January - February 2022 Volume 13, Issue 1

Caregiver Network News

A newsletter for caregivers of loved ones with dementia

Love Doesn't Fail

A Caregiver's Thoughts

1. How long have you and your spouse been living with dementia?
We have just passed our first full year with a diagnosis. However, I go back 5-plus years, and can now say, "hmm, that's why he did this and that."

2. What was your initial reaction to receiving the diagnosis?
Being told my husband had a probable diagnosis of Frontotemporal Dementia I was gobsmacked and completely at a loss, not having a clue what that meant. All I heard was - dementia?!; he's just 60-years old. He was at that time still physically capable of maintaining a competitive edge as a professional equestrian. Are you sure this is not depression facilitated by middle life crisis? I had to immediately relinquish my judgement that dementia was relegated to senior citizens well into their golden years.

3. What was your husband's reaction to the diagnosis? Does he currently acknowledge that he has this condition?
My husband has no awareness of his diagnosis or the limitations it has imposed upon him. *Anosognosia* thwarts him from realizing that something is wrong, or that the prognosis is fatal. The doctors we have visited have explained what the probable diagnosis is, and he can't process what they are saying to him. I have read the medical reports to him, being very diligent to transpose every medical term into a layman's verbiage. His typical response is to chirp, "I'm fine; I'm great."

I was exhausted and emotionally bruised by his loops, as well as the declarations, "You have no right to control me!" or " You are ruining my life." I needed to change the channel. I stopped arguing or thinking there was any discourse that would end with us mutually landing in the same spot. I love him and there is an organic reason behind everything that was happening, and my ego needed to be checked. Yes, I feel the loss of my partner but not the feeling of love or being loved.

4. As the disease has progressed, what changes or situations have been especially difficult or challenging

for you?

Learning to affirm when actually I am saying "no" is not natural.

It took me quite a while not to buy into the gaslighting, and react thinking I was being lied to constantly. My learning curve was steep, and it was necessary for both of us. I am the one who has to figure out a way to keep us both safe. The progression and timing with FTD is completely an impossible course to plot. The nebulous state you live in as a caregiver is a gnawing mystery, and has me living life in 3 to 6 months chunks of time. I live eyes-wide-open knowing a shift is coming, and with FTD it is plateau and step down — how expansive is this latest plateau and how far will we fall with the next step down? For me, all I can do is file information and not expect anything but what I need to deal with today.

5. What have you done to address these changes?

I have heard other caregivers, family members and friends say, "oh it is difficult to "lie" to them." I am not sure what it says about me, but there was never a thought that what I was doing was a lie — I love him too much not to employ every technique to help ensure his safety and my survival. Living in the twilight of reality where life is tethered between here and there, I need to constantly try out new approaches to achieve a result that helps me meet the moment and challenges presented.

I learned that my ego was not served by conflict; however, his was soothed when his ego got stroked. Successful redirection and distraction was most effective when I showered him with loving words; flattering phrases. Making him feel good about "things" made my life easier, and gave me a person I could work with and keep safe. Actively embracing "letting go" and not holding a grudge is an on-going struggle — it is very frustrating that there is no one **with whom** to "work-it-out with." But then, I am the one who is still fully processing, and not losing sight of my humanity and compassion is one of the mantras that guides me daily.

6. What have you found that works and that doesn't work?

The most difficult place to get to was learning to say YES when I really needed to say NO.

My ego was the greatest impediment to getting there. It took months of frustrating exchanges; unfulfilled expectations and wishful thinking that he'll come back into my "world" before I learned how to gently negotiate to where we needed to go. Flattery helped slow down a spiral. Accepting responsibility for any and all disappointment — belting out, "I am sorry" no matter the situation. I started to pay close attention to questions that triggered a loop. I recall pointing out a unique color of a car — well, that turned into an immediate frenzy of requests to get his driver's license reinstated. Best I ask that he check the GPS for our estimated time of arrival.

7. How do you look after yourself and keep a positive attitude?

Self-care, the greatest need, and probably the most neglected.

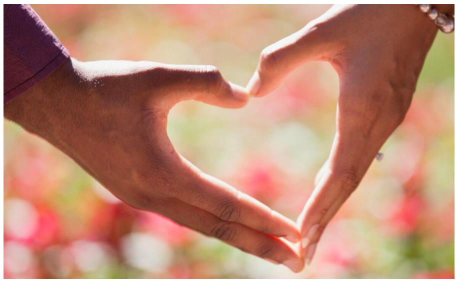
We were presented with our FTD diagnosis as the world went into lockdown, immediately limiting resources for safely receiving support. I have managed to develop a routine that serves us both —

- Daily walks at his favorite parks to keep interest alive
- Visits with friends that are still within memory's reach
- Puttering around the garden without any expectation
- Personally, I have a developed an online support system with other caregivers that specifically focuses on the FTD journey
- I have enrolled both my husband and myself in research studies: this experience has to be bigger than ourselves
- I journal often, and admittedly, have found myself releasing a primal scream into

the void

I am fiercely focused on our relationship, not what we do or don't accomplish during the day but making sure there is a joyous shared moment. Nobody ever died from not taking a shower, and I am continuing to learn which battles are really important. I have to release steam or explode - making him laugh releases steam for both of us, and is immediately effective therapy. I steal moments for myself throughout the day, much like a new mother with a newborn.

I am not a successful caregiver 100% of the time, and I have been known to lose my temper. I give myself a timeout, and a reassuring pep-talk. It is a gift to be loved, and a sacred responsibility to be the keeper of our memories.



8. What advice would you give to other caregivers?

The disappointment, anger and confusion is due to a disease that is attacking their mind, but not their heart. *Love and being loved has not failed.* As caregivers we need to be aware as changes in cognition and motor skills sputter - practice just being in the moment. A realistic assessment is continuing visited upon me — am I; can I continue to offer the care that is needed? Naturally we feel despair, and overwhelmed by the creeping isolation, it's vital to find community; myriad Zoom groups are occurring, and establishing relationships with other caregivers gives me perspective and lets me know I am not alone.

This caregiver reveals an insightful awareness of what he has learned along this journey with dementia…but he isn't the only one who is engaged in on-the-job training. Most of you are doing the same thing – learning as you go, struggling on the difficult days and treasuring the unexpected moments that make you smile – forgiving yourself for the mistakes, and always, always being mindful that you are the "keeper of the memories." It is, indeed, a sacred responsibility.

Here, other caregivers offer their observations on how they achieve a balance between caring for a loved one and caring for themselves:

- A Caregiver needs to remember to pause and to take care of self. There is a mind-body connection. Physical health **IS** related to mental health! Prolonged stress can result in poor health. For the benefit of the person in our care, we self-Givers must also be self-Carers. To sense and feel my own needs, my first step was toset a daily place and time. Doing it keeps me more balanced!

- The idea of being in touch with our own needs seems counter-intuitive when we are so focused on someone else's needs. However, both are important, both need attention, and both are vital to the journey. Self-care isn't selfish!

- I was getting burned out quickly from the demands of caregiving. Now I start each day, while my wife is still asleep, by writing long emails to friends. It's my version of keeping a journal, and it helps me pour out my frustrations to someone I know who cares. I am better able to face what comes during the day when I have had my "e-therapy." PS: sometimes it works out that I do this in the late afternoon instead of in the morning, when I can enjoy a beer like I used to do after a round of golf. You wouldn't believe how something this ordinary can feel so good.

- I have learned to do meditation. It was really difficult for me at first to try to keep my thoughts from jumping around, but the more I practiced it the better I got – and I'm much calmer and less irritated by things than I used to be. I'm still not good at it, but I'm good enough to get some benefit from it.
    - *[Don't know how to get started? Visit this link to get the basics of meditation: https://www.mindful.org/how-to-meditate/]*

- I putter. When I get some free time (my husband is taking a nap), instead of trying to cram as many errands or chores in as I can get to, I become like that TV commercial of the woman eating a piece of chocolate: I slow down, I let go, I allow myself to sit on the porch and enjoy the birds, or I leaf through a magazine, or I pull some weeds. Not every minute has to be productive, and I find that the down-time is therapeutic for me.

- One of the things that stood out for me from taking [MemoryCare's] Caregiver College was the importance of making lists of things for ME – I have plenty of lists of my husband's medications, and his PT and doctor appointment schedule, and TV shows and foods that he likes – but now I also keep a list of things that are good for ME, people that I like to stay in touch with, favorite jokes or emails or videos that are guaranteed to make me smile, a playlist of my favorite songs that make me feel good, a list of little projects that I want to accomplish when I get a few minutes (and let me tell you how good it feels to cross something off this list!), and a growing list of blessings in my life to help me focus on all the good things that I still have, even in the face of this awful disease. Dementia will try to suck up your life, but you don't have to let it!

"Life is a balance between holding on and letting go." -Rumi

Rotarians Moving to Fight Dementia

The Rotary Club of Asheville-Biltmore is hosting "Rotarians Moving to Fight Dementia" a 24-hour walkathon to fight dementia!

Friday Noon - Saturday Noon
February 25/26, 2022
Deerfield Episcopal Retirement Community,
Community Center Blue Ridge Room

Rotarians are people of ACTION. We exist to be of service, supporting clean water, food security, medical care, and other basic needs. Join in supporting this fundraiser and join us in making a difference in fighting dementia and supporting much-needed care. Dementia is a defining challenge of our time. Meeting challenges is what we do. This marathon is our way of making a difference and of putting our values into results. Join in supporting the best research and caregiving: CART and MemoryCare

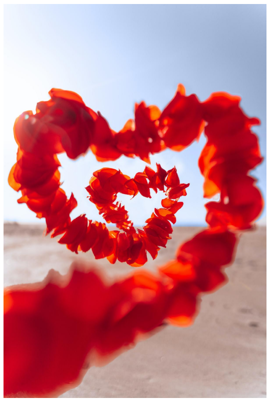
Click here to sign up to walk or make a donation.
Click here for an event brochure.

A special thanks to the sponsors of this newsletter:

Deerfield

GilreathShealy law
estate planning & administration

Valentine's Day for CareSpouses



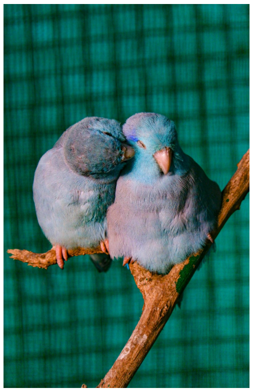
Valentine's Day – when we think of flowers, candy, and romantic candlelit dinners with our sweeties. But if your sweetie has Alzheimer's Disease or some other form of dementia, Valentine's Day may no longer be quite the same for you.

Caring for a spouse who has dementia is perhaps the biggest challenge of caregiving. "CareSpouses" must adjust both to the increasing decline of the person they love, as well as to the grief and loneliness of losing their life's companion. The person they have lived with and loved is changing, disappearing, leaving. CareSpouses often find themselves in a no-man's land of still being married, yet no longer having a marriage.

CBS News Correspondent Barry Petersen, author of *Jan's Story*, talks about the impact of his wife's early-onset Alzheimer's Disease: "...It robs us of sharing daily experiences, and robs her of savoring the good things that are a part of all of our daily lives....I am losing more than a friend...also slipping away is the one person who was my confidante, with whom I could and did share everything."

Like other caregivers, CareSpouses experience an array of emotions, including anger, resentment, denial, sadness, and frustration, especially in the early stages of the disease when their spouses appear normal to outsiders. As the disease progresses, they may add depression, betrayal, guilt, loneliness, and a feeling of failure when dreams are dashed, when lifestyles are altered, or when moving to a nursing facility becomes the only option. The first time they attend a social event alone is a sobering milestone.

Coming to the realization that the relationship you had with your spouse is being forever changed is not an easy thing to confront. You may now be more of a parent than a partner. One wife observed, "I'm no longer his wife; now I'm his caregiver." Barry says in his book, "I know only too well the feeling of being alone. We are slowly losing our best friend....They are not and will never again be the person we married."



But in the face of all the sadness, there can still be joy. Focusing on what is left, rather than what is lost, can help sustain a loving relationship for a while longer. Accepting that the disease has altered your loved one, and acknowledging the changes you must make to accommodate this, will help you hold onto the relationship, albeit a different one. Learning to accept silence where there was once conversation, anger where there was once tenderness, distance where there was once intimacy, is difficult to do, but it's much easier than resisting reality. It all comes down to adjusting your expectations, and to reminding yourself that the person you love is still in there somewhere.

Finding new ways to enjoy time together by going on walks or drives, listening to music, reminiscing with photo albums, having a picnic, feeding the ducks at the pond, watching old movies, or sharing simple household tasks can be meaningful opportunities for closeness. Your loved one may not instigate it, but they may respond to it. You might be surprised at how much there is still left to enjoy.

So make a list of what you still have, and hold onto it. It won't be what you once had, nor will it fill all of the void in your heart, but it will help you stay connected, if only for a short time, to the person you love.

Programs and Events

MemoryCaregivers Network

Peer Support & Education Groups

During the COVID-19 pandemic, all MemoryCaregivers Network Support Groups are being held online only (via Zoom) every
1st, 3rd, and 4th Tuesday from 1:00-3:00pm.

Network meetings are open to the public. Participants will receive a link via email the day before each meeting.

If you are not currently attending a MemoryCaregivers support group, please email network@memorycare.org to join the mailing list. If you do not use email but would like to talk with a support facilitator, please call Mary Donnelly at 828.230.4143.

For more information about the MemoryCaregivers Network, contact:

Mary Donnelly	**Pat Hilgendorf**
828.230.4143	828.301.0740
network@memorycare.org	patricia.hilgendorf@gmail.com

Mary and Pat are available on the 2nd Tuesday of every month as well.
Contact Mary for additional information if interested in participating.

The Network relies on charitable support to keep its program going .

Donate Now

Caregiver College

A series of six lectures will be provided for caregivers of persons with memory disorders. Sessions are designed to improve caregiver understanding of different aspects of dementia care. The course is led by MemoryCare staff members with guest lecture by attorney Caroline Knox, Esq.

2022 Course Schedule

Thursdays from 2:00-5:00 pm

Spring	Summer	Fall
April 21 to May 26	**July 7 to Aug 11**	**Oct 13 to Nov 17**
Register for Spring	Register for Summer	Register for Fall

Until further notice, Caregiver College will be provided as a**live-broadcast for online attendance only.** The ability to access Zoom through a computer, tablet or smartphone with a reliable internet connection is necessary to attend. *If you are unable to attend virtually, please contact us to be placed on a communications list for the next in-person attendance opportunity.* **Related course materials will be provided via email.**

Call 828-771-2219 or email education@memorycare.org with questions.

Move for Memory

Now EXTENDED into 2022!!!

(if you were previously registered for the 2021 courses ending December 16, you will need to re-register for the new 2022 course dates which began on January 10)

Join us for MemoryCare's Adult Exercise Program, led by Dr. Tiffany Salido! **Classes are free and open to the public and will be provided weekly through Zoom for online attendance** (choose which day(s) of the week to attend below).

"Whether sitting or standing, my wife and I get exercise, have fun, sing along and drink our water. Tiffany is a Godsend!" - Move for Memory Participant

This class is intended for people with memory impairment to participate *with* their caregiver in fun and simple exercises. The exercises incorporate movements that can improve daily activities and general mobility. Group exercise will be approximately 40 minutes, followed by a time to answer questions. Exercises can be performed standing or seated.

Please note you will be required read and acknowledge a disclaimer when registering to join. *The ability to access Zoom through a computer, tablet or smartphone with a reliable internet connection is necessary to attend.* Email **education@memorycare.org** or call 828-771-2219 with questions.

2022 Registration

Mondays

9:30 - 10:30 am
January 10 through May 23

Register for Mondays

Wednesdays

9:30 - 10:30 am
January 12 through May 25

Register for Wednesdays

Research Opportunity

Appalachian State University Research Study

Are you a caring for a loved one or friend with Alzheimer's Disease or Dementia? Do you have Alzheimer's Disease or Dementia and get help from a family member or friend?

Researchers at Appalachian State University are looking to recruit participants for a study to understand how people living at home with Alzheimer's Disease and dementia, and their family caregivers, use programs and services in their communities. Their goal is to learn more about the types of programs and services that people with Alzheimers/dementia and their caregivers use, as well as about services that they don't currently use but would find helpful.

Participation in the study would involve a one-hour interview with a member of their research team. Interviews could be conducted in-person, by phone, or over Zoom depending on your preference. They are offering $25 gift cards to each interviewee as appreciation for their time ($50 for interviews in which both a caregiver and their loved one with Alzheimer's Disease participate).

Interested participants could let them know about their willingness to do an interview by completing their brief survey to collect contact and demographic information: https://appstate.az1.qualtrics.com/jfe/form/SV_3DiOMMsneTfItIW

MemoryCare is not affiliated with Appalachian State University or this research opportunity. It is shared here for information sake.

Do you need a program for a group event?

The MemoryCaregivers Network staff presents on a variety of subjects, including Recognizing Early Warning Signs of Memory Loss, Facts and Fiction about Dementia, Better Communication Techniques, and more.

We are happy to speak at your event to raise awareness and knowledge about Dementia. Contact Mary Donnelly at network@memorycare.org

To see a list of OTHER COMMUNITY RESOURCES

CLICK HERE

Caregiver Network News and The MemoryCaregivers Network are auxiliary programs of MemoryCare. *Caregiver Network News* is written and compiled by Mary Donnelly. Contact network@memorycare.org for more information.

Subscribe to Caregiver Network News

MemoryCare™

is a charitable non-profit organization whose mission is three-fold:

To provide specialized medical care to older adults with cognitive impairment;
to support caregivers with education, counseling, and improved access to services; and to

provide community education.

We rely on charitable donations to continue these programs!

Please consider donating...
perhaps in honor of a loved one's birthday...
or a memorial...
or a sustaining gift to support families like yours
who depend on the services that MemoryCare provides!

Make a difference. Make a donation.
Thank you for your interest and support!

Donate Now

Visit Our Website

MemoryCare is a 501(c)3 public charity as determined by the Internal Revenue Service, Federal Tax ID: 56-2178294. Financial information about this organization and a copy of its license are available from the Charitable Solicitation Licensing Section at 919-814-5400. The license is not an endorsement by the State.