



CAREGIVER SUCCESS STORY: TRACY READING

We received overwhelmingly positive responses to our recent “deeper dive” interview with fellow family caregiver, Lin Garvey – and so we have decided to continue with this Q&A approach. Next up, we sat down for a conversation with Tracy Reading, husband of member, Pauli. Read on to hear what Tracy shares about building an impressive support team, adjusting to the “new norm,” and the surprising gifts awaiting caregivers along the dementia journey

The Ivey: What was your initial reaction to Pauli being diagnosed with early onset Alzheimer’s at age 54?



Tracy: The real earthquake was when I said, “Okay, dammit I don’t wanna hear that but all right. If there’s four stages of cancer, is she at stage one?” And the doctor said, “Well, there’s actually seven stages of Alzheimer’s, and I think she’s at stage five.” I was like, “I don’t even know how to comprehend this.” Prior to hearing that, I was always agitated, in denial, mad because I didn’t know what was going on with her. The minute I heard what she had, it was a complete game changer. And I just basically said, “Alright, she can’t control this. She can’t impact this. We’re in this thing together.” I have a whole different outlook now.

The Ivey: Tell me about the Army of Angels. Where did the idea come from? What role has it played? How has it evolved?

Tracy: First, I created a vision and the mission statement. I’ve gotta protect her and I’ve gotta love her and I gotta keep her happy. But I knew it was going to be hard and that I needed to get help.” So I literally just said, “I’m gonna go ahead and create an army.” When I started, I only had three people in the army. It was me, my Mom and her best friend. That was it. And over two-and-a-half years, I now have over 100 in my army. I never was trying to go out and recruit as many people as I could. It’s not like Facebook, “Will you be my friend? Will you be my angel?” I always was very selective. I was all about quality, not quantity. What I realized, it’s not so much for her as it is for me. Because we all have different talents. I leverage people’s talents on how they can help me in any capacity.

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Save The Date @ The Ivey

John Leon Lewis Musical Performances

Monday 11:00 - 11:45 am March 4, 11, 18, 25 April 1, 8, 15, 22	Tuesday 1:30 - 2:30 pm March 19 April 16
Wednesday 11:00 - 11:45 am March 27 April 24 1:30 - 2:30 pm March 6, 13 April 3, 10	Thursday 11:00 - 11:45 am April 11
	Friday 11:00 - 11:45 am March 1, 15, 22, 29 April 5, 19 1:30 - 2:30 pm April 26

Senior Scholars

NEW DAY ADDED in response to growing high cognitive membership!
Senior Scholars sessions are now scheduled **THREE** days each week.
Tuesday, Wednesday & Thursday

The Ivey Support Group Meetings

12 Noon - 1:15 pm
The Ivey
6030 Park South Drive
Charlotte NC 28210

Tuesday Group 1st & 3rd Tuesday of each month	Wednesday Group 1st & 3rd Wednesday of each month
Younger-Onset 2nd & 4th Friday of each month	Male Caregiver 4th Wednesday of each month

For more information or to RSVP, call Eileen Behan or Leah Cooper at 704-909-2070.

Care services and lunch are available for your loved one during our meeting time (with advanced notice) at no charge. As a not-for-profit organization, donations are always appreciated.

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The Ivey: How did you find your way to The Ivey, and how did you know the time was right?

Tracy: For a year, I was organizing everything for her, and it just started taking more of a toll on me. Finally, a good friend said, "I think you need to meet with Lynn about The Ivey." So I met with Lynn and she said something profound to me: "Tracy, there's another disease that nobody knows. It's called caregiver's disease." And I kinda laughed because that year I literally called 911 twice because I thought I was having a heart attack. The stress was that hard. She said, "Listen, you've done an amazing job for the past year, but this is what we do professionally." I said, "This is where she needs to be." Literally I could not be standing here today if it wasn't for The Ivey. There's no way. I've got my Mom and I've got my army but this is a whole different dynamic. This place, the way they just go about it, is just amazing. I couldn't do it without them.

The Ivey: Many people at your age in life are perhaps still mid-career, preparing for retirement, enjoying life. Pauli's diagnosis has at least put some of those plans in flux or on hold. What is your perspective on this?

Tracy: You never think in your wildest dreams that it would ever happen to you. It had a major impact, but I immediately then decided that we'd go traveling. We did three cruises in three consecutive years. I wanted to travel as much as I could with her to create those memories and I'm really grateful that I did.. Now she's not at a point where we can do that. Now, this is uncharted water I'm in because I am gonna be 57. I've got about two more years and then I'm gonna retire. I might have a year or two years left with her, maybe longer, but I doubt it. All I know right now is I've gotta just stay focused on her, I gotta go through this journey with her the best way that I can and gracefully as I can and with as much dignity for her, and then after I've done that then I know I've done my part. And then at that point, I'll figure it out.

The Ivey: What would you say is the hardest part of the caregiving journey? And what's the surprising gift in it?

Tracy: I think the hardest part is, from a caregiver's standpoint, you've gotta figure out how to take care of yourself. That's the number one key. As far as the most rewarding part, Winston Churchill had a great saying: "When you're in hell, keep on walking." As a caregiver, there are times when you feel like you're in hell. It's like a grind, day after day after day. And you can try to put on your happy face, but it's hard. If you can just enjoy every moment that comes your way, that's the beauty of this whole journey.

The Ivey: Can you give us an example?

Tracy: Pauli's now at a point when she was looking at herself in a mirror, and I was near her, and she's making all these funny faces. And she's waving. I said, "What are you doing?" It was sad but it was really humorous in a way. She says, "This lady here is hilarious." She didn't recognize it was her. I'm looking at her, and she's having so much fun. She says, "Come and look. Look at how beautiful this lady is." And instead of freaking out, which I would have done three years ago, I looked in the mirror with her and I said, "You're right. She is so beautiful." That's where you just gotta take moments like that and just say, in her world this is what she sees. So why can't I go into her world and look at the beauty of what she sees? When you can do that, and just know that everything's gonna be okay and every day has beauty in its own way, it just makes it so much better. There's part of me now that just feels so blessed. She has always made me a better man in my life. And now I think she's even making me better in so many more ways. I think God has given me this opportunity. Every day you've gotta choose how you're gonna look at this thing and how you're gonna tackle this thing. Are you gonna do it with strength and grace and love and compassion? Or are you gonna do it with feeling sorry for yourself? I've been really grateful.



Challenges to Family Caregiving

Summary of an article originally by Alan Stevens, Carole White, Marcia G. Ory and Sandhya Sanghi from theconversation.com

Most Caregivers of People with Dementia are Family Members, and They Need Help

Family care of an older adult has emerged as an essential element of the U.S. health care system, with 83% of long-term care provided to older adults coming from family members or other unpaid helpers. As the population of older adults grows, so too does the expectation of family care for persons living with dementia.

Family caregivers experience multiple challenges daily when caring for a person with dementia. More recently, AARP reported that 36% of family caregivers who were not currently in the labor force said they retired early or quit their jobs because of family caregiving concerns. Despite the critical role that family caregivers play, support programs are not widely available. Moreover, caregivers are often marginalized or ignored by formal health care providers of the person with dementia.

Interventions that combine education about dementia and advice about specific “do’s and don’t’s” of dementia care with guided training and practice appear to be of greatest value to family caregivers. Still, health care and social service providers do not routinely provide support programs based on evidence-based interventions. Family caregivers are often left alone to provide care that can be complicated and exhausting 24/7.

Existing evidence-based interventions require dedicated personnel who must be trained to deliver the intervention, yet the delivery of the intervention are not covered by Medicare and other third-party payers and sadly, family caregivers are often either unaware of existing services, or they are unable to participate due to emotional stresses, time commitments or scheduling concerns.

Our care system depends heavily on family caregivers. If their needs are not recognized and addressed, family caregivers risk burnout from the prolonged distress and physical demands of caregiving, and the nation will bear the costs. Here are a few ideas:

- Health care providers should be encouraged to document the role of the family caregiver in the patient’s electronic health record.
- Health care providers should make every attempt to involve the family caregiver in all health care interactions, especially in discharge planning after a hospital stay.
- Health care systems can also facilitate a dementia-friendly approach by directing families to community-based support services to address common challenges such as getting medications and transportation to health care appointments.
- Colleges and universities could help prepare a dementia-friendly health care work force to meet the needs of the growing numbers of persons with dementia.
- All sectors of our society need to more formally recognize family caregiver services.

Know Your
RISK FACTORS



Gum Infection Linked to Alzheimer’s Disease

A new study suggests the bacteria *Porphyromonas gingivalis* that destroys gum tissue in the mouth is linked to dementia and Alzheimer’s.

Researchers observed the bacteria in the brains of people with Alzheimer’s disease and tests on mice also showed that gum infection led to an increased production of amyloid beta, known to be present in Alzheimer’s brains.

Learn more at <http://advances.sciencemag.org/content/5/1/eaau3333>

In our 12th year as Charlotte's only memory wellness day center!


6030 Park South Drive
Charlotte, NC 28210



Lynn's Attitude of Gratitude

When I read the interview with Tracy Reading in this issue of our quarterly newsletter, I was struck by the realization that he embodies gratitude in such a powerful way.

Reflecting on his caregiver role alongside his wife, Pauli, on her dementia journey, he emerged with this amazing perspective: "She has always made me a better man in my life. And now I think she's even making me better in so many more ways." These are the people who can serve as sources of inspiration for all of us, provided we take the time to hear their stories. Tracy, thank you for sharing yours.

Lynn Ivey, Founder and CEO