



Virtual Dementia Tour™

“Your Window Into Their World”

A Program of **Second Wind Dreams**

A Non-Profit whose mission is to fulfill the dreams of the those living in nursing homes

WHAT IS DEMENTIA?

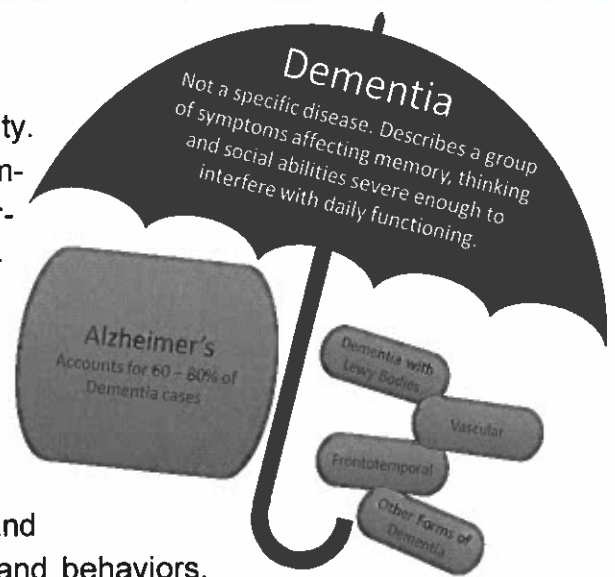
Dementia is an illness that affects the brain, causing cell death.

Dementia can significantly affect judgement and personality. People with dementia can have extreme reactions to common events, misinterpretation of surroundings and over-reaction to something overwhelming or annoying. Dementia causes confusion, leading a person to act in ways that can put the person and others in danger. **And, they don't even know it.**

The results of the illness:

Those with the illness experience a decline in memory and other thinking skills; are unable to explain their feelings and behaviors. They will also experience limited social skills, difficulty communicating and unpredictable behavior. Eventually they will lose the ability to care for themselves.

Sadly, they have no way to describe what is happening to their brain.



MORE THAN 5 MILLION AMERICANS are living with **Alzheimer's**

By 2050, this number could rise as high as **16 MILLION**

In 2018, Alzheimer's and other Dementias cost the United States \$277 billion. By 2050, these costs could rise as high as \$1.1 trillion. From 1999 to 2014 the death rate due to Alzheimer's disease increased 55% (In 2014, over 93,500 deaths occurred due to Alzheimer's in the United States). Of those 5 million currently living with Alzheimer's, 70% live at home or outside a

long-term care facility, within a community setting. The number of deaths in medical facilities has declined from 15% to 7% in the same period. The number of Alzheimer's deaths at home has

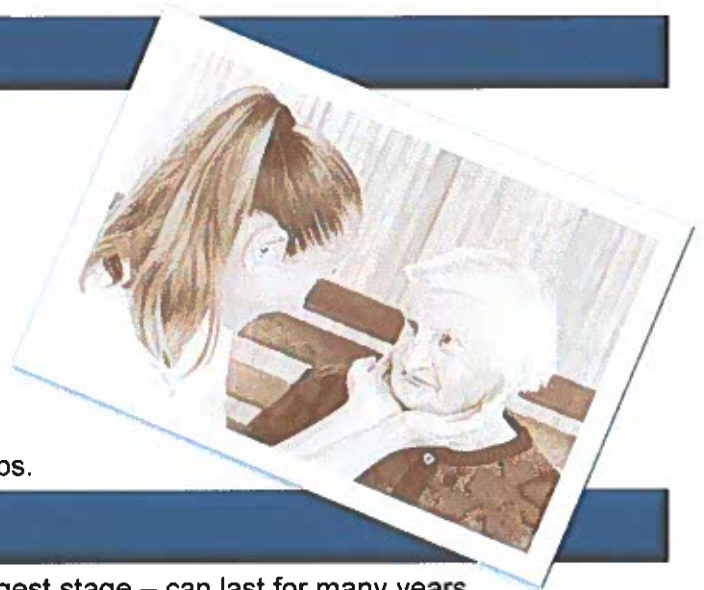
NORMAL AGING

People often become concerned that they are in the early stages of dementia, when they are actually aging normally. So, it is important to recognize what is normal aging.

- ◆ Sometimes forgetting names or appointments but remembering them later.
- ◆ Occasionally making errors when balancing a checkbook.
- ◆ Getting confused about the day of the week but recalling it later.
- ◆ Sometimes having trouble finding the right word.
- ◆ Making a bad decision once in a while.
- ◆ Sometimes feeling weary of work, family and social obligations.
- ◆ Developing specific ways of doing things and becoming irritable when a routine is disrupted.
- ◆ Misplacing things from time to time, such as a pair of glasses or remote control, and retracing steps to find them.

EARLY SIGNS OF DEMENTIA

- ◆ Memory loss that disrupts daily life.
- ◆ Challenges in planning or problem solving.
- ◆ Difficulty completing familiar tasks.
- ◆ Confusion with time or place.
- ◆ Trouble understanding visual images or spatial.
- ◆ New problems with words in speaking or writing.
- ◆ Decreased or poor judgement.
- ◆ Withdrawal from work or social activities.
- ◆ Changes in mood and personality.
- ◆ Misplacing things and losing the ability to retrace steps.



MIDDLE STAGE OF DEMENTIA

This is the stage in which most placements are made. Longest stage – can last for many years.

- ◆ Damage to brain cells makes it difficult to express thoughts and perform routine tasks.
- ◆ Symptoms become noticeable to others and the problem can no longer be covered up.
- ◆ Forgetting their personal history, address, phone number. Inability to recognize friends & family.
- ◆ Personality and behavior changes including suspiciousness, delusions or compulsive, repetitive behavior (hand-wringing or tissue shredding).
- ◆ Uninhibited behavior and lack comprehension of social skills. They may speak inappropriately.
- ◆ Mobility and coordination affected by slowness, rigidity and tremors.
- ◆ Get frustrated, angry or act in unexpected ways. Unusual reasoning.
- ◆ Confusion about where they are or what day it is.
- ◆ Need help choosing proper clothing for the seasons.
- ◆ Confusing words and rambling speech.
- ◆ Changes in sleep patterns.
- ◆ Risk of wandering or getting lost.
- ◆ Moody, withdrawn.

LATE STAGE OF DEMENTIA

Final stage – last several weeks to several years

- ◆ Lose their ability to respond to their environment.
- ◆ Become bed-ridden.
- ◆ Intensive, round-the-clock care.

ECONOMIC IMPACT

70% of older adults with dementia live in the community. Of that 70% - 74% live with someone; 26% live alone.

THE PUBLIC HEALTH IMPACT

People diagnosed with Alzheimer's live 4 to 8 years after the diagnosis. Some will live up to 20 years – The long duration of the illness before death contributes significantly to the public health impact. According to 2014 Medicare claims data, about one third of all Medicare beneficiaries who die in a given year have been diagnosed with Alzheimer's or other dementias. Between 2018 and 2025, every state across the country is expected to experience an increase of at least 13% in the number of people with Alzheimer's*.

**Alzheimer's Association, 2018*

Alzheimer's is the most expensive illness in the nation. The projected 2019 cost of assisted living nationally averages \$132 per day, \$4,000 per month and \$48,000 annually. The average annual costs of nursing home care is between \$89,297 – \$100,375 annually*. Medicaid (not Medicare) is the only public program that covers long nursing home stays that most people require in the late stages of the illness. Nationally, state Medicaid programs are shifting long-term care services from institutional care to home-and community-based services as a means to both reduce unnecessary costs and to meet the growing demand for these services for older adults.

**Seniorliving.org*

WHO PAYS?

In 2016 the Alzheimer's Association conducted a survey with more than 3,500 respondents. Twenty-eight percent believed that Medicare covered the cost of nursing home care and 37% did not know whether it covered the cost of nursing home care.

Medicare does not cover long-term nursing home care. The Medicaid program covers long-term nursing home stays. Beneficiaries must have low incomes. They must spend all of their Social Security income and any other monthly income, except for a very small personal needs allowance, to pay for nursing home costs.

There is a shift. According to the Long-term Services and Supports Expenditure Report, in 2014, for the first time in the Medicaid program's history, more than half of Medicaid funding for long-term care (53%) was spent on home and community-based services aimed at keeping people of all ages out of institutions.

The proportion of individuals with Alzheimer's who died in nursing homes or medical facilities decreased by 26% between 1999 and 2014. During the same period, individuals with Alzheimer's who died at home increased from 14% to 26%.



As a greater percentage of the population chooses to remain at home and have home health care, community organizations, fire, EMS and law enforcement, families and businesses will all face greater challenges.

THE ECONOMIC VALUE OF CAREGIVING

In 2016, 15.9 million family and friends provided 18.2 billion hours of unpaid assistance to those with Alzheimer's and other dementias, a contribution to the nation valued at \$230.1 billion.

Caregivers of those with dementia report providing 27 more hours of care per month than average caregiver of non-dementia persons (22 hours/week). Forty-two percent of caregivers of people with dementia provide an average of 9 hours of care per day.

The physical and emotional impact of dementia caregiving is estimated to have resulted in \$11.4 billion in healthcare costs in the US in 2017. Hospitalization, and emergency room visits were more likely for dementia caregivers, as well as greater use of over-the-counter and prescription medications. In a recent national poll – 45% of respondents indicated that caring for someone with dementia was very rewarding. But had higher stress levels. Approximately 30 to 40% of family caregivers of people with dementia suffer from depression (compared to 5 to 17% of other caregivers).

\$329,360*

The average lifetime cost of care for a person with Alzheimer's in 2017. Families bear 70% of that cost through out-of-pocket expenses and the value of unpaid care.

** 2018 WebMD*

CAREGIVERS IN THE WORKPLACE—ANOTHER ECONOMIC IMPACT

Businesses in the United States lose an estimated

\$33.6 billion

in lost productivity from full-time working caregivers. Costs associated with replacing employees, absenteeism, workday distractions, supervisory time, and reductions in hours from full-time to part-time all take a toll. The average annual cost to employers per full-time working caregiver is \$2,110.20* *AARP

6 in 10 caregivers of people with dementia were employed in the past year while also caring for someone. They worked an average of 35 hours per week to leave time for care responsibilities.



Of those 6 in 10:

- ◆ 57% reporting having to go in late or leave early for caregiving responsibilities.
- ◆ 18% have reduced their working hours due to caregiving responsibilities.
- ◆ 9% have given up working all together to care for a person with dementia.

THE PERSONAL ECONOMIC BURDEN

In 2016, the out-of-pocket costs of caregivers of someone with dementia averaged \$10,697, compared to \$5,785 for non-dementia caregivers. 48% have had to cut back on spending, 43% have cut back on saving due to out-of-pocket costs. 4 in 10 caregivers indicated “food they bought just didn’t last and they didn’t have money to buy more.”

DEMENTIA FRIENDLY COMMUNITIES

A Dementia Friendly Community is defined as a community that is informed, safe and respectful of individuals with dementia and their families/caregivers. There is a nation-wide effort to raise awareness and transform attitudes about dementia. Businesses, faith communities, healthcare organizations, first responders, and other entities work together to foster the ability of people living with dementia to remain in their community and engage and thrive in day to day living. Four foundations of Dementia Friendly Communities:

- ◆ Place – The physical environment (housing, neighborhoods, transportation, businesses) supports people with dementia.
- ◆ People – Families, friends, neighbors, health and social care providers support people with dementia and their caregivers
- ◆ Resources – Sufficient services and facilities that are appropriate and supportive of people with dementia
- ◆ Networks – Those who support people with dementia communicate, collaborate and plan together. They provide the best support for people with dementia and their caregivers.

70% of people living with Alzheimer’s live in a community. This means that every community will come in contact with people who have dementia, their families and caregivers. Whether they are paying their utility bill, are employed in the community, or purchasing groceries.

DEMENTIA FRIENDLY BUSINESSES

- ◆ The cost of doing business includes awareness of how dementia affects the workplace.
- ◆ On the customer front, making it easier for people with dementia to do everyday business out in the community has clear benefits:
 - ◆ Retain existing customers
 - ◆ Attract new customers – 60% of people with dementia live at home, often with support from families, friends and the community. Staying engaged in community life means using the businesses that are easy to navigate and helpful aware staff.
- ◆ Front line service staff are trained to recognize and respond appropriately to people with dementia.
 - ◆ Difficulty remembering and finding items: People with dementia may have forgotten what they came in to buy. They may have a list, but have problems finding the things they want.
 - ◆ Difficulty making choices: While having choices is good, for someone with dementia, too much can be confusing.

BEHAVIORS OF ALZHEIMER'S/OTHER DEMENTIAS

- ◆ **Negative Statements** — Feelings of frustration/anxiety in their challenges and inability to function.
- ◆ **Mumbling/Humming** — It is soothing to hear their own voice in their heads under stress. It may be aggravating to those around them, but we need to view it as a way they use to calm themselves down.
- ◆ **Requests for help** — They may beg for help, because they are afraid. They know they are supposed to do something, but they don't know what that is. We need to respond to their desire for help.
- ◆ **Very little interaction with others** — It is rare that people with dementia to actually interact with other people with dementia. Also, they may be so focused on what they are doing, they are unaware that anyone else is near them.

This gives us insight into why socialization for those with dementia should be initiated by us. Socialization has been shown to decrease cognitive decline and improve functioning.

- ◆ **Inappropriate or Strange Behavior** — Strange behavior that makes no sense to us makes perfect sense to them. They just have no way to articulate the reasoning for their behavior. This is an important area of understanding – the behavior is a function of the brain damage.
- ◆ **Agitation** — They become agitated when they are bathed, fed, taken from place to place.
- ◆ **Shadowing** — They may follow people. It is likely they feel more secure doing what another person is doing since they were unsure of themselves.
- ◆ **Wandering** — Wandering is used as a coping strategy to make sense of their environment. This is also why they wander out into the environment. They are trying to make sense using what they do know, even though that environment only exists in the brain.
- ◆ **Hoarding** — It is a way to try and control the thing around them. Hoarding can present itself in several different ways. Recognize that they take something that is “pretty” and put it in their pocket. Hoarding is normal in the confines of dementia – they see it, they like it, they take it. They are unable to process the consequences attached to the object. They are not “stealing.”
- ◆ **Rummaging** — They were looking for something to do, all in an attempt to make sense out of their environment. Allow people with dementia to safely rummage through things. They will put things in strange places and it is up to the others to try to keep track of things.
- ◆ **Repetitive Behavior** — Because of damage to the brain, some people with Dementia like to do the same thing over and over again. If they can continue doing it, they feel comfort in that.
- ◆ **Gave up** — It is devastating when a person realizes that they are unable to function in the world around them and they simply give up. They don't know what they are supposed to do so “stopping” makes sense to them.

WHAT ABOUT THE CAREGIVERS?

Caregivers need all the support they can get, as 35% of caregivers for people with dementia report their health has gotten worse due to care responsibilities. (*compared to 19% of caregivers for older people without Dementia*).

How you can help:

- **Be specific** — General offers of help can be hard for a caregiver to accept. If you want to support a friend caregiver, make a concrete offer. For example: "I've got a couple of hours free tomorrow afternoon. May I sit for you while you take time for yourself?"
- **Check in** — Sending a card, calling, texting, and emails are ways to show support — but personal visits are better. Contact with the outside world can help lift a caregiver's spirits.
- **Recognize signs of caregiver stress** — Keep in mind that some caregivers have a difficult time accepting help, mistakenly believing they should do everything themselves. This attitude can be harmful not only to the caregiver, but also to the care receiver. Caregiver stress can lead to irritability, anger, exhaustion, social withdrawal, anxiety, depression and other problems.

If your offers of help aren't accepted, be gently persistent. Remind the caregiver that he or she doesn't have to do this alone — and the best way to take care of someone else is to first take care of yourself.

COMMUNICATING WITH SOMEONE WITH DEMENTIA

Ongoing communication is important, no matter how difficult it may become or how confused they appear.

- ◆ They might not respond to what you are saying or asking.
- ◆ Or they may respond by pushing you away, crying or making sounds.
- ◆ These responses are called “behaviors” but often they are simply a form of communication for the person with Dementia.
 - If a person can no longer tell you it hurts to be moved, she may push you away.
 - If everyone is moving quickly and it is loud in the room, he may not be able to tell you to slow down, he may cry.

Tips for communicating with a person with Dementia

- ◆ *Recognize what you're up against.* Dementia gets worse with time. People with dementia will gradually have a more difficult time understanding others, as well as communicating in general.
- ◆ *Come from the front, identify yourself, and keep good eye contact.*
- ◆ *Avoid distractions.* Try to find a place and time to talk when there aren't a lot of distractions present.
- ◆ *Speak clearly and naturally in a warm and calm voice.* Avoid 'babytalk',
- ◆ *Refer to people by their names.* Avoid pronouns like “he,” “she,” and “they”. Names are also important when greeting someone with dementia. For example: “Hi, June. It's me, Jeff,” rather than, “Hi. It's me.”
- ◆ *Talk about one thing at a time.* Someone with dementia may not be able to engage in the mental juggling involved in maintaining a conversation with multiple threads. Use short, simple phrases and repeat as needed.
- ◆ *Use nonverbal cues, maintain eye contact and smile.* This helps put them at ease and will facilitate understanding.
- ◆ *Listen actively.* If you don't understand something your loved one is telling you, politely let them know.
- ◆ *Don't argue.* Your conversations won't go very far if you correct every inaccurate statement. It's okay to let delusions and misstatements go.
- ◆ *Have patience.* Give the person extra time to process what you say. If you ask a question, give them a moment to respond. Don't let frustration get the better of you.
- ◆ *Understand there will be good days and bad days.* While the general trend of dementia sufferers is a downward decline, people with dementia will have ups and downs just like anyone else.

Thank you for participating in the Virtual Dementia Tour. If you have questions, please contact Judi or Connie, Program Developers, at the Dancing Sky Area Agency on Aging.

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