



Caregiver Network News

A newsletter for caregivers of loved ones with dementia



Upcoming Events

Caregiver College

Spring

April 15 to May 20, 2021
Thursdays; 2-5:00 pm

Registration is required. Please call our office at 828-771-2219 or email education@memorycare.org to register.

The Spring session begins soon! 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.

See the Ongoing Programs section towards the end of this newsletter for more details as well as the Summer and Fall 2021 dates.

MemoryCare Educational Series

Join us to learn more about caring for your loved one and yourself. Courses are free and open to the public and will be presented as a live online broadcast via Zoom from **2-3:30 pm** on the below dates. Click on the corresponding course date for more information and to register. *You must register for each individual session you would like to attend.*

June 3

"Lifestyle Medicine for Brain Health"

Presented by Dr. Brian Asbill

June 10

"Planning Ahead: A Practical Guide to Advance Care Planning and End of Life Decisions"

Presented by Dr. Stelley Gutman

June 17

"Restoring Balance when Dementia's Symptoms Escalate"

Presented by Cloud Conrad

June 24

"Let's Talk Caregiver Resources"

Presented by Lindsey Kremer, BSW, and Carly Woods, BSW

THE LONG-TERM CARE DECISION

Part 1

It's a question that is in the back of every family's collective conscience from the day they hear a diagnosis of dementia: "When will we have to move our loved one to long-term care?" Even though for most families this decision is still years away, it remains one of the most worrying issues of caregiving.



When you are making decisions that affect another's person's health and wellbeing – especially if they are unable to make those decisions themselves – there is enormous pressure to "get it right:" the right reasons, the right place, the right time, the right words to say. However, even though you may understand the need for the move, it is still likely that you will second-guess it right up to and even past the moving day.



We all have a deep-seated avoidance of institutional living. Even if it's clear that our loved one requires a level of care that is beyond our ability to provide, the choice is typically not accepted easily. How many family caregivers have said, "I SHOULD be able to do this on my own" and then had to deal with feelings of remorse and a sense of defeat when it becomes too much? Or if at some point they promised their loved one that "I'll never move you to a nursing home," the guilt looms even larger. There's no denying it – deciding to move your loved one to a care community

will be one of the most difficult and guilt-inducing decisions you will face in your journey with dementia.

The Caregivers' Perspective:

- "Don't let guilt drive your decision. Loving that person and not wanting to "send them away" as well as fearing loneliness aren't reasons to keep them at home. The guilt is what made me keep him home too long."
- "Someone told me that I wasn't moving her to a "home" but to the "next level of care." Do not feel guilty about moving your loved one to the next level of care because it's what they need."
- "I hated the thought of moving her...but I knew it was probably inevitable. I cannot over-emphasize how difficult this decision is...but it was my decision and it was the right one."
- "Realize that there are many ways to be an excellent caregiver. Plans and needs change and each situation is different. There is no wrong way to provide care unless you are causing harm. For me, our relationship was being harmed."

Common Reasons to Move to Long-Term Care

1. **The person's care needs have increased**– they may have started falling, have become incontinent, have left the house on their own (elopement), have progressed to using a walker or wheelchair, or require care beyond what one person can provide.
2. **The person has had to be hospitalized** – from a fall or injury, a stroke or other acute episode, an infection, or a complication from a physical issue apart from their dementia.
3. **The caregiver's health is affected** – they may be sleep deprived, show signs of

caregiver burnout, stress, or depression, or may develop health issues (digestive upset, headaches, depression/anxiety, chronic conditions, etc.).

4. The person has become aggressive or hostile

The Caregivers' Perspective:

- *"He was up and down all night and I wasn't getting any rest."*
- *"Others had encouraged me to do it sooner. In retrospect I may have waited too long."*
- *"I was signing him up for a week of respite care and was given the opportunity to place him permanently and I took it. I should have done it months earlier."*
- *"There were many reasons. Mostly recommendations from several people, but ultimately it was her safety and comfort. I couldn't always oversee what she was doing. Incontinence was also a factor."*
- *"Two reasons: one, her health was suffering and she was depressed, sitting around in her robe all day. Two, our relationship was suffering and we were becoming more estranged. Even though I didn't think she'd ever stay willingly, it seemed liked the only solution."*
- *"She had become incontinent and difficult to care for and I had reached the end of my rope, physically and mentally. I knew (but wouldn't admit) that she would get better care there."*
- *"He became more frustrated because he couldn't communicate, and his nature changed from being sweet to being angry and he was pushing and shoving and I didn't want things to escalate."*
- *"I just woke up one day and realized that I can't do this anymore."*

Nobody can walk in another's shoes. While it is useful to hear how other families arrived at this decision, do not compare your choice to what someone else did or did not do. Other people may question your reasons or motives, but until they have been in your shoes, they do not know the whole story. Some people get to "Done" sooner than others. Every person, family, and situation is unique, so know that whatever decision you make will be the right one for your own particular needs.



Preparation and Planning

The first step is to **go visit some care communities**. Ideally this should be done now – BEFORE you are actually considering a move. This is the 'data-gathering' phase of the process, for without knowing exactly what your options are, you cannot make a reasonable conclusion about what you are facing. If possible, take a friend along; two sets of eyes and ears are always better than one, and because of your emotional involvement you may miss some key elements.



For many caregivers, the first couple of visits to a care home can be a bit upsetting. Give yourself a chance to get used to how they look and feel by spreading your visits over several days. When you find one or two that seem okay, go back a few times to get more familiar with the feel of the place. Observe the staff with the residents, and if possible, talk with other family members. Try to look past the chandeliers in the lobby and focus instead on how the staff interact with the residents. A caring, compassionate staff will mean much more to your loved one than the décor.

The marketing representative will be able to answer most of your questions about services and costs, but dementia presents unique caregiving challenges. You will want to be as up-front as you can about your loved one's level of care. Ask specific questions about how the facility handles any challenging situations (i.e., refusing to shower or becoming angry when approached). Their answer will tell you a lot about how experienced they are in dementia care and if they are willing to look for solutions rather than simply walking away.

Be sure you are clear about **costs**. Most care communities cost between \$5,000-\$9,000 per month, depending on factors such as care needs, type of facility, and area of the country. **Medicare does not cover the cost of long-term care except for the 90-day period after hospitalization and even that is limited if your loved one does not qualify for skilled services such as physical therapy.** If you have long-term care insurance, review it so you are clear about what it covers. This is also a good time to consult with your financial advisor or elder-care attorney about your financial options. Do not be surprised if Medicaid is one of them. The average time that a person with dementia stays in long-term care is three years, so do the math. If you think you may run out of money, a reputable professional can help you qualify for Medicaid assistance. Know that not all care communities accept Medicaid, so you will want to ask about that when gathering information at each facility you are considering.

It is important that you not involve your loved one in the planning If their dementia is progressed to the level that you are considering placement, chances are that they will not be able to identify or understand the process or the reasons behind it, and talking about it with them will only create anxiety for both of you. Only after the groundwork has been done and the plan is in place should you let them know about it, and then only a day or two prior to the move. If this seems dishonest or manipulative to you, try to remember that this is the kindest thing you can do for them. (This will be covered more in Part 2.)

The Caregivers' Perspective:

"It was hard for me to do all of this without telling my wife, but in retrospect I realized that was the right decision. She would not have understood why she had to go and as guilty as I already felt about it, that would have made it worse. It all turned out OK."

However, there are other things you can do to ease the transition for the person with dementia. For instance, after you have narrowed your search to one or two communities, take them there for lunch once or twice prior to the move, so that staff can meet and interact with them. Keep it light and present it simply as lunch at a new senior center, nothing more. Avoid the tendency to explain or try to "sell" the place to your loved one; let it just be an ordinary lunch outing.



Another option is to ask if the facility offers **respite** opportunities. If they do, you might arrange for your family member to stay there for a few days. This not only gives you the chance for a "trial run," it provides you several days off that you can use any way you choose.



If you are not already using **home care or an adult day program**, this might be a good time to start. These options provide opportunities for your family member to not only socialize with different people but also learn to trust other caregivers, ultimately making the transition to a facility easier. Having one or more home care aides who have become accustomed to the person with dementia – and vice versa – is a valuable resource not only now but

later: when it's time for the transition, they can be of help on moving day and they can serve as a familiar face at the new location for the next few weeks while your loved one is

adjusting.

The Caregivers' Perspective:

- *"Get on a list, I repeat, get on a list (or lists) of facilities because when you need a room, you will probably REALLY need a room. You can decline if it isn't the right time but still hold your place in line."*
- *"Start your search early enough where you have choices when the time comes. These decisions can't be taken lightly. If you wait until the last moment your options are few."*
- *"Planning and educating myself for the move was important. I think by having a plan in place gave me some mindset on the subject and helped me recognize the potential need."*
- *"Listen to your heart and you will know when it is time. Do not try to prolong your decision because it will not make a difference to your loved one."*
- *"I should have moved him months earlier. If someone asks if you have considered this, take it as advice that it's about time."*
- *"It was the right decision...but just because it's right doesn't make it easy."*

(to be continued in "Part 2: Making the Move", in the next issue of CNN)

Caregiver Tip: How to Ask for Help

This letter was composed by a caregiver who needed some help with her husband. She sent it to friends, neighbors, and family members, many of whom had asked what they could do to help. As you read it, be thinking of how you can modify it for your own situation, and who should receive it. Then send out a few and see what comes of it!

Greetings Friends,

I write to invite your creative thinking on finding folks you can recommend to help my husband John, age 74. John has dementia. This means that he gets easily mentally fatigued. While he enjoys social interactions and can be quite friendly, engaged, and cheerful, at times he seems confused, apathetic, or tired. This is due to his brain disease. In addition to dementia, John has some physical issues that make it difficult for him to walk. Thus, he is walking with a walker, and he finds it most comfortable to be seated. I am able to be with John most of the time, but sometimes it would be helpful if I could hire someone to be with him to give me some free time. We have both had our COVID vaccines. As well, we have an outdoor porch that provides a comfortable place for social distancing.

Here are some areas of assistance I am thinking about:

1. **Exercise Coach:** His physical therapist has devised a fairly simple set of strength and balance exercises and suggests we hire someone to coach John through this routine which could take from ½ hour to one hour.
2. **Walking Coach:** It would be helpful to hire someone to drive John to the lake near our home, unload his walker, and walk with him for a few minutes, sit on a bench and watch the kids and ducks, and continue walking for a few minutes... as tolerated. This could be about an hour as an enjoyable outing. (John does not and should not drive. A driver could use our car or their own car.)
3. **Companion/Conversationalist:** I would hire someone to come to the house and read or sing to John or have discussions over coffee. He is still very social and enjoys interacting with other people. He is quite a political contrarian, so conversations can get heated. If you don't like politics, John enjoys other topics such as _____, and even certain TV shows! John is an accomplished, lifelong artist, but he has stopped doing art. He might draw with someone who wanted to draw or even color with him. Watching birds and listening to their songs is fun, too. This time frame could be an hour or two.
4. I am not thinking of combining all these activities into one long four-hour session, as this would be fatiguing for John. However, any one or possible two of these suggestions might work in one- or two-hour sessions, but I am flexible and would be happy to discuss

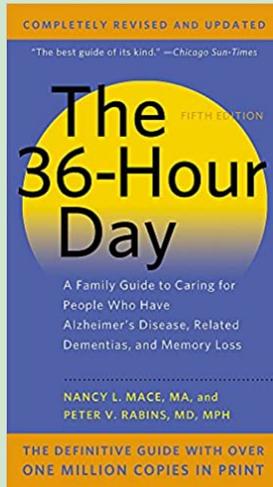
other ideas.

5. **Other ideas:** I am open to suggestions folks may have, both of how to be helpful and of caring, dependable people who may be looking for this kind of work. Please send me a text or an email.

Thank you for your support and friendship!

Caregiver name, address, cell phone & email

We Need Your Help!



Have a copy of The 36-Hour Day you are no longer using?

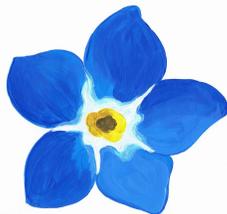
If you have a copy you would be willing to donate, MemoryCare families are in need.

Consider helping a family by sharing your copy! If you have one you would like to donate, please feel free to drop it by or mail to our office at:

The SECU Center for MemoryCare
100 Far Horizons Lane
Asheville, NC 28803.

For any questions email grieco@memorycare.org.

Thank you!



Be Healthy & Stay Well

- Avoid close contact with those who are sick
- Avoid touching your eyes, nose and mouth
- Wash hands often with soap and water for at least 20 seconds
- Wear a face mask when in public settings



Ongoing Programs
Open to the Public

MEMORYCAREGIVERS NETWORK

Peer Support & Education Groups

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

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.

Network meetings are open to the public.

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

TO MAKE A DONATION, [CLICK HERE](#)

For more information about the MemoryCaregivers Network, contact:

Mary Donnelly
828.230.4143
network@memorycare.org

Pat Hilgendorf
828.301.0740
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)



Caregiver College

2021 Course Schedule

Thursdays from 2:00-5:00 pm

Spring

April 15 to May 20

Summer

July 15 to Aug 19

Fall

Oct 7 to Nov 11

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 and attorney Caroline Knox.

Until further notice, courses 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. For a physical copy of the materials, you may reserve a binder for pick-up at our office for \$20 or we can mail one to you for an additional \$10 with request for mailing required two weeks in advance of the course start date.

IMPORTANT: In an effort to evaluate course effectiveness, attendees will be expected to complete a 3-part participation survey: one prior to, one

immediately post, and a final several months after the course.

Registration is required. Please call our office at 828-771-2219 or email education@memorycare.org to register.

MemoryCare Educational Events



Move for Memory

Join us for MemoryCare's Adult Exercise Program, led by Dr. Tiffany Salido! **Classes have been extended through October!** (if you were previously registered, you must re-register to attend these new sessions)

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).

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.

Mondays
9:30 - 10:30 am
through October 25

Register for Mondays

Thursdays
9:30 - 10:30 am
through October 28

Register for Thursdays



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



Caregiver Network News is written and compiled by Mary Donnelly.
Contact network@memorycare.org for more information.

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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!

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