIC highlighted a sub-study with caregivers of individuals living with dementia during some of the hardest days of the pandemic, when many communities were in lockdown and the vaccine was

not yet available. Forty-six caregivers completed online surveys, watched educational videos about COVID-19 and advanced care planning, and participated in study sessions one day, one week, and one month after viewing the videos.

Participants completed the Advanced Care Planning (ACP) Engagement Survey before and after the intervention—which included watching videos and participating in the study sessions. After the intervention, about one third of total (N=46) participants increased their scores about ACP knowledge, thoughts, plans, and readiness to be a substitute decision-maker or to make decisions for their loved one if they became very sick.

I was humbled by the bravery with which caregivers answered one question in particular: “How ready are you to discuss with your loved one's doctor whether or not there are certain health situations that would make your loved one's life not worth living?” Seventy-four percent of participants increased their engagement score immediately after the intervention, showing that educational materials about the topic could help them feel more prepared to face this situation. Overall, 57 percent reported that they engaged in ACP conversations after the intervention.

Why does this matter?

Today, we don't have a treatment to slow or stop the progression of Alzheimer's disease. Dementia cannot yet be undone. High-quality care is about dignity and personhood at every stage. It honors cultural values and wishes for goals of care at the end of life. By talking about these difficult topics ahead of time, caregivers are more likely to feel as though they have done what their loved ones would have wanted at a time when they will likely be unable to speak for themselves. Empowerment can happen through education. Our team is continuing to study how and when caregivers and families would benefit most from this education.

There was a heightened focus on the social determinants of health and their potential impact to increase or reduce the risk of dementia. In a pre-conference workshop, *Addressing Dementia Risk Through Social Determinants of Health*, Craig Thomas, CDC Director, Division of Population Health Centers, highlighted loneliness as a public health threat and social connectedness as the strategy to fight against it. He said that loneliness is a health risk that rivals smoking, obesity, and physical inactivity, and it is a serious public health issue. Human beings are social by nature, and high-quality social relationships are vital for health and well-being. As a professional in the field, and a caregiver myself, this got my attention.

We know that loneliness is something that many caregivers and people living with a diagnosis of dementia struggle with. Dementia presents challenges to communication, it changes the dynamics of relationships, and it makes the logistics of travel, being out in public, and navigating everyday experiences like grocery shopping or eating in a restaurant difficult. These challenges may promote loneliness for individuals living in the greater dementia community.

We also know that there are strategies to combat loneliness and protect your health and your future. Today we do not yet have a cure for dementia, but we do have care for those living life with a diagnosis and their caregivers. For me, the way to turn inspiration into action is through connection. I think that is why it is so critical that we continue to come together. Whether we are caregivers attending a support group or scientists in a lab, the power of connection is undeniable.

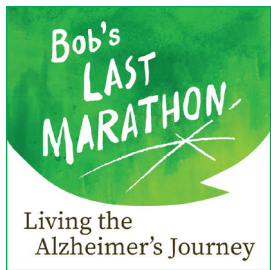
No one person on his or her own can care for an individual living with dementia. In the same way, the cure for Alzheimer's disease will not be discovered by one scientist or even one organization. This makes it even more critical that everyone in our community be connected. During a workshop on research engagement, we were reminded that you can't manage

what you don't measure. Our research community is called to a commitment for inclusion, to make sure that studies are accessible and culturally appropriate for all racial, ethnic, geographic, and socioeconomic groups. This will allow for a full understanding about our risk of developing dementia and meaningful strategies to provide treatment, care, and support.

Our scientific community knows that the world is waiting for a cure. AAIC showcases the dedication of the worldwide efforts to move us in the right direction for risk reduction, more accurate diagnosis, treatment, and a cure. If you are a person living with a diagnosis or a caregiver who is interested in learning more, go to www.ALZ.org/aaic to read about this year's conference. Consider attending the 2023 conference in person or online July 16–20, 2023. Complex solutions require the inclusion of all voices. Be a part of the chorus, the rallying cry, that we must move faster toward the care that families need today and the cure that we demand for tomorrow.

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TRANSCRIPT

Early-Onset Dementia and the Young Caregiver

Mike and I were both 29 when we sat in an exam room at Boston's Beth Israel Deaconess Medical Center. Dr. Galaburda, Chief of Cognitive Neurology at the time, listened patiently to my list of concerns and reviewed all of Mike's medical records from the year before. He asked Mike to list all the words he could think of that began with the letter "F." Mike could only think of one. It was one that I didn't want Mike to repeat in front of our almost one-year-old son. When neither Dr. Galaburda nor I joined Mike in his laughter, he abruptly ended the test, standing up and announcing his need for a toilet. Once we were alone, Dr. Galaburda turned to me and said, "It is very bad."

Dr. Galaburda was the eighth medical professional to see Mike and the first to diagnose him correctly with behavioral variant frontotemporal degeneration. Frontotemporal degeneration, also known as FTD, is an umbrella term that refers to a group of brain disorders that impact the frontal or temporal lobes of the brain. Each disorder is identified by the symptoms that appear first and most prominently. Primary progressive aphasia creates changes in the ability to speak and understand language. Corticobasal syndrome and progressive supranuclear palsy impact movement. And, as in Mike's case, behavioral variant FTD creates behavioral symptoms such as apathy, loss of empathy, impulsivity, and problems with executive functioning. These disorders are progressive in nature, causing dementia and often striking people in their 40s or 50s. FTD is known as the most common young-onset dementia, a dementia diagnosed under the age of 65. Through education about FTD, I understood that Mike's diagnosis at the age of 29 was incredibly early, making him unique, even within this rare disease community.

The appointment that day was just for Mike, but a dual diagnosis was given: one of "patient" for him and one of "caregiver" for me. It was a time in my life when I was leaning into new motherhood, planning my son Noah's first birthday party, and imagining what it would be like to see him take his first steps. I had never heard of FTD, and I didn't know that young people could be diagnosed

with dementia. Memories of visiting my grandfather at his nursing home flooded my mind as Dr. Galaburda's words washed over me. I felt unprepared to swim, drowning in this new and terrible information. Before I walked out of the clinic that day, Dr. Galaburda handed me a lifeline. It was a single piece of paper with a name and email address written at the top. Underneath, he had written "FTD Support Group."

Looking back, that referral to the support group was the most powerful prescription we ever received in our journey with dementia. In the space of the support group, my questions were normal, and I received practical information about resources for care and strategies to manage the challenging behavioral symptoms of dementia. It was especially critical because, as a young-onset caregiver, I lacked connection with peers who had traveled the journey before me. I could call any number of girlfriends to talk about potty training or the best local playgrounds. A skilled nursing facility with a five-star rating? No chance.

The support group gave me the new tribe that I desperately needed, alleviating my fears that I was the only one living life with this unusual and unexpected diagnosis. In addition to emotional support, I learned practical information that empowered me as an advocate and increased my self-confidence as a caregiver. I realized there was a larger community dedicated to understanding young-onset dementia and increasing access for care and support. I learned that in 2018, the National Institute on Aging funded the Longitudinal Early-Onset Alzheimer's Disease Study, or LEADS, to explore the development of young-onset Alzheimer's disease and how it compares to the more common late-onset Alzheimer's variant. And, in 2020, Congress included key provisions of the Younger-Onset Alzheimer's Disease Act to reauthorize the Older Americans Act, ensuring that individuals of any age with Alzheimer's disease and related dementias are now able to receive services and caregiver respite support through their local Area Agency on Aging. Our community wasn't invisible.

Despite this wonderful connection for support, to meet my family's high care needs, I made the decision to leave my professional job. With both Mike and me out of work, this meant a significant shift in our family's income. FTD and early-onset Alzheimer's disease are both recognized on the Social Security Administration's List of Compassionate Allowances, meaning that applications from individuals with those diagnoses will be fast-tracked for approval for Social Security disability. This gave me assurance of a small stream of income, allowing me to build a new household budget. I signed us up for Medicaid to provide health insurance and, later, long-term care insurance coverage for Mike's stay in a skilled nursing facility. We benefited from the federal Supplemental Nutrition Assistance Program, or SNAP, for food assistance, and I was even able to apply for a reduced fee at our local YMCA, where Noah learned to swim and enjoyed the child care room while I took a yoga class each week. Layering resources from multiple agencies required time and research, ultimately creating a social safety net that helped us stay afloat until I was ready to return to work.

The cost of dementia care is often one of the biggest stressors for families, and it can be exacerbated for individuals living with a young-onset diagnosis because their loved ones are more likely to be working full time, requiring more paid help. Expert guidance from a certified elder law attorney is best suited for identifying local and federal aid programs, as well as legal and financial planning after a diagnosis of dementia, regardless of the age of onset. As soon as possible, seek an attorney with experience helping families navigate the journey of young-onset dementia by contacting your state's chapter of the National Academy of Elder Law Attorneys. Ask for help connecting with an attorney who has worked with individuals with a dementia diagnosis under the age of 65. By working with an expert, you can make a plan that maximizes your assets, local resources, and goals of care.

April 19, 2022, was the tenth anniversary of Mike's passing. I know that our experience with young-onset dementia was made easier by the network of

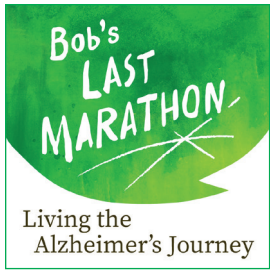
expert clinicians, seasoned professionals, and veteran caregivers. With layers of individual counseling, supportive friends, and family grief support through hospice, I built a path that led to a new present.

Earlier in 2022, I had heard of the Goosefields Windphone, a refurbished phone booth that had been set up as a "grief phone" on a beautiful farm in Portsmouth, Rhode Island. The Goosefields Instagram welcomed people to come and visit the booth if they had "words to send on the wind." Exactly what I needed. When I arrived at Goosefields, I parked at the top of the driveway, wanting to walk a bit in the field, lifting my face to the wind, feeling the spring sunshine splash across familiar tears. I stepped into the phone booth, hearing the whoosh of the folding door as it closed tightly behind me. As I lifted the bright red receiver of the antique phone, a burst of wind rattled the walls of the booth. I didn't feel afraid. I thought about all the things I would want to tell Mike. I could talk about the new home I purchased myself. Or gush about how, at the age of 14, Noah was already six feet tall. That I hoped he was proud of us. I imagined my words floating on the wind, a strong force able to bear the heavy burden of grief and the weight of love, jumping time, traveling to wherever they needed to land.

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TRANSCRIPT

Genetics and Alzheimer's Disease

A lot of us are concerned about our risk of developing Alzheimer's disease, particularly if we've watched parents or siblings die of the disease. If we've lost partners to Alzheimer's disease, we may wonder whether our children are destined for the same course. Researchers have found that we're more likely to worry about having dementia than to actually develop it, and this gap is even more pronounced in people who have had a family member with dementia. So if we've watched our relatives die from Alzheimer's disease, we tend to assume that we're destined for the same fate—even when we don't have any symptoms.

When we think about our familial risk of Alzheimer's disease, we're in part considering whether there's something wrong with our DNA. We're asking whether the seeds of Alzheimer's disease were sown in our bodies years ago at the moment we were conceived—and whether we have any power to change our fate as adults.

We often think of genetics as a black-and-white indicator; if you have a mutation then you'll get a disease, but if your DNA is normal, you'll emerge scot-free. When it comes to Alzheimer's disease, the story turns out to be far more complicated. For the vast majority of people with Alzheimer's disease, we can't point to a single genetic mutation as the cause of the symptoms. Instead, Alzheimer's disease is usually the result of complex genetic and environmental factors, some of which we still don't even understand.

Most people with Alzheimer's disease carry mutations in some of the 70-odd "risk genes." This is a group of genes that are associated with an increased risk of developing Alzheimer's disease, but each of them alone isn't enough to cause disease 100 percent of the time. Environmental factors such as education, diet, and head trauma also contribute to the risk of getting Alzheimer's disease, so genetics alone don't account for everything by any means.

The most famous risk gene for Alzheimer's disease is called "ApoE." This was the first risk gene that scientists identified, and it's still the most strongly correlated with the disease. Each of us has two copies of the ApoE gene, and each copy comes in one of a few different versions, called ApoE2, ApoE3, and ApoE4. ApoE3 is the most common version of the gene. People who carry two copies of the ApoE2 version turn out to have a much lower risk of Alzheimer's disease, whereas those who carry one or two copies of ApoE4 have a much higher risk of Alzheimer's disease. Researchers estimate that about 50 percent of people with Alzheimer's disease are ApoE4 carriers. For people who report lots of family members having Alzheimer's disease that starts in their 60s, 70s, or 80s, we often wonder whether ApoE4 might be playing a role.

Patients often ask whether they should do genetic testing to find out if they are ApoE4 carriers. Some people even come to our clinic after finding out from 23andMe or another similar genetic testing company that they carry one or two copies of ApoE4. There are a couple of things to consider when it comes to finding out your ApoE status. First, knowing if you carry ApoE4 won't tell you whether or not you will get Alzheimer's disease. We've seen many people in our research center who have two copies of ApoE4 but do not have symptoms of Alzheimer's disease, and likewise we know that half of people with Alzheimer's disease don't have any copies of ApoE4. In the end, knowing your ApoE status doesn't tell us much more about your genetic risk of Alzheimer's disease than what we can already glean from your family history. Second, it's important to keep in mind that we don't typically recommend any changes to family-building plans based on the result of ApoE4 testing. Even if you are an ApoE4 carrier, we don't recommend using reproductive technology to decrease the risk of passing it on. In short: Outside of research endeavors, it's not usually clinically useful to find out your ApoE status.

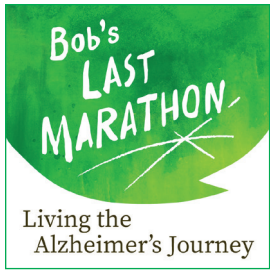
So, when should you do genetic testing for Alzheimer's disease? We tend to suggest this in patients who have symptoms before age 65 and also have a strong family history of Alzheimer's. These are the people at the highest risk of carrying a mutation in one of three genes that can single-handedly cause Alzheimer's disease. Less than 1 percent of people with Alzheimer's disease carry a mutation in one of these genes—so it's very uncommon, even in people where the disease starts before age 65—but identifying people with these mutations can help families make decisions about genetic testing and management.

If you're wondering if you're in this group, consider bringing it up with a neurologist and asking whether you should see a genetic counselor. Genetic counselors often work closely with neurologists to help decide which genes could be useful to evaluate and also to help patients and their families cope with the prospect of receiving genetic information.

While we don't have control over our genetic status, there are lifestyle changes that can significantly affect our risk of developing disease. A recent study found that 40 percent of the burden of Alzheimer's disease is attributable to modifiable risk factors like high blood pressure, diabetes, and obesity. Regardless of what's contained in your genes, one of the most effective things you can do to decrease your risk of Alzheimer's disease is exercise. The best outcomes come from doing at least 40 minutes of aerobic exercise, three to four days a week. Diet-wise, the Mediterranean diet has been associated with the lowest risk of Alzheimer's disease, but limiting alcohol and not smoking have also shown a huge benefit. Finally, social and intellectual engagement are critical for preserving cognitive function.

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TRANSCRIPT

Public Policies to Help Us Live Well with Dementia

My colleague, Steven Arnold, talked about how we've made and we will continue to make some path-breaking and even spectacular advances in developing better diagnostics and, especially, better therapeutics. Particularly the therapeutics that target the mechanisms of the diseases. And I can identify the patients who are most likely to respond to those therapeutics.

So, what does that mean? Well, we should expect that Alzheimer's disease is becoming a treatable disease—or, as pharma calls it, a “druggable” disease. But we shouldn't expect that every cause of disabling cognitive impairments will be treatable, certainly not curable. Not everyone is eligible for the drugs that have been developed, and the finding from research over the last 20 or 30 years has been heterogeneity. Namely, that the typical person with Alzheimer's has not just Alzheimer's pathology, but other pathologies.

So there's a real policymaking implication to that, which is that we're going to have to learn how to live with disabling cognitive impairments, or, in a word, how to learn to live with dementia, and disabling cognitive impairments. Treatments may slow, for some patients, the course of their disease—perhaps for some, completely arrest it—but we need to live with the fact that we will have to live with dementia.

So let's talk about that. How can we set up a society in America that allows us to live well with dementia? I think we can break this into two parts. First, how will persons living with dementia and their caregivers carry on with their lives—in particular, with benefits from the kinds of interventions and supports that Felicia Greenfield described?

Second, how will persons living with dementia die of it?

Let's first start with living with the disease. Felicia explained that we have the means to make these diseases livable. For both patients and for caregivers, we have what's known as long-term care services and supports. That's what she described. But those aren't

routinely available. In America, we have a federally funded social insurance program for health care. It's called Medicare.

In the Medicare statute, signed into law in 1965 by President Johnson, there is an explicit list of items of interventions that Medicare does not cover. They include hearing aids, plastic surgery, and “custodial care.” In 1965, that was the term used to describe the care that someone gave to another person who was disabled from an illness. Custodial care. Think about what that word suggests. It's as if the person is a building to be swept and mopped, etc., not a person who needs care. But that was the way we thought about it back then, was custodial care, and the statute explicitly prohibits it. So long-term care services and supports are not supported by Medicare. Medicare supports hospital-delivered services, and outpatient-delivered services. It supports the delivery of *medical* care.

For example, Dr. Arnold talked about some spectacular diagnostics and therapeutics that are coming out. Those may be covered by Medicare. There's been debate about that, but I expect that they will be. However, the kind of services that Felicia Greenfield talked about are *not* routinely provided. Indeed, at Penn Memory Center, access to people like Felicia and her colleagues is available, but it's made possible by a generous gift from a grateful patient's spouse. Without that donation, we couldn't provide the long-term care services and supports that are the standard of care after diagnosis.

Put another way, if we relied on Medicare billing to support our memory center, we would not be able to provide services and supports that are so essential. And again, I'm very encouraged about the prospects of treatments that will slow the progress of the disease, but that will only extend the period of time that people need long-term care services and supports. We're not going to drug our way out of the need to care, so we're going to have to face that as a society. Right now, access to social insurance for long-term care services and supports

is made possible on a state-by-state basis through *Medicaid*. Not Medicare, but *Medicaid*. Medicaid is a means-tested program, though, where you have to qualify for certain poverty thresholds in order to receive the supports. It also varies from state to state how much support is available. And frankly, because of legal matters that are excepted, essentially long-term care services and supports through Medicaid are rationed when the funds run out in a state in any given year.

I think a lot of what we're witnessing in supports for caregiving in America reflects that term that was in that Medicare statute: custodial care. At the same time that America committed to paying for medical care, it was unable to even conceptualize what it means to provide care for someone who is disabled. Indeed, the word "caregiver" wasn't even in use in the English-language lexicon at that time. It was not until the 1980s that we began to use the word "caregiver" to describe that person who essentially supports the mind of another person whose mind is being transformed by a disease.

The concept of caregiving is as old as the Bible and the Book of Ruth. Naomi is cared for by her daughter-in-law Ruth. And yet nowhere in the Book of Ruth does it call Ruth a caregiver. She's just a good daughter-in-law, doing what good daughters-in-law do when their mother-in-law has no one else to care for them.

I thought that the pandemic would make us realize how important humans are to care for other humans, because as we all know, when humans were put into lockdown and taken away from access to visitors in long-term care residential facilities, or visitors in hospitals, that we would realize that not all visitors are visitors. They're essential mind support for a damaged mind. Much like lecanemab is a support for the mind that was damaged by beta-amyloid plaques.

I thought that after the pandemic we would realize that we needed to support America's caregivers. But that hasn't happened. In the language that was drafted after the pandemic, in the Inflation Reduction Act, there was clear support to expand the wages paid to providers of long-term care services and supports. But that was rapidly lined out in the negotiations. It

was never part of the Inflation Reduction Act. And so we never made any progress in expanding long-term care services and supports. And this matters, because the hours spent caregiving are the argument for why this disease is such a problem. The triple-digit, billion-dollar cost of Alzheimer's in America, of dementia, is not the cost of providing medical care, it's taking the hours that a spouse, a daughter, and rarely, a son, spend caring—and putting a wage on it, and calculating wages spent by America's families caring for a disabled family member, disabled from dementia.

These wages are wages that are not available for other things a family needs, like paying for college tuition. These wages cause people to have to be out of the workforce, and therefore not paying into Social Security or advancing their jobs. So America is paying for long-term care services and supports, but it's the American family paying out of their strained pocket that's doing this.

What this will take is amending Medicare to expand its coverage for long-term care services and supports. This isn't a radical idea. In Japan, Germany, the Netherlands, long-term care services and supports are backed up by the government. Germany has had a system in place for over 25 years paid for by a payroll tax. It's solvent and it works. It keeps the German family from the fiscal threat that they would face when a family member is diagnosed with dementia. So we can do this, we just have to muster the political will.

We also have to recognize that for persons living with dementia, the theory of at-home-is-best has to be questioned. Increasingly, over the last decade or so, Medicaid has directed its funds towards what are known as home-based, community-based services and supports in the home. This means that they'll provide support for a family member to give care in the home. But sadly, as we know in this disease, there comes a time when "home" is no longer working. The person being at home is lonely, the person caring for them is overwhelmed, and a residential setting, with experts in how to care for people with damaged minds, is what's needed. But unfortunately, the trend in America is not to provide good-quality residential care. Indeed, the

nursing home has become a dreaded place, and also an industry used by venture capital in order to simply make money. Not to deliver care. So we really need to rethink what it means to have residential long-term care.

Finally, we need to think about in the beginning of the disease, the laws that we've set up to support someone to exercise their autonomy. Right now, you're either competent and capable, or you're not competent and not capable. That's the way that we've all envisioned things. For the vast majority of people living with these diseases, they have marginal capacity. They're able to make decisions, but they need someone else to support them. That's oftentimes the caregiver. But we don't recognize the role of the caregiver in the law to help people make decisions. There's a concept known as supportive decision making, developed in the world of disability rights, that allows an adult to be designated as the supporter for another adult, to help them make decisions. This isn't a guardianship. It doesn't strip the right from that individual, but it recognizes, for financial matters, for medical matters, that this other person should be there and be part of the decision making process. This could go a long way to support the lives of persons with mild cognitive impairment (MCI) or mild-stage dementia.

Finally, I'll close with a somewhat dark topic: It's all very well to know when to *start* the treatments that Dr. Arnold talked about, but when should we stop them? And after we stop those treatments, how should we care for someone? Hospice benefits are limited to people who have six or fewer months of life left to live. Prognostication of dementia is extremely difficult, to know how long someone has to live. Many a time, when I've referred one of my patients to hospice, the family will say to me, "Gosh, I wish we had access to this earlier. Why not?" and I unfortunately have to say to them that they're lucky to have gotten it when they've gotten it, given controversies of access. So we need to rethink what palliative care is for this disease—when the mind oftentimes is more damaged than the body. When palliative care is needed. I thank you for this opportunity to talk about some of the policy initiatives that are needed: expanding access to

long-term care services and supports, recognizing the role of supportive decision making, rethinking and revolutionizing residential long-term care. These are things that we can do. We know how to do them. We just have to muster the political will to do it.

Question: You talk about these very ambitious goals, and one of them is, how do we improve residential care? Where do we begin? How would you go about doing that?

Dr. Karlawish: Number one, we really need to rethink the financing that surrounds nursing homes. There are huge conflicts of interest in nursing home ownership, such that the owners of the nursing home also will own the businesses that supply the nursing home. In a sense, for many corporations, nursing homes have become just simply real estate ventures. That's what they're there for. So we really need to scrutinize the business models that surround nursing homes. More generally, also, the memory care units are often embedded in assisted living facilities. I have no fundamental problem with assisted living, except assisted living sort of operates on a state-by-state, ad hoc basis. There are some really good models out there for developing residential settings for individuals living with dementia. I think the Green House model is a good example of how architecture and staffing can be thoughtfully deployed to create a space that allows an individual's mind to be supported, but this just requires the recognition that the sort of hospital ward design that we have for residential long-term care just simply doesn't serve a mind that needs support. So those are all steps that we can do. Reforming the regulations, the financing structures, and embracing, frankly, the building of facilities that adhere to the kind of principles developed by programs like the Green House program.

Question: I'm not aware that a U.S. payroll tax to pay for LTS has ever been legislatively proposed. Is it realistic that it will be?

Dr. Karlawish: The last effort in the United States to create a system of long-term care services and supports was in the 1980s. The 1988 presidential election. Every single candidate lined up in support

of creating an essentially Medicare-style benefit for long-term care services and supports paid for out of the payroll tax. Because you have to have a tax that essentially covers everyone who is going to tap into a widely spread risk. Hence the payroll tax is a good model. Long-term care '88 never became statute, because there was one candidate who just wouldn't come down in favor of it, and that was George Herbert Walker Bush, who of course would go on to win the election.

Since then, the political climate has been one that has never advanced any significant legislation to address this. The CLASS Act was buried in the Affordable Care Act (Obamacare), when it was widely recognized from the moment it was written that it was actuarially unsound, and essentially died even after passage. So let me give you sort of a bleak statement. One half of the American political system, if you look at it by the parties, has come down plainly saying that raising taxes is anathema to what we're doing. So as long as you have a political party simply saying that any tax increase or attempt to increase revenue is a non-starter, you pretty much have a non-starter for addressing the problem through taxation, which is disappointing.

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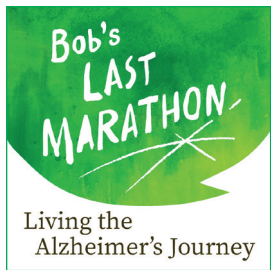
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TRANSCRIPT

Making Time Together

Finding ways to stay socially connected can be challenging at any age—but it may be especially difficult for people living with dementia. The person's cognitive impairment might make them feel uneasy in social situations. And negative stereotypes about people with dementia may cause friends to feel fearful or uncomfortable, and fade out of the picture.

Research shows that these hurdles are well worth surmounting. Meaningful social engagement has proven to be a key factor not only in maintaining brain health as we age, but also in slowing disease progression in people with dementia.

Keeping the person living with dementia socially engaged can be a burden for the loved one who often carries the brunt of caregiving responsibilities, and is already exhausted or overwhelmed by the emotional, physical, financial, and social strains of managing their loved one's care. And the dementia component of caregiving can be especially weighty. Compared with non-dementia caregivers, dementia caregivers have higher levels of depression and anxiety, take more medications, and are generally in worse physical health. Half of dementia caregivers report feeling caught in a vicious cycle: The stresses of care contribute to health problems that in turn compromise their ability to provide care. And one in four reports financial hardship due to the costs of care.

In short, caregivers need a break.

Fortunately, there are some excellent social support programs available for people with dementia. Home care and adult day centers, for example, can be great resources for social interaction. However, community programs are few and far between, and agencies for home care may be cost-prohibitive because insurance coverage is scarce, nonexistent, or exorbitant. Also, people in early stages of dementia may only need social interaction—not the high level, and cost, of more advanced care such as day programs.

To help address these common issues, a program called Time Together was developed at the Penn Memory Center, where I am Executive Director.

Time Together trains college students to provide companionship and socially engage with older adults living with dementia—at a fraction of what an agency would charge. We conduct interviews to help make careful matches between the students and older adults. The trained students visit their matches in their homes or online for up to 10 hours a week of conversation, games, other recreation, or going for a walk.

Our evaluation of the program found several benefits of the Time Together model. The stimulation of connecting with people outside their typical social circle was, in itself, of value. Connecting with younger people with similar interests put participants in a mentorship role, which helped give these interactions a gratifying sense of purpose. They looked forward to sessions as a meaningful way to fill gaps in the day, especially during the pandemic. Through interviews and focus groups we got the sense that the relationships built through the program would have a lasting positive impact on everyone involved—the people living with dementia, their caregivers, and the students.

Here are some of their stories. Please note that some of the names have been changed to protect their privacy.

Kristina's mother, Nancy, was diagnosed with primary progressive aphasia, which basically means she has difficulty with language or speech. Communicating through conversation is a frustrating challenge for her, and Kristina often felt stuck. When asked about her mom's experience in Time Together, Kristina was enthusiastic. She says Nancy looks forward to the weekly meeting with her student match, Isabel, who shares a similar ethnic background. Isabel, recognizing Nancy's difficulty speaking, reads to her and engages in storytelling activities. Their bond has been especially valuable during COVID, offering genuine connections through one-on-one interaction that would not have

otherwise existed. Over the past year and a half, Nancy's communication abilities have continued to decline—but her relationship with Isabel has blossomed. They have an easy relationship, free from the biases and worry that family members may carry. The weekly meetings also give Kristina a much appreciated break.

Paula's husband, Stewart, has dementia. Since COVID, he's been meeting with his student match, Jessica, over Zoom. When they first began, Paula would delight in Stewart's attention to his appearance—combing his hair and getting dressed up for the Zoom meetings signaled that he was engaged. It is now the highlight of his week. The two of them hit it off well from the start. Over time, he has become a mentor to Jessica, giving her advice on her studies. Paula loves that the program gives her a reprieve from caregiving, but there are other personal benefits, too. She also enjoys talking with Jessica, and it makes her feel especially good to see how much her husband enjoys himself. She notices that it boosts his confidence because he feels like he's making a difference in Jessica's life.

Wes is living with mild-stage Alzheimer's disease. He and his wife, Mary, have a home two hours from Philadelphia, so their student, Kate, has been meeting with them over Zoom. Mary says it's been a lifesaver. They have much in common with Kate. Both Mary and Wes had careers working with people living with a disability, and Kate is pursuing a master's in occupational therapy. Plus Kate and Wes graduated from the same university, and both are music lovers. Mary loves that the program opens opportunities for Wes to have meaningful interactions, and Wes says how much fun it is meeting with Kate. Another plus for Mary is that these social interactions happen in the comfort of their own home.

The benefits of Time Together also extend to the students. They note how much they appreciate the way learning firsthand about dementia and dementia care helps inform their career paths—sometimes it helps them improve their listening skills, and develop more patience.

Time Together is a working model for filling the gap when meaningful social engagement is hard to find. It can be replicated relatively easily by professionals or organizations that have access to colleges and universities. For the individual caregiver, Time Together might spark ideas for creating purposeful engagement for your loved one on your own. Just keep two things in mind.

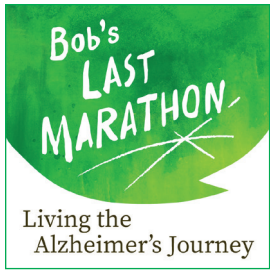
First, don't be afraid to ask people in your social network for help. Friends and family often really want to help—but they just don't know how. Which brings me to the second point. Prepare for these meetings with simple activities that you can suggest the companion and your loved one do together. Take your cues from the stories I just told. Choose activities that are meaningful to your loved one and can be carried out by someone besides you. It can be as simple as enjoying a walk together or going out to lunch. Or engaging in shared interests like listening to music, visiting a museum, and painting or coloring together. These can be fun and relaxing ways to spend an hour, and be a backdrop for easy conversation. Meaningful time together can bring joy to both the person with dementia *and* the companion, as the Time Together program has shown.

Time Together has been virtual through the Penn Memory Center since the pandemic began, but we are returning to an in-person model this fall. If you are in the Philadelphia area and are interested in participating, you can contact me at felicia.greenfield@pennteamcenter.org.

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TRANSCRIPT

Lifestyle and Diet in Alzheimer's Disease Prevention

When we talk about memory and thinking as we get older, many people comment on “senior moments” or trouble juggling two things at once. What may surprise some people is that in fact most, but not all, of our cognitive abilities peak around age 20. A number of large and compelling studies show that memory span, processing speed, and attention all decline throughout our adulthood. But to keep it in perspective, this decline is within a narrow range—and some things do improve. Language, knowledge of the world, and judgment are examples of what does get better as we age.

But what happens when people fall off these normal curves? When there is a clear and *noteworthy* change from a person's usual abilities, but they are still able to get things done, we call this mild cognitive impairment, or MCI. A person may take longer to get bills paid, do the shopping, or fix dinner, but they manage. But if memory and thinking abilities decline to a point where they need help with these kinds of day-to-day activities, that's when we use the term *dementia*.

If you or someone you know is seeing a decline, it is important to get checked out by your health care provider. Some of these declines in mental abilities are caused by health conditions that can be readily treated. An underactive thyroid gland or low vitamin B12 levels, for example, can affect brain functioning and show themselves as MCI or dementia. These can be reversed. An MRI or CT scan of the brain is also important to look for strokes, tumors, or fluid collections, many of which are also treatable. But while these are so important to look for, they are a minority of the causes of MCI and dementia. About 70 to 80 percent of cognitive decline in later life is due to Alzheimer's disease. About 20 to 40 percent may be due to vascular disease, mini-strokes, or small vessel disease, which used to be called hardening of the arteries. Five to 10 percent may be related to Parkinson's disease-related conditions, and another 5

percent or so to frontotemporal dementia. All in all, Alzheimer's disease, often mixed with vascular disease, is the major player.

The big question is, is there anything we can do to prevent disease or to slow disease progression? What can we do to lower our risks for getting the disease?

There are a number of risk factors for developing dementia in later life. Some of these we can't control—like age and our genetics. But there are other factors that we can change as individuals or as a society. As a society, one example is education; not just the years but the quality of education seems to be a risk factor for many subsequent health problems. The same goes for access to good health care. As individuals, there are many risk factors we do have control over. The cardiovascular risk factors associated with high blood pressure, diabetes, high cholesterol, obesity, low physical activity, and tobacco use all increase our risk for developing dementia and probably drive progression of dementia once we have it. Hearing loss in early, mid-, or late life increases our risk. Head injury, of course, damages the brain and makes it more vulnerable to the effects of any other diseases that come along, so care and protection against injury is important. We are also recognizing how depression, loneliness, and anxiety can increase our vulnerability to dementia, likely through stress mechanisms.

What is the evidence that modifying these risk factors can decrease the chances of our getting dementia? One important program that studied this is the FINGER study, conducted in about 1200 people in Finland who had either normal cognitive abilities or mild cognitive impairment and were at risk for dementia because of their age and some of the risk factors I just mentioned. People in the study were assigned to one of two groups—a regular health advice group or an intervention group where they had both personal and group sessions for diet planning and nutrition counseling, exercise

training with physical therapists, and cognitive training and counseling sessions with different games and exercises. After two years, the people in the intervention group showed a small but significant performance advantage in cognitive tests.

Another study, called PreDIVA, was conducted in the Netherlands in more than 3500 people, split into two groups, one that received usual care and the other a more intensive intervention program where they visited a trained nurse every four months for six years for lifestyle counseling and medical care to address risk factors such as smoking, diet, exercise, weight, blood pressure, blood sugar, and lipids. This modest intervention ultimately did not show any difference between the groups in terms of how frequently people developed dementia.

A third study, conducted in France and Monaco in almost 1700 people with memory complaints or mild cognitive impairment but not frank dementia, tested a combination of high-dose fish oil and group sessions involving physical activity and nutritional and lifestyle counseling, again with no statistically evident effect.

So, the jury is still out on whether making these types of modest changes in our health care and lifestyle in later life helps prevent or slow down dementia. But I'd like to emphasize a few points. These lifestyle modifications were implemented in older adults, many of whom already had some degree of cognitive decline. It is hard to overcome a lifetime of wear and tear from possible bad habits, and it is hard to change our habits overall. While we don't know for sure, we believe that if we optimize our lifestyle and diet choices early on, we can prevent decline as we enter the vulnerable years. The other point is that the changes people made were relatively modest. Perhaps a more intensive lifestyle and diet change would be more effective. There are some small research studies looking at this now.

I am often asked about dietary supplements and natural products. There are literally hundreds

of these on the shelves of health food stores and pharmacies and online that are touted for their benefits for memory health and focus. These range from traditional Chinese and Ayurvedic medicines to jellyfish proteins to sage extracts and other herbal tinctures. In fact, in laboratory mice and Petri dishes, many of these have been shown to decrease the amyloid or tau pathology of Alzheimer's disease, reduce inflammation in the brain, improve metabolism, improve blood flow to the brain, or promote synaptic health. So there is reason to think they may be helpful. But unfortunately, these success stories have so far only been demonstrated in mouse models or other laboratory experiments. Mice aren't people, and we still await the clinical research to determine their effects on people.

One example of interest is a class of compounds called anthocyanins—a group of antioxidants found in blueberries and other berries—believed to reduce inflammation, decrease oxidative stress, reduce the misfolding of tau proteins, regulate insulin signaling in the brain, and reduce neuroinflammation, all of which can slow cognitive decline and may play a role in Alzheimer's disease prevention and treatment. But clinical data is lacking.

Another potentially beneficial nutrient is quercetin, which belongs to a group of plant pigments called flavonoids. Quercetin is found in apple peels and many other fruits and vegetables. It has been shown to have powerful anti-inflammatory effects, improve mitochondrial metabolic functioning, protect against cell death, and decrease the amount of amyloid and tau pathologies. It makes a lot of sense, but we are still waiting for data in humans.

Polyphenols come in many different forms in a large variety of foods—honey, grape seeds, berries, and many vegetables and legumes—and have many beneficial properties, including prevention of neurodegenerative diseases, but the data is limited to cell culture and animal models.

S-allyl cysteine, an organosulfur compound present in garlic, decreases endoplasmic reticulum (ER) stress, which helps repair misfolded proteins. In mouse models, S-allyl cysteine has been shown to decrease tau pathology, protect against neuron death, decrease inflammation, and protect memory.

The last specific topic I'll note is the microbiome. The microbiome is of huge interest now. The bacteria in our gut can produce a host of beneficial biochemicals as well as harmful ones. Prebiotics are nondigestible components of food that are beneficial to our microbiomes. Probiotics are live microorganisms. Both are popular nutritional supplements that can regulate and enhance the healthy resident bacteria of our microbiomes. They can enhance synaptic repair and plasticity; decrease inflammation; increase neurotransmitters like serotonin, dopamine, and GABA; as well as have a host of other effects on brain function.

Within the last 40 years, there has been increasing evidence that diet and lifestyle changes may reverse the progression of coronary heart disease, early-stage prostate cancer, and other chronic conditions. Alzheimer's disease shares some of the underlying biological mechanisms of these diseases—for example, chronic inflammation and oxidative stress. A number of clinical studies are now being conducted to learn about how lifestyle changes—such as diet, stress management, exercise, and directed group support—can slow down, lessen, or reverse the symptoms of Alzheimer's disease. You can contribute to this effort by asking your doctor or social worker if there are trials in your area, and joining as a study participant.

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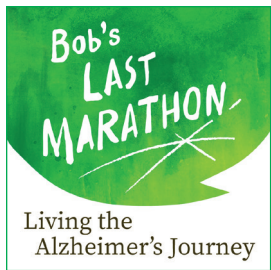
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TRANSCRIPT

The Male Caregiver

One day, while working as a clinical psychologist in a primary care practice, I was asked by the family doctor meeting that morning with a 72-year-old woman with moderate dementia to see her 75-year-old husband for counseling for possible depression. Within the hour, I watched the couple arrive at our front desk. The husband was a big man gently escorting his petite wife by the elbow. While she stood there blankly, he joked with the receptionists. As they were led down the hallway to a medical exam room, he shook hands with every medical assistant and doctor they passed. This guy, I thought, looks cheerful, not distressed. When I briefly stopped by the exam room a few minutes later, he said with a broad smile, “I’m fine, doc. My wife has looked after me for 50 years. I can take care of her now. That’s the wedding vow I made.”

I was impressed by this husband’s dedication but wondered if he was truly fine. Many spousal dementia caregivers struggle emotionally watching their life partners decline. I also knew that male caregivers, especially spouses, tend to be stoical, avoiding expressions of negative feelings, and often declining others’ help. Another male dementia caregiver once told me that male dementia caregivers strive to be “a pillar of strength” to better support their spouses. If they’re not strong and hard as marble, that man had explained, then they fear they and their spouses might crumble and collapse.

During my more than 30 years as a psychologist specializing in supporting family caregivers, I’ve learned that being rigid as a pillar, unfortunately, can sometimes cause male caregivers to crack under dementia caregiving’s prolonged pressures and eventually become unable to continue providing care. I’ve also learned, though, that male caregivers usually refuse any suggestion to take care of themselves, viewing that as giving in to personal weakness. I’ve had to seek other ways of helping them feel more of their emotions and, consequently, become more flexible in their approach to caring for their spouses.

There is a common misconception that almost every

family caregiver is female. But that has never been true and is less so now than ever. More men are stepping into this difficult role. According to the 2020 “Caregiving in the U.S.” report by the National Alliance for Caregiving and AARP, the number of American male caregivers increased from 16 million or 35 percent of all family caregivers in 2015 to more than 20 million or 39 percent in 2020.

Men often make great spousal dementia caregivers. They are frequently energetic, selfless, and single-mindedly determined to support their partners, refusing even the help of their adult children. My job has not been to criticize them for those qualities—they don’t generally put up with that, nor should they—but to help them self-reflect and consider other strategies to make their caregiving more sustainable.

I frequently start by talking about emotions. Not about their emotions per se. Men too often regard feelings as bothersome mental states like fatigue to ignore or push through. Instead, I say that many people have emotional reactions to seeing a loved one decline from dementia. I then engage them in a conversation about why human beings have emotions in the first place. After some discussion, we usually conclude that human beings are hard-wired with emotions like fear, sadness, anger, and guilt as important signals to them to pay better attention to the stressors in their environment and to prompt them to protect themselves and others. Seeing it from this perspective, some male caregivers begin to wonder if it is still a good idea to ignore those signals by shunting their feelings aside.

The next topic that frequently arises is men’s fears that feeling emotions will sap, not bolster, their resolve. This was the concern expressed by the man who wanted to be a pillar of strength and believed it would be impossible to feel sad and remain strong at the same time. Other men have told me that if they let themselves stop focusing on the many caregiving tasks that need to be done and, instead, attend to their emotions, it would be akin to “opening Pandora’s box.” So much feeling would pour forth that they would feel overwhelmed,

lose control, and become unable to carry on.

I tell them that, in my experience from speaking with hundreds of male dementia caregivers over the years, the guys who keep their feelings buried inside are not stronger or less apt to become overwhelmed; rather, they tend to struggle more and eventually burn out. The guys who allow themselves to experience whatever they are feeling and then are curious about the meaning of those internal signals seem to carry on with dementia caregiving better and longer.

Lastly, I ask male dementia caregivers about the pros and cons of being, like actor Gary Cooper of yore, the “strong, silent, unemotional type” in their relationships with the spouses they’ve vowed to help. They nearly always respond by pointing out that, by keeping their emotions locked away, they are protecting their spouses from having to feel upset or guilty that their husbands are experiencing distress. I respond that care receivers with dementia almost always have their own fears, anger, and deep grief in response to the devastating changes overtaking them. I ask: What happens when those care receivers turn toward their spouse to be a warm, comforting partner during those difficult times and the male caregiver is attempting to be a cool marble pillar instead? Important tasks, such as keeping medical appointments or managing medications, may get done more quickly and efficiently without concession to feelings, but the relationship suffers. Pushing past feelings to stay strong tends to make those life partners more emotionally distant from one another at a time when they are both facing enormous stress. In contrast, commiserating in mutual sadness brings spouses together in loving communion and support.

Other family members, too, find male stoicism to be a problem. I’ve heard many adult children complain that their fathers are being stubborn and controlling by playing the he-man and not allowing them to help their mothers with dementia. They don’t think it’s fair to them to be deprived of the opportunity to give back to parents who took care of them earlier in their lives. They also worry their fathers will burn out or develop their own health problems because of chronic

caregiving strain. “I’m losing my mother,” some have said. “I don’t want to lose my father as well.”

To these adult children, I offer three pieces of advice:

- Don’t fight for control of the caregiving. Male dementia caregivers often need to feel in charge to better control their feelings. Trying to wrest part of the caregiving role away from them would mean exposing them to guilt and whatever other emotions they’ve been avoiding. They will dig their heels in and fight to prevent that.
- Don’t offer help; ask for it, such as their watching grandchildren or fixing things. It sounds paradoxical, if not cruel, to say to oneself, “Gee, Dad seems exhausted. Let me add to his pile of chores by asking him to help me.” The advantage, though, is that the adult child will be appealing to, rather than challenging, the male dementia caregiver’s cherished role. Once that role has been acknowledged and supported by the adult child, the father may be less rigid about accepting help from the child in return.
- Try showing up. Adult children can bring over a covered dish because they “accidentally” made too much of a delicious meal. They can arrive with a mower to trim the parents’ lawn without having to be asked. Or they could just stop by unannounced to provide pleasant company. It’s the churlish father who would reject outright those sweet gestures.

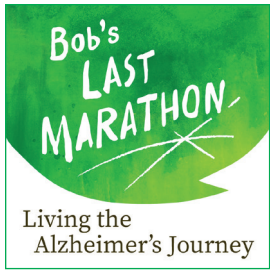
Without question, hardworking and long-devoted male dementia caregivers do enormous good. But to continue to be able to provide care, they need encouragement to bring all of themselves—including their emotions and some degree of flexibility—to caregiving. Otherwise, they will check off tasks on a to-do list but keep others at a distance. There is so much loss already with dementia, it would be tragic for them to compound those losses further through their efforts to protect themselves.

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TRANSCRIPT

Wandering

With the changes that come with Alzheimer's and other related dementias, a symptom known as wandering can occur. Wandering and getting lost is an emergency. Wandering can be on foot or by car, bus, train, or even airplane. If your person living with dementia is ambulatory, they are a wander risk.

Years ago, Bill, a man with mild dementia, went missing, and we searched in the area close to his home in San Jose, California, where he was last seen. He had been driving, but his wife assured us he never drove out of the area, just a few miles from home. So we scoured the area—the market, the library, the coffee shop, and local friends' houses. All his regular destinations.

We learned that Bill was a businessman who had taken many trips over his career and knew his way around an airport. His wife shared that he had been talking about going on a business trip and not wanting to miss his flight—even though she reminded him that he was retired.

He was found confused, but fortunately in good shape—across the country in Boston, a frequent destination when he was working.

Wandering and getting lost, which is called elopement, can be a life-threatening situation. This is because the person with dementia is stressed and rarely asks for help. They can't focus and reason their way out of a difficult situation as before. They can be impulsive and emotional. Fear can take over very quickly, which pushes people to keep moving, instead of staying put and thinking it through.

Susan was a member of a support group I led. One day, after a routine doctor's appointment, she and her husband parted to use the restrooms. When her husband came back, she was gone. It was raining and he was holding her coat, umbrella, and purse—which he did routinely because normally she would never leave without her purse. He was relying on her thinking and

behaving as before. As it turns out, Susan walked for hours and hours, until she was found long after dark and soaking wet by a good Samaritan—in another city.

The majority of those who wander and become lost are on foot. Some do not even realize they are in a vulnerable situation. Driving down a rural highway one sunny afternoon, I noticed an older man walking along the median—a dangerous place for a pedestrian. When I stopped and asked if he needed help, he said his name was Frank and he was on his way to his brother's house. I offered him a ride, but he didn't have an address, instead suggesting we just drive around until we found it. I wasn't doing that!

I said I'd take him home instead, but he couldn't tell me his own address, or even his last name. He didn't have an ID or a MedicAlert bracelet, which would have made it easy to get help. But now, I had to decide where to take him. I knew the police station and ER were hectic, stressful places where, because no one could watch him, he would likely leave and become lost again. Instead, I decided to try the local adult day program, praying that someone might know him there. As we walked through the door a staff member said, "Oh hi, Frank." My prayers were answered.

Certain events can trigger elopement. Has there been a change in routine? A new caregiver or a recent move or a new medication? Even moving the furniture around can cause confusion. Have they been ill? A cold or urinary tract infection can be enough to create disorientation. Even pleasant activities like a family gathering, visiting grandchildren, or a vacation can create enough confusion to cause wandering.

I worked with a woman whose husband had early Alzheimer's disease. They were extensive travelers, and Ellen wanted to get in one last big trip while they still could. She assured me she would never leave his side and that Steve was excited about the trip.

They flew to Italy and checked into the hotel; exhausted from the trip, Ellen instantly fell asleep, leaving a heavy suitcase against the door to deter her husband's wandering. When she woke up, he was gone. Ultimately, he was found at a local restaurant ordering coffee—in his pajamas. A nice person bought him some coffee, called the police, and chatted with him until his wife could arrive.

Of course, it's better to prevent a wandering incident than respond to it. Listen to your loved one—they may be giving you warning signs that they're getting set to wander off. Are they hinting at going to work, like Bill and his business trip? Or wanting to pick up young children, or go visit a relative? Do they just want to go *somewhere*, but can't articulate where? Or are they heading for the door stating, "We have to go"?

I worked with a former nurse who talked about going to work. At first the family would remind her she was 80 years old and long retired. This just upset her. I coached them to tell her, "Today is a holiday, so you can spend the day with me. Shall we go walk to get some frozen yogurt?"

When I worked at the adult day program, women frequently told us they needed to leave and pick up their young children. To help with their anxiety, we'd say their family had called to say they picked up the children and wanted them to spend the day with us. We would assure them that they were good mothers and not to worry. And yes, sometimes we would have to repeat this a few times until we could get them engaged in the activity.

Here's a big one: Daughter comes to visit and when leaving says goodbye, and Mom says, "Take me with you." Trying to rationally explain why she can't go results in anger, tears, and subsequent wandering behaviors.

In this situation I often coach families to simply leave and not say goodbye—I acknowledge that it may not feel right, but not saying goodbye in this situation is a kindness. Of course, do not do it abruptly. Other family

members or the care aide could and should distract Mom. Leaving this way eliminates the emotional and stressful goodbye.

Mary visited her mom twice a week, and now that Mom's dementia had advanced, the leaving was becoming more difficult. I asked her not to say goodbye. Once Mary was gone, Mom often forgot that she had even visited. If she did notice the daughter's absence, the care aide would say, "Oh, she got called in for work. She is a VIP after all." Mom knew her daughter had a high-powered career and was proud of her daughter's success. This answer satisfied her most of the time.

Sometimes your loved one just needs to move. In this case insisting that they sit down can be counterproductive. I coach anyone who will listen that our folks need physical activity, just like everyone does. Moving is healthy, uses energy, and often reduces agitation and the urge to wander. In fact, exercise is a great pre-emptive strategy. I have counseled families who can't hire someone to walk with their loved one. It has multiple benefits: a respite for the caregiver, a healthy activity, another person to engage with. A win-win.

Securing the home environment can also help. Consider motion sensor systems. Or inexpensive, easy-to-install alarms for doorways. You can go low-tech with a simple latch in an unexpected place—high up or near the base of the door. But do not use a dead bolt that requires a key on the inside; this is a fire hazard. You could also disguise the doors, especially at night, with a quilt or curtain.

As an added precaution, consider one of the many GPS-like devices that come in the form of phones, watches, and even shoes. If your loved one is still driving, put one in the car.

No matter what else you do, if your loved one is at risk for wandering, which could include any person with dementia, I strongly recommend a lightweight MedicAlert bracelet—the type that is almost impossible

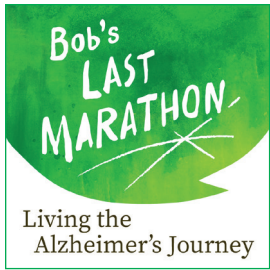
to remove. If your loved one does wander off and is found by strangers, these bracelets can identify them and help get them home. If your loved one is reluctant to wear the bracelet, contact MedicAlert or your local Alzheimer's program for tips. My favorite idea is for a beloved grandchild to give the bracelet as a gift and put it on them right then and there. Done.

If after all your planning, your loved one wanders off, how will you handle it? There are steps you can take now to prepare for the possibility. Call your local Alzheimer's group or go online to review the tips. But if your loved one does wander, and you can't find them after a quick, preliminary search, your first and most essential step is to get help from the local police, fire department, or search and rescue teams. They are literally lifesavers.

Alexandra Morris

Geriatric Care Manager

www.youtube.com/watch?v=rkn8hxaoqIw



TRANSCRIPT

Failure to Recognize

Many people caring for individuals with Alzheimer's or other forms of dementia notice that, as their disease progresses, their loved one lives more and more in the past. While past experiences remain intact, they are challenged in forming new memories. Over time even these memories begin to lose their clarity, and details disappear. This often results in the person failing to recognize their homes, friends, and family—and even themselves.

A woman I worked with whose husband had Alzheimer's relayed a story of a recent family gathering. She told me that during the party a woman spoke to her husband in a familiar manner, but he didn't know who she was and was too embarrassed to ask her. After the conversation he asked his wife who the woman was. It was his oldest daughter. He told her the woman did not look like his daughter. To him, in his moment of fatigue and confusion, his daughter was a 20-year-old college student, not the 40-year-old woman chatting with him.

This can even happen with the person closest to you, your spouse, as was the case with a woman I was coaching. Jeannie noticed that her husband was having trouble recognizing her in the early evening. Increased confusion and agitation in the late afternoon/early evening is quite common. There is even a term for it, sundowning. More on this later.

At first, Jeannie found it easy to reorient her husband: When he asked who she was, she gently replied, "Sweetheart, we have been married for over 50 years. I know we both look different." Then with a light tone she turned his attention to a photo from a cruise 20 years prior with their adult children. She calmly and happily shared how much fun that family vacation had been, and how they had a wonderful family. Then she would redirect with the statement, "Let's get ready for dinner."

This strategy worked for a month or so, until one night he replied in an agitated voice, "You are not my wife. You are too old." Shaking his fist, he shouted at her to

leave the house. Jeannie sat on the porch for 10 minutes, willing herself to calm down. She walked back into the house and said in a sunny voice, "Hi, honey, I'm home." Looking relieved, he said, "Oh, I am so glad you're home, I was worried."

Let's unpack this story. When her husband was confused but calm, Jeannie began by gently reorienting him, being careful not to quiz him or otherwise make him feel uncomfortable. She briefly mentioned the family vacation, a pleasant memory, then transitioned to their dinner and nightly routine. This is a good strategy, but as we have seen, it does not always work.

As I consistently coach families: Expect to be surprised. Good dementia care requires adaptability. When Jeannie's husband reacted so negatively to her efforts to reorient him, she switched gears. And when that didn't work, she took the best course of action: leaving the immediate environment. Not only would it have been ineffective to continue insisting they were married, but it might also have been dangerous for her.

Often caregivers feel that if they just repeat something enough times or in different ways, their loved one will eventually get it. But the result is often more confusion, anxiety, and sometimes even aggression.

By the way, I recommend that the primary caregiver keep an extra set of keys hidden outside, in case they get locked out. If you live in an area that can be dangerously hot or cold, hide the car keys, as well.

Let's talk for a few moments about sundowning. Sundowning is a symptom of Alzheimer's and other forms of dementia and often occurs in late afternoon and early evening. The causes of sundowning are not fully known, but fading light and fatigue are certainly contributing factors. Some ways of managing sundowning are to create a calm environment and engage in fewer tasks later in the day. Keep a daily routine; the same time starting and ending the day

is helpful. Reduce the light to promote rest, but be careful to ensure that the person can still see clearly and avoid shadows. One woman told me that when her husband started getting more confused in the evening, she would turn off the TV, turn on gentle music, and dance with him for a few minutes.

Failure to recognize familiar places, other people, and themselves often does not happen suddenly. If the person is aware that they are changing and/or family are closely observing, small slips can be detected. In my early-stage support group, a man relayed a story about planning a backyard garden. He was visualizing his backyard and where he would plant new flowers. But when he went into his yard, he was startled to find it wasn't as he expected: He realized he was imagining the yard he had 20 years ago. He suddenly understood, in those moments, that he was living in the past, not the present—in those moments the past 20 years were gone.

His story helped us all understand how a person living with dementia can forget more recent experiences, perhaps the past several years, and coupled with confusion, this may lead to not recognizing their current home at all.

I have a client with mild dementia who is experiencing more of these moments. I was helping Sam move into a senior community. One day I picked him up for errands and lunch. When we got back to his apartment he said, "Isn't it funny how this place looks like the other place?" I believe he was tired from our outing and didn't fully perceive he was indeed in his own apartment. As Sam was in a good mood, I responded, "Well, it is a nice place, and I am glad you live here."

But if he'd asked to go home, what would I have done? Here are some responses I'd consider:

Saying, "Okay, let's go," and taking him on a walk around the facility. As we approached his apartment I would announce, "Well, good, you're home now."

Or saying, "Let's stay for dinner. I heard they're having your favorite dish, lasagna," then changing the subject or doing something else.

In that case, we started folding and putting away his laundry. By the time I left, Sam was calm and comfortable in his apartment.

People living with dementia may not only fail to recognize their home or people in their lives, they may also stop recognizing themselves. As more recent events fade from their memories, they may believe they are 60 or 40 or 20 years old and tell stories about working or having young children, their young adult experiences or their parents, as if they were happening right now.

If they are calm, it's okay to go along. Make comments that show you're engaged with the story, such as "That sounds like a wonderful trip," or "I didn't know you learned Russian in the army, how interesting is that!" If the storytelling is enjoyable and going well, that is a gift. If the conversation heads to a dark place, quickly and gently nudge to a more pleasant topic: "Can you tell me more about your trips to Hawaii? Did you surf?"

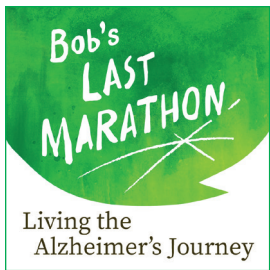
Sometimes the person will embrace two thoughts that don't logically coincide, such as believing they went to school with their daughter. Again, no need to correct or challenge their version of reality. Instead, the daughter might talk about her wonderful childhood, and being so grateful to her mom. Or she might talk about the ranch where Mom grew up. Always keep it as light and pleasant as possible.

All in all, the details and facts are far less important than the positive feeling your loved one has when they are with you. This is what they will recognize, and what will ground them.

Alexandra Morris

Geriatric Care Manager

www.youtube.com/watch?v=rkn8hxaqIw



TRANSCRIPT

Update on Diagnosis and Treatment of Alzheimer's Disease

We've made tremendous strides in our ability to diagnose Alzheimer's disease and other causes of cognitive decline, of dementia in older people. And in terms of treatment, we've had a major scientific advance this past year, with the news that amyloid-lowering immunotherapies can slow down the progression of Alzheimer's. I'll be coming back to the new amyloid treatments, lecanemab, or Leqembi, as it's called by its brand name. And aducanumab, or Aduhelm. But first, let me talk about where we are with diagnosis.

So, as we get older, we all experience changes in our memory and thinking. There are "senior moments" where you may have trouble remembering a name, or why you walked into a room. Or maybe it takes more effort to get organized and out the door in the morning. These experiences are almost universal as we age. But when it's more than a little trouble, when there's a significant difference in our memory and thinking from usual, and especially if it's interfering with our daily functioning, this is a signal that there may be a disease. There are lots of causes of cognitive impairment. Not everything is Alzheimer's disease. So it's important to get a proper diagnosis with an experienced health care provider. The first step is to determine if there truly is a problem. Aside from recognizing the symptoms of memory loss, there are a number of good screening tools, brief memory and thinking tests, that can help see if there is a problem or not. Sometimes, though, it takes more in-depth testing by a neuropsychologist to suss out if someone has a memory problem. In Boston, we sometimes get these physics professors coming in worried that they have Alzheimer's because they can only think 12 moves ahead in a chess game when they used to be able to think 18 moves ahead. And these folks may do fine on a cognitive screening test, but based on where they started from, they actually may have a serious problem emerging. And so a neuropsychology evaluation could help. Then it's important to have a

good general medical checkup with lab tests. Thyroid disease, certain vitamin deficiencies, side effects from some medicines people use for sleep or bladder control, can cause memory problems. Depression is another condition we want to be on the lookout for. Most everyone has ups and downs, but if depression takes hold, everything in the brain can shut down. Thinking and memory get foggy, and it can look like dementia. We also recommend an MRI or CAT scan of the brain to make sure there are no tumors or fluid collections or silent strokes. Some of these conditions that we discover from time to time also are quite treatable. If there is a noteworthy cognitive decline, and a good medical and neurologic exam doesn't turn up any alternative explanations, then statistically, Alzheimer's is the most common cause in people over 60. But there are other causes that can look very similar. Vascular cognitive impairment is due to the long-term effects of high blood pressure, affecting small blood vessels feeding the brain. They used to call this hardening of the arteries.

Lewy body disease is a cousin of Parkinson's disease that also causes symptoms that overlap with Alzheimer's disease. Frontotemporal dementia is another, and there's a very long list of other rare conditions that do so, too.

We used to say that the only way you could be 100 percent sure that a person has Alzheimer's was if you looked at brain tissue under a microscope after they'd died, and it showed the telltale amyloid plaques and tau tangles of Alzheimer's disease. Based on the clinical symptoms alone, even the most experienced Alzheimer's neurologist is correct with the diagnosis only 70 percent or maybe 80 percent of the time. And this may have been okay when we had no real treatment for Alzheimer's, but now it's not good enough, as we enter a new era with medications that specifically target Alzheimer's disease, amyloids, but also come with some

possibly serious, even fatal, side effects. And we need to be very confident in our diagnosis if we're going to give someone one of these medicines. And diagnosis is where the Alzheimer's field has made huge progress. If the disease is defined by the amyloid plaques and tau tangles, then we have to be able to detect and measure them to make a certain diagnosis.

We now have a range of biomarker tests that can tell us if there are plaques and tangles in the brain with very high certainty—almost 100 percent. So the most widely available are spinal tap tests that measure amyloid and tau in spinal fluid. But there are also PET scans that use radio-label tracers to show brain amyloid on X-ray—and these amyloid PET scans are expensive and not widely available or used, but if positive, they are diagnostic of the disease. There are also PET scans to measure the amount of tau tangles in the brain with Alzheimer's. And these are still only used in research, where they're especially helpful in measuring how far the disease has spread through the brain. The newest, most exciting, and potentially transformative advances coming right now are diagnosis with blood tests. These are mostly used in research so far, but new ultrasensitive laboratory tests can measure the very low levels of tau proteins that leak out into the blood from the brain or spinal fluid. And if the tau levels are high, the accuracy for diagnosis, based on the blood test, compared to spinal fluid or PET scans, is around 90 percent. This is good enough for screening, but if you're about to commit someone to a new course of immunotherapy, you'll need to be even more certain with a spinal fluid test or PET scan.

So let me move on to treatment. There are medicines like donepezil, or Aricept; rivastigmine, or Exelon; galantamine, or Razadyne; memantine, or Namenda; and we've had these for the last 20 to 30 years. These are safe, and most people have no, or very mild, side effects with them. But they provide only very modest benefits for some vague number of people—keeping people stable in their daily functioning for a little longer than if they were not taking them. But the big news over the last year is the accelerated approval by

the FDA for two anti-amyloid immunotherapies, and a third drug in this family that's likely to follow soon. Aducanumab and lecanemab are drugs that attack and clear out amyloid plaque proteins from the brain in Alzheimer's. The drugs are administered by an intravenous infusion once or twice a month, and what we've learned from the large clinical research trials with these drugs is that they're both very effective at clearing amyloid. Lecanemab reduces amyloid load in the brain an average of maybe 70 percent, and aducanumab even more, reducing amyloid maybe as much as 90 percent. And this reduction actually brings people's amyloid levels back down almost to normal, if not normal. And as a secondary effect, they also reduce tau levels. So that is what the biomarkers show with these new drugs.

What happens clinically to people? This is what we really care about. Over the course of the 18-month clinical trial for lecanemab, most everyone in the placebo and the active lecanemab groups still got worse in terms of memory and functioning. But the people receiving lecanemab declined more slowly—27 percent more slowly.

Statistically, this was a highly significant difference and benefit for the active drug. For aducanemab, there were two big trials. One of them showed no clinical benefit between the active drug and the placebo groups. And the other showed marginally slower decline in the active aducanemab group.

Now, I want to emphasize that these findings are a huge scientific advance. After 40 years and billions of dollars of research chasing amyloid, these studies do, for the first time, convincingly demonstrate that if you can clear amyloid in the brain in people with Alzheimer's, not just lab mice with Alzheimer's disease, but people, that clearing this can moderate the clinical course of the disease. But do you change it enough to make a meaningful difference in someone's day-to-day life? That's still a question that we have. And at what risk and cost? About 20 to 40 percent of people can have side effects, including brain swelling

and micro-hemorrhages. Most of these are benign and just noticed incidentally on MRI scans. But they can be serious, causing headache, stroke, seizures, or even death. And the financial cost of the drugs would be high, between \$25,000 and \$30,000 per year, plus the cost of infusion services, MRI scans, and other laboratory tests to monitor for side effects and more. So while they are successful, in that clearing amyloid or reducing amyloid does *moderate* the course of Alzheimer's disease, it's not enough. One thing that is clear in the data from these amyloid immunotherapies is that Alzheimer's dementia is driven by more than just amyloid plaques or tau tangles. It's complicated. You know there are important roles for inflammation, vascular factors, metabolic factors, oxidative stress, neuroplasticity, and many other fundamental cell biology factors that go off in the disease, and any combination of these may be even more important than the amyloid or tau. And that's why continued research is so important into these contributors. But while the research moves forward, there are other things that we can all do now to optimize the brains we have, in whatever shape they are. Physical exercise, mental and social stimulation, a heart-healthy, brain-healthy diet, restful sleep and stress management. All of these are helpful. And for people in the throes of dementia, our most effective treatment is good care.

Question: Do we now accept amyloid and tau as causes of AD?

Dr. Arnold: So yes, but it's not sufficient. I think we define the disease by the presence of amyloid and tau, the plaques and tangles of Alzheimer's disease. And that's actually how we've defined it since 1900, when Alois Alzheimer first started discussing it, or showing it. But I think that we do recognize that the causes may be much more complicated. And whether amyloid and tau are cause or consequence, or both, of more fundamental brain neuronal changes or inflammatory changes in the brain, that is still a question. For some people, it is primary. There are some rarer forms of Alzheimer's disease that are genetically based.

In other, more sporadic, and much more common, and heterogeneous, forms of Alzheimer's disease, amyloid and tau may be part of the complicated web of changes that occur with aging, so it gets a little tricky to say that it is the cause. We know, and I think we do feel confident, that it is a contributor, and may be a major contributor, and for some people it may be the first cause, but for other people it may just be in the mix of things.

Steven E. Arnold, MD

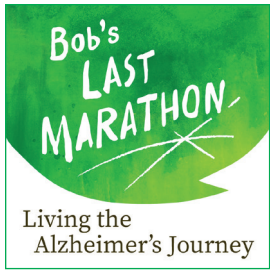
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TRANSCRIPT

A Person-Centered Approach to Caregiving

I'd like to begin by acknowledging that outpatient clinical practices that treat people with Alzheimer's disease and related dementias are limited by what they can do, by what they can do by way of care. As you just heard from Dr. Arnold, by and large, at this point in time, non-pharmacological approaches to care are considered the gold standard in caring for people living with dementia. These approaches, implemented and delivered by caregivers, can be applied in community-based settings, such as at home, and in long-term or memory care facilities.

In his seminal work on dementia, scholar Tom Kitwood highlights relationship, uniqueness, and embodiment as the elements of personhood, or sense of self. Because Alzheimer's and related dementias can rob us of our sense of self, we should prioritize person-centered care for those living with dementia. Person-centered care is a philosophy of care that prioritizes the needs of the person living with dementia. This is achieved by knowing the individual through an interpersonal relationship and understanding that a person's environment has as much effect on the brain as the brain does on the person's abilities. High-quality, person-centered care affirms selfhood through recognition. People with dementia need comfort in order to feel safe, when they might otherwise feel as if they're falling apart. It's care that's respectful. People with dementia need attachment, and they so often feel out of place. And it's also one of trust: People with dementia need to be involved in past and current interests and sources of meaning, and they need an identity. This helps them know who they are, and have a sense of continuity with the past. Caregivers are key in helping them maintain their identities. This can be done by helping people whose cognition is declining by upholding or telling their story as a way of maintaining their individuality and their humanity.

Through research, commonalities among models and practices of person-centered care have been identified. These include supporting a sense of self through relationship-based care and services, providing individualized activities and meaningful engagement, and providing education and coaching for caregivers in their efforts to support the person living with dementia.

At this point, I'd like to share six recommendations for delivering person-centered care. These recommendations were published in *The Gerontologist* journal in 2018, in an article titled, "The Fundamentals of Person-Centered Care for Individuals Living With Dementia." These recommendations are meant for families caring for a person with dementia in the home, as well as for facility-based care professionals.

The first recommendation put forth is to really know the person with dementia. The person living with dementia is more than a diagnosis. It's important to know the unique and whole person, including his or her values, beliefs, interests, abilities, likes and dislikes, both from the past and in the present. This information should inform every interaction and experience. Family members can be called upon to tell a person with dementia's story if they're unable to do it themselves. For example, what did they do for a living? From what do they derive a sense of joy, meaning, and purpose? Who do they love, and what made, or makes, them happy? In a care facility, mementos of these qualities can be displayed in the room through pictures or symbols of their life before dementia.

Next, it's important to recognize and accept the person's reality. We need to see the world from the perspective of the individual living with dementia and avoid trying to get them to join you in your version of reality. Doing so recognizes behavior as a form of communication, thereby promoting effective and empathetic communication that validates feelings, and connects

the person in their reality. One way that this could be done is implementing the rules of improv comedy, by taking a “Yes, and” approach. If the person living with dementia insists, for example, that the dome on the top of the building across the street is spinning, don’t argue. Join the person in their reality by exclaiming, “Wow, would you look at that!” and then either redirecting them or having a little fun by going further with them. There’s a wonderful episode on the *This American Life* podcast called “Magic Words,” and it’s in the August 15, 2014, archive. I would encourage you to listen to that for more on this technique.

The third recommendation is to identify and support ongoing opportunities for meaningful engagement. Every experience and interaction can be seen as an opportunity for engagement. Engagement should be meaningful to, and purposeful for, the person living with dementia. It should support their interests and preferences, allow for choice and success, and recognize that even when dementia is severe, a person can still experience joy and comfort and meaning in life. This brings us back to the first recommendation: Draw on what you know about the person’s past occupation and what brought meaning to their life. These are at the core of a person’s identity, which tends to remain static. If the person was a doctor before they had dementia, consult with them about a symptom. Ask questions they may have answers for. Ask for medical advice, even if you don’t use it.

When a former physicist that was in our care began pulling copper out of old television sets, and contorting it into sculptures, his wife began collecting old TVs and encouraged him to spend his time doing this thing that seemed to calm him and provide a sense of purpose. She even went so far as to frame some of his work, and they were invited to show his work at a local art gallery, which brought them both an immense amount of joy.

The fourth recommendation is to nurture and build authentic, caring relationships. People with dementia

should be part of relationships that treat them with dignity and respect, and where their individuality is always supported. This type of caring relationship is about being present and concentrating on the interaction rather than the task. It’s about doing *with* rather than doing *for*, as part of a supportive and mutually beneficial relationship. If the plot of a television program can no longer be followed, just sitting together and holding hands with the television on, like you used to do, can feel warm and comforting to both people. If language is compromised, just being together and doing something enjoyable, like a walk in nature, or planting flowers in the garden, can bring people together in a relationship.

The fifth recommendation is to create and maintain a supportive community for individuals, families, and long-term care staff. The supportive community allows for comfort, and creates opportunities for success. It’s a community that values each person, and respects individual differences, celebrates accomplishments and occasions, and provides access to and opportunities for autonomy, engagement, and shared experience. Involve friends, family, neighbors, or facility staff in parties or celebrations that recognize the person with dementia. I personally know of two couples who renewed their marriage vows in front of an audience while the spouse with dementia was in memory care. Too often, support networks begin to shrink, so it’s contingent upon the caregiver to create opportunities for community and connection. Don’t be afraid to ask, even if people don’t come around or call as much as they used to.

Finally, evaluate care practices regularly, and make appropriate changes. There are tools available to assess person-centered care practice. It’s important to regularly evaluate practices and models, and make changes to interactions, programs, and practices as needed. As the illness progresses, modifications will need to be made. The recommendations provided here may need to be revisited or revised as the person with dementia changes over time.

I want to thank you for your time, and I would like to recognize that the recommendations I put forth demand much from caregivers who may already feel overwhelmed. So it's important to know that there are resources such as counseling and coaching available to help you with this process.

Question: One of the biggest struggles I face as a geriatrician, caring for older adults with dementia, and daughter-in-law of a person with Alzheimer's, is the cause of hiring good caregiving help.

I 100 percent agree that good caregiving is the most important intervention we have, and I'm concerned that Medicare may pay for expensive diagnoses and immunotherapy, though it doesn't cover caregiving. What should we do?

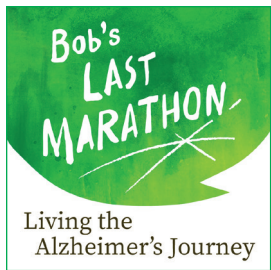
Felicia Greenfield: I think that Dr. Karlawish addressed that, when he spoke about what Medicare does and doesn't cover. Medicare doesn't cover in-home caregivers. So you might need help with activities of daily living, bathing, grooming. You might not be physically able to do that for the person for whom you're caring, and you might need to bring someone into the home. The average cost in Philadelphia is about \$25 an hour with a three-hour minimum for that level of care, and it's not covered by Medicare. There are some waivers available through area agencies on aging, and, again, like Medicaid, they are income-based. So it is expensive.

Felicia Greenfield, MSW, LCSW

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TRANSCRIPT

The Road to Diagnosis

When friends struggle to encourage their family members to get tested for cognitive impairment, they sometimes ask how long it took me and Bob to talk to his doctor and start the process. It surprises my friends when I tell them that my best estimate is six years—six years after the first symptoms of cognitive impairment were noticed by me and by our family.

The first signs seemed innocuous enough. About six years before Bob was formally diagnosed, I began noticing oddities in his day-to-day activities. Once or twice, he mistakenly folded away used bed linen instead of putting it through the washer and dryer. When he came to the airport to pick me up after my business trips, it started to take him an unusually long time to find his car in the parking garage.

Three years before diagnosis, on what was to be our last trip to Paris, he had forgotten all the street names and metro stops that he used to know so well.

Two years before diagnosis, at the prompting of his daughter Kim, he went through neuropsychological testing, but the results were equivocal. At the time, we were told he tested “fine,” and to come back in a year—a direction that we both promptly forgot and ignored.

Two years later came the drama. On a small cruise ship with 20 cabins in the Galapagos Islands, the captain instructed all passengers to keep our cabin doors always unlocked for safety reasons, in case of an emergency. While I slept soundly through the night, Bob was caught on camera wandering through the ship, opening cabin doors to look inside. Later he would explain that he was looking for his car, thinking we were at home and that the cabin doors opened to our garage. The ship captain confronted me with it, and I had a hard time convincing him that I did not bring my husband on the trip knowing that he was cognitively impaired. We spent the rest of the cruise with the ship doctor keeping Bob company in the daytime while I went on day tours. At night, I would block our cabin door with our luggage

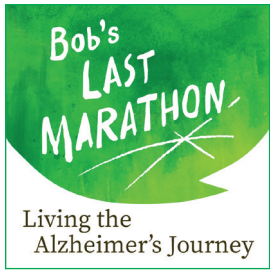
so Bob could not venture out. Once we came home to California, I scheduled the testing. This time, the diagnosis was clear. I remember that day, on a hot and sunny California afternoon, when Bob and I literally stumbled onto the streets after being told by a newly minted neuropsychologist that his mental skills were, in her words, “profoundly impaired.” All I could remember were the words “profoundly impaired,” repeated over and over again, like a judgment, a sentence for life.

Later, we would find our way to Bob’s primary care doctor, a referral to a neurologist, a diagnosis of mild cognitive impairment and, eventually, mixed dementia—a case of Alzheimer’s disease and vascular dementia.

In retrospect, that diagnosis, difficult as it was—both getting to the test and the lack of compassion in the delivery of the results—was a positive turning point in our journey with Alzheimer’s disease. The guessing, the suspicion, and the denial were over. Bob’s future, and mine as his caregiver, were now in our hands. Follow-up visits with his primary care doctor, his neurologist, the clinical social worker at our health system; consulting the leadership at our local senior community, contacting the local chapter of the Alzheimer’s Association, and reaching out to friends—all played a part in formulating a road map to live our journey to the best of our ability and, ultimately, to thrive despite the unfavorable prognosis. A key milestone was when Bob and I were parking our car at the garage as we walked to the Alzheimer’s support program that was about to begin. I turned to Bob and said, “We are going to an Alzheimer’s support program. The key word is ‘Alzheimer’s.’ This is the diagnosis. This is what we both must accept and live with, from this point on.” We took the first step—acceptance. And doors opened as we learned to find our way to the resources we needed—the doctors, social workers, day programs, therapists, home care—that ultimately helped Bob live well despite the many challenges that kept coming our way.

After Bob passed away, when I received his medical records from the health system, I learned that during the first visit to the neuropsychologist, two years before the definitive diagnosis, the neuropsychologist noted that Bob did not appear as intelligent as would be expected for his education level. Bob was a career engineer with a doctoral degree in clinical psychology. Although the neuropsychologist did not tell me, his written notes indicated that cognitive impairment *could not be ruled out* at the time. Somehow, the neuropsychologist was not able to tell that to me directly—because I did not stay in the waiting room and had left the premises when the testing was completed, and when the neuropsychologist came looking for me. Looking back, I now know why. I didn't want to know. And as I watch people around me put off their testing, I wish I knew how to tell them that there is so much more to gain than to lose. Knowledge is power, even when knowing hurts.

Lena Chow Kuhar



TRANSCRIPT

We Have a Diagnosis. Now What?

A dropped word here, a missed appointment there. A fender bender, forgetting the name of a neighbor. Are these warning signs of cognitive decline? Not necessarily, but sometimes they are. It's not uncommon for families to brush off some of these signs and to minimize or ignore them, even when the signs rise to the level of real concern. Pursuing a diagnostic workup can be scary. Some common questions among families are, "What if there is a problem? What will happen to us? There isn't a treatment anyway, so why bother?" These are normal and understandable concerns. But I want to make the argument that getting a workup early on, when the signs are still mild and subtle, has real value.

As difficult as it can be to face reality and seek out a diagnosis, doing so could provide a sense of relief. First of all, not every dropped word or memory blip leads to a dementia diagnosis. Sometimes there are reasons why a person is experiencing memory loss that can be treated. Significant anxiety or depression can be resolved with medications and/or therapy, or someone might have a vitamin B deficiency that if resolved can reverse symptoms. But if the diagnosis does reveal pathology causing Alzheimer's disease or a related dementia, families have that information and can begin to make plans for the future. Once a diagnosis is received, it can at first feel overwhelming and unreal. But those who do are not alone—there are resources and support to help families navigate the difficult terrain of aging and dementia.

Getting an accurate diagnosis can be complicated, so, if possible, seek out a neurologist, geriatrician, or psychiatrist who is considered a memory specialist, someone who has training in diagnosing and treating dementias. A proper workup consists of tests of one's memory and thinking, a neurological examination, labs, and imaging. Ideally, the person being evaluated will

be accompanied by a spouse or other family member who knows them well and can serve as a "reliable informant"—someone who can share examples of some of the problems the person is experiencing in life. Often, a person with memory impairment doesn't remember or have insight into the problems, so an accurate description of daily function by such an informant is a valuable part of the diagnostic process. If your doctor's office doesn't offer such tests, you may ask for a referral to a more comprehensive practice where these tools are available. It's important to remember that there is variability in the process and that it's okay to seek a second opinion.

Once a diagnosis has been determined, this information will allow you to take action. Education, securing resources for support, financial planning, and creating a safe environment are just a few examples of actions families can take to help them maximize quality of life while living with dementia. Educate yourself on the diagnosis and learn what to expect as it progresses. If you live near an NIH-designated Alzheimer's Disease Research Center (or ADRC), you may have access to a social worker who can connect you with resources in the practice or in your community. If this service is not available, the Alzheimer's and Related Dementias Education and Referral Center (or ADEAR), the Alzheimer's Association, and the Alzheimer's Foundation of America have websites brimming with information about the dementias and what to expect. In addition to education, your provider's office or one of these organizations can connect you with resources for social and emotional support.

Families who know they have a dementia diagnosis can make plans, and can get their legal, financial, and long-term planning affairs in order. When a diagnosis is given early, when the person affected is in the mild stages, they still have the capacity to make their own decisions

about their will, living will, and medical and financial powers of attorney. They can also express their wishes about long-term care as their illness progresses. Meet with an elder law attorney to help draft these legal and financial documents. If you don't have an elder law attorney, you can visit the National Academy of Elder Law Attorneys on the Internet to find one.

People experiencing dementia can benefit from strategies to help them compensate for memory loss and maintain independence. Simple memory aids like calendars, whiteboards, and pillboxes can help people remember appointments and manage medications. Family and friends can be called upon to help with meal preparation or delivery services, bill paying, shopping, or transportation. Technology should be considered for medication management and for safety concerns, such as door alarms or emergency response tools. Technology is available for tracking people with dementia should they get lost. On the topic of safety, we can't avoid talking about driving. Dementia causes changes in the brain that result in impaired judgment and a slower reaction speed or response time, which makes driving unsafe. Talk to your doctor if you have concerns about driving, or if you are supporting someone with dementia that you have concerns about. If their ability to drive safely is questionable, seek an independent driving evaluation. In some cases, if the person with dementia is deemed too impaired to drive, your doctor may have to file a report about the diagnosis to the DMV. No one takes pleasure in this, but it is the law in many states and is not designed as a punishment, but as a way to protect the driver and everyone else on the road.

One of the biggest reasons to seek an early evaluation is treatment. Donepezil and memantine can be prescribed to slow the progression. A new drug, lecanemab, was recently approved by the FDA as a treatment for Alzheimer's disease, and it is only available to individuals in the early stages of disease. Finally, there are many clinical trials that may be available to people in the early or mild stages of

disease. Ask your doctor about treatments or clinical trials or do an Internet search for information on research opportunities near you.

There are things you can do to improve the quality of life for a loved one who receives a dementia diagnosis. Staying healthy by increasing physical exercise, eating a Mediterranean or heart-healthy diet, and remaining socially engaged can help them feel, and function, better. Staying cognitively engaged can help slow progression, so make a plan for increased brain stimulation. Playing cards, reading the paper or a good book, or going to lectures in your community or online are great ways to do this. If low mood is a concern, find a counselor or consider an antidepressant. If you or your loved one is struggling to accept cognitive change, or if you are having difficulty with relationship changes since the diagnosis, a therapist can help you navigate and accept some of these changes. Ask your doctor for a referral to a therapist with expertise in aging or dementia care.

If your loved one is still in the workforce and receives a diagnosis of dementia, consider talking with them about reducing their hours or switching to a less demanding role. Talk to family and friends about whether to retire or strategize for safe, effective ways to continue working while still in the early stage of illness. There are options such as family leave, disability benefits, or other benefits that might be available.

If you know a person experiencing dementia who lives alone, there are things you can do to support them. Is there an adult child or other family member you can reach out to? Is there a spiritual community that can be called upon to help? It's important that someone in the person's community check in regularly, and that an emergency contact be identified. A consultation with an occupational therapist can help modify the person's house to promote independence and safety. A structured day with activity and routine can be helpful, so enrolling in a day program is a great way

to promote engagement and socialization for anyone with dementia and is particularly important for those who live alone.

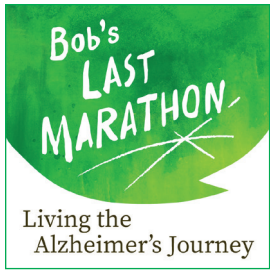
As tempting as it can be to sweep warning signs under the rug or look the other way, doing so will ultimately prevent the person with dementia from securing valuable resources early on, when they are most beneficial. Knowledge, treatment, planning, and support are critical in optimizing well-being for families living with dementia, and these resources can only be accessed once a diagnosis has been given. You are not alone on this journey; don't be afraid to ask for help from the professionals available to serve as your guides.

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TRANSCRIPT

The Promise of Biomarkers

More and more, the term “biomarkers” is being used in the context of diagnosing and monitoring Alzheimer’s disease and related disorders. But what does the term “biomarker” mean? In essence this is a biological feature of a disease that we can measure either through imaging, laboratory tests, or other kinds of recordings from the body. Let’s use an example that most everyone can relate to. Say you go to the doctor complaining of shortness of breath and maybe a cough. Now, there are many illnesses that can cause these symptoms, and the treatment will vary accordingly. The causes might range from an upper respiratory viral infection to bacterial pneumonia to asthma, emphysema, heart failure, or cancer. The doctor can suspect some of these based on history or examination findings. But to be sure, she may order a variety of biomarker tests. These might include a chest X-ray, an electrocardiogram, a CT scan, or lab tests on blood or sputum and more. With these biomarker data, the physician can make an accurate diagnosis, recommend the right treatment, and follow whether a person is getting better or worse.

Now let’s take the case of someone going to the doctor with memory decline. Based on symptoms of forgetfulness or word-finding difficulties, how long the symptoms have been present and the like, the doctor can suspect what might be causing the cognitive impairment. She might suspect Alzheimer’s disease. However, she’ll want to make sure other things that can cause cognitive decline aren’t present, so she may order some common biomarker studies—a brain MRI scan or head CT scan to look for evidence of strokes, tumors, or fluid collections. She might order some blood tests to look for hypothyroidism or vitamin deficiencies. If all these tests come back negative, then her suspicion of Alzheimer’s disease may be higher. These biomarkers rule out other causes of memory loss, but she still hasn’t made a positive identification.

We used to say that the only way to be sure that Alzheimer’s disease is the cause of someone’s cognitive decline is if you look at someone’s brain tissue under a microscope after they die and see the telltale amyloid plaques and tau tangles that define the disease. This would be a positive ID. What has transformed the field of Alzheimer’s disease over the last two decades is the development of biomarkers using molecular neuroimaging, spinal fluid laboratory tests, and, most recently and importantly, blood tests that indicate the presence or absence of these brain amyloid plaques and tau tangles with a very high degree of certainty.

Let me briefly discuss the different types of biomarkers for Alzheimer’s disease.

PET scans, or positron emission tomography, are a kind of brain imaging test that is now used to visualize the presence, absence, or amount of specific molecules in the brain. The most important kinds of PET scans used in Alzheimer’s disease are glucose, amyloid, and tau PET scans. Glucose PET scans have been used for many years to look for patterns of metabolic activity in the brain. Amyloid PET scans are now approved for clinical use as well as research, although their cost is usually not covered by insurance. Tau PET scans are still for research use only.

The way PET scans work is that a radio-labeled tracer is injected into the bloodstream through a vein and then it circulates throughout the body. When the tracer reaches the brain, an amyloid tracer for example, it will bind temporarily to amyloid plaques if there are any. Tau tracers will bind to tau tangles. And glucose will be taken up by metabolically active brain cells. When the tracer sticks to its target, it emits positrons that are detected by the scanner before the tracer washes out. Radioactivity is always a health and safety concern, but the amount of radioactivity from a PET scan is relatively low, similar to what one gets from a chest X-ray.

Glucose is the major fuel for brain cells. In Alzheimer's disease, frontal lobe dementias, and possibly even Lewy body dementias, there are distinctive patterns of metabolic activity. These scans are approved and usually covered by insurance and can provide useful biomarker information for distinguishing different types of dementia whose symptoms can often look similar.

Amyloid PET scans are especially accurate for identifying the presence or absence of Alzheimer's disease in the brain. Beyond helping with clinical diagnosis, amyloid PET neuroimaging was extremely informative in the recent clinical trials for Alzheimer's disease treatment using anti-amyloid immunotherapy. In these trials, there was a dramatic lowering of amyloid in the brain, as measured by amyloid PET imaging, sometimes down to normal undetectable levels.

Tau PET imaging, while still pretty new and not yet approved for clinical use, may turn out to be even more informative than amyloid PET. The reason for this is that tau PET imaging allows us to see not only if the disease is present in the brain, but how far it has spread through the brain. This ability to stage the disease may be very important in selecting the right treatment for the right patient at the right time.

Spinal fluid tests are also extremely informative in the diagnosis of Alzheimer's disease and other types of dementia. A sample of the spinal fluid, which is safely collected in the lower part of the back in a simple procedure called a lumbar puncture, can be used to measure a host of brain proteins and other chemicals. Spinal fluid analysis provides an enormous amount of information about the health of brain cells. Not only can we measure levels of amyloid and tau, but we can measure many more and varied proteins for inflammation, degeneration of synapses and different types of brain cells, oxidative stress, injury to the blood vessels of the brain, and metabolism. Spinal fluid tests for amyloid and tau are approved for clinical diagnosis and usually are covered by health insurance, and they

provide equivalent information or more compared with amyloid PET scans.

The most exciting and important progress in the dementia field over the last few years has been the development of blood tests for Alzheimer's disease. With new, highly sensitive and specific lab reagents and technologies, we can now detect the extremely low levels of tau, amyloid, and some other brain proteins that are produced in Alzheimer's disease and leak out into the bloodstream. While these tests are as yet not as accurate as PET scans or spinal fluid tests, they will be extremely useful for screening purposes and possibly for monitoring response to new treatments. They will help in establishing a positive diagnosis of Alzheimer's disease or other conditions affecting our cognitive abilities as we age. They are also essential in clinical research for new treatments for Alzheimer's disease as they allow us to measure whether a new drug or other treatment is working and give us insights into how the drug might be working—for example, by looking at changes in the levels of amyloid, tau, inflammation, or other features of neurodegeneration with use of the drug.

Biomarkers are an active area of research. As more biomarkers are discovered and as we better understand the information that each biomarker is giving us, how to measure them, and how to use them, the value of biomarkers in understanding, diagnosing, treating, and monitoring Alzheimer's disease will continue to increase.

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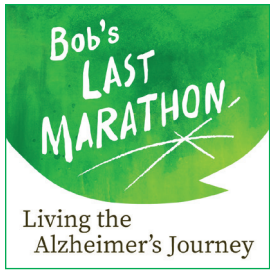
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TRANSCRIPT

AAIC 2023 Reflections



TRANSCRIPT

AAIC 2023 Reflections

The Alzheimer's Association International Conference, or AAIC, is the world's largest dementia research conference. This past July, AAIC was live in Amsterdam and also offered virtually. AAIC supports the community's efforts to advance research and care that are so important to so many people, and this year there were nearly 9,500 attendees representing 103 countries. I had the opportunity to attend the conference as a poster presenter, and given my role as a social worker supporting dementia caregivers, I attended many of the sessions on dementia care. Though hundreds of the presentations were scientific in nature and shared fascinating data in disease nuances, diagnostics, imaging, and drug discovery, I will, in this podcast episode, share the findings presented in my colleagues' and my poster along with takeaways from other presentations that support the work we do.

In an earlier episode, I talked about the importance of social engagement for people living with dementia and highlighted the Penn Memory Center's Time Together program. My colleagues and I were honored to be asked to present our pilot findings at AAIC. Time Together offers opportunities for older adults with dementia to interact meaningfully with college students while giving care partners a break. The primary aim of our study was to evaluate the impact of Time Together on mood and socialization for the person with dementia, self-care for care partners, and career preferences for student volunteers. In our pilot study, our qualitative evaluation showed that in the person with dementia, mood either improved or remained the same after participation. For care partners, we learned that most faced challenges with socialization as well as self-care as a result of their caregiving responsibilities. At baseline, all care partners interviewed reported that poor time management or not prioritizing self-care resulted in missing out on cherished opportunities such as travel, volunteering, or time to themselves. After participating in the pilot program, caregivers reported an increase in

self-care activities to promote physical health, mental health, social support, time management, and cognitive engagement. By getting small pockets of time when students were providing respite, caregivers were able to prioritize diet and exercise, meditation or other relaxing activities, talking to family or friends, and reading or engaging in brain exercises. We learned that most students who participated were comfortable working with older adults, although many lacked prior experience. Coming into the program, students had hoped to gain connection, improve socialization, and enhance qualities such as compassion, reflection, altruism, and wisdom. These were achieved, along with stress relief as noted by some. Prior to participating, students experienced fears and anxieties about their capacity to interact meaningfully, about encountering health or personal care issues, or about not being able to find meaningful activities. After participating, all students reported decreased anxieties about these concerns, though their career preferences were not influenced by their participation in the program. All in all, we conclude that as a respite program using student volunteers, Time Together benefited the person with dementia, the care partner, and the student. We envision future quantitative research based on a larger, more diverse sample, with a control for comparison. The study also pointed out that care partners can benefit from additional training or coaching in time management, prioritizing self-care, and identifying resources.

There were many rich sessions on improving outcomes for caregivers. Researchers shared ways to tailor caregiver programs specifically for Black care partners by broadening family as a resource, training Black facilitators to lead caregiver training programs, streamlining educational materials, and using culturally specific examples. They also highlighted the importance of considering cultural factors such as honoring parents and spouses and understanding the

importance of staying home rather than moving a loved one to a facility in the later stages. They noted that Black caregivers report higher levels of racism and discrimination that prevent them from seeking help or participating in research, and so it's important to consider caregivers' intersectionality, or multiple social and political identities such as race, gender, and class that might put people of color at a disadvantage, and to involve stakeholders when tailoring interventions. In short, for caregiver programs that are intended for diverse populations, deeper-level customization is critical.

The Care Ecosystem out of University of California San Francisco was highlighted as a model to address gaps in care and prevent emergency room admissions for people living with dementia. It uses a care team navigator, an unlicensed trained professional who manages a caseload of families. The navigator triages families to expert care when needed and provides care coordination. The model is organized around caregiver support, decision making for legal and financial matters, and caregiver coaching to manage difficult behaviors. The navigator reconciles medications through regular screening and consults with a pharmacist as needed. The model emphasizes the importance of assessing the patient's stage of dementia and teaching caregivers appropriate skills depending on whether the person with dementia is experiencing a mild, moderate, or severe level of impairment. In the randomized clinical trial findings presented, the Care Ecosystem resulted in lower care costs for health systems and families and reduced caregiver burden. This model is well positioned to meet the requirements of a newly announced Centers for Medicare & Medicaid Services (CMS) model, Guiding an Improved Dementia Experience (or GUIDE), which aims to support people living with dementia and their unpaid caregivers by using a care navigator and reduce hospital or ER admissions for patients. There is also reimbursement for in-home or facility-based respite care as part of the model. Stay tuned for a future *Bob's Last Marathon* episode dedicated to the GUIDE model.

Technology to support people living with dementia and their care partners was another highlight. Technology can be used to promote safety, encourage functional well-being, monitor for mental status, and give voice to the caregiving experience. A presentation using tech for home safety discussed in-home monitoring to support caregivers. The use of radar, light sensors, and smart energy tech along with fall detection and nocturnal well-being was discussed. Researchers shared their findings on a tablet-based assessment tool to detect elder abuse in older adults and those in the early to moderate stages of dementia—another example of how technology can help improve safety. Technology can also be used to support cognitive function. We learned about a health app to improve outcomes of people with mild cognitive impairment by offering tips to increase social activity and physical health, while tracking behavioral changes. We also learned about adaptive video games that can offer direct feedback for early detection of cognitive impairment and using memory games to promote cognitive rehabilitation. Another health-promoting app was tested in a rural Southern community. The researchers recruited high school students and faith-based health educators to serve as mentors who trained older adults to use smart watches to track behaviors in order to detect early cognitive decline. The use of technology as a form of narrative therapy was also presented. A group from India presented on their use of film and digital media to develop cost-effective, culturally sensitive interventions to improve outcomes by filming caregivers telling their stories as a way to better understand their experience, which proved therapeutic. I share these highlights with you to illustrate ways in which technology can be used for improved outcomes in older adults, early detection, behavioral change, and caregiver support.

I hope that everyone listening to this podcast is aware of the Alzheimer's Association's free 24-hour helpline. It receives more than 800 calls a day and connects callers to master's level care consultants. Nancy Hodgson is the Chair of the Department of

Biobehavioral Health Sciences at the University of Pennsylvania School of Nursing, and her team was asked to evaluate the effectiveness of the helpline. Many of the people who call the helpline are caregivers, and the care consultants fielding the calls provide them with emotional support, action steps to solve issues, and resources on how to find support groups. Clinicians were trained to guide callers to consent to research participation, and they administered pre- and post-surveys to evaluate the efficacy of the intervention. In her analysis, Dr. Hodgson found that 80 percent of callers to the helpline benefited in some way after a single call. She also discovered that the 20 percent who did not benefit had greater emotional needs than those who did, and she and her team tested the effectiveness of providing a callback to this cohort. Indeed, Dr. Hodgson reported that the majority of the caregivers who received a callback had an improved ability to manage their stress levels and discouragement. I thought it was important to share these findings as a way to encourage caregivers to use this helpline as another resource or tool. The Alzheimer's Association's 24-hour helpline number is 800-272-3900.

There were far too many interesting topics covered for a single podcast episode, but I hope you found the ones I shared helpful or insightful in some way. Next July, AAIC will hold the conference right here in Philadelphia. Please consider registering and reach out to me if you'd like to visit us at the Penn Memory Center while you're in town! For more information, visit www.aaic.alz.org.

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