



# Caregiver Network News

*A newsletter for  
caregivers of loved ones  
with memory loss*

## DEMENTIA - A FAMILY AFFAIR

Ah, families. They can be wonderful, they can be awful, but they are nearly always complicated. Family dynamics are often challenging, even among the closest of relatives. Relationships and roles form early and will continue to develop and transform and evolve as lives and situations change. Sometimes they bring out the best in us...other times, not so much.

A diagnosis of dementia can strain these family dynamics to the breaking point. Dementia affects the entire family, often sending it into an emotional roller-coaster of fear, denial, loss, grief, frustration, resentment, and acceptance that can last for years. Each family member will experience these differently. Each must face the realities of dementia in their own way. And it is these differences that can create misunderstandings or tension among family members.



For many families, it seems natural to hold a family meeting to openly discuss the impact of a dementia diagnosis and a plan for dealing with future challenges. For others, the idea of such open and direct interaction may be impractical, or even impossible. But one thing is certain: the changes are coming, and at some point your family will have to confront them. Without some communication, without some advance planning, you could be blindsided by one crisis after another for which you are unprepared. This makes a difficult journey even more so, and in so doing raises family differences and conflicts to a new level.

**How do we start?** As the saying goes, it's usually best to start at the beginning. Sending an email is quick and easy and keeps everything in writing so that there's no confusion about details. Ideally this would be done by the primary caregiver, but in many instances the primary caregiver - if it's the spouse or someone who's right in the thick of things - may simply be dealing with so much that he or she can't take on one more job. Perhaps another family member with more free time might offer to reach out to the others, just to get things started.

**Where should the meeting take place?** In person is best, with everyone in the same room, but that isn't always possible when family members don't live close by. In those situations, it often works to arrange the meeting around another family gathering, say a reunion or holiday event, when people are together anyway. Or you might take advantage of some of the free online meeting rooms (Zoom.us or GoToMeeting.com are two that offer free options), so that those who can't be physically present can join in with their computer or tablet.



**Should we include our loved one with dementia?** Many families have begun this process early enough in the disease that their loved one is still cognizant enough to participate and contribute. If your loved one with dementia is in attendance, hear what they have to say and be respectful of their wishes, whether or not you agree with them. Your job at this stage is to let them know you love and support them. However, keep in mind that some people with a diagnosis of dementia may not yet have accepted their condition and can become extremely upset at the mention of it. Trying to convince them of the reality of their diagnosis is nearly always unsuccessful - so putting them in the midst of a discussion about their future may not be the wisest choice. Many families have had to face this option; it is a difficult decision to exclude a loved one from a family meeting, but try to keep in mind that doing so may be the kindest and most sensitive thing you can do.

**What should we talk about?** The short answer is, whatever's on your mind. In the early stages, you will probably be just trying to wrap your head around how everybody feels and what this could mean for your family. Addressing legal and financial affairs early in the process is a must. Putting this off could have serious implications on your family's ability to care for your loved one, protect your assets, and provide you legal authority to act on their behalf. Try to have any pertinent documents available to facilitate this discussion, and/or consider having an attorney attend this part of the meeting.

If you are dealing with an immediate crisis (Mom needs help NOW or Dad has fallen and is in the hospital) you will have to put that fire out before moving on to deal with other issues. And because dementia is a progressive disease, you'll be needing subsequent meetings to address changing circumstances. If possible, submit items for the agenda in advance so that everyone knows ahead of time the issues to be discussed. Provide a copy of the list to each person, and be sure to address each item so that nobody's concerns are missed.

### **Other Suggestions for Family Meetings\***

- Limit participants to immediate family. Less people mean quicker decisions.
- Some family members may not be on board with the idea and may drag their feet about agreeing to a time or place. Rather than putting off the meeting until they choose to comply, simply make the arrangements to suit the majority and then be sure to follow up by sending them a written account of any decisions reached.
- This meeting is about your loved one with dementia. It is not a time to air long-standing difficulties, grudges, or grievances among family members. If you are concerned that this may become an issue, consider using a mediator - a neutral party, a professional mediator, advisor, attorney, or social worker - rather than a family member to be the moderator.

- Be aware of the difference in what you WANT versus what is NECESSARY. Your family may want your loved one to remain at home throughout the duration of the disease (nearly all families do), but you'll need to understand what it will take to accomplish that, i.e., hiring home care aides, incurring additional expense, and the possible impact on the health of primary caregiver, etc. Start those conversations now to give your family time to get used to the idea of alternative options for care.
- Allow each family member equal time to share their concerns. Consider passing around a timer to help everyone be aware of the equal-time rule.
- There is usually a primary caregiver who takes on the bulk of the care responsibilities, but those who do not live nearby can and should contribute in other ways. Discuss options for who does what, and how everyone can play a contributing role in the care and decisions even from a distance.
- Don't expect everything to get decided at one time. This is an ongoing process and will require additional sessions as situations change.
- Like anything new you try for the first time, it may not go smoothly. The next one will be better. Keep at it.

\* adapted from *I Love You...Who Are You?*  
By Patti Kerr



## DEMENTIA (IT'S MORE THAN JUST MEMORY LOSS)

*In this series, Caregiver Network News (CNN) will address a myriad of common symptoms of dementia, maybe even some that you hadn't been aware of, and will take a deeper look at what is happening and how you can respond.*

*Our focus for 2018 will be on what are commonly referred to as Executive Function skills, which include judgment, decision-making, insight, logic and reason, sequencing, safety awareness, social filters, and self-awareness. These are our higher thought processes, and are located in the prefrontal cortex of the brain. Nearly all forms of dementia target this area early in the disease - but often the changes are not obvious or even very noticeable to the casual observer.*

### **Part 3 - SEQUENCING**



Have you ever thought about how many steps it takes to brush your teeth? First you find the bathroom. Then you find the toothbrush. Then you find the

toothpaste. Then you take the cap off the toothpaste. Then you run water on the brush. And so on. For such a simple task, there are really quite a lot of steps. It's the same for making coffee, or getting ready for bed, or a host of other things.

These are activities we do every day, by rote, without thinking about them - yet when you break them down, they are actually fairly complex sequences which must be performed in a certain succession in order to be effective. For instance, consider the outcome if you squeezed the toothpaste before removing the cap, or if you put the coffee in the machine before you put in the filter.

Performing tasks in a certain order - sequencing - is something we learn from early childhood. We do it automatically, a hundred times a day...unless we get dementia. Then our ability to sequence through a task becomes impaired, and as a result, we begin making mistakes.



Families may start noticing this in a loved one who is having difficulty following a recipe, or doing laundry, or mowing the grass, or refilling the bird feeder, or making a sandwich, or shaving, or using the bathroom, or getting dressed, or going out to walk the dog. Each of these, along with hundreds of other tasks we do regularly in the course of our day, contain multiple steps that must be followed in order. When they are not, problems often arise. Sometimes the results are simply annoying

(spilling the birdseed or forgetting to put the detergent in the washer), but sometimes they can be more serious.

For instance, think about what could happen if a person got in the car and took it out of gear before starting the motor? Or if they signed a check and gave it away without filling in the amount?

## What Can You Do?

- First, simply be aware. Observe your loved one, especially if he or she has had difficulty with this job before. Often you can pinpoint where the trouble is and avoid a calamity before it occurs. Being watchful does take your time ("Here's the filter for the coffee, Mom"), but it probably takes less time than cleaning up the coffee maker.
- Don't set your loved one up to fail. Realize when you ask them to do something, you may need not only to get them started (see Part I, "Initiative"), but also remain attentive to how they complete it.
- Try to come up with jobs that consist of only one or two tasks that are done over and over (raking leaves or folding laundry), or ones where the sequence of steps isn't as important (setting the table, sorting items, or emptying the dishwasher).



***WANT TO READ THE PREVIOUS INSTALLMENTS?***

[CLICK HERE](#) to read Part 1, *Loss of Initiative*, in the Jan-Feb issue

## CAREGIVER TIP of the MONTH

"When my wife was diagnosed with dementia, our family discussed ways we could preserve our memories of her. We prepared a list of questions to ask her about her life, and hired a videographer to come to the house and video us "interviewing" her. At first we were nervous about the camera, but then we forgot about it and had a wonderful time laughing and reminiscing with her. It took us two sessions to get it all done, but the result was wonderful. As her condition progressed, we would often play the video for her and she would always respond by laughing along and saying 'I didn't know that!' when she heard herself tell a story!"



**REGISTER NOW FOR MEMORYCARE'S**  
**CAREGIVER CONFERENCE**  
**FOR PROFESSIONALS AND FAMILIES**



**Keynote Speaker:**  
**Melanie Bunn**  
 RN, MS, GNP

Melanie has been in nursing for over 20 years, providing care to elders in a host of clinical settings. She received her B.S. in Nursing from UNC-Chapel Hill and her M.S. in Family Health Nursing with Clinical Concentration in Geriatrics from Clemson University, and completed the Gerontological Nurse Practitioner Program at Duke. She is a dynamic speaker and gifted clinician for those living with dementia.

## **TUESDAY, OCTOBER 16**

### Conference for Multi-Disciplinary Healthcare Professionals Caring for People Living with Dementia

With an aging population, caring for persons living with dementia is an increasingly common challenge. This conference will be a day of learning about dementia care, resources, and strategies for those providing direct care to persons living with dementia and students who anticipate working in these areas. Information presented will help participants understand dementia more fully and prepare them for practical issues such as communication, managing behaviors, offering support at end of life, and more.

Target Audience: RNs, LPNs, CNAs, PTs, PTAs, OTs, OTAs, SLPs, SWs, health educators, mental health professionals and other adult care staff working with persons living with dementia.

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 A scholarship for students who plan to care for persons living with dementia will be awarded at the conference. Contact Senior Program Officer- Lee Henderson-Hill at Community Foundation of Henderson County (828) 697-6224 to learn how to apply.



For additional information: [www.memorycare.org](http://www.memorycare.org) or call 828-771-2219

Blue Ridge Community  
 College  
 Technology Building  
 Conference Hall

49 East Campus Drive  
 Flat Rock, NC 28731

Tuesday, Oct 16th 2018  
9 am – 4 pm

Registration begins 8:30am

\$20 fee includes bag lunch  
 Scholarships available

## **Notable Quotable**

*"Life is ten percent what happens to you  
 and ninety percent how you respond to it."*

- Charles Swindoll



## ONGOING PROGRAMS

*Open to the Public*

### **MEMORYCAREGIVERS NETWORK** **PEER SUPPORT & EDUCATION GROUPS**

#### **FLETCHER GROUP**

First Tuesdays, 1:00-3:00 p.m.

Fletcher 7th Day Adventist Church

Howard Gap Road and Naples Road, Fletcher, N.C.

(just past Park Ridge Hospital)

#### **NEW HOPE GROUP**

Third Tuesdays, 1:00-3:00 p.m.

New Hope Presbyterian Church

3070 Sweeten Creek Road, Asheville, N.C. 28803

(across from Givens Estates)

#### **NORTH ASHEVILLE GROUP (formerly the Weaverville Group)**

Fourth Tuesdays, 1:00-3:00 p.m.

Woodfin YMCA at Reynolds Mountain

40 N. Merrimon Ave (exit 23 off I-26 West)

*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:*

## "CAREGIVER COLLEGE" MemoryCare's ongoing educational series for caregivers

A series of six lectures will be provided for anyone caring for a person with a memory disorder. The program is taught by one of the MemoryCare physicians, and is designed to improve caregiver understanding of different aspects of dementia care. Related presentation materials will be provided.

There is no cost for families who are enrolled in MemoryCare. For those not enrolled, the cost is \$85 for the 6-part series.

### **Course Content:**

**What Is Dementia?**

**Transitioning from Independence to Interdependence**

**Functional and Behavioral Changes of Dementia**

**Dementia Treatment Options & Risk Reduction**

**Caring for the Caregiver**

**Dementia and Legal Planning Issues**

***The next ASHEVILLE session of Caregiver College  
began on Thursday, July 19  
and continues on consecutive Thursdays through August 23  
2:00 - 5:00pm  
at the SECU Center for MemoryCare  
on the campus of Givens Estates***

***Watch this space for information about the next Waynesville session!***



### **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](mailto:network@memorycare.org)

***Caregiver Network News and The MemoryCaregivers Network are auxiliary programs of***



***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.**

[CLICK HERE](#) to donate.

For more information about MemoryCare, click this link to visit our website:  
[www.MemoryCare.org](http://www.MemoryCare.org)

**Thank you for your interest and support!**

## **OTHER COMMUNITY PROGRAMS & EVENTS**

(The following programs are not part of MemoryCare but help our community by serving those impacted by memory impairment.)

### *Side by Side Singing - "In the Good Ol' Summertime!"*



*These are the dates for our  
summer Side by Side Sing-a-longs:*

*August 9 (Thursday) 2pm*

*Calvary Episcopal Church - 2840 Hendersonville Rd. Fletcher  
Parish Hall (entrance for parking is on Old Airport Rd.)*

*August 15 (Wednesday) 2pm*

*Hendersonville Library*

*August 23 (Thursday) 2pm*

*Calvary Episcopal Church*

*August 30 (Thursday) 2pm*

*Calvary Episcopal Church*

*Sept. 27 (Thursday) 2pm*

*Hendersonville Library*

All sessions are free and open to the public. Please feel free to invite your friends!

You need not be an experienced singer or be able to read music to participate fully.

Lyric sheets are provided.

We sing well-loved favorites such as: Take Me Out to the Ballgame, Let Me Call you Sweetheart and Oh What a Beautiful Morning.

For more information [CLICK HERE](#)

**COMMUNITIES**

People living with dementia can continue to be active in their chosen pursuits for years following their diagnosis. The entire community benefits when all members are allowed to contribute.

We provide interactive community education programs to raise awareness and dispel myths about dementia. Contact us to schedule a 60 – 90 minute training session.

**THE MANY FACES OF DEMENTIA**

"As a caregiver, I have a much deeper appreciation for the time we have together as a family and I have learned to focus on all that we can do together. It just takes a lot more planning and patience."  
*Michelle Goyeau*

**JOIN US AS WE CREATE A SUPPORTIVE COMMUNITY**

[www.LandofSky.org/DementiaFriendly](http://www.LandofSky.org/DementiaFriendly)

**Cathy Hebert:**  
828-712-4811  
cathyhebert87@gmail.com

**Nancy Smith Hunnicutt:**  
828-778-0063  
nva8@aol.com

WNC Dementia Friendly Communities@gmail.com

A Member of the Dementia Friendly America Network

Supported by the Area Agency on Aging at **LAND of SKY** REGIONAL COUNCIL

**DEMENTIA FRIENDLY WNC**

Committed to the well-being of people living with dementia and their families through a welcoming and knowledgeable community

Meetings are open to family members, professionals, or anyone interested in making WNC more Dementia Friendly!

For more information, contact [wncdementiafriendlycommunities@gmail.com](mailto:wncdementiafriendlycommunities@gmail.com)

or call Land of Sky at 828.251.6622

### **West Buncombe Caregivers**

An education & support group for caregivers sponsored by Pisgah Valley Retirement Community

**Meets every second THURSDAY**

**1:00 - 3:00p.m.**

Pisgah Valley's Community Center  
6 Rhododendron Way, Candler NC

**Free and Open to the Public**

**Mary Donnelly**

**828.230.4143**

**marydd60@charter.net**

**Pat Hilgendorf**

**828.301.0740**

**patricia.hilgendorf@gmail.com**

**Memory Loss Caregivers of East Buncombe**

An education & support group for caregivers  
sponsored by the Highland Farms Residents' Corporation

**Meets every second Tuesday**

**9:30-11:30 a.m.**

Lounge Room 3 (lower level),  
J-K entrance of Brookside Building  
Highland Farms Retirement Community, Black Mountain, NC

**Free and Open to the Public**

For more information, contact:

**Mary Donnelly**

**828.230.4143**

**marydd60@charter.net**

**Pat Hilgendorf**

**828.301.0740**

**patricia.hilgendorf@gmail.com**

**Henderson County Caregiver Support Group**

**Meets every third Tuesday, 1:30 - 3:30**

**First United Methodist Church**

**204 6th Ave W, Hendersonville, NC 28739**

*For more information, contact Lisa Kauffman at 828.696.9799*

**Haywood County Caregiver Support Group**

**First United Methodist Church of Waynesville**

**4:30 on the fourth Tuesday of each month**

*For more information, contact 828.926.0018*

**Mitchell County Caregiver Support Group**

**"Care & Share"**

**First Friday of each month, 1:00-3:00 p.m.**

**Hospice & Palliative Care of The Blue Ridge**

**36 Hospital Dr., Spruce Pine**

*For more information, contact Jane Ouzts at [jnutouzs@yahoo.com](mailto:jnutouzs@yahoo.com)*

**Support Groups for Persons Living With Memory Loss**

*Initial screening required for all early-stage groups.*

**Memory Loss Navigators (The New Hope Group)**

**1:00-2:30 p.m. on the third Tuesday of each month**

**(meets concurrently with the Memory Caregivers Network New Hope Group above)**

**Memory Loss Navigators (The Biltmore Group)**

1:00-2:30 p.m. on the second Thursday of each month  
Biltmore Methodist Church  
376 Hendersonville Road Asheville, 28803 (Exit 50 off I-40)  
Contact Mel Kelley, 828.301.0529, [avant\\_garden@msn.com](mailto:avant_garden@msn.com)

**Memory Loss Navigators (The Highland Farms Group)**

9:30-11:00 a.m. on the second AND fourth Tuesdays of each month  
(2nd Tuesday group meets concurrently with the Memory Loss Caregivers of East Buncombe above)  
Contact Mel Kelley, 828.301.0529, [avant\\_garden@msn.com](mailto:avant_garden@msn.com)

**The Hendersonville Group**

1:30-3:30 on the second and fourth Tuesdays of each month  
Mud Creek Baptist Church, 403 Rutledge Rd., Hendersonville  
Contact Patty Williams at 828.692.1262 or [patty@mudcreekchurch.org](mailto:patty@mudcreekchurch.org)

**Support Groups at the Creek**

Two separate groups for those in early stages of dementia and their significant others  
Every Thursday afternoon from 1:30-3:30pm  
Mud Creek Baptist Church, 403 Rutledge Rd., Hendersonville  
REGISTRATION REQUIRED  
Contact Patty at [AlzMaze@gmail.com](mailto:AlzMaze@gmail.com)

**THE MEMORY LANE CAFE**

**Reminisce & Visit.....Socialize & Laugh.....Relax & Enjoy!**

2nd Monday of each month  
1:00 - 3:00 pm  
Mud Creek Baptist Church  
403 Rutledge Drive, Hendersonville NC

No registration necessary, but those with a diagnosis must be accompanied by a caregiver unless they drive themselves to the Memory Lane Cafe.

*For more information, contact Patty at 828.692.1262 or [alzmaze@gmail.com](mailto:alzmaze@gmail.com)*

***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.**

Caregiver Network News is written and edited by Mary Donnelly.  
Contact [network@memorycare.org](mailto:network@memorycare.org) for more information.

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