

## ***Dementia Fact Sheet***

- Prevalence of dementia: of the total U.S. population,
- More than 1 in 9 people (11.3%) age 65 and older has Alzheimer's dementia.
- The percentage of people with Alzheimer's dementia increases with age: 5.3% of people age 65 to 74, 13.8% of people age 75 to 84, and 34.6% of people age 85 and older have Alzheimer's dementia.
- People younger than 65 can also develop Alzheimer's dementia, but it is much less common and prevalence is uncertain, but is known to have a hereditary component.
- Dementia: multiple causes:
  - Alzheimer's disease (most common, accounting for 60-80% of people with dementia): results from the buildup of amyloid and tau proteins in the brain – form into plaques and tangles. Memory loss is thought to start in the hippocampus, the brain region controlling memory. Other symptoms include word finding difficulties, irritability, and confusion. Preventive measures include controlling high blood pressure, maintaining a healthy weight through diet and exercise. On average, people live 3 to 20 years beyond diagnosis, depending on other health issues.
  - Vascular dementia: results from impaired blood flow to brain cells due to changes in the blood vessels that feed the brain. Brain cells require oxygen and when this is constrained, cells die in a short period of time. Brain failure with dementia results when enough cells die or malfunction. Contributory causes include strokes and heart disease. Symptoms vary depending on affected area of the brain.
  - Lewy Body: A Lewy body is a clump of a protein called alpha-synuclein. Lewy bodies develop for unknown reasons and effect depends on where formed in the brain. Often starts with movement difficulties; muscle rigidity, tremors, and a shuffling walk are common. Other symptoms include visual hallucinations, sleep disorders, and difficulty carrying out mental tasks. Memory may be minimally affected. Affects autonomic nervous system, controlling blood pressure, heart rate, sweating and digestion. Blood pressure volatility can cause temporary blackouts and falls.
  - Frontotemporal dementia (FTD): develops when the frontal and temporal lobes of the brain shrink due to cell damage caused by the tau protein or TDP-43. Frontal and temporal lobes control executive functions, used to make plans, solve problems, and make decisions. Impaired functions include mood regulation, emotional control, and inhibitions. Wide mood swings and lack of empathy are common. Disinhibition can result in odd behaviors and salty language unlike normal behaviors.

- Parkinson's Disease: twin of dementia with Lewy bodies. Both diseases affect brain cells through the presence of Lewy bodies; experts disagree on whether they are two separate diseases. Unusual physical symptoms occur, such as visual hallucinations, shouting or thrashing about during sleep, and loss of facial expressions.
- Mixed dementia: most often Alzheimer's disease and vascular dementia combination; usually evident in those older than 80.
- Creutzfeldt-Jakob Disease: rare brain disease that causes dementia, with vast majority of cases developing with no known origin. The rarest cause is contamination from infectious sources (one in a million cases).
- Sensory changes in people with dementia
  - Vision
    - Loss of peripheral vision, so need to approach slowly from the front
    - Inability to process what one sees: a black door may appear to be a hole, causing individual to fear going through
    - Non-contrasting colors may cause objects to disappear (eg, white toilet on a white floor)
    - Difficulty interpreting information from a mirror, making it difficult to see one's image (or another)
    - Increase lighting in seating areas
  - Hearing
    - Inability to filter out background sounds, so may need to reduce noises by turning off the television, vacuum cleaner, or other appliances
    - When talking, sit close, make sure have eye contact, and speak slowly
    - Give person time to process information
  - Taste/Smell
    - Loss or change in sense of taste, making eating less enjoyable
    - Loss or change in sense of smell, making it difficult to distinguish good from spoiled foods or reducing person's appetite
  - Sense of touch
    - Increased sensitivity to falling water, making shower uncomfortable or painful
    - Loss of sensitivity to temperature changes, making it easier to get frostbite (in extreme cold) or be burned (in extreme heat)
- Caregiving
  - Eighty-three percent of the help provided to older adults in the United States comes from family members, friends or other unpaid caregivers.
  - Nearly half of all caregivers (48%) who provide help to older adults do so for someone with Alzheimer's or another dementia.
  - More than 11 million Americans provide unpaid care for people with Alzheimer's or other dementias.
- Dementia Stages: there are various staging systems for dementia classification
  - Alzheimer's Association: three stages (early, moderate, late; see <https://www.alz.org/alzheimers-dementia/stages>)
    - Early (mild): 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.
      - Coming up with the right word or name.
      - Remembering names when introduced to new people.
      - Having difficulty performing tasks in social or work settings.
      - Forgetting material that was just read.
      - Losing or misplacing a valuable object.
      - Experiencing increased trouble with planning or organizing.
    - Middle (moderate): Symptoms are more pronounced. The person may confuse words, get frustrated or angry, and act in unexpected ways, such as refusing to bathe.

- Being forgetful of events or personal history.
- Feeling moody or withdrawn, especially in socially or mentally challenging situations.
- Being unable to recall information about themselves like their address or telephone number, and the high school or college they attended.
- Experiencing confusion about where they are or what day it is.
- Requiring help choosing proper clothing for the season or the occasion.
- Having trouble controlling their bladder and bowels.
- Experiencing changes in sleep patterns, such as sleeping during the day and becoming restless at night.
- Showing an increased tendency to wander and become lost.
- Demonstrating personality and behavioral changes, including suspiciousness and delusions or compulsive, repetitive behavior like hand-wringing or tissue shredding.
- Late (severe): dementia symptoms are severe. 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, significant personality changes may take place and individuals need extensive care.
  - Require around-the-clock assistance with daily personal care.
  - Lose awareness of recent experiences as well as of their surroundings.
  - Experience changes in physical abilities, including walking, sitting and, eventually, swallowing
  - Have difficulty communicating.
  - Become vulnerable to infections, especially pneumonia.
  - Benefits from interactions such as listening to music or gentle touch.
- Preparing for dementia stages
  - Establish communications with health care providers
    - Current physical
    - HIPAA release
    - Accompany loved one to medical visits
  - Complete legal and health directives
    - Last will and testament
    - Medical Power of Attorney
    - Directive to Physicians (Living Will)
  - Identify resources
    - Information – what do loved ones understand; what do they want from life and what do they want from health care?
    - Social support – socialization opportunities
    - Care support – family and outside
  - Think ahead
    - Financial planning
    - Living options

Managing behaviors/conversations

<i>Issue/Comment</i>	<i>Try This</i>	<i>To Help You Cope</i>
Gets lost when driving	<p>If person has been gone unaccountably long, contact local law enforcement immediately</p> <p>If it happens just once with a safe outcome, consider it a wake-up call that the person can no longer drive safely</p>	
Says hurtful or inappropriate things	<p>At first, draw a line (“please don’t talk to me like that”)</p> <p>Avoid dramatic shushing or shaming</p> <p>Look for an underlying trigger</p> <p>Mention a tough case to the doctor</p>	<p>Let yourself grieve</p> <p>Don’t assume bad words are loved one’s “real personality”</p> <p>Use humor to cut the discomfort (“You sound like someone in an R-rated movie)</p> <p>Remember, “it’s not the person, it’s the disease.”</p>
Says “I want to go home”	<p>Skip trying to orient the person by saying, “But you are home.”</p> <p>Hear home as a feeling (“I’m uneasy” or “I’m scared”)</p> <p>Offer reassurance in the form of a hug</p> <p>Use verbal reassurance (“You’re safe with me”)</p> <p>Use home as a springboard for distracting conversation (You really miss home - tell me about it”)</p>	Separate your emotions from what’s being said
	Don’t take personally and	

<p>Acting aggressively</p>	<p>avoid reacting in kind</p> <p>Back off</p> <p>Stop doing whatever was happening at the moment and avoid returning to the activity</p> <p>Stick to a calm response and pleasant expression (“Everything’s all right now”)</p> <p>Step out of the room</p>	<p>Don’t be surprised later if the person acts as if nothing happened</p> <p>Find outlets for your own feelings</p> <p>Know it’s common to feel as though you’re living with a stranger</p> <p>Assess what was happening before and after the event: noisy room; tired individual; etc.</p>
<p>Follows you everywhere</p>	<p>Reinforce efforts to maintain predictable household routine</p> <p>See if you can identify a pattern</p> <p>Say something reassuring (“Hello, dear”)</p> <p>Use music to soothe</p>	<p>Be sure to arrange regular respite for yourself</p>
<p>Hallucinates, seeing or hearing things that aren’t there</p>	<p>Avoid correcting or trying to prove illogic of perception</p> <p>Acknowledge (“I’m glad the police took care of it and everything’s safe”)</p> <p>Use empathic phrasing (“That must have been scary”)</p> <p>Assure loved one you’ll take care of it</p>	<p>Remember that many hallucinations are harmless</p>
<p>Hoarding</p>	<p>When the person’s asleep, thin the collection</p> <p>Repeat cleanups regularly</p> <p>If asks where items are gone, “gave to family in need”</p>	

<p>Starting and Ending a Conversation</p>	<p>If person doesn't recognize you, introduce yourself.</p> <p>Say, "I came to visit you" and ask "Is this a good time?"</p> <p>When it is time to leave, remind the person how much you have enjoyed the visit, and ask if you can come again.</p>	<p>Close-ended questions:</p> <p>Do you like to watch television?</p> <p>Would you like to go on a walk with me?</p> <p>Open-ended questions:</p> <p>What television programs do you like to watch?</p> <p>What do you like to do?</p> <p>Tell me a story about when you were little.</p>
<p>Not Understanding the person</p>	<p>Acknowledge what is happening: "It is frustrating, isn't it?"</p> <p>Ask close-ended questions: "Does it have to do with ... (food, room, temperature, clothing, sleep, another person, etc.)"</p>	
<p>Ways to Say "No"</p>	<p>"I wish I could."</p> <p>"I don't know. I will see what I can find out."</p> <p>"That's an idea, but this isn't a good time."</p>	
<p>Sundowning</p>	<p>Identify patterns other than time of day</p> <p>If identify a trigger, try to eliminate</p> <p>Expose the person to plenty of sunlight early in the day</p> <p>Encourage movement</p> <p>Try to discourage unusual</p>	<p>Reassure yourself if it becomes a big problem</p>

	<p>sleep-night cycles</p> <p>If unusual behaviors, tell doctor</p>	
Touching	<p>Ask whether you may touch (eg, "I could really use a hug. Any chance you can give me one?")</p> <p>If person expresses a need for animal and that is not possible, provide soft stuffed animal or baby doll for person to hold.</p> <p>Some people like hand massages; use lotion to massage person's hands and arms.</p>	