



*Treatment and Support for  
Families Affected by  
Alzheimer's and other  
Cognitive Impairments*



## **Caregiver Network News**

*A newsletter for caregivers of loved ones with dementia*

### **Going to the Hospital - Is It the Best Option?**

***CNN recently interviewed a husband whose wife, age 76, had been in a dementia-care facility for two months, and was sent to the hospital. What follows is their story.***

***Please note that this article is not intended to be a condemnation of hospital staff, most of whom are caring and competent, but rather to provide useful information for other caregivers who may face similar situations with their loved ones.***



**Your wife ("K") was recently sent to the hospital from the long-term care facility where she lives. What precipitated the trip?**

On a Friday morning I noticed blood in her stool. Not a huge amount. The staff at the facility thought it was a bit excessive and recommended a 911 call.

**Did you agree that a trip to the hospital was appropriate? Did you suggest other options? Was her long-term care facility supportive and open to your thoughts?**

I foolishly agreed with the 911 call. This was **MISTAKE #1**.

I did not suggest other options. This was **MISTAKE #2**.

The facility would have supported my thoughts on options or if I had just said “No.”

### **Please describe your hospital experience.**

K got to the ER around noon on Friday. She underwent the usual tests and they determined there was in fact some blood in her stool and they decided to admit her for further tests. I agreed. This was **MISTAKE #3**. I should have asked for more information and discussed other options. I think the hospital staff does not understand dementia and they will always err on the side of caution.



They wanted to perform an upper and lower GI on K, and indicated that they would do it “tomorrow,” which was a Saturday. An upper and lower GI is very intrusive and requires drugs necessary to sedate the patient. I agreed (**MISTAKE #4**) to the test and believed they would actually perform it on a Saturday. **MISTAKE #5**. Saturday passed with no tests and then they said it would be Sunday; that did not happen either.

K finally had the tests on Monday and of course they were inconclusive. K ate very little from Friday noon, she had to fast from Sunday night to Monday and then she was comatose until Tuesday when she was released. She lost about 8 pounds on a slim 117-pound frame.

### **Did the hospital staff seem familiar with or trained in how to interact with patients with dementia? What did you notice that went well, and what didn't?**

For the most part, no. I would explain to staff that K couldn't understand or communicate her basic needs, and most would have a basic understanding of what they were dealing with. But with the ever-changing shifts involving many different people, as well as what appears to be minimal staffing on weekends, there was no continuity of care. They would keep charts on the last blood test, IV changes, and bowel movements, and empirical data, but they could not “chart” the nuances of caring for a dementia patient. It was bare, minimum, basic care but not “patient-centered” care.

If K had had had a broken hip (or anything “mechanical”), they could probably have handled that fine. It was a very stressful four days for me and, in retrospect, ultimately harmful to K.

### **How long was K in the hospital? Was there a difference in her cognition, level of confusion, and/or physical condition after being released? Did she recover to the condition she was in before the hospital stay?**

K was released back to her long-term care facility on Tuesday, four days after being admitted. It has been about one month since this happened and K has definitely declined since the hospital visit. She is nowhere near the level she was before the hospital. She had been walking well with some assistance before, now she is in a wheelchair. Her cognitive abilities have declined. She seldom drinks without assistance and must be fed

all the time. She has increased hand activity (reaching, squeezing, pulling and pushing), increased rocking back and forth and her eyes are shut more often. I have been told that these are all common with the progression of dementia, but it all happened very quickly after the hospital visit.

## **What would you have done differently? What will you do if a hospital visit becomes necessary in the future?**

There are many things I would have and should have done differently:

- A person with dementia must, I repeat MUST, have an advocate with them at all times who understands the basics of how a hospital stay can affect a person with dementia, who can be prepared to say “No” to procedures or tests that may be unnecessary or unwarranted.
- If tests are recommended, ask what will be done with the results of the test and why it needs to be done. Ask what other options there are. Ask what effect the procedure could have on the person’s wellbeing or cognitive function. Listen politely to the answers to those questions and then make up your own mind. You are the one who has your loved one’s best interest at heart.
- If your loved one is enrolled at MemoryCare or has another dementia specialist, try to contact them for guidance.
- If your loved one does end up in a hospital, say “No” to waking them up in the middle of the night for blood tests, IV’s, or any other tests for the convenience of the hospital staff.

**There will be no more hospital visits for K  
if I can prevent them.**



## **What do you think is wrong with the system?**

Our hospitals are simply not prepared to address or treat dementia.

The business-as-usual procedures at a hospital are steeped in the tradition of “First, do no harm.” This is embraced by all the medical staff. However, many of these procedures, while in other instances are necessary to test, evaluate, and treat traditional patients, are often inappropriate for dementia patients because they can have long-term effects on the person’s quality of life. Most doctors would not order these tests, treatments and procedures for a patient with a terminal disease. They need to realize that dementia is also a terminal disease and that many procedures may not be warranted or may even cause irreversible harm to the patient.

Medical and hospital staff need to understand how to handle a patient who has dementia and apply the “First, do no harm” rule in a manner that takes into account the particular challenges of this condition.



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***CNN recommends that families complete a MOST form (Medical Order for Scope of Treatment) with their primary care physician or dementia specialist, outlining specific goals of care for the person with dementia, discussing consequences of their choices, and updating the form as those goals may change through the progression of the disease. To be valid, the MOST form requires the signature of both the physician and the patient or the patient's authorized representative.***

**[CLICK HERE to download a sample NC-MOST form](#)**  
***(Ask your physician for an official copy. Note that this form is specific only to North Carolina residents.)***

**Additional resources for advance planning conversations  
and end-of-life care:**

**[Advance Care Planning  
MOST form FAQs](#)**

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## Caregiver Tips

### Keeping a "Go-To Bag"

My husband with Alzheimer's was taken to the hospital unexpectedly, and I had to make several trips back and forth to get things from home. Since then I keep a "Go-To" bag ready to go at a moment's notice so I'm better prepared for the next trip...wherever it may be.

Suggested items to take:

- Copies of Power of Attorney, Healthcare Power of Attorney, Do Not Resuscitate (DNR), and MOST form. Note: sometimes you may be asked to provide the original documents, not a copy, so be sure you know where to locate them.
- Insurance card and ID card for patient

- List of medications that the patient currently takes, along with dosages and the doctor's name who prescribed them. Also have a couple of days' worth of medications.
- Notebook and pen for writing down details of procedures, tests, patient's condition, discussions with doctors, etc. If you don't write them down you'll forget or get them mixed up.
- A familiar blanket or pillow or whatever may be comforting for the patient
- Small toiletries for the patient as well as for you
- Change of clothes for the patient as well as for you
- Phone charger and earbuds if you like to listen to music
- Books/magazines/tablet/crossword puzzles to pass the time
- Sign for above the patient's bed: "This is Fred, he has Alzheimer's Disease. Please do not expect him to answer questions about his condition. Please address all questions and instructions to his wife, Jane. If she is not present, she may be reached at \_\_\_\_\_."
- If possible, make prior arrangements with a home-health agency so that a sitter can stay with your loved one part of the time and let you go home to get some rest.



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## Upcoming Memory Care Events

# Upcoming MemoryCare Educational Events

Join us Thursday afternoons **2:00 - 3:30 pm** in the **Bernhardt Education room at the SECU Center for MemoryCare** to learn more about caring for your loved one and yourself! Courses are **free and open to the public**.

Donations are deeply appreciated.

**Registration is required** due to limited space. To register, call (828) 771-2931 or email [office@memorycare.org](mailto:office@memorycare.org) with your full name, phone number, physical address, and which course(s) you would like to attend.

<b>August 29th</b>	<b>"Doing the Wrong Things for the Right Reasons, Maybe There's a Better Way!"</b> Mary Donnelly, MemoryCaregivers Network Coordinator and Teepa Snow Trainer
<b>September 5th</b>	<b>Book Club</b> <b><i>Dementia Reimagined</i> by Tia Powell, MD</b> (available on Amazon.com) Discussion led by Pam Lessig, MA, MBA, LPC, Caregiver Consultant
<b>September 12th</b>	<b>"Safe Driving Skills—How Are They Impacted by Aging and by Dementia?"</b> Jan Stephanides, MS, OTR/L, CDI, Certified Driving Rehab Specialist, Mission Health CarePartners Outpatient
<b>September 19th</b>	<b>"Community Services for Caregivers"</b> Juanita Igo, Caregiver Specialist, Buncombe County Council on Aging Speaker TBD, Land of Sky Regional Council

**Caregiver College** Resumes October 3rd to November 7th;  
Please see flyer or visit [www.memorycare.org](http://www.memorycare.org) for details!



## Notable Quotable



**"The true art of memory is the art of attention."**

-Samuel Johnson



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, NC  
(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, NC 28803  
(across from Givens Estates)

### **NORTH ASHEVILLE GROUP**

**Fourth Tuesdays, 1:00-3:00pm**

Newbridge Baptist Church  
199 Elkwood Avenue and Merrimon Avenue, Asheville NC 28804  
(enter at glass doors adjacent to the gym)

**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



**"Caregiver College"**  
**MemoryCare's ongoing education series  
for caregivers**

Caregiver College is a series of six lectures are 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 \$180 for the 6-part series. Scholarship funds are available, let us know when you register if you require scholarship assistance.

**Registration is required, and space is limited.**

**To register, please call our office at 828.771.2219**

**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 begins Thursday, October 3***

***and continues on consecutive Thursdays through Nov. 7***

***2:00-5:00pm***

***at***

***SECU Center for MemoryCare***

***100 Far Horizons Lane, Givens Estates, Asheville***



**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)

To see a list of  
**OTHER COMMUNITY RESOURCES**

[CLICK HERE](#)

*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.](#)

Thank you for your interest and support!



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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[CLICK HERE to visit our website](#)