Theme: The Changing Face of Memory Care

On the Trail of the Memory Thief
For the Love of Food
Loving and Caring for a Parent with Alzheimer’s
A LETTER FROM THE EDITOR

When the engage! managing board met to create an outline for this issue, many ideas emerged. However, I did not anticipate the abundance of content that resulted from our collective efforts. In fact, what these pages could not accommodate will appear on our blog, complementing the features herein. While the seriousness of the theme, The Changing Face of Memory Care, is evident, as I read, edited and digested the submissions, it gained even more import.

Few lives remain untouched by Alzheimer’s disease and other dementias — just engage in everyday conversation with your neighbors, friends, co-workers, relatives and others. Inevitably, you’ll hear stories, both tragic and triumphant, about cognitive decline. Nationally, every 70 seconds someone develops Alzheimer’s; an estimated 150,000 people in New Jersey have the illness.

While 5.3 million Americans are living with Alzheimer’s disease, about 200,000 below age 65 have younger-onset Alzheimer’s, dispelling its exclusive attribution to the elderly. Worldwide, only one in four people with Alzheimer’s disease are aware of their status. Lack of access to healthcare, dismissing symptoms, experiencing only mild impairment, protective support networks, desire to stay at home for as long as possible, or other factors may help explain this gap.

You’ll find informative statistics scattered throughout this issue, underscoring the need for expanding the current research to solve this medical puzzle. While much is known, preventive and curative treatment has not yet materialized. Unless a cure is found, more than 16 million Americans will have the disease by 2050.

As a leader in senior services, four of United Methodist Homes’ full service communities offer a Memory Support Residence (MSR). Within these pages, you’ll learn about the customized and specialized practices and processes, as well as the compassionate professionals who meet the needs and ensure the safety of this very specialized group.

Janet M. Carrato, Editor
Alzheimer’s disease typically progresses slowly in three general stages — mild (early-stage), moderate (middle-stage), and severe (late-stage). Since Alzheimer’s affects people in different ways, each person will experience symptoms - or progress through Alzheimer’s stages - differently.

Did you know?
People with cognitive changes caused by Mild Cognitive Impairment (MCI) have an increased risk of developing Alzheimer’s or another dementia. However, not all people with MCI develop Alzheimer’s.

Overview of Disease Progression
The symptoms of Alzheimer’s disease worsen over time, although the rate at which the disease progresses varies. On average, a person with Alzheimer’s lives four to eight years after diagnosis, but can live as long as 20 years, depending on other factors. Changes in the brain related to Alzheimer’s begin years before any signs of the disease. This time period, which can last for years, is referred to as preclinical Alzheimer’s disease.

The stages below provide an overall idea of how abilities change once symptoms appear and should only be used as a general guide. They are separated into three different categories: mild Alzheimer’s disease, moderate Alzheimer’s disease, and severe Alzheimer’s disease. Be aware that it may be difficult to place a person with Alzheimer’s in a specific stage as stages may overlap.

Mild Alzheimer’s Disease (Early-Stage)
Although the onset of Alzheimer’s disease cannot yet be stopped or reversed, an early diagnosis can allow a person the opportunity to live well with the disease for as long as possible and plan for the future.

In the early stages of Alzheimer’s, a person may function independently. He or she may still drive, work and be part of social activities. Despite this, the person may feel as if he or she is having memory lapses, such as forgetting familiar words or the location of everyday objects.

Friends, family or neighbors begin to notice difficulties. During a detailed medical interview, doctors may be able to detect problems in memory or concentration. Common difficulties include:

- Problems coming up with the right word or name
- Trouble remembering names when introduced to new people
- Having greater difficulty performing tasks in social or work settings
- Forgetting material that one has just read
- Losing or misplacing a valuable object
- Increasing trouble with planning or organizing

Moderate Alzheimer’s Disease (Middle-Stage)
During the moderate stage of Alzheimer’s, individuals may have greater difficulty performing tasks such as paying bills, but they may still remember significant details about their life. Moderate Alzheimer’s is typically the longest stage and can last for many years. As the disease progresses, the person with Alzheimer’s will require a greater level of care. You may notice the person with Alzheimer’s confusing words, getting frustrated or angry, or acting in unexpected ways, such as refusing to bathe. Damage to nerve cells in the brain can make it difficult to express thoughts and perform routine tasks.

At this point, symptoms will be noticeable to others and may include:

- Forgetfulness of events or about one’s own personal history
- Feeling moody or withdrawn, especially in socially or mentally challenging situations
- Being unable to recall their own address or telephone number or the high school or college from which they graduated
- Confusion about where they are or what day it is
- The need for help choosing proper clothing for the season or the occasion
- Trouble controlling bladder and bowels in some individuals
- Changes in sleep patterns, such as sleeping during the day and becoming restless at night
- An increased risk of wandering and becoming lost
- Personality and behavioral changes, including suspiciousness and delusions or compulsive, repetitive behavior like hand-wrining or tissue shredding

Severe Alzheimer’s Disease (Late-Stage)
In the final stage of this disease, individuals lose the ability to respond to their environment, to carry on a conversation and, eventually, to control movement. They may still say words or phrases, but communicating pain becomes difficult. As memory and cognitive skills continue to worsen, personality changes may take place and individuals need extensive help with daily activities.

At this stage, individuals may:

- Require full-time, around-the-clock assistance with daily personal care
- Lose awareness of recent experiences as well as of their surroundings
- Require high levels of assistance with daily activities and personal care
- Experience changes in physical abilities, including the ability to walk, sit and, eventually, swallow
- Have increasing difficulty communicating
- Become vulnerable to infections, especially pneumonia

Visit the Alzheimer’s Association website www.alz.org for additional resources or call their 24/7 Helpline at 800-272-3900.

Alzheimer’s disease affects over 5 million Americans, is the sixth leading cause of death and has an economic burden of $214 billion annually.
They walk into the Marketing Office at Francis Asbury Manor holding hands. “How cute,” I think. I figure they’re in their 80s. “They’re in good shape,” I say to myself.

Then, she sits him down and speaks to him like a child. I immediately guess about the hand-holding. It’s romantic. And necessary. She reminds him to behave. He smiles at her. She turns to me and walks me through the pages of her life.

“By Patricia Darcey

They’ve traveled a lot. He had a good job. They have adult children. She asks about memory care, but she can’t let go. Not yet. Maybe one day. She looks at him. He’s the man she married more than 50 years ago. He’s the Navy veteran who looked so handsome in his uniform. He’s the father of their children. But where is he?

Her eyes, flushed with sadness, let loose the tears that flow so freely now. She’s sorry for crying. He looks at her, not understanding about the crying. Not understanding about anything. She takes the application. Shall we back?

Mary sees her mother-in-law’s microwave plugged in on the wrong side of the stove. The cord runs across the stove and is showing signs of melting. Mary has seen other frightening signs, too. “Repairmen were coming to her home on a frequent basis,” Mary says, “but now she’s simply asking for help. She takes Alzheimer’s medication.

She looks over at him. Her face reveals the happy years of marriage tumbling by… the years before Alzheimer’s. They’ve traveled a lot. He had a good job. They have adult children. She asks about memory care, but she can’t let go. Not yet. Maybe one day. She looks at him. He’s the man she married more than 50 years ago. He’s the Navy veteran who looked so handsome in his uniform. He’s the father of their children. But where is he?

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As a nurse it is important to establish relationships with families when their loved ones become residents. Often they have projected the funds needed to ensure their care at a particular level. However, their preparations do not consider changes which may occur with aging — especially Alzheimer’s and dementia.

The nursing staff may be the first to observe the subtle changes in residents. Communication is crucial in assisting families to understand the progression of dementia and cope with the cognitive losses. Our associates know the importance of learning about the routines, likes, dislikes, and preferences of affected residents early on. As the dementia advances, these become essential in helping to maintain a sense of normalcy.

For families, watching their loved one progress with dementia is like going through the five stages of grief: denial, anger, bargaining, depression, and acceptance. They see the role change from child to caregiver. Nurses can be instrumental through communication and by providing support and resources.

Dementia plays no favorites, afflicting regardless of income, education, gender, or other status. United Methodist Homes’ Clinical Services Manager, Jean Ennis, knows this well — her mother Grace not only resides in the MSR at Pitman Manor, but also, retired after working there as an administrative assistant. Jean visited there as a child, worked in dining services as a teen, and later in various roles as a registered nurse.

Jean stated that after more than 50 years of marriage, her mom became widowed and like many others, saw the logic in electing assisted living after finding the maintenance of a large house and property overwhelming. Jean feels grateful that Grace made the decision easy for her and her siblings. Grace adjusted well to the transition, despite being in the early stage of dementia.

Grace’s condition progressed, necessitating skilled nursing. At this critical juncture, Jean relied upon communication and support from the nursing staff, especially when Grace moved into the MSR. Jean added, “As children you may not always see the reason for changes in the level of care because you may not necessarily see the changes the nursing staff does.

Nurses can play a key role helping families adjust to the changes by communicating timely and effectively in terms they understand.”

She draws several conclusions from her experience: since there is no prescription for caring for someone with dementia, nurses need to embody understanding, honesty and support when dealing with people who want practical help and emotional support. Nurses may help families explore new interests, routines and outlets for fun that can benefit residents during the various stages of dementia.

Dementia always brings unexpected challenges and adjustments. Jean feels confident that whenever a MSR resident transitions to skilled nursing, while difficult for their family, they can rely and trust Pitman’s nursing staff. “Acceptance is a lot easier when you have good communication, support and someone to listen to you.”

DaLinda Love is Corporate Director of Clinical Services.
**ASSOCIATE VOICES**

Q: How do you prepare yourself to “step into the Memory Support Residence world” before your shift?

A: “I try to get myself as relaxed as possible, because I know I will need to provide a lot of attention to people who really need it. The residents can sense if I feel tensed and stressed out, and it is all about creating a pleasant day for them.”

(Alex Wegner, LETS/CMA, Francis Asbury Manor)

Q: What entails a typical day working with Memory Support residents?

A: “We give all of our residents the time they need to finish activities of daily living in the morning. This of course, takes longer and requires more tender loving care than residents without impaired memory. We provide emotional support and cueing. A lot of them feel better with support and guidance. When residents sundown, we come up with interventions per each resident to help with their symptoms, such as play soft music, sit and talk or provide a quiet activity. Each day is different and special working with residents with dementia.” (Kelly Weaver, RN, Pitman Manor)

Q: What has guided you to work in this specialized niche of healthcare?

A: “I have always loved to work with the elderly, but the Memory Support area, I feel, is my best reward!”

(Denise Toma, LPN, Bristol Glen)

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**BE OUR GUEST**

We welcome you to our Open House and Lunch and Learn events. Community life brings offsite trips, lectures, cards, crafts, book clubs, walking, Bible study, Chef Center Stage, manicures, music, and much more. Visit any of the full service community websites (back cover) and click events to see the current month’s calendars including the Open House and Lunch and Learn dates.

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**EDITORIAL CALENDAR FOR 2016**

**Winter 2015-2016**

Alternative Therapies

**Spring 2016**

Community Outreach and Industry Trends

**Fall 2016**

Fitness

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**FALL AHEAD = PLAN AHEAD**

Have visions of winter and home maintenance crept into your thoughts? Come explore senior living options for yourself or a loved one. Did you know breaks are available at any of our five full service communities? United Methodist Homes offers a variety of services including independent, residential and assisted living, short-term rehab, respite, memory support, and professional nursing care 24/7. Respite stays allow a trial run for as short as one week or as long as three months. It includes a private apartment, delicious meals, weekly housekeeping and plenty of activities in a friendly, safe, caring environment. Say goodbye to snow removal! Call the community of your choice (see back cover for complete listing) or start online at www.umh-nj.org/.

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**More to Follow on the UMHNJ Blog...**

- **September 24**
  A Glossary of Alzheimer’s and related terms

- **October 8**
  Caregiver Tips from the Pros

- **October 22**
  Prayer Pals Prosper from Intern’s Initiative

Blog.umh-nj.org
It’s so easy to become frustrated when talking to someone with dementia or Alzheimer’s,” says Paula Spencer Scott, senior editor of Caring.com. Ms. Spencer Scott, a 2011 MetLife Foundation ‘Journalists in Aging’ fellow, awarded by the Gerontological Society of America and New American Media, serves on the board of the University of North Carolina Science and Medical Journalism Program.

When engaging in a conversation, she advises Alzheimer’s caregivers to “get the patient’s attention in an obvious, direct way.” She suggests gently approaching from the front while saying the patient’s name. “This will keep the focus on you and prevent any surprise element.” She notes that older patients may be somewhat deaf, and this direct approach also makes it easier for them to hear you.

Ms. Spencer Scott offers eight easy steps to help caregivers communicate with Alzheimer’s and dementia patients:
1. Slow down your usual speaking style a bit.
2. Enunciate your words to be as clear as possible.
3. Give the person plenty of time to think about what you’ve said and to reply.
4. Stick to common, plain words and short sentences whenever possible.
5. Construct sentences that include only one main thought; ask only one question at a time; and give instructions one-step at a time.
6. Keep your voice pleasant and inviting, not overly loud (unless deafness is a real issue).
7. Be careful not to express anger or frustration – even when you’re reaching your limit.
8. Reduce background noise and distractions.

“If the person doesn’t understand something you’ve said, repeat it exactly the way you said it the first time; that will give him more opportunities to figure it out,” she concludes.

Patti Kerr is the author of a book on Alzheimer’s: part textbook, part heart-wrenching caregiver stories. Patti’s book begins with her own story. “Despite all she had forgotten,” Patti writes, “my mother still remembered and enjoyed manicures.” Patti says, as she was putting the finishing touches on her mother’s nails, her mother looked into her eyes, smiled, “and in the sweetest, gentlest voice said, ‘You are always so nice to me.’” Patti smiled, her heart melting. Her mother continued, “I love you.” Patti says she was about to tell her she loved her too, but before she could get the words out, her mother added, “Who are you?” That became the title for her book: I Love You… Who Are You? Loving and Caring for a Parent with Alzheimer’s.

Patti tells the story of Kitty, a caregiver, who writes, “I wish someone had told me there are worse things than dying.” Janice, another caregiver, comments, “I wish someone had told me this disease is not just about your parent, but the whole family. It can thoroughly break a family.”

“Alzheimer’s doesn’t discriminate,” Patti says. “It strikes our neighbors, co-workers and the man we pass on the street as well as presidents, prime ministers, authors, college professors and celebrities. Since there is no typical or predictable path the disease follows, everyone’s journey with – and story about – Alzheimer’s is different.”

Caregiver Statistics:

• Two-thirds of caregivers are women age 65 or older.
• 41% have an income of $50,000 or less.
• One-half are caring for their parents.
• 74% reported that they were “somewhat concerned” to “very concerned” about maintaining their own health since becoming a caregiver.

• In 2014, caregivers incurred $9.7 billion in additional health care costs of their own.
• In 2014, more than 15 million Americans provided more than 17.9 billion hours of unpaid care for people with Alzheimer’s disease and other dementias.
At United Methodist Homes, the dining focus is on resident choice and independence. We want residents to choose not only what to eat, but when and where to dine. Memory Support residents are given simple phrases that make it easy to visualize menu choices at their table. At times, wait staff provides pictures and/or sample plates to further assist the decision process.

Extended meal times and food available at all hours meet the needs of residents who are not always hungry at the standard times. For example, a late breakfast accommodates those who prefer to sleep in, as late snacks do for night owls. Dining venues are kept small to limit distractions and at the same time, give the perception of home. To promote fond memories and old traditions, associates use the outdoors for barbecues and special events.

Besides maintaining independence, our dining programs offer the best in nutritional care. Colorful plates and place mats help those with memory loss identify food items, improve ability to self-feed and increase food intake. Finger foods allow residents who can no longer handle utensils to easily compensate. Similarly, snacks and handheld foods prove convenient for those who do not wish to sit at the table for long periods of time.

The sense of smell is very important to stimulate appetite and cues memory impaired residents that it is mealtime. Reminiscence of foods cooked at home makes dining a familiar and comforting experience. Engaging residents in cooking demonstrations or simple food preparation is always enjoyable. The aromas of cookies baking in the oven or freshly-perked coffee certainly bring smiles to the faces of both the residents and staff.

With a passion for resident wellness, the MSR associates invest great effort, planning and creativity to foster good nutrition and dining habits. As George Bernard Shaw observed, “There is no love sincerer than the love of food.”


**OUR SACRED MISSION**

**A SACRED TRUST**

By John Callanan

“Whatever you did for one of the least of these … you did it for me” (Matthew 25:40, NIV)

We honor memory impaired residents’ dignity by offering options that free them to feel cared for, happy and secure, when they can no longer manage the activities of daily living. We hold this ministry as a sacred trust, which connects us with John Wesley’s compassionate care for the most vulnerable and Jesus’ mandate to “care for the least of these.”

Providing spiritual care is a key way that we uphold that trust. In addition to offering individual pastoral visits at all full service communities, chaplains at Bristol Glen and The Shores lead “Music and Memories” services and hymn sings which use favorite hymns, Psalms and creeds to engage residents’ faith memories. It’s exciting to see people “come alive” by singing Amazing Grace or by reciting the 23rd Psalm or the Apostles’ Creed.

Likewise, at Francis Asbury Manor, Memory Support residents gather to “Chat with the Chaplain.” They often close with an old hymn and The Lord’s Prayer. Rev. Hubbard notes, “This is the part they enjoy most and participate in most completely. Even non-verbal residents bring songs and prayer up from the deep reservoirs of their past faith-filled lives, which still brings tears to my eyes.”

Memory Support residents at The Shores similarly draw upon that reservoir by ringing in the Swinging Bell Choir, which performs in worship monthly and gives an annual concert. While at Bristol Glen, Nicole Kaufmann, a seminary intern, invited MSR residents to be “Prayer Partners.” She observed, “Praying for the needs of others gave them an increased sense of purpose and was calming and uplifting.”

I’m proud of how we care for persons living with Alzheimer’s disease and dementia. We honor their individuality and make vibrant, if brief, connections with them in the moment, by engaging their spiritual memory. Touching their reservoir of faith energizes them and us with the reassuring power of God’s love; a sacred trust indeed.
Full Service Communities

At the heart of United Methodist Homes' resident-driven services and amenities is a team of highly-qualified professionals delivering a continuum of care to adults 65 years and over:

**Bristol Glen**
200 Bristol Glen Drive
Newton, NJ 07860
www.bristolglen.org
973-300-5788

**Collingswood Manor**
460 Haddon Avenue
Collingswood, NJ 08108
www.collingswoodmanor.org
856-854-4331

**Francis Asbury Manor**
70 Stockton Avenue
Ocean Grove, NJ 07756
www.francisasburymanor.org
732-774-1316

**Pitman Manor**
535 North Oak Avenue
Pitman, NJ 08071
www.pitmanmanor.org
856-589-7800

**The Shores at Wesley Manor**
2201 Bay Avenue
Ocean City, NJ 08226
www.theshoresretirement.org
609-399-8505

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973-676-9057

**Covenant Manor**
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973-746-0003

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