Life gets better.

# Understanding Dementia's Effects on Your Loved One and Family

Guidance for what to expect





The feelings that an older adult experiences at the onset of dementia and memory loss—namely frustration, anxiety and fear—are also felt by family members. And just as the person with dementia depends on sources of comfort, security and consolation, that individual's family often requires support, as well.

Families need to understand what their loved ones are going through and how to add quality to their lives, but also how to cope with these changes. And, if families feel they can't care for them on their own, this is understandable and acceptable. That's when they may need guidance in selecting an excellent memory support program. RETIREMENT COMMUNITI

# Understanding and managing memory loss

#### Several levels of memory loss

#### "Senior moments"

As we grow older, we shouldn't be surprised to experience some degree of memory loss. Normal age-related memory issues include occasionally forgetting where we put something, a name of an acquaintance, an appointment and/or what we're preparing to say.

These are common occurrences and shouldn't be alarming. They result from a decline in brain activity, surfacing in our 50s and affecting most people after 65. Though they may be frustrating, we can generally shrug them off as "senior moments."

#### Mild cognitive impairment

Between occasional forgetfulness and dementia is the middle ground of mild cognitive impairment (MCI). This typically involves frequently misplacing items, forgetting information and having difficulty following conversations.

#### Dementia

Sadly, for some people, memory loss extends beyond MCI. Forgetting names of family members and placing items in strange places then losing them can be signs of dementia.

Dementia refers to one or more debilitating diseases of the brain. The Mayo Clinic lists symptoms of dementia as "impairment in memory, reasoning, judgment, language and other thinking skills." Additional signs include inappropriate behavior, loss of communication skills, disorientation and movement problems. Dementia threatens our intellectual ability to perform routine tasks and interact with people.

## "Being a caregiver to someone with dementia

means having to periodically change expectations of what his or her loved one is capable of and comfortable doing. Everything from conversations to where couples can travel are areas of life that a caregiver must rethink in order to provide the best care possible."

–Joel Kroft, Executive Director of Memory Support Services at Country Meadows Retirement Communities

#### Types of dementia

Alzheimer's disease accounts for 60-80% of dementia cases. The onset of Alzheimer's is marked by having difficulty remembering names, conversations and events, as well as feelings of apathy and depression. Later symptoms are impaired communication, poor judgment, disorientation, confusion, behavioral changes and difficulties with speaking, swallowing and walking.

About 10% of dementias are labeled as vascular dementia, marked by an impairment in judgment or decision-making ability. Mixed dementia is the combination of more than one type of dementia, generally Alzheimer's and vascular dementia, but also of others as well. Additional types of dementia are dementia with Lewy bodies, Parkinson's disease, frontotemporal dementia, Creutzfeldt-Jakob disease, normal pressure hydrocephalus, Huntington's disease and Wernicke-Korsakoff Syndrome.

# ASSESSING MEMORY LOSS

#### Initial assessment

Here are a few questions for the adult children or spouse to ask themselves to determine if their loved ones are having difficulties:

- Home: Are they frequently misplacing items or forgetting where they are? Is their home becoming more cluttered?
- **Driving:** Do they drive safely? Have they had close calls or been driving too slowly? Have they been denting the car or getting tickets or warnings?
- Health: Are they eating well? Is their personal hygiene acceptable? Do they take medications as directed? Has their mood or outlook changed?
- Finances: Are they paying their bills on time? Do they know where they keep their financial and legal information?

To help measure the degree of one's cognitive impairment, HelpGuide, a resource on mental health and well-being, has prepared a 21-question assessment to be completed by a family member or friend. Simply visit www.HelpGuide.org and search for "Age-Related Memory Loss." The questionnaire shouldn't be used for diagnosis, but rather to help determine if further assessment by a physician is needed. Of course, should you become concerned about a family member's profound changes in memory at any point, schedule an appointment with a physician.

#### An estimated 5.4 million Americans



(one in nine people)

age 65 and older have Alzheimer's disease. -Alzheimer's Association Though the rate of progression varies widely, **on average**, those with **Alzheimer's disease live** 

#### eight to 10 years after diagnosis,

8 to 10 years

but some

#### survive 20 years or more.

20 years or more

It is best to have a support plan in place. -Mayo Clinic

# AND CONFUSION

# Medical diagnosis and treatment

A family physician will conduct a physical exam and lab testing to help identify the cause of symptoms. The cause of memory loss or confusion may not be dementia. Other causes, mostly treatable, are depression; anemia; infection; diabetes; vitamin deficiency; hypothyroidism; kidney or liver disease; alcohol abuse; dehydration; heart, blood vessel or lung problems; minor head injury; brain tumor; and medications.

A family doctor may make a referral to a neurologist, a physician who diagnoses and treats disorders of the nervous system, including the brain. The neurologist can evaluate for conditions other than Alzheimer's that could be causing the difficulties, such as stroke, Parkinson's disease, brain tumors, fluid on the brain and other neurological illnesses that can impair memory or thinking. A neurologist is often part of a memory clinic's multidisciplinary team of professionals. The memory clinic staff can provide comprehensive evaluation and diagnosis; treatment, including medications, to address symptoms; and mental exercises to slow memory loss.

# CARING FOR SOMEONE WITH DEMENTIA

Many people find that caring for a loved one with dementia is an emotional journey that encompasses frustration, fear, depression, guilt, and sometimes even joy, often all within the same day. And as a loved one's health condition changes, so do the commitment and responsibility. Caregivers need to be flexible and willing to adjust expectations in order to provide the necessary support or find outside resources to help.

# Recognizing the psychological and emotional impact

The first effects begin with the diagnosis, when the individual is likely to experience a combination of grief, loss, anger, shock, fear and disbelief. Depression and anxiety are common, as is concern about the impact on loved ones.

At some point, you may observe profound changes in emotions—less control over feelings, mood changes or disinterest in activities and conversation. Family members should realize these emotional responses are involuntary and due to changes in the brain.

#### Validating self-worth

At Country Meadows, our staff uses the Validation Method in caring for residents with dementia, and we encourage its approach by family and friends, as well. It's based on the concept that rather than trying to bring the person with memory loss back into our reality, it is more beneficial to enter his or hers. With Validation training, caregivers can listen actively with empathy and ask questions to help those with memory loss express their concerns and frustrations. The purpose is to reduce anxiety and resolve worries that are preventing them from enjoying social interaction.

Questions starting with "Who," "What," "When," "Where" and "How" are encouraged to explore their emotions and enter their world. Listening and responding without judgment allows them to express themselves in a supportive setting and result in creating trust.

#### **Communicating properly**

Learning how to communicate with someone with dementia is a work in progress. Though we can learn from our mistakes, following these guidelines can help maintain your relationship with your loved one and assist you in dealing with difficult behavior.

- Speak pleasantly, positively and respectfully.
- Limit distractions and be sure to get his or her attention.
- Use body language appropriately facial expressions, eye contact, touching, hand holding, hugging to help convey what you are saying.
- Break down activities into several steps to better manage a task.
- If the individual becomes upset or agitated, try changing the subject or environment.
- Use humor when possible. Many people with dementia still enjoy a laugh.

## Encouraging independence and building self-esteem

Dementia can lead people to feel insecure and lacking in selfconfidence as it affects so many areas of their lives. Caregivers can help them stay independent and in control as much as possible.

- Find ways to simplify their self-care routine—brushing teeth, combing hair, washing face, shaving.
- Acknowledge successes and offer encouragement and praise.
- Be supportive and positive. Don't criticize.
- Give them the time they need to engage in activities they enjoy.
- Help them maintain social contacts and form new relationships.

### Managing behavioral and emotional difficulties

Emotional outbursts and strange behavior are common in individuals with dementia. The National Center on Caregiving lists flexibility, patience and compassion as the keys to managing such difficulties. Also helpful are keeping a sense of humor and not taking hurtful remarks or actions personally. As much as possible, try to accommodate, not control, the individual's behavior. When necessary, try disrupting the behavior with a different approach, but bear in mind that a solution that works one day may not be effective the next one.

# VISITING PERSONS WITH DEMENTIA



Older adults with dementia can benefit greatly from visits with friends and family members. Continuing those social ties can help dispel some of the confusion, frustration and fear they may be experiencing.

#### Tips for successful visits and social interaction

Here are a few tips, based on the Validation Method, that can help improve the self-worth of individuals with dementia during your visits:

- 1 **VISIT** at a time of day when they are generally at their best.
- 2 RELAX and speak slowly and clearly.
- 3 MAINTAIN EYE CONTACT and use their name to make a connection and show respect.
- 4 SET ASIDE YOUR EXPECTATIONS, listen without judgment and don't upset them by correcting them.

- 5 TALK ABOUT GOOD NEWS and fond memories, which can comfort and reassure them.
- 6 ASK OPEN-ENDED, BROAD QUESTIONS to understand and explore their concerns.
- 7 ENGAGE IN ACTIVITIES that they enjoy, e.g., games, puzzles, crafts, walking, cooking or gardening.

#### Sundowning

Some people with dementia are more agitated and anxious late in the afternoon or early evening. In some cases, they may become aggressive or delirious. This condition of the brain, evidently triggered by fading light, is known as "sundown syndrome" or "sundowning." Though it can't be prevented, it can be managed by keeping the environment calm, relaxed and at a comfortable temperature. Monitor their activity as they may be inclined to wander. Limit or avoid caffeine after morning, large evening meals, naps and exercise late in the day, smoking and alcohol. If problems are hard to manage and persist, consult your loved one's physician, who may need to adjust his or her medications.

### Celebrating the holidays together

The holidays can be difficult for families dealing with dementia. The Alzheimer's Association offers these ideas for making your time together less stressful and more enjoyable.

- Inform guests about your loved one's changes to avoid confusion and embarrassment.
- Move evening celebrations to during the day before sundowning takes effect. Or, if you keep to the evening, ensure the room is well-lit and free of triggers (loud music, blinking lights, etc.).
- Try to keep the day's routine similar to your loved one's normal experience.
- Involve him or her in the holiday preparation performing a familiar task like setting the table or selecting a memory or song to share during the celebration.
- Bake his or her favorite holiday dish or dessert.

#### Family caregivers spend more \$5,000 a year

caring for someone with Alzheimer's disease. -Alzheimer's Association

#### Helping children understand and cope

Dealing with a loved one's dementia is difficult for everyone involved, including children. Adults may become so consumed with the emotional and physical challenges of dementia care that they may neglect to notice that children are upset, frightened or confused.

Parent magazine has suggested explaining dementia to small children by saying, "When you're sick, you might have a fever or a cough. Grandma's brain is sick. She has an illness that affects how her brain works." Kids may be comforted by knowing the behavioral change is due to a disease and no reflection on them.

The Alzheimer's Society suggests involving children by encouraging them to show affection, making sure time with their grandparent is as enjoyable as possible and reminiscing with photos and mementos from earlier, happier times with Grandma or Grandpa. Download our tip sheet, "Talking to Your Children About Dementia," in our "Tips Library" on the "Advice" section of our website, www.CountryMeadows.com.

An excellent way to explore the issue with children and engage them in conversation is through stories. You can get our new book for children about dementia, *The Unforgettable Adventures of Grandma's Cape*, for free by stopping by the front desk at any Country Meadows campus.

We recommend seven additional books in our "Tips Library" on the "Advice" section of www.CountryMeadows.com. Regardless of age, driving a car conveys feelings of freedom and independence. So, it's understandable that giving up driving can be a major disappointment and frustration for older adults who value their independence. That's why discussions about limiting or stopping driving have to be approached with sensitivity and understanding. These difficult conversations can be stressful and threatening to families. But these talks are vital.

In many cases, family concerns over driving arise when an older loved one begins to show signs of dementia. If that individual is exhibiting confusion, hesitancy, stress or anger while driving, those are red flags that driving should be curtailed or discontinued. For many families, this is the beginning of learning how to care for a loved one with dementia.

Here's a simple test: Can Mom or Dad master other multistep tasks like following a recipe, doing laundry or playing cards? Similar thinking is required to drive a car. Here are a few steps you can take:

- Ride along to observe their driving, watching for slips in mental functioning and motor skills.
- Look for other signs—damage to the car or traffic tickets.
- Talk to their physician about a check-up. The doctor might observe new symptoms since the last visit.
- Contact an area organization that assesses driving ability—a VA Medical Center, hospital or rehabilitation center, or a driver rehabilitation specialist.
- Contact the motor vehicle division of your state transportation department. All states have procedures, such as driving evaluations and license reviews, to address your concerns.

Throughout this trying process, be sure to show your loved one that you are concerned about his or her well-being and will help resolve the issue of alternative transportation. The unknown future can be frightening, and your show of support and solidarity is crucial to a positive outcome.

### LEGAL AND FINANCIAL PLANNING

The Alzheimer's Association (AA) advises that legal plans, if not already established, should be made at the onset of memory loss so those with dementia can be involved in decisions related to their future care. It also eliminates guesswork for families.

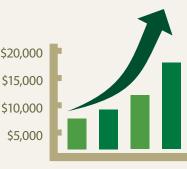
Legal planning, according to the AA, should include the areas of health care and long-term care, as well as finances and property. It also should cover designating someone to make important decisions on behalf of the one with dementia. Be sure that the individual with dementia understands everything he or she is signing. If you're not sure, consult a physician who can assess his or her mental fitness and abilities.

Meeting with an attorney, particularly one specializing in elder law, can be helpful. The AA says the three key issues to discuss with a lawyer are options for health-care decision making, options for managing personal care and property and possible coverage of long-term care services. Before meeting with the attorney, ask what documents and paperwork you are expected to bring to the appointment.

Regarding financial assistance for health care related to dementia, possible resources include Medicare, Medicaid, Medigap insurance, other private health insurance and long-term care insurance. Family members should look into all of these options to see what will and won't be covered for future health-care needs.

Elderly persons showing early signs of dementia are particularly at risk of being scammed. Declining judgment skills, which may indicate Alzheimer's disease, can lead to giving away large sums of money. Seniors exhibiting this behavior may be in need of memory support or dementia care.





# MEMORY SUPPORT PROGRAMS

#### When is it time for a memory support program?

As a caregiver, you may reach a time when your loved one's needs become more than you can fulfill. Deciding on the need for a residential memory support program can be difficult. Each situation is different, and families must evaluate their own unique circumstances. We understand and suggest you answer the following questions based on your needs:

- Has my loved one been diagnosed with a condition that causes memory loss?
- Might his/her current living environment be unsafe?

- How much is my loved one able or unable to do for himself/herself?
- Has my loved one told me what he/she would like?
- Is the care I am providing beyond my physical capability?
- Am I becoming impatient with my loved one?
- Am I neglecting my personal life (family, job) to care for my loved one?
- Is there anyone else who can help me care for my loved one?

#### Selecting a memory support program

With more residential memory support program options today than ever before, choosing one can feel overwhelming. To help you select a quality program worthy of your loved one, here are some guidelines and questions to ask:

#### PRESERVING RESIDENT DIGNITY

- Do residents look well cared for, with attention paid to details such as shaving, nail care and hair care?
- Is their clothing properly cared for, i.e., free of stains and wrinkles?
- Does the staff address residents by their preferred names?
- Is the environment free of odors?

#### **QUALITY OF STAFF**

- What training have staff members received?
- How do they deal with challenging resident behaviors or situations?

#### QUALITY OF PROGRAMS

- Do residents have access to the same quality of programs as those living outside the secured area?
- Are there opportunities for worship? Who leads these sessions?
- Are there small-group as well as largegroup activities?

- Are residents given choices in what they wear, when they wake and how they spend their time?
- Do residents have adequate access to privacy? To the outdoors?
- Is a manager present in the evening and on weekends?
- Does the staff acknowledge and interact appropriately with residents?
- Do staff members have a clean, neat appearance themselves?
- How often do residents leave the secured neighborhood? The campus?
- Do residents have a choice in the meals they eat? How is this offered?
- What opportunities are there for physical activity? Who leads these sessions?

### Anna's story

Anna's adult children were growing concerned. Just a few months ago, they thought she was doing very well for a woman who was 88, living on her own and proud of it. But recently they were beginning to notice changes beyond the routine forgetful moments that are characteristic of someone her age.

Fortunately, both Susan and Brian lived nearby and were able to check in on their mother on an almost daily basis generally with a quick visit but sometimes with a phone call instead.

Comparing their observations, they confirmed that, yes, their mother was definitely having some memory issues. Susan discovered a few days earlier that Anna had left the stove on from morning until late afternoon when she stopped in. Brian reported a dinnertime visit when he found Anna was still in her pajamas—totally out of character for their mother. And both noticed their mother wearing some odd combinations of tops and bottoms that she never would have just months earlier. She still knew her children's and grandchildren's names and routinely flashed her wonderful sense of humor, but she wasn't the sharp-asa-tack mother they had always known. Something wasn't right.

They convinced Anna that she was due for a check-up with Dr. Bell, her family physician. He had last seen her a year earlier, when he proclaimed her in excellent physical and mental health. Now, he was surprised to see her looking frailer and wearing the colors and patterns she had chosen. (Susan and Brian had decided to let their mother wear what she chose for the appointment.) Some cognitive testing revealed moderate memory loss—for example, FDR is no longer President of the United States. Anna had raised two children who, like her, didn't drag their feet when making a decision and taking action. Knowing that their jobs prevented them from caring for their mother during the week, they arranged for in-home care for a few hours a day on weekdays. For now, on weekends, they would devise a schedule that included them, their spouses and two of Anna's neighbors who volunteered to help. Eventually, if necessary, one of them would sleep there as well.

Dr. Bell had referred Anna to a memory clinic, where she would meet with a neurologist for a more comprehensive evaluation and, in all probability, be prescribed an appropriate medication and some daily mental exercises to do with her caregivers' help. Though Anna seemed a little puzzled by all of these changes, she took them in stride with her generally sunny disposition.

At the same time, Susan and Brian accepted that their mother's condition could worsen, or that the caregiving situation might have to change, and they wanted to be prepared. They began visiting area senior living communities with memory care programs, intending to decide on one soon that would become Anna's new home when she could no longer remain in hers. Based on their planning, no matter what happened, Anna would be in good hands.

# CONNECTIONS MEMORY SUPPORT SERVICES AT

At Country Meadows, we realize that memory loss can be unsettling and even debilitating for some older adults. That's why we developed our Connections Memory Support Services, which is available in our personal care and assisted living levels of care, as well as in secured settings.

Memory loss can be challenging and frightening for the affected individuals and their loved ones. Connections Memory Support Services provides specific assistance and emotional support for residents and their families.

#### Caring for the whole person

Country Meadows is a leader in providing care for those with memory loss caused by Alzheimer's disease or other forms of dementia. Over the last 30 years, our Connections Memory Support Services has assisted more than 20,000 people coping with memory loss. This experience has led us to develop and hone a unique approach that focuses on building bonds and caring for the whole person. Connections Memory Support Services:

- Provides a personalized support plan to match an individual's needs and wants.
- Addresses common emotional needs, like frustration, anxiety and loneliness, through the Validation Method.
- Offers fun and intellectual stimulation with brain fitness activities.
- Focuses on the whole body with customized exercise programs to promote balance, stretching, strength and endurance.
- Builds bonds and connections with My Life Story projects.

#### Connections Club

Residents in our communities who experience mild cognitive losses may be candidates for our Connections Club. This program was designed to alleviate feelings of frustration and anxiety that accompany early-stage memory loss.

Our staff proactively identifies these gradual changes and intervenes so our residents can continue to experience success in their current environment. A program manager works with each resident member individually to develop a personalized plan for support. Using this plan, our club manager acts as a personal coach to help each resident member through the challenges and joys of daily living.



In addition to developing comfortable and enjoyable plans and routines for our club members, we offer monthly support group meetings for their families.

#### **Connections Neighborhood**

Individuals with more serious memory loss, who require the structure of a supervised setting or safety of a secured living area, benefit greatly from our Connections Neighborhood. This Neighborhood provides secure entrances and exits while including outside access to enclosed garden areas and walking paths.

Residents in the Connections Neighborhood receive all of the programs offered in the Connections Club, but with added support for daily activities, hygiene, continence management and personal care. Residents also receive more extensive therapeutic programming, including activities that help reduce anxiety and frustration.

#### **Compass Program**

At Country Meadows, we realize that dementia can be a long journey, but we also know that people with dementia have a broad range of understanding and abilities. We use the Compass Program, developed by Genesis Rehabilitation Services, our rehab therapy partner, to deliver every aspect of care based on residents' individual needs. By tailoring our care to each individual, we can better ensure his or her needs are met and dignity remains intact.

All Country Meadows staff members who are involved in resident care are trained in the Compass Program and use it to deliver care and services. This includes nurses, therapists, personal care and dining associates, chaplains and community life directors. Here is an example of the Compass Program in action:

Before entering a resident's room, a personal care associate checks the doorframe for a small colored magnet. The color is red, meaning the resident has stopped acting independently and requires assistance. The care associate enters and meets the resident at eye-level and says his name. Smiling, she asks him, "Would you like to hear some music?" He doesn't respond right away, but she knows to wait at least 90 seconds. She then turns on his favorite CD, pours a glass of water and places crackers on a plate for him. She knows he last ate two hours ago, and, even though he might not be able to tell her, she knows he might be starting to feel hungry.

We are continually looking for ways to improve our care for residents with dementia and Alzheimer's disease to provide them the best possible support and quality of life.

Find more guidance for your family on our website, www.CountryMeadows.com, in our "Advice" section under "Tips Library":
Dealing with Memory Loss
When is it Time for a Memory Support Program?
What to Look for When Choosing a Memory Support Program

- Re-connect with Loved Ones with Dementia
- Tips for Successful Visits with a Loved One with Dementia
- Creating Meaningful Moments with a Loved One with Dementia
- Caring for a Loved One with Dementia in a Weather Emergency

#### Helping Children Understand Dementia

- Talking to Your Children About Dementia
- Children's Books About Dementia
- Children's Coloring Activity Pages

You can get a free copy of our new children's activity book, The Unforgettable Adventures of Grandma's Cape (Understanding the Forgetting Disease: Dementia), at any Country Meadows community.

For more tips, visit our website at **CountryMeadows.com/tips**, or talk to one of our experts. If you feel that you and your aging family member could benefit from the services of a senior living community, we hope you will contact us to arrange a personal visit. At Country Meadows, we specialize in caring for individuals with memory loss and take pride in offering a fulfilling living experience and compassionate services every day.



Allentown | Bethlehem | Forks of Easton | Frederick, MD | Hershey | Lancaster South Hills of Pittsburgh | Mechanicsburg | Wyomissing | York-South | York-West