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Office of Integrated Health Health & Safety Information

Dementia Health and Safety Alert

What is Dementia?

Dementia is a blanket term referring to a wide range of specific medical conditions, including Alzheimer's disease. Disorders grouped under the general term "dementia" are caused by abnormal brain changes. These changes are a collection of symptoms affecting cognition and memory caused by a number of different diseases that damage brain cells and affect daily functioning. They also affect behavior, feelings and relationships (Alzheimer's Association, 2019). Dementia ranges in severity from the mildest stage, when it is just beginning to affect a person's functioning, to the most severe stage, when the person must depend completely on others for basic activities of daily living (National Institute on Aging, 2017).

Alzheimer's disease is the most common form of dementia, causing 60-80% of dementia cases (Alzheimer's Association, 2019). Other common diseases that may cause dementia include vascular dementia, frontotemporal lobar degeneration, dementia with

YouTube Video – What is Dementia?

Alzheimer's Association, 2017

<https://www.youtube.com/watch?v=fmaEqI66gB0>



Lewy bodies, and Parkinson's disease dementia. Mixed dementia refers to a combination of diseases, often Alzheimer's disease and vascular dementia (National Institute on Aging, 2017). There are also other conditions that can cause symptoms of dementia, including some that are reversible, such as thyroid problems and vitamin deficiencies (Alzheimer's Association, 2019).

Dementia is the sixth leading cause of death in the United States, with one person diagnosed roughly every sixty seconds. (Alzheimer's Association, 2019). There are an estimated 150,000 adults age 65 or older currently living with Alzheimer's disease in Virginia. This number is expected to rise to 190,000 by 2025. For more information on

this data, including the prevalence rates of Alzheimer's disease for Medicare beneficiaries at the county level, please visit <https://alzpossible.org/data-and-data-sets/>

Individuals living with intellectual and developmental disabilities (ID/DD) are increasingly living longer lives, though life expectancy remains lower than for the general population.

Individuals with Down syndrome are at highest risk for developing Alzheimer's disease or a related dementia, and typically develop it in their 50s or earlier (Virginia Alzheimer's Disease and Related Disorders Commission (VADRDC), 2019).

Similarly, prevalence for other individuals with DD is thought to be higher than for the general population, although with a similar age of onset and time frame (VADRDC, 2019).

Risk Factors

Individuals with intellectual disability are at increased risk of developing dementia if they have a history of severe or multiple head injuries, or a family history of Alzheimer disease (Strydom, Chan, King, Hassiotis & Livingston, 2013). Individuals with intellectual disability (not due to Down syndrome) are at least the same risk if not greater risk for developing dementia as they age to greater than 59 years (Strydom et al., 2013) and individuals with Down syndrome over the age of 40 are at a substantially increased risk of developing Alzheimer disease (Pritchett, 2017).

- Age. The risk of developing dementia doubles every five years after the age of 65 (Alzheimer's Association, 2019).
- Genetics/family history affects individuals who have a parent, or sibling diagnosed with dementia making them more likely to develop the disease (Alzheimer's Association, 2019).
- Smoking and alcohol use are directly related to increased risk for vascular dementias.
- Atherosclerosis (deposits of fatty substances, cholesterol, and other matter in the inner lining of an artery).
- Plasma homocysteine. Research has shown that a higher-than-average blood level of homocysteine, a type of amino acid, is a strong risk factor for the development of Alzheimer's disease and vascular dementia.
- Diabetes increases the risk for both Alzheimer's disease and vascular dementias.
- Mild cognitive impairment (Stanford Health Care, 2019).

Signs and Symptoms of Dementia

The symptoms of dementia vary widely by individual and specific disease, but typically include significant impairment of at least two of the following areas: memory, communication and language, ability to focus and pay attention, reasoning and judgment, and visual perception (Alzheimer's Association, 2019).

Symptoms may include:

- Sporadic memory lapses.
- Getting lost or misdirected.
- Problems with gait or walking.
- Confusion with familiar tasks or in familiar situations.
- Increased frustration and lack of patience.
- Changes in personality. (Jokinen, Janicki, Keller, McCallion & Force, 2013).

Complications of Dementia

- Severe intellectual deterioration.
- Immobility.
- Falls.
- Seizures.
- Difficulties with swallowing.
- Respiratory and breathing problems.
- Complete loss of self-care skills.
- Conditions leading to death (Jokinen, et al., 2013).

Any of a number of medical complications including pneumonia, aspiration, UTI and/or sepsis commonly precede death (Pritchett, 2017).

The clinical presentation of dementia in person with ID can differ from the general population. Personality and behavioral changes can start occurring earlier in the course of the disorder. Individuals with Down syndrome show early behavioral changes, which are believed to be linked to frontal lobe malfunctions (Strydom, Shoostari, Lee, Raykar, Torr, Tsiouris, & Maaskant, 2010). By age 55, three out of every five individuals with Down Syndrome will be diagnosed with Alzheimer's disease or another neurodegenerative condition (Rubenstein, Hartley, & Bishop, 2019).

Symptoms of Early Stage Alzheimer's

- Forgetfulness.
- Recent memory loss.
- Cognitive decline.
- Individual awareness of cognitive changes.
- Gradual dysfunction in vocational or social skills.

This stage is difficult to distinguish from normal aging and has no distinct physical presentation (Pritchett, 2017).

Symptoms of Middle Stage Alzheimer's

- Distinct problems with language.
- Pronounced loss of memory and cognitive abilities.
- Frequent confusion and disorientation.
- Loss of self-care skills.
- Personality and behavior change (Pritchett, 2017).

Symptoms of Late/End Stage Alzheimer's

- General disorientation and confusion.
- Unable to recall events from the past.
- Disordered and fragmented speech.
- Basic skills forgotten.
- Incontinence.
- Weight loss.
- General physical deterioration.
- Parkinsonian features.
- Immobility, rigidity and frequent falls.
- Totally dependent (Pritchett, 2017).

Symptoms in the terminal stage typically manifest over the course of 3-5 years (Pritchett, 2017).

Diagnosis and Treatment

To diagnose dementia, physicians first assess whether a person has an underlying treatable condition such as abnormal thyroid function, normal pressure hydrocephalus, or a vitamin deficiency that may relate to cognitive difficulties (National Institute on Aging, 2017).

As with the general population, there is no single diagnostic test for Alzheimer's disease or dementia in the ID population (Pritchett, 2017). The diagnostic process often begins with a preliminary assessment of cognitive and physical functioning to confirm suspicions and to determine the presence of any neuropathological indicators associated with dementia. Because of preexisting cognitive issues, standard cognitive instruments used in detection and progression in the general population make early stage dementia detection difficult in people with ID. The process includes neuropsychological examinations, blood tests, assessments for delirium or depression, and brain scans such as CT or MRI. An accurate diagnosis involves a confirmation of data from the assessment and a firm understanding of intellectual disability and causes of dementia (Bishop, Hogan, Janicki, Keller, Lucchino, Mughal, & Wolfson, 2015).

To measure early onset aging conditions, the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID) was developed and designed for caregivers to complete to determine the symptoms of dementia in the adults with ID. DSQIID scale evaluates a change from a person's "normal" level of functioning; the indication areas that are considered such as loss of memory, confusion, loss of skills, social withdrawal, behavioral changes, psychological symptoms, physical symptoms, sleep disturbance and speech abnormalities (Deb, Hare, Prior, & Bhaumik, 2007).

Dementia Scale for Down Syndrome (DSDS): The Dementia Scale for Down syndrome (Gedye, 1995) is an information based tool designed to assist in the diagnosis of dementia in adults with Down syndrome. It can also be utilized to establish a baseline for those at risk. The items are grouped into early, middle, late and very late stages of dementia (Pritchett, 2017).

Cambridge Examination of Mental Disorders of the Elderly-Down Syndrome (CAMDEX-DS): The Camdex-DS (Holland & Ball, 2008) is designed for use in the community by trained healthcare professionals. It is a set of tests grouped together for comprehensive assessment that can be somewhat time intensive. It is structured about areas of function likely to change with the onset of dementia. It also collects information on cognitive and functional decline, current mental and physical health and best level of functioning (Pritchett, 2017).

Dementia Questionnaire for Mentally Retarded Persons (DMR): The Dementia Questionnaire for Mentally Retarded Persons (Evenhuis, 1992). The DMR is based on observation of caregivers over the previous two months. It is applicable for individuals with the mental ages of 2-10 but is not appropriate for individuals with profound or severe ID with other severe physical, motor or hearing impairments. The DMR does not have use restrictions nor is specialized administrative training required (Pritchett, 2017).

Pharmacological treatment in individuals with intellectual disability may include: Acetylcholinesterase inhibitors (donepezil, rivastigmine, galantamine) and N-methyl-D-aspartate receptor antagonists (memantine) by the Food and Drug Administration (FDA) in the United States. There have been few clinical trials assessing the potential benefits of these agents in people with intellectual disability and dementia. The trials that have been conducted have studied dementia in Down syndrome only and the results have shown no benefit to treatment (Sheehan, Ali, & Hassiotis, 2014).

Prevention

Active management of symptoms can improve the quality of life, but do not slow or stop the damage caused by Alzheimer's disease. Exercise and cognitive stimulation may be beneficial, although the research is incomplete. Active management includes; appropriate use of available treatments, effective management of other health conditions, care coordination, participation in meaningful activities, opportunities to connect with others living with dementia, caregivers becoming educated about the disease and planning for the future (Alzheimer's Association, 2019).

In 2004, the Virginia Alzheimer's disease and Related Disorders Commission created a statewide "Virtual Alzheimer's Disease Center." In 2006, the Commission refined this effort so that over the long term it will create a centralized mechanism for ascertaining patient and training needs and mounting coordinated responses to those needs before they reach crisis proportions. Initially titled the Virginia Alzheimer's Commission AlzPossible Initiative (VACAPI) (2019), the effort is now most frequently referred to as "AlzPossible".

Guided by Virginia's Dementia State Plan, the mission of AlzPossible is to promote workforce development through training in person-centered, ethical dementia care and to ensure the development of a broad range of well-integrated programs, services and research designed to reduce the burden of the disease on the citizens of the Commonwealth of Virginia (VACAPI, 2019).



Supportive Resources of "Virginia Alzheimer's Disease AlzPossible Initiative" Link: <https://alzpossible.org/>

- *Virginia Department for Aging and Rehabilitative Services.*
- *Virginia Alzheimer's disease and Related Disorders Commission.*
- *Virginia Commonwealth University Department of Gerontology.*
- *World Events Forum, Inc. (VACAPI, 2019).*

Recommendations

Guidelines for structuring dementia care for people with intellectual disabilities have been published by the National Task Group on Intellectual Disabilities and Dementia Practices. Suggestions for best practice are divided by stage of dementia (early, mid, and late/end-stage) and into recommended actions, symptoms, care focus, environmental modifications, trainings, and outcomes. The focus is on holistic, person-centered care and strategic planning to support home and community living for as long as possible. This is consistent with other imperatives for 'ageing in place' as a means of maintaining quality of life and delaying institutionalization of people with dementia (Bishop, et al., 2015).

Early Stage

1. Engage the individual and their family, and other caregivers and/or guardians in advance care planning. Prepare advance directives if not already completed.
2. Identify and assess the environmental challenges to help maintain community living.
3. Establish a daily routine that provides purposeful engagement based on individual needs and preferences, but is organized to not cause anxiety and/or confusion.

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4. Provide ongoing clinical supports to address behavioral and psychological symptoms associated with dementia.
 5. Restructure day activities and programs so that participation in valued activities and opportunities for interaction with others continues and respite for families and other caregivers is possible (Jokinen, et al., 2013).

Mid-Stage

1. Facilitate resources and provide education to the individuals, friends, and families as well as staff to better understand the diagnostic process and progressive nature of dementia.
2. Use a detection/screening tool on a regular basis to capture early warning signs that may or may not indicate dementia.
3. Assess for medication induced adverse drug reactions or other conditions mimicking, exacerbating or masking dementia.
4. Report to a healthcare professional or clinician the screening tool findings. If the results indicate the presence of dementia, initiate the referral process for a formal health assessment to be completed.
5. Advocate that trained professionals familiar with assessment and diagnosis of adults with intellectual disabilities and cognitive/functional decline become involved.
6. Have a person familiar with the Individual to always accompany the Individual to the assessment appointments.
7. If a diagnosis of dementia is obtained, revision to the Individual's support plan will need to be made. Meetings with the Individual, family members and service providers are necessary to determine the level of essential supports (Jokinen, et al., 2013).

Late/End Stage

1. Arrange for non-ambulatory care management.
2. Implement staff training to develop an environment more structured around nursing and personal care including the support of family caregivers who wish to maintain the person at home.
3. Obtain support from palliative care or hospice specialists.
4. Develop procedures to maintain dignity, comfort, and address pain and symptom management.
5. Coordinate end-of-life supports and post-death arrangements (Jokinen, et al., 2013).

Resources

VA State Plan for Dementia 2020-2024

<https://alzpossible.org/wp-content/uploads/2019/10/2020-2024-VA-Dementia-State-Plan-Final.pdf> (Virginia Alzheimer's disease and Related Disorders Commission, 2019).

The National Institute of Aging offers all types of Alzheimer's and Dementia resources for healthcare professionals.

<https://www.nia.nih.gov/health/alzheimers-dementia-resources-for-professionals> (National Institute on Aging and the U.S. Dept. of Health and Human Services, 2017).

Healthy Brain Initiative 2018-2023 Road Map has a guide that includes the practical steps that can be taken to achieve better outcomes for individuals diagnosed with Alzheimer's and dementia. <https://www.cdc.gov/aging/pdf/2018-2023-Road-Map-508.pdf> (Alzheimer's Association and the Centers for Disease Control & Prevention, 2018).

The Virginia Department of Health's Brain Health Virginia

Offers training modules for Options Counselors, Care Transitions Coaches, Information and Referral Specialists. <http://www.vdh.virginia.gov/brain-health/> (Additional links to these modules are available at <https://alzpossible.org/training/>)

The Virginia Geriatric Mental Health Partnership (GMHP) in collaboration with the Riverside Center for Excellence in Aging and Lifelong Health (CEALH) and Virginia Commonwealth University's Gerontology College of Health Professions has created the Mental Health and Aging Training Initiative (MHATI). MHATI brings together all of Virginia's resources into an easy-to-use, web-based training platform which includes more than 20 webinars to train community-based staff and providers as well as family caregivers. You can find the MHATI web-based training platform here: <https://www.worldeventsforum.net/mhati/> (MHATI, 2019).

The National Institute on Aging (NIA)

The National Institute on Aging's (NIA) and the Alzheimer's and related Dementias Education and Referral (ADEAR) Center offers information and free print publications about Alzheimer's disease and related dementias for families, caregivers, and health professionals. ADEAR Center staff answer telephone, email, and written requests and make referrals to local and national resource. Phone contact: 1-800-438-4380 (toll-free), Email: adear@nia.nih.gov Website: www.nia.nih.gov/alzheimers (National Institute on Aging, 2019).

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