

The CAREGIVER

*A Bridge to Understanding
Your Options*

Newsletter of the Duke Dementia Family Support Program

Volume 37, Issue 2

SPRING 2020



Younger-Onset Dementia

By Bobbi G. Matchar, MSW, MHA

I didn't choose it. I can't deny it. My goal is to adapt to it as well as I can.

- Joe, living with younger-onset dementia

No one chooses a diagnosis of younger-onset dementia. Yet an estimated 5-6% of the nearly 6 million Americans living with dementia have a diagnosis of younger-onset dementia. Also referred to as early-onset dementia, it affects people younger than age 65. We prefer the term, “younger-onset,” because “early-onset” is easily confused with the stage of the disease. People living with younger-onset dementia can be in the early, middle or late stage of the disease. In the early-onset group, the most common diagnoses are Alzheimer’s disease and frontotemporal dementia (FTD). As with later-onset dementia, the progression and symptoms of younger-onset dementia vary significantly from person to person.

Arriving at an accurate diagnosis of younger-onset dementia is difficult and often takes years; and families tell us that receiving the diagnosis is overwhelming. The impact of living with dementia in mid-life is enormous; and the challenges differ from a later-onset diagnosis. We see younger people with dementia who are still working and driving at the time of diagnosis, have kids at home or parents they care for, as well as financial obligations such as mortgage payments and college tuition. Not what we generally associate with the words “dementia” or “Alzheimer’s.”

We’ve learned about life with younger-onset dementia from families who have participated in our support groups, including our newly formed Younger-Onset Support Group, established with urging and guidance from Triangle families. Inside this newsletter you’ll find first-hand stories from some of those individuals and families – and we are grateful for their honesty and their advocacy. We dedicate this issue to all those living with younger-onset dementia and their families who are facing an unexpected journey with courage, dignity and strength.

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Dementia Alliance of North Carolina

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Lewy Body Dementia Association

LBD Caregiver Link: 800-539-9767
 National Office (Atlanta, GA): 404-935-6444
<http://www.lbda.org/>

Family Caregiver Alliance, National Center on Caregiving

Office (San Francisco, CA): 800-445-8106
<https://caregiver.org/>



This free support group is for persons diagnosed with younger-onset dementia (65 or younger) and their care partners.

A diagnosis of younger-onset dementia is probably not what you had planned for at this time in your life. You will face unique challenges when it comes to family, work, finances and future care.

But you have the power to make a new plan and determine how you choose to live your best life with the disease.

The Younger-Onset Support Group meets monthly in-person in Durham (near the Wake County border), and twice monthly via a virtual platform during COVID-19. The group is open to both persons living with memory loss and care partners. Pre-registration is required for first time attendees. To learn more about the group, please contact Janeli McNeal at 919-660-7565 or janeli.mcneal@duke.edu.

NC REGISTRY FOR BRAIN HEALTH HELPS ADVANCE RESEARCH ON ALZHEIMER'S DISEASE

By Kathleen Welsh-Bohmer, PhD, Professor of Psychiatry and Brenda Plassman, PhD, Professor of Psychiatry & Neurology, Duke University School of Medicine

A year ago the research world was stunned when interim analysis of the Alzheimer's disease investigational drug aducanumab found the drug to be ineffective at improving symptoms and markers of the disease in the brain. In earlier studies, the medication had shown promising results in patients with a mild form of the disease. The drug targets the removal of beta amyloid, the abnormal protein that accumulates in the brains of patients with Alzheimer's disease. Surprisingly, in October, the company developing the drug announced that with more data, the drug does indeed seem to be working in patients that were given the maximal dosage over the life of the study. The FDA has now approved the company to continue to study the drug in patients who were previously enrolled in the clinical trials for the drug. The company expects patients will start receiving the drug again this spring. While the drug is not yet approved for clinical use, the findings are encouraging and suggest that we may have turned a corner in developing effective treatments for Alzheimer's disease. Recently, there have also been other promising drugs that target inflammation and metabolism, mechanisms believed to also play a role in the disease. New lines of investigation are launching to explore ways to prevent the disease and to slow, stop, or perhaps even reverse its course in those who are affected by the disease.

A major hurdle for research in this area is quickly finding research participants who are interested in helping. To address this challenge, researchers at a number of universities in North Carolina have joined efforts to create the North Carolina Registry for Brain Health. The Registry has received support from the NC State Legislature and its mission is two-fold: to increase awareness of Alzheimer's disease and other dementias, and to involve more people, including under-represented groups, in investigations of brain health and prevention research. Currently, over 5600 individuals have joined the Registry and the number continues to grow daily. The consortium of universities involved in the Registry currently includes Duke University, University of North Carolina at Chapel Hill, Wake Forest University, Eastern Carolina University, and North Carolina Agricultural and Technology

State University. Additional universities will join the consortium as it strives towards its goal of providing opportunities to participate in brain health research across the state of North Carolina. Investigators with funded research to improve brain health or leading sites for clinical trials to prevent and treat Alzheimer's disease, are able to use the Registry to help recruit participants who are interested in helping in these types of studies.

Who can join the NC Registry for Brain Health?

Individuals 18 years and older who live in North Carolina can join the Registry. People with or without memory disorders are welcome to join. The portfolio of studies and clinical trials going on across North Carolina have different needs. Some are clinical trials, designed to treat conditions like Alzheimer's disease and other dementias. Whereas, other studies are designed for those who do not have memory problems and are aimed at activities to promote brain health and prevent disease.

How do I join the Registry?

Just go to <https://ncbrainhealth.org>. Click on 'Join the Registry' and answer a few simple questions. It only takes 5 minutes to join online.

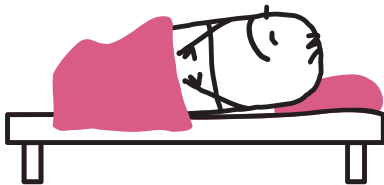
What happens after I join the Registry? Periodically, you will receive emails about the latest findings on brain health. You will also receive emails sharing information about research studies in which you might be interested in participating. It is entirely up to you whether you agree to participate in any particular research study. On the NC Registry for Brain Health website, you can also find out more about available resources in our communities to help people with memory disorders and their families.

Who do I contact if I have questions about the Registry? Just email: ncbrainhealth@duke.edu or call 919-613-8633.

We hope you will consider joining others across North Carolina to find effective ways to prevent or treat Alzheimer's disease by joining the **NC Registry for Brain Health**.

Caregiver Tip Sheets

Sleeping



WHY DOES THIS HAPPEN?

Changes in sleep can happen for many reasons:

- changes in the brain may cause the body's natural "clock" to change – the body can feel awake during the night and sleepy during the day
- pain from arthritis or other illnesses can wake the person
- the person needs to go to the bathroom
- the person may have problems breathing while they sleep; this can cause loud snoring
- feeling very sad or nervous can wake the person

Sleeping problems are common for people living with Alzheimer's or other dementias. Many people are restless at night and feel tired during the day. Poor sleep can also lead to other health problems.

WHAT CAN YOU DO?

KEEP A REGULAR SCHEDULE

- begin each morning at the same time and the same way
- keep them as active as possible during the day—walks, gardening, and other daytime activity is good
- avoid naps later in the day
- make sure to keep the same relaxing routine before bedtime

OTHER THINGS YOU CAN DO

- provide as much bright light as possible during the day
- if they really want to be up at night, do not force them to be in bed or to sleep
- keep everything quiet and dark at nights
- help them avoid drinking coffee, tea, or soda with caffeine after 2PM
- give less liquids in the evening
- keep a light on in the bathroom to avoid accidents
- massages may help some people

SPEAK WITH A DOCTOR IF:

- they have pain
- they snore badly
- they go to the bathroom a lot
- they seem very sad or nervous

Don't use sleep medicines of any kind without speaking with a doctor first. Sleep medicines can cause confusion and falls.



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THE BEST DAUGHTER A FATHER COULD ASK FOR: JAY REINSTEIN HONORS CARE PARTNER ELIZABETH

Reprinted with permission from the Alzheimer's Association.

I am living with Alzheimer's.

While Alzheimer's can devastate a family, it brought my daughter Elizabeth and I much closer together. Most 24-year-olds would rather spend the majority of their time with their friends, but Elizabeth wants to spend extra time with me.

Alzheimer's disease isn't something I wanted in my life. No one does. But the disease has given my daughter a platform to advocate and to be a voice for caregivers. I couldn't be prouder of her.

My Diagnosis

My Alzheimer's story began two years ago. After 25 years in local government, most recently serving as the assistant city manager in Fayetteville, NC, I began to experience issues with information recall and my short-term memory, which caused a great deal of anxiety in both my work and personal life.

At age 57, I was diagnosed with younger-onset Alzheimer's, three words that would change my future and impact my life forever.

Following a very brief pity party, I recognized that by going public with my diagnosis, I could help educate folks, raise awareness and reduce the stigma associated with this disease. I began to get involved with the Alzheimer's Association Eastern North Carolina Chapter, which opened the door to many new opportunities, from speaking engagements to events at my local Walk to End Alzheimer's.

From Daughter to Care Partner

When I was invited to be a member of the Alzheimer's Association National Early-Stage Advisory Group, I began to consider who would be my travel companion for engagements associated with this role. My wife's job does not provide her with a lot of time off, so I needed to identify someone else to travel with me. We discussed this need at dinner one evening, and my daughter said, without any hesitation: "Dad, I'll be your companion."

During a recent trip to Chicago, Elizabeth helped me navigate my itinerary, checked me in at the airline kiosk — a major challenge for me — and stayed by my side throughout the trip.

Elizabeth now accompanies me to all of my younger-onset support group meetings and is a very



vocal member of the group. She even volunteered to create and manage a private Facebook page, enabling our support group members to share updates about issues we all face, upcoming social opportunities and helpful educational resources. It gives me such pleasure to see her so engaged with this community that we are both now a part of.

Elizabeth has worked tirelessly to support me during Walk to End Alzheimer's events and is always my biggest supporter. Recently she called and said "Dad, have you heard about goat yoga? I signed us up for a session. Oh, and by the way, the following week we're going tubing down the Cape Fear River." Before I could respond, she said, "I love you and we've got to go!" (In case you don't know, goat yoga is yoga practiced while surrounded by — and sometimes in tandem with — live goats!) She has brought a sense of adventure back to my life.

While my diagnosis had the potential to break her spirit, instead it has made her stronger, better-educated about the disease, a superb care partner and the best daughter a father could ask for.

I love you, Elizabeth.

About: *As a member of the National Early-Stage Advisory Group, Jay wants to leverage his skills in local government to advocate for increased research funding and encourage greater participation in clinical trials. Jay and his wife Angela live in Raleigh, North Carolina.*

A CAREGIVER'S GOAL: GOOD DAYS

By Kathy Rausch



There's nothing that really prepares you to receive the diagnosis of Alzheimer's, especially when you're only 53 and in the prime of your career. It's easy to look back now and pick out all the signs that were there, long before the diagnosis, but at that young age it's about the farthest thing from your mind. So, the long road started from doctor's office then across the street for an MRI to where we are now over 2 ½ years later.

Many things changed in our lives and our relationship in these past few years. As time goes by and your loved one loses their ability to do things they did before, like cook or drive, you have to come up with a new plan and a new way of doing things together. The hardest thing for Rob to give up was driving. None of us can imagine losing the freedom of getting where you want, when you want, so losing his independence was difficult. It's also hard because all of the driving falls to me. Which means that all errands, shopping, and traveling became my responsibility. But even though Rob isn't driving, he's an integral part of shopping, running errands and most important, telling me how to drive!

Most household responsibilities are mine now

but it's very important that I communicate them with Rob and that he feels he is still part of the household decision-making process. In our circumstance, allowing Rob to keep his dignity and feel secure in our home is very important to me. Small things, that we take for granted, are hard for Rob at times. I learned to help him try and work through what he's doing, be supportive and not just do it for him, but allow him to try himself. As a former engineer and business executive, he was good at decision-making and problem solving. It's important for him to continue with that as long as he can.

After the diagnosis, I did a lot of research on the disease, using the Alzheimer's Association website, and contacted our local chapter. The information was invaluable to me and the support we have received through our chapter has been so wonderful. We encourage everyone to utilize both of those resources to help you get through this long journey. As a caregiver, my goal is for Rob to be happy, feel secure, loved and hopeful that every day will be a good day. Together as a family, with our two dogs, we make the most of each day we have together.

IT IS ALL ABOUT LIVING

By Lisa Giannini-White



Hi to all the Early-Onset Fighters and Caregivers, I started having cognitive challenges at work in 2016. My profession was veterinary medicine and I was Director of Operations/Co-Owner. I was bought out and was devastated.

I credit my loving husband as he researched Mayo Clinic and Johns Hopkins, two of the top cognitive clinics in the USA. My husband picked Johns Hopkins. My neurologist was amazing!! He started testing and I wasn't doing so well. I started to cry then he pulled out his stethoscope and said, "What is this?" I perked up and said with a big smile "it's a stethoscope." I asked why did he do that? He said, "because I knew you would know what it was as it is ingrained into you!!!" So, I was finally successful!

My second visit was doing a spinal tap and MRI. We drove back to North Carolina to await the results.

It was December 26, 2018, when I received the call from my neurologist. He said you have Alzheimer's and you have had it since 2016. The spinal tap showed 100% Alzheimer's. My husband and I were a deer in headlights. I went online to get educated with ALZ. In addition, my husband was already going to a caregiver support group prior to the diagnosis. This is what I did; since my husband was getting support, I decided to look for Early-Onset Alzheimer's support groups.

The closest support group was in New York!!

So I shared my findings with my husband and I said "this is nuts, why isn't there any Early-Onset ALZ Support groups for the patients?????" My husband and I formulated a model as to what it would look like. We submitted it to Duke Dementia Family Support Program. Within a few months they approved the model. Our first Early-Onset support meeting was July 9th, 2019. We had approximately 19 participants which included the patient and caregiver. We meet once a month on the second Tuesday. We currently meet at a church in Durham 7PM-8:30PM.

How Marc and I cope: We still laugh and have fun. When I have challenging days, I am kind to myself and don't get frustrated. Each day is different. I do my best to have friends over, however two hours is my max. I am making the best of this Early-Onset stage. The hardest part is, at some point, knowing that I won't know who he is. It breaks my heart.

I am deeply grateful for: (not in any order)

My Early-Onset peers as we are in it together!

Having eyesight and hearing

My family and friends

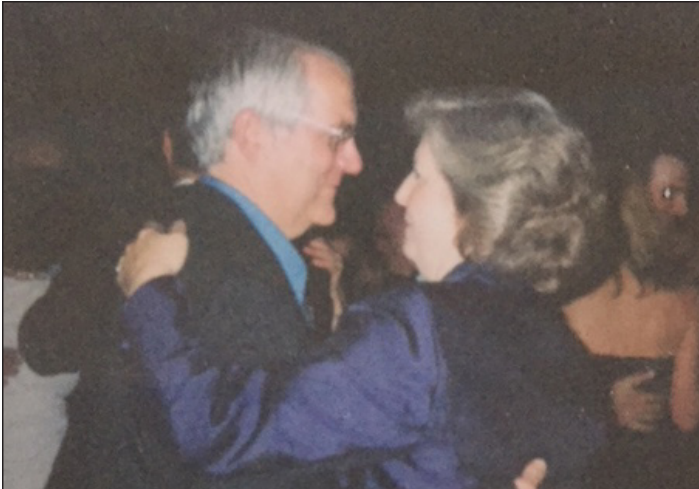
My husband and dogs

Dr. Richard O'Brien at Duke for taking me as a patient

Dr. John Probosco at Johns Hopkins for going the distance

YOUNGER-ONSET DEMENTIA OVER TWENTY YEARS: A MOTHER AND DAUGHTER REFLECT

By Kathy and Sara LaFone



Tim and Kathy enjoying tranquil moments of music and dance at a family wedding.

Making Lemonade

By Kathy LaFone (2010)

What is it like to be an Alzheimer's caregiver?

- ~It is to love without condition or expectation.
- ~It is to value the predictability of routines yet to be flexible enough to jettison them when your loved one needs something not called for in the schedule.
- ~It is to hug long and strong and often whether or not your loved one can hug back with one arm, with both arms, or not at all.
- ~It is to laugh, dance, and cry with your loved one.
- ~It is to accept the gifts of warmth and comfort while holding hands in silence.
- ~It is to keep smiling (while fighting back tears) when a spouse of 20+ years asks, "Are you my mother?" while you are helping him bathe.
- ~It is to honor and continue to provide life-long preferences like classic rock and roll (tuned up really loud), dark chocolate, dark greens in salads, and Dr. Pepper.
- ~It is to remember a loved one's distaste for cauliflower (the evil vegetable).
- ~It is to not take myself too seriously.
- ~It is a relentless, ever changing experience that requires a heart of gold and nerves of steel.

~It is to find joy in eye contact and gesturing when words are no longer possible.

~It is to be "compassion in action" and a warrior against the darkness of dementia.

~It is an adventure and a work in progress.

~It is an incredible journey of love.

This piece was originally published on July 10, 2010, on The Alzheimer's Reading Room website. I shared it with the Duke Dementia Family Support Program staff member, Edna Ballard, that year in an effort to honor my husband, Tim, to take positive action, to "Make Lemonade". It was on a particularly distressing day, a day when I experienced strong feelings of swimming against the tide in my efforts to be a loving, helpful, and compassionate spouse and caregiver.

How was Tim honored while he lived for more than 18 years with Frontotemporal Degeneration (FTD)?

We Kept Making Lemonade...

- ~Trying to focus on Tim's gifts, abilities, and outrageousness, while being mindful of the increasing unexplained challenges he was facing in language, movement, and cognition while still a young man in his 40s.
- ~Doing many typical things families enjoy together such as raking leaves, playing with our dogs, shooting hoops, and eating pizza on Friday evenings.
- ~Supporting the school, musical, and social endeavors of our young daughter, Sara.
- ~Hosting Raquel, a delightful and gifted Rotary Exchange Student from Spain.
- ~Finding and using supportive community resources to help with transportation and companionship to minimize Tim's sense of isolation when he was no longer able to drive, work, or manage long stretches of time on his own.
- ~Traveling with family & friends to hike, fish, enjoy campfires, and visit an apres-ski venue at which Tim had regularly performed with his band years before. He was pleased beyond measure to revisit his old stomping grounds.
- ~Supporting Tim's musicianship through music therapy sessions, visits with friend-musicians, and making sure Tim had a harmonica in one of his pockets when he dressed each morning.

continued on page 9

REFLECT *(continued from page 8)*

~Finding joy when playing harmonica for friends in front of Duke's Memory Disorders Clinic became busking when Tim received an unexpected tip from passersby.

~Attending a Rolling Stones concert. Tim was having increasing difficulty navigating the event - the parking, the shuttle, the crowd, the stadium steps - was something akin to being contestants on America Ninja Warrior. Tim stood for the entire concert. I held my breath from start to finish and was grateful that we were with friends and our daughter. Was it worth the uncertainty, energy and effort required? Unquestionably! Tim exclaimed "that was great" countless times, for many days after.

~Attending caregiver conferences and learning from more experienced caregivers and folks with varying dementia diagnoses.

~Assuring Tim's participation in a support group for men affected by younger-onset cognitive challenges. Tim's insight was valued, and he found fellowship, acceptance, friendship, a sense of belonging, and opportunities to help others.

~Joining two other couples on a panel at the *Alzheimer's 2002: What's New and What's True?* Duke's annual dementia conference. Tim was always at ease at a microphone. His responses to the questions of 500 attendees flowed easily that day as he spoke openly and honestly. A performer at heart, Tim "brought the house down" with laughter as he continued to bring joy to others.

~Journaling to capture emotions, unforgettable moments, and to note people and things for which to be grateful.

~Attending support groups and completing training to become an Association for Frontotemporal Degeneration (AFTD) support group leader.

~Moving to another home that required less maintenance and was closer to my workplace, Tim's day program, and Sara's school to simplify our daily schedule.

~Balancing the need to empower and protect Tim as the disease progressed into every aspect of our lives.

~Developing and updating a list of "Tim Tips" when he could no longer live at home alerted staff members to Tim's needs and preferences. As a result, Tim received more consistent care from staff and felt safer and more comfortable.

~Giving Tim constant access to a wide-ranging collection of classic rock n' roll, folk, & blues CDs plus

recordings of his performances.

~Joining or organizing long-term care Family Councils and helping to forge friendships, share resources, support & learn from other families as we advocated for quality residential care.

~Taking leaves of absence from my work at critical times when the disease process accelerated, Tim's needs changed, and plans for care needed to be modified.

~Creating and gifting Team Tim shirts with his words "thank you, thank you very much" to show appreciation for help and to acknowledge the reality that something much bigger than our family was at work in our lives.

~Saying "YES" to visits from unexpected gifted volunteers during Tim's final days at the Hospice Pavilion. These visitors brought exceptional live music, an extraordinary therapy dog, presence and peace.

How has Tim been honored since his nearly 2-decade long marathon with FTD ended four years ago?

We Continue Making Lemonade...

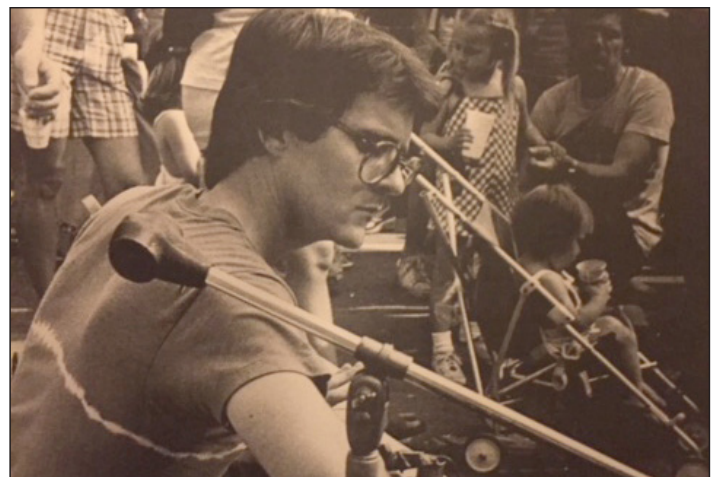
~Despite missing Tim terribly, we sing, laugh, dance, and we are joyful remembering him.

~We served Tim's favorite cheesecake and chocolate at his memorial service.

~Company, comfort, prayer, conversation, music, literature and laughter are shared in Tim's memory with those no longer able to leave their bed, room, or home.

~Nods from the universe are acknowledged regularly.

Hearing one of Tim's set list songs on the radio, in a store or at a concert.



*Tim playing his lap dulcimer at a street arts fair.
Circa 1980's*

REFLECT *(continued from page 9)*



Tim set his camera up on a tripod and took this photograph right smack in the middle of Morgan Imports in Durham NC. December 1991

Bumping into and reminiscing with Tim's long-time friends.

Pausing to marvel at the on-going generosity of family and friends, an awesome guitar riff, the beauty of a bird in flight.

~Responding with a "YES" and a sense that Tim's spirit is nudging me when organizations ask me to speak, support, or contribute to those diagnosed with dementia and/or caregivers.

The Incredible Journey of Love Continues...

Vanished Away
By Sara LaFone (2003)

Where have you gone?
You're losing yourself
Bit by bit
Vanishing Away

Your life is an hourglass
Each grain of sand a precious memory
They're falling, slowly
Vanishing Away

When your body is but an empty shell
Feeling numbly through this world
Know that all will remember you
As you were before
For I will always sing your song

And hear you singing with me
When you have Vanished Away

I emailed this poem to my mother when I was ten or eleven years old and I am now 28. I feel extreme vulnerability bordering on embarrassment when re-reading childhood poetry.

I was eight years old when I became aware that something was happening to my father. It started with him stumbling over words and forgetting how to do the things he had always done. My father was a musician and a born jokester – at his gigs he started to forget words to songs he had known for decades. He began to do a lot of eyebrow-furrowing and nervous wringing of his hands, but I wasn't totally clear as to why this was. We hadn't found a name for it yet.

There were sticky notes on cabinets, on remotes, on bathroom mirrors - reminders of how to interact with items he had known all of his life. Soon he wasn't working his regular job anymore. One day I came home from school to find my father home, but his Mazda truck was missing from the driveway. Confused, I asked him where his truck was, and he wove the sensational and unbelievable tale that it had "blown up". It turned out that he had sold the truck for an illogically small amount of money.

All of these early milestones are impossible for me to place neatly on a timeline, but in the midst of all of this was his first dementia diagnosis in the year 2000. I knew my father would suffer – it was made very clear to me



Tim and Sara celebrate middle school musicianship excellence.

continued on page 11

REFLECT *(continued from page 10)*

that he would continue to lose more of what he had left.

I had little scholarly language to articulate my devastation. I was full of questions about my father's all-consuming illness, most of them beginning in "Why?" I was angry with God – I couldn't comprehend that the same God that I had been spending my Sundays dressing up for and singing to could allow such a slow, cruel fate to befall a fundamentally good man. Before his illness, my father was a kind and optimistic man, consistently bringing two gifts into every situation: humor and music. He carried these essential parts of him through his illness - even when his spoken words failed to put themselves in the correct order, you could tell by his mischievous expression that he was attempting a joke. He kept a harmonica in his pocket for as long as he could walk.

I think of him every time I hear a song he used to sing, and every time I go to a show that I know he would have loved. I look upward and ask him what he thinks; I tell him that I wish he was there with me. Luckily for me, and my continuing relationship with my father, music is everywhere.

My father loved being the center of attention, so my mother and I felt that it would be best to bring everyone else in on this musical communion through TIMFEST, an annual celebration of all things Tim LaFone. For the past two years we've filled a local bar with good folks, musical entertainment courtesy of my father's friends and bandmates, and with my dad's favorite foods. I wander from person to person, gleaning stories from all of the characters in my father's life – I meet new folks and learn more about him each year. To quote my surprisingly insightful 11-year-old self, we continue to "sing his song".

I have respect for my younger self for writing "Vanishing Away" without fear of mediocrity or judgement – the lessons we learn from the things we surprise ourselves by doing might be the most powerful kind.

Thank you to my father for pushing me to sing his story and mine in a new way - as long as there's music to be made, heard, and felt, there will be no vanishing on my watch.

Kathy LaFone spent thirty years as a NC public school educator.

Sara LaFone is a social work graduate currently working with a biotechnology company.



The members of the last band with which Tim performed, the Geezors.

JOIN US IN CELEBRATING THE LIFE OF
TIM LAFONE

AND RAISING AWARENESS

ABOUT
FRONTOTEMPORAL
DEGENERATION

A FOOD FOR THOUGHT EVENT



SAT OCT 6TH * 6:30 TO 11PM * NASH STREET TAVERN * HILLSBOROUGH NC

HOUSE RECOGNIZES AND RESPONDS TO CARE NEEDS FOR PEOPLE LIVING WITH YOUNGER-ONSET ALZHEIMER'S

The Key Provisions of the Younger-Onset Alzheimer's Disease Act included in House Reauthorization of the Older Americans Act (OAA)

WASHINGTON, D.C., October 28, 2019 — The Alzheimer's Association and the Alzheimer's Impact Movement (AIM) are celebrating the inclusion of the key provisions of the Younger-Onset Alzheimer's Disease Act in the reauthorization of the Older Americans Act (OAA) by the House of Representatives.

"Too often, people living with younger-onset Alzheimer's have been unable to access fundamental programs and services because of their age," said Robert Egge, Alzheimer's Association chief public policy officer and AIM executive director. "We are grateful to the cosponsors of the Younger-Onset Alzheimer's Disease Act and the House of Representatives for voting today to ensure individuals living with younger-onset dementia and their caregivers have access to these services."

The Younger-Onset Alzheimer's Disease Act (H.R. 1903/S. 901) was introduced by Reps. Kathleen Rice (D-N.Y.), Pete King (R-N.Y.), David Trone (D-Md.), Elise Stefanik (R-N.Y.), Maxine Waters (D-Calif.) and Chris Smith (R-N.J.), and Sens. Susan Collins (R-Maine), Bob Casey (D-Penn.), Shelley Moore Capito (R-W.Va.), and Doug Jones (D-Ala.) in March, and endorsed by the Alzheimer's Association and AIM. Advocates held hundreds of meetings with members of Congress to grow bipartisan support for the bill, leading to 216 House and 36 Senate cosponsors.

Since 1965, the OAA has provided support to America's seniors in their homes and communities by organizing and delivering nutritional programs, in-home services, transportation, legal services, elder-abuse prevention and caregiver support. However, only those over the age of 60 are OAA-eligible, leaving Americans living with younger-onset Alzheimer's unable to access the vital OAA-funded programs and services that older Americans rely on.

The reauthorization of the OAA includes the key provisions from the Younger-Onset Alzheimer's Disease

Act, including providing access to support services including nutritional services, supportive services, and respite care through the National Family Caregiver Support program.

"Today's action by the House is an important step to ensure individuals living with younger-onset Alzheimer's have access to critical support services," said Egge.

In June, the Senate Health, Education, Labor and Pension (HELP) Committee included elements of the Younger-Onset Alzheimer's Disease Act in its draft language of the Older Americans Act reauthorization bill. The Alzheimer's Association and AIM will continue to work with lawmakers to continue to build bipartisan support for the Senate bill and ensure it is signed into law.

Alzheimer's Association

The Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support and research. Our mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health. Our vision is a world without Alzheimer's. For more information, visit www.alz.org.

Alzheimer's Impact Movement

The Alzheimer's Impact Movement (AIM) is a separately incorporated advocacy affiliate of the Alzheimer's Association. AIM works to develop and advance policies to overcome Alzheimer's disease through increased investment in research, enhanced care and improved support. For more information, visit alzimpact.org.



EXCERPTED WITH PERMISSION FROM “SURVIVING ALZHEIMER’S: PRACTICAL TIPS AND SOUL-SAVING WISDOM FOR CAREGIVERS”

By Paula Spencer Scott

David Troxel: Give ‘Em a Reason to Get Up in the Morning

Meaningful activities improve mood, cooperation, and even cognition – but planning things to do needn’t be a burden on you, says this expert on Alzheimer’s therapy.

“Alzheimer’s? What’s that?” friends would ask David Troxel back in the mid-1980s, when he began working at the University of Kentucky Alzheimer’s Disease Research Center (one of the first such centers funded by the National Institutes of Health). “There were no medications, fewer services, and little awareness,” says the dementia-care consultant. But there was, also in Lexington, one of the first day programs for people with Alzheimer’s, founded by Virginia Bell. Frustrated families would bring in loved ones, warning, “Mom’s so ornery!” or “Dad won’t do anything!” Hours later, having done some art and exercise, maybe set a table or talked with others, they’d leave almost as if a different person. Troxel began to focus extensively on activity-as-therapy.

In 1996, he and Bell developed the “Best Friends model” for Alzheimer’s care, which holds that what each person with dementia needs most is a steady friend who will provide loving care, accept their illness, and learn the “knack” of boosting quality of life. The duo also wrote the oft-quoted “Dementia Bill of Rights.”

Troxel, whose mother, Dorothy died of Alzheimer’s in 2009, is a past president of California Central Coast Alzheimer’s Association.

With Bell, he co-authored *A Dignified Life: The Best Friends Approach to Alzheimer’s Care, a Guide for Family Caregivers and The Best Friends Book of Alzheimer’s Activities*. Though written mainly for long-term care professionals, you’ll find the two activity guide volumes dizzyingly fully of great ideas, including advice on tailoring them for different stages of dementia.

Why you don’t want to flick on the TV and park your loved one: It might seem easy, but ultimately, it’s not helping you or your family member. People with early stage Alzheimer’s have told us they value creative activities as a tool for maintaining quality of life. All

through the disease, interacting with others and doing absorbing things can improve mood, provide a sense of meaning and accomplishment – and enrich lives (theirs and yours).

Socialization is treatment for Alzheimer’s disease. Boredom is the enemy. If nothing is going on, it often leads to the challenging behaviors that we see – agitation, aggression, crying, wandering.

Current medications for memory are modest in their impact. The good news, though, is that we’ve learned a lot about how to help people with Alzheimer’s through activities and engagement.

I’m not talking about just being generally kind and loving. It’s about building pleasure into the day. Use activities as a tactical strategy to foster cooperation and success as a care partner. This kind of approach can turn a “no” into a “yes.”

Dignity is key. Keep things on an adult level. I’m not for crayons or baby dolls, which can feel demeaning and lead to frustration or anger (although everyone is different and some people are comforted by dolls). Think about your parent’s or partner’s life story and build rituals around that. Are there parts of their life story that evoke a smile or pleasant memory? My mother, a Canadian, loved a cup of Earl Grey tea with milk, and it would soothe her on a bad day. Maybe your mom loves to talk about her childhood on a wheat farm in Walla Walla, or your dad likes to revisit his famed hole-in-one and do a little putting with you.

People often ask me, “Do you think I should...?” And I usually say, try it! Want to take Dad to a ballgame? Sure. Have a plan B – bring a pal with you to help, be prepared to leave early. But don’t fear failure. There’s a bit of emphasis in the world of Alzheimer’s care on “failure free” activities and sticking with what works, but I think people with dementia are like the rest of us – they like novelty.

Always doing the same, safe activity can get stale and boring. It’s good to be bold. (Using common sense, of course – maybe a 43-day road trip in a Winnebago isn’t such a good idea!) You’ll know soon enough if something isn’t working. And you can regroup.

continued on page 14

SURVIVING ALZHEIMER'S *(continued from page 13)*

Start with categories of activities like these:

- **An ongoing project.** My all-time favorite came from a woman in New England whose mother loved ice cream. (Don't they all?!) One summer, she decided they'd visit every ice cream store in the area and create a scrapbook about it. They had their picture taken together in front of each shop, saved souvenirs like menus and napkins, and rated and reviewed each place. It was like their own Zagat guide. By the end of summer, they'd been to 23 ice cream shops and had a wonderful scrapbook to reminisce over.
- **Anything musical.** Lyrics can stay in the brain even after language skills are lost. Music can be a real source of joy. My mother loved to listen to the 40s and 50s music channels on cable TV. I'd also rent old musicals on Netflix – if you turn on closed captioning, the song lyrics pop up. We'd have a sing-along. Later, when she lived in a care facility, I'd talk up taking her to a "concert." We'd make ourselves nice to go hear, say, Luciano Pavarotti (even if it was just a CD playing in the music room).
- **Just being outside.** Take a walk, sit on the front porch, wheel your mom out in her wheelchair. You don't have to DO anything. Twenty minutes outside gives a day's worth of Vitamin D.
- **Doing things for others.** When Santa Barbara neurologist Robert Harbaugh gives a diagnosis of Alzheimer's, he also tells patients, "Now I want you to go to church / go to Macy's and spend your husband's money / volunteer somewhere." He knows that being social is key. Your mom might not want to do an art project, but she'd make something for her grandchildren. One woman and her mom baked dog biscuits for local animal shelters. Intergenerational activities work on multiple levels.
- **Simple chores.** People with dementia still need to feel productive – arranging flowers, sorting and organizing, folding clothes, hammering nails. When my mother was in assisted living, I'd keep rolls of wrapping paper, bows, and supplies in her room. I kept buying new things for her to help me wrap – for a friend, I'd tell her. She had so much fun, picking the paper, holding the ribbon while I tied the bow.
- **Solicit advice.** I'd bring my mom half a dozen

dress shirts and neckties, and ask for her help. She loved matching the shirts with the best neckties. It's empowering to feel you have a say in things.

- **Yes, exercise.** You already know the evidence shows it's so powerful. It may even be able to slow the progression of Alzheimer's disease. But one of the unsung benefits is that it provides small successes, a sense of accomplishment to take that short walk, or stretch with a therapy band, or do simple yoga. Bonus: Exercise builds strength and balance, reducing the risk of falls. And it's good for you, the caregiver, when you do it together.

Socialization and engagement shouldn't fall completely on your shoulders. Don't wait to tap into services near you. Look for an adult day center that has a dementia program. They're hard to find, but you're in luck if there's one near you. Or see if you can get someone with an upbeat personality to come into the house to talk and do simple projects with your relative, someone who's lively and laughs.

You don't have to structure every moment of the day. The idea is to improve your lives, not make it harder on you by being a one-person activity committee. Try to build in three or four anchor activities throughout the day, things that become part of your routine, such as a morning stretch followed by a favorite music show or nature video, time before lunch to play with or groom a pet, then afternoon tea or happy hour. When you think about your life or mine, we don't have every minute planned out. Sometimes we're busy, sometimes we nap or just sit on the sofa.

Doing nothing is also doing something. People with dementia tend to want to be with you. "Activity" can sometimes mean just being next to you while you do your own thing – going driving, going to the grocery store (if Mom isn't an aggressive wanderer), or just holding hands with you while you sit and read.

Don't overlook simple pleasures. My mom loved nothing more than going for a drive and listening to old music. Then we'd pull into a drive-through restaurant and order a hot dog followed by ice cream, so we didn't have to get out of the car and deal with waiting at a table and all that. Plus, it had all the winning elements many people with dementia seem to love – driving, music, and ice cream!

Nov 2019


Valuing the Invaluable:

Understanding the Contributions of Family Caregivers

In 2017, about 41 million family caregivers provided an estimated **34 billion hours of unpaid care** to an adult with limitations in daily activities. The estimated economic value of their unpaid contributions was about **\$470 billion in 2017**.

HOW MUCH IS \$470 BILLION?

Family caregiving estimated value	\$470B (\$1,450 for every person in the US)
Out-of-pocket spending on health care	\$366B
Total long-term services & supports (LTSS) spending	\$366B
Medicaid spending on LTSS	\$154B



FAMILY CAREGIVERS AREN'T WHO YOU THINK THEY ARE...



Nearly 1 in 4
(24%)
is a millennial.



40%
are men.



About **40%**
represent multicultural communities.

FAMILY CAREGIVERS ARE...



Becoming more **diverse**.



Paying for care themselves. (**\$7,000**, on average, in 2016)



In most cases, **juggling paid work** while caregiving. (60% of family caregivers)



Carrying out increasingly complex tasks, like **wound care and giving injections**.

THE CARE GAP IS GROWING

Rising demand and shrinking families will increasingly strain family caregivers and those they care for.



In 2010, there were **7.1 potential family caregivers** for every person 80+.



By 2030, there may be only **4.1 potential caregivers** for every person 80+.

POLICY AND PRACTICE: CHANGE IS ACCELERATING



At the federal level:

RAISE
Family Caregivers Act

- Congress enacted the **RAISE Family Caregivers Act** in 2018.
- **Expanded Medicare reimbursement** for several services benefit family caregivers.
- Supplemental benefits under **Medicare Advantage** can now include LTSS and supportive services.
- **Managed LTSS programs** have begun to recognize and support family caregivers.



At the state level:

CARE
Caregiver Advise, Record, Enable Act

- The **Caregiver Advise, Record, Enable (CARE) Act** has been enacted in **43 states and territories**.
- There is growing momentum and support for **paid family leave** in the workplace.
- Some states are beginning to provide **financial relief** for family caregivers.
- Washington State established the first public long-term care insurance program in 2019.

MORE ACTION IS NEEDED TO HELP CAREGIVING FAMILIES



The aging of the population and its impact on families can **no longer** be viewed as a private, family-only issue.



America's public policies have **not kept pace** with changing demographic and social trends.



Investments in family caregiving supports today will **build a more caring society** for our families and ourselves tomorrow.

BOOKSHELF

Ambiguous Loss: Learning to Live with Unresolved Grief, by Pauline Boss, 2000. *Ambiguous loss is simply an unclear loss. It is a term I coined in the 1970's to label the all too common experience of having a loved one disappear without evidence of whereabouts or being dead or alive. Such disappearance can be physical, as in the case of a loved one gone missing, or psychological, as in the case of dementia when memory and emotion fade away.*

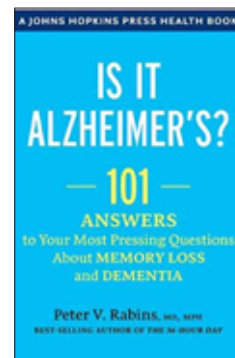
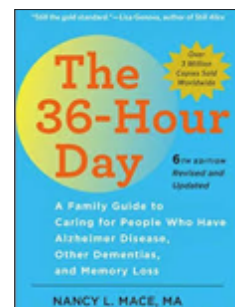
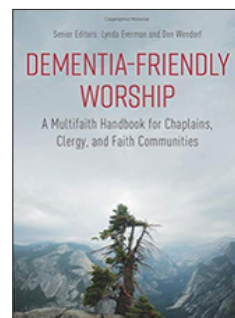
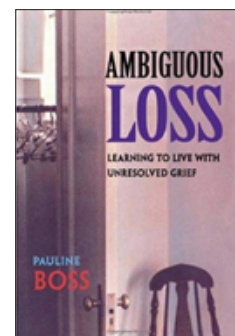
Boss, a researcher and therapist, is best known for this book in which she illustrates the effects of ambiguous loss through relatable stories of real families. More than just narratives, Boss suggests strategies to help families experiencing this painful uncertainty. "Ambiguous Loss" is engaging and easy to read.

Dementia-Friendly Worship: A Multifaith Handbook for Chaplains, Clergy, and Faith Communities, by Lynda Everman and Don Wendorf (senior editors), 2019. *Dementia-Friendly Worship offers a deeper dive into how faith communities may include and support individuals and families facing the challenges of dementia. The book includes several articles written by people from different faiths who are living with dementia; and the rest of the book features chapters from clergy of many different religions. Since religion, worship and spirituality are important to so many people living with dementia, this book is a welcome new tool for faith leaders.*

The 36-Hour Day, 6th Edition, by Nancy L. Mace and Peter V. Rabins, 2017. This comprehensive and easy-to-read classic explains the medical and behavioral symptoms of dementia and offers suggestions for handling problems, managing transitions, and coping with the impact of being a family caregiver. While especially useful to select relevant chapters to read as needed, if you find yourself short on reading time, it's also available as an audiobook. Written by professional experts, with input from experienced family caregivers, *The 36-Hour Day* is simultaneously practical and supportive, and is recommended for both new and longtime caregivers.

Is it Alzheimer's? 101 Answers to your Most Pressing Questions about Memory Loss and Dementia by Peter V. Rabins, 2020. "Is it Alzheimer's?" by the trusted geriatric psychiatrist author of "The Thirty-Six Hour Day," takes readers far less than 36 hours to make personal sense of contradictory reports on risks for dementia, what is known, not known or may be known soon. There are brief but deft, helpful suggestions on responding to false accusations, demands for the "real" husband she no longer recognizes, and inevitable sleep changes.

Dr. Rabins' plain language, positive bottom-line guidance for tough care decisions and answers to questions about "truth" will resonate with family caregivers. The slim book reads like an authentic reasonable conversation with the doctor we all seek, blending the essence of clinical wisdom, a strong ethical base and up-to-the-minute evidence-based, relevant research findings.



BOOKSHELF *(continued from page 16)*

The Last Ocean: A Journey Through Memory and Forgetting, by Nicci Gerrard, 2019. Gerrard, an award-winning British journalist and co-author of thrillers written under the pseudonym Nicci French, writes about dementia after her father's death. This beautifully written book describes dementia from the perspectives of those living with cognitive disorders, their caregivers, physicians and researchers; and offers a unique combination of memoir and investigative journalism.

Gerrard's father John is almost a backdrop of the book that switches among different families in a way that is sometimes confusing. Yet she provides enough about John to capture the readers' interest. "The Last Ocean," includes moving accounts of her father's painful journey along with glimpses into other families facing similar challenges with getting a diagnosis, experiencing stigma, and searching for quality care.

My Life Rearranged, by Susan G. Miller, 2018. In "My Life Rearranged," Susan Miller chronicles her years of caregiving for her husband who was diagnosed with younger-onset dementia at age 55. The book is divided into three sections – the beginning, middle and final stages of her husband's illness. Miller uses poetry to share her feelings and experiences during each stage in a way that is honest, sometimes painful, and according to care partners who recommended the title, very relatable.

Here is one of Miller's "musings," from the beginning stage section:

anger

You get to do whatever you want.

You get to be not accountable, while I pick up the pieces, do the work of two.
You get to focus on yourself; your privilege bestowed upon you by the disease.

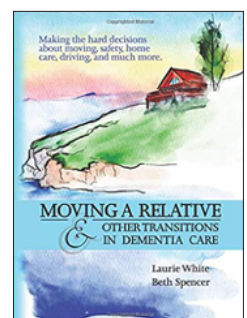
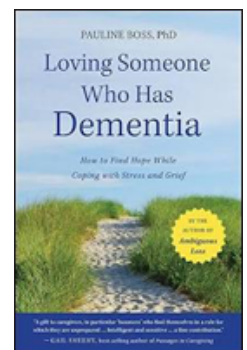
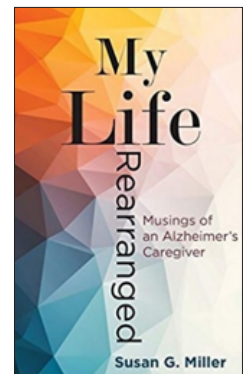
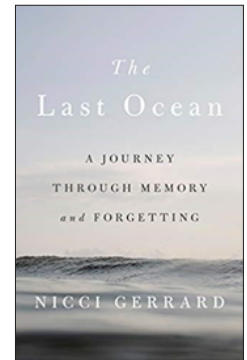
You are accommodated, looked after, taken care of, and worried about.

I am exhausted, alone, weary, carrying both of us.

Symbiotic victims – one excused, one invisible.

Loving Someone Who Has Dementia: How to Find Hope while Coping with Stress and Grief, by Pauline Boss, 2011. Another book based on Boss' research and clinical experience, this one focuses on the ambiguous loss of dementia and the limbo of living with someone who is simultaneously here and not here. Boss offers readers strategies not typically discussed in caregiver books, such as finding hope and meaning, managing mixed emotions, and even thinking about your own future. Although longer than "Ambiguous Loss," families will find "Loving Someone with Dementia" a manageable read with a conversational style.

Moving a Relative & Other Transitions in Dementia Care, by Laurie White and Beth Spencer, 2019. This well-organized guide offers information about cognitive changes, getting a diagnosis, safety issues, and moving a family member with dementia. The chapters on moving include the basics, plus some less-commonly addressed information, such as a script for a family meeting with a person with dementia, action items when moving someone from out of state, and how to help facility staff get to know your relative. The authors' use of case studies, tips and resources, all highlighted with graphics, make this book uniquely easy to understand and practical.

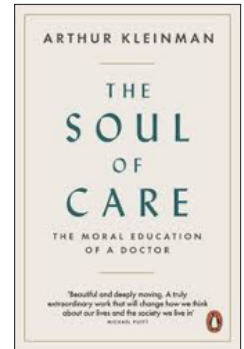


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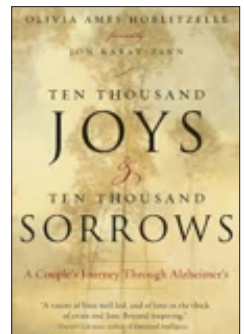
BOOKSHELF *(continued from page 17)*

The Soul of Care: The Moral Education of a Husband and a Doctor, by Arthur Kleinman, 2019. In “The Soul of Care,” Kleinman, a psychiatrist and medical anthropologist, tells two stories – one about his early years and medical training, and the other about life after his wife is diagnosed with dementia. Woven through both stories is the author’s commentary about the shortcomings of America’s health-care system.

Caregivers might want to skip the first six chapters and just read about the decade of his wife’s illness and the author’s humbling transformation as her caregiver

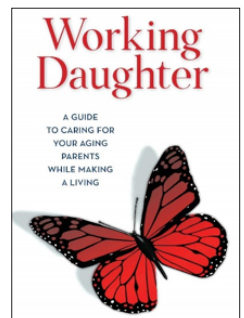


Ten Thousand Joys & Ten Thousand Sorrows: A Couple’s Journey Through Alzheimer’s, by Olivia Ames Hoblitzelle, 2010. In this beautifully written and moving memoir, Hoblitzelle describes her courageous husband’s six-year journey with Alzheimer’s, beginning with his diagnosis at age 72. The author used Buddhist teachings to help her husband live a good life in the face of accelerating losses, to navigate the most difficult times, and then ultimately to let him go. This book also offers readers practical suggestions, based on what worked well for the author and her husband. Each chapter ends with an insightful section of Reflections, Suggestions and Seed Thoughts (brief prayer-like statements).

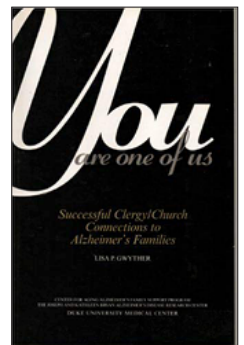


Working Daughter: A Guide to Caring for Your Aging Parents While Making a Living, by Liz O’Donnell, July 2019. O’Donnell shares personal stories and lessons she learned while caring for her mother and father, juggling young children, and working full time. She writes with candor about managing her parents’ crises in the face of her own exhaustion, her frustration over well-intentioned suggestions to take care of herself, and her dismay with the lack of support at work.

O’Donnell also offers practical ideas about setting priorities and boundaries, about what to do when elder care interferes with work, and how to have “the conversation” with parents about accepting help. Working Daughter is well-written and an easy read that we recommend for caregivers and employers.



You Are One of Us: Successful Clergy/Church Connections to Alzheimer’s Families by Lisa P. Gwyther, 1995. Our Program’s founder, Lisa Gwyther, has always been at the forefront of dementia caregiving, and her wisdom is apparent in *You Are One of Us*, which she wrote 24 years ago – before inclusiveness and accessibility were everyday terms. Lisa created this brief paperback because she listened to families who missed the much-needed support they had expected from their church communities. *You Are One of Us* offers clergy and church members the basics of Alzheimer’s symptoms, stages and communication tips, followed by practical suggestions for how a church community may better support congregants living with dementia and their family members. Lisa readily admits some of the language is dated and that she wrote this for a Southern audience; but *You Are One of Us* remains a classic resource for faith groups.



THANK YOU, DONORS

For the Duke Dementia Family Support Program

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Durham, NC 27710



The CAREGIVER

Newsletter of the Duke Dementia Family Support Program

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YOUNGER-ONSET *(continued from page 1)*

Younger-Onset Dementia Resources

If You Have Younger-Onset Alzheimer's Disease

Alzheimer's Association - <https://www.alz.org/help-support/i-have-alz/younger-onset>

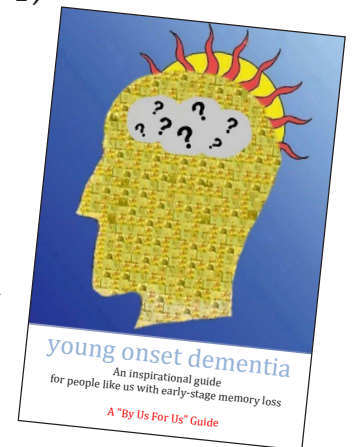
The Association for Frontotemporal Degeneration - <https://www.theaftd.org/>

Young Dementia UK - <https://www.youngdementiauk.org/>

“young onset dementia: An inspirational guide for people like us with early-stage memory loss” - A “By Us For Us” Guide

https://the-ria.ca/wp-content/uploads/2018/11/BUFU-Guide-Young-Onset-Dementia_AODA.pdf

See page 2 for contact information for the Duke Dementia Family Support Program, including the Younger-Onset Support Group, and other organizations that may be a source of information and support.



Early-Onset Alzheimer's is a Social Security Compassionate Allowance Condition

Compassionate Allowances are a way to quickly identify diseases and other medical conditions that, by definition, meet Social Security's standards for disability benefits. The CAL initiative helps reduce waiting time to reach a disability determination for individuals with the most serious disabilities. The Compassionate Allowances program identifies claims where the applicant's disease or condition clearly meets Social Security's statutory standard for disability. By incorporating cutting-edge technology, the agency can easily identify potential Compassionate Allowances to quickly make decisions.

<https://www.ssa.gov/compassionateallowances/>