Daryl Washington, LCSW
Commissioner

COMMONWEALTH of VIRGINIA
DEPARTMENT OF
BEHAVIORAL HEALTH AND DEVELOPMENTAL SERVICES
Post Office Box 1797
Richmond, Virginia 23218-1797

Telephone (804) 786-3921
Fax (804) 371-6638
www.dbhds.virginia.gov

**Office of Integrated Health**
**Health & Safety Alert/Information**

# Overview of the National Task Group (NTG) Training on Intellectual Disabilities and Dementia Practices Health & Safety Alert

## Introduction

### What is Dementia?

Dementia can be described as a loss of cognitive function severe enough to interfere with a person's daily functioning. Changes may affect memory, thinking, reasoning, communication, personality, behavior, and the ability to complete activities of daily living. Dementia is not a normal part of aging (20).

For individuals with intellectual and developmental disabilities (IDD), recognizing dementia can be challenging because cognitive and functional differences may already be present. Intellectual disability reflects lifelong limitations in intellectual and adaptive functioning, while dementia involves a decline or loss of abilities and skills the person previously had (20). Therefore, recognizing changes from the individual's usual or baseline level of functioning is especially important.

Do not assume a decline in memory, behavior, communication, or daily functioning is simply part of the individual's disability or normal aging. New or progressive changes should be documented and evaluated.

### Aging, IDD, and Dementia Risk

- Aging is a lifelong process, and each person ages differently. Adults with IDD experience many of the same patterns of aging as other adults. Most adults with intellectual disabilities are not at greater risk for dementia than the general population; however, adults with Down syndrome have a significantly increased risk for Alzheimer's disease and may develop symptoms at an earlier age (19) (20).

People with Down syndrome have an extra copy of chromosome 21, which contains the gene that produces amyloid precursor protein (APP). This genetic difference contributes

to the increased risk for Alzheimer's disease. Although many people with Down syndrome develop Alzheimer's disease as they age, not everyone will develop dementia (18).

Because individuals with IDD have varying lifelong cognitive, communication, and functional abilities, comparison to the general population may not accurately identify decline. Knowing the person's baseline, what is typical for that individual, is essential for recognizing meaningful changes as they age (20).

Changes to monitor may include:

- Memory and cognition
- Communication and language
- Behavior or personality
- Activities of daily living and self-care
- Mobility, balance, or gait
- Previously learned skills
- Sleep patterns
- Bladder and bowel control

For adults with intellectual disabilities other than Down syndrome, monitoring changes in capabilities beginning in the 50s can assist with early recognition. For adults with Down syndrome, monitoring changes from baseline should begin earlier, around age 40 (20). Clinical guidelines also recommend annual assessment for changes from baseline in adults with Down syndrome beginning at age 40 and emphasize obtaining information from the individual and caregivers who know the person well (30).

Know the individual's baseline before significant decline occurs. Early recognition of change can support timely medical evaluation, planning, and adjustments to care and support.

## Recognizing Changes / Early Warning Signs

### Common Areas of Change

- **Memory:** People may forget familiar routines, get lost in familiar places, or become confused in situations they once understood (18).
- **Communication:** Dementia can affect processing abilities, making it difficult to understand or express thoughts. This may lead to withdrawal or agitation when the person cannot communicate effectively (20).

- **Personality:** Individuals may become irritable, withdrawn, or unkind without clear reason. These changes are often subtle at first but tend to progress over time (20).
- **Physical Functioning:** Problems with balance and gait may develop. Declines in self-care, eating, swallowing, sleep, and continence can also emerge (30).
- Self-care skills may diminish, including bathing, dressing, grooming, and toileting. Additional support and step-by-step guidance often become necessary as dementia progresses (20).
- Close monitoring of nutrition and hydration becomes essential, as reduced intake can contribute to weight loss, dehydration, and increased constipation. Trial and error with temperatures and textures of foods will be a challenge. A dietitian can provide finger food suggestions that fit the nutritional needs.
- Swallowing difficulties (dysphagia) may increase aspiration risk. Collaborate with a Speech-Language Pathologist (SLP) for assessment and ongoing support (30).
- Sleep patterns often change, including increased daytime sleep, nighttime wakefulness, and difficulty maintaining regular sleep cycles (19).
- Falls may become more common as changes in balance, gait, strength, vision, judgment, or mobility occur. Advocate for Physical Therapy consultation for baseline recognition and future treatment needs with decline (30).
- Reduced mobility and impaired swallowing increase the risk of infections such as aspiration pneumonia and skin breakdown. Preventative strategies including repositioning, oral care, and monitoring for signs of respiratory illness are essential (30).
- **Social Engagement:** Interest in social activities may gradually decrease, leading to isolation or reduced participation (20).

While dementia causes gradual decline, similar symptoms can arise from other treatable conditions (20).

## Rule Out Other Causes

Before assuming that symptoms are dementia-related, it is important to rule out other medical or environmental causes (20).

### Possible Contributing Factors

- **Acute Illnesses:** Conditions such as urinary tract infections, dehydration, constipation, or even the common cold can lead to sudden changes in behavior or

cognition (30). Constipation often worsens due to decreased mobility, reduced nutritional intake, and medication side effects. Addressing bowel habits early helps prevent discomfort, agitation, or further cognitive changes

- **Pain:** Always consider pain when immediate changes in mood or responsiveness occur; it can significantly affect behavior and communication (20).
- **Medications:** Interactions or side effects, especially from new prescriptions, may cause confusion or behavioral changes (30).
- **Normal Aging:** Sensory changes like vision and hearing loss are common and may be more pronounced in individuals with dementia (18).
- **Vision:** Peripheral vision often declines; approach the person from the front at eye level.
- **Hearing:** Evaluate hearing before assuming dementia is the cause of communication difficulties. In dementia, misinterpretation of sounds may occur—background noises such as television or radio can be perceived as voices or hallucinations (20).
- **Sleep Disturbances:** Common in dementia and should be carefully investigated. Consider factors such as clothing comfort, room temperature, and outside noise before using sleep aids. A sound machine can help promote restful sleep. Creating a calm, comfortable environment often improves sleep quality and reduces nighttime confusion.
- **Nutritional Deficiencies:** Low levels of vitamin B12 or folate can mimic dementia symptoms and should be checked regularly (30).
- **Delirium:** Sudden confusion, changes in alertness, or a rapid change in behavior or functioning may indicate delirium and require prompt medical evaluation. Possible causes include infection, dehydration, medication effects, pain, metabolic changes, or other acute illness (30).
- **Environmental Stressors:** Changes in surroundings or overstimulation can resemble dementia symptoms, causing confusion, withdrawal, or discomfort that may lead to negative behaviors (20).

### 💡 Caregiver Tip

Observe and document changes from the person's usual level of functioning. Approach calmly, provide reassurance, and create a predictable environment that supports comfort and orientation (20).

When sudden changes occur, seek medical evaluation promptly rather than assuming dementia progression.

## Screening, Assessment, and Diagnosis

Early recognition begins with knowing the individual and identifying changes from their previous level of functioning. Family members, direct support professionals, and other caregivers who know the person well are often the first to notice subtle changes in memory, communication, behavior, self-care, mobility, or other established skills (20).

When changes are identified:

- Observe and document what is new or different from the person's baseline.
- Consider the onset, frequency, and progression of the changes.
- Share observations with the individual's healthcare provider.
- Ensure other medical, sensory, psychiatric, medication-related, and environmental causes are considered.
- Seek further assessment when changes are persistent or progressive.

Other possible causes of cognitive, behavioral, or functional change should be considered before assuming the change is caused by dementia (20). A sudden change in cognition, behavior, alertness, or functioning should not automatically be attributed to dementia and may require prompt medical evaluation.

## NTG-Early Detection Screen for Dementia (NTG-EDSD)

The NTG-Early Detection Screen for Dementia (NTG-EDSD) is an informant-based administrative screening tool developed to help caregivers and organizations record observations of changes in function in adults with IDD. It is designed to be completed by family caregivers and staff who know the individual and can be used to support conversations with healthcare professionals when observed changes may warrant further assessment (20).

The NTG-EDSD can help:

- Establish and document baseline functioning.
- Record observed changes in function and behavior.
- Track changes over time.
- Identify concerns that may warrant further assessment.
- Support communication between caregivers and healthcare professionals.

The NTG-EDSD is a screening tool and does not diagnose dementia. Findings that suggest cognitive or functional decline should lead to further clinical evaluation by an appropriate healthcare professional (20) (30).

Observe. Document. Compare to baseline. Communicate concerns. Seek evaluation.

## Supporting the Person as Dementia Progresses

As dementia progresses, supports should be adapted to the individual's changing abilities and needs while promoting dignity, safety, comfort, and quality of life (11).

### Early Stages of Dementia

During the early stages of dementia, individuals often strive to remain independent, even as daily tasks become more challenging (20) (11). At this point, the caregiver's primary focus should be on maintaining safety while supporting independence.

### Goals:

- Encourage what the person can still do successfully.
- Provide assistance only where needed to preserve autonomy.
- Promote activities that support physical and mental engagement, helping maintain dignity and self-esteem.

### Helpful Strategies:

- Document familiar and enjoyable experiences such as hobbies, favorite songs, or family traditions to use later when memory recall becomes more difficult.
- Create memory aids like photo albums, scrapbooks, or short family videos to offer comfort and connection as the disease progresses.

### Common Early Symptoms:

- Poor judgment
- Difficulty managing finances
- Losing track of dates or seasons
- Struggling to hold conversations or respond appropriately
- Misplacing items

These changes may seem minor at first but often signal the beginning of cognitive decline.

## 💡 Caregiver Tip

Keep activities routine and familiar, and provide a structured, safe environment. Adapt daily tasks as needed to match the person's abilities. Offer clear directions, cues, and verbal prompts, and use visual aids or direct observation to guide them. Above all, focus on maintaining function and independence for as long as possible while ensuring safety and emotional well-being.

### Middle Stages of Dementia

As dementia progresses into the middle stages, individuals may require increasing support with daily activities, communication, and safety. Care should focus on adapting supports to the person's changing abilities while maintaining familiar routines, meaningful engagement, and quality of life (20) (11).

### Goals:

- Simplify tasks and provide step-by-step guidance to reduce frustration.
- Maintain familiar routines to promote a sense of stability and security.
- Encourage participation in meaningful activities, even if assistance is required.
- Use calm, reassuring communication and avoid correcting or arguing when confusion arises.

### Helpful Strategies:

- Label rooms or objects to help with orientation.
- Offer choices rather than directives to preserve dignity.
- Monitor nutrition and hydration closely, as appetite and swallowing may decline.
- Create a soothing environment with consistent lighting and minimal background noise.

### Common Middle-Stage Symptoms:

- Increased confusion and disorientation
- Difficulty recognizing familiar people or places
- Repetitive speech or actions
- Sleep disturbances and changes in appetite
- Heightened emotional sensitivity or anxiety

### 💡 Caregiver Tip

Provide one-on-one support for safety and assistance with daily activities. Set up tasks for success by offering one or two choices and using closed-ended questions. Use validation and reassurance to meet the person where they are, and avoid arguing, as this can increase distress and confusion. Maintain a structured routine and adjust the environment to reduce overstimulation. Begin future planning during this stage by assessing long-term needs, including advance directives and end-of-life discussions (30).

### Late Stages of Dementia

In the later stages, the person may lose most verbal communication and require full assistance with daily care. The focus shifts to comfort, sensory connection, and maintaining dignity (20) (11).

### Goals:

- Provide gentle physical care and emotional reassurance.
- Use touch, music, and familiar scents to evoke calm and connection.
- Ensure safety and prevent discomfort through attentive monitoring.
- Support family members and caregivers with respite and emotional resources.

### Helpful Strategies:

- Speak softly and maintain eye contact when interacting.
- Use short, simple phrases and allow extra time for responses.
- Keep the environment peaceful and free from unnecessary stimulation.
- Collaborate with healthcare providers to manage pain and maintain comfort.

### Common Late-Stage Symptoms:

- Limited or absent speech
- Loss of mobility and coordination
- Difficulty swallowing and eating
- Incontinence and increased sleep
- Withdrawal from surroundings
- Seizures may occur in the late stages of dementia as neurological functioning declines.

- Increased sleep is also common as the body conserves energy.
- Pain should be assessed frequently, as individuals may no longer verbalize discomfort.

### 💡 Caregiver Tip

Honor the person's presence, not just their memory. Speak softly, maintain gentle routines, and use sensory comfort such as music, scent, and touch to connect. Remember, caring for yourself emotionally and physically is part of providing compassionate care.

## Communication and Behavioral Changes

As dementia progresses, changes in memory, reasoning, language, and the ability to process information can affect how a person communicates and responds to others. A change in behavior should not simply be viewed as something that needs to be stopped or controlled. Behavior often has meaning and may be a form of communication indicating an unmet need, discomfort, stress, fear, confusion, or difficulty understanding the environment (20).

A sudden change in behavior, cognition, alertness, or functioning should not automatically be attributed to dementia. Sudden changes may indicate delirium, infection, pain, dehydration, medication effects, or another acute medical condition and require prompt medical evaluation (20).

When a behavior occurs, caregivers should consider what the person may be communicating and what happened before the behavior. Consider possible contributing factors such as:

- Pain, illness, hunger, thirst, fatigue, or other unmet needs.
- Changes in the person's physical, mental, or emotional status.
- Noise, lighting, clutter, too many people, or other environmental stimulation.
- Changes in familiar routines, surroundings, or caregivers.
- The time of day and what was happening immediately before the behavior.
- Caregiver interactions, including tone of voice, body language, rushing, arguing, or expecting the person to complete a task that has become too difficult.

Caregiver communication should be adapted as the person's abilities change. Helpful strategies include:

- Approach calmly and provide reassurance.

- Use simple, familiar words and short statements.
- Give one direction or step at a time.
- Allow additional time for the person to process information and respond.
- Avoid rushing, arguing, repeatedly correcting, or trying to reason with the person.
- Acknowledge the person's emotions and respond to the feeling being expressed.
- Reduce unnecessary noise, distractions, and overstimulation.
- Maintain familiar routines, people, objects, activities, and surroundings whenever possible.
- Be flexible. A strategy that works today may need to be changed as the person's needs and abilities change.

Predictable routines and familiar surroundings can reduce confusion and anxiety and provide a sense of safety and reassurance (20). Communication should remain person-centered and focus on helping the individual feel safe, respected, and understood. Ask, “What is the person communicating?” rather than simply trying to stop the behavior. Observe what happened before, during, and after the behavior, identify possible unmet needs or triggers, and adjust the caregiver approach or environment when appropriate.

## Dementia-Capable Environment

Dementia can change how a person sees, understands, and moves through their surroundings. Changes in depth perception, visual processing, memory, balance, and orientation may make previously familiar environments confusing or unsafe. The environment should be adapted as the person's abilities change to support safety, comfort, independence, and quality of life (20).

Helpful environmental strategies include:

- Keep spaces calm, familiar, and uncluttered.
- Provide adequate lighting and reduce glare, reflections, and shadows.
- Remove or reduce fall hazards and confusing floor patterns.
- Use clear visual cues to help identify rooms, objects, and important areas.
- Use color contrast to make objects easier to recognize.
- Keep frequently used items in familiar and consistent locations.
- Maintain predictable routines and familiar surroundings whenever possible.

- Reduce unnecessary noise, movement, and overstimulation.
- Reassess and adapt the environment as mobility, vision, cognition, and other abilities change (20).

## Use Color and Contrast to Support Independence

Changes in dementia may make it difficult to distinguish an object from its background. Simple use of contrasting colors can help a person identify important items more easily. For example, a plate that contrasts with the table or placemat may make food and eating utensils easier to see. Similar contrast can be used for doorways, light switches, grab bars, bathroom fixtures, and other frequently used objects (20). Color contrast can help a person with dementia more easily identify food, dishes, utensils, and other objects in the environment.



(Orange Grove Center, Chattanooga, TN. Used with permission, Dementia Care Strategies Copyright 2023)

The place setting on the right (dark blue tablecloth) is the most dementia-capable because the strong color contrast makes the plate, cup, utensils, and other items easier to see and distinguish. In comparison, items on the white setting blend into the background, while the busy floral pattern may make it more difficult to distinguish individual items.

## Pulling It All Together

Dementia changes a person's abilities, but it never takes away who they are. The most powerful thing caregivers can do is pay attention. One must notice what's different, see what's harder, and respond with patience and respect. Recognizing changes early gives the person safety, comfort, and stability at a time when they need it most.

As dementia progresses, the person will rely more on others for daily tasks, communication, mobility, and staying healthy. But even during these challenges, connection is still possible. Calm voices, familiar routines, clear guidance, and supportive environments help reduce fear and frustration and allow the person to feel understood.

Bringing it all together means honoring the individual, adapting care as their needs change, and focusing on dignity at every stage. Your presence, your observations, and your compassion truly shape their experience. With steady, person-centered support, you help them remain safe, valued, and deeply cared for through every step of the dementia journey.

## Looking ahead to the future….

Emerging research has begun to explore other risk factors for dementia in individuals with IDD.

### Highlights of these studies include:

Birth trauma and early brain injury (EBI)

- Early-life neurological injuries such as oxygen deprivation (perinatal asphyxia), intracranial hemorrhage, or structural birth trauma frequently result in lifelong cerebral palsy, intellectual disability, and early-onset seizure disorders. Current research indicates the long-term consequences of perinatal hypoxia-ischemia may contribute to the development of Alzheimer's disease in later life (28).
- The connection of "birth injuries" to late-life dementia is often clouded by the cognitive, physical, and developmental delays that become the primary focus throughout childhood in someone diagnosed with cerebral palsy (birth-related brain injury). However, the cumulative effect of common conditions associated with early brain injury (EBI) on the body lowers the baseline *cognitive reserve*, resulting in vulnerability to secondary vascular, metabolic, and traumatic brain insults over the lifespan, creating an increased risk of dementia (31) (32).
- Although recognized by researchers, there is often a disconnect between previous birth injuries (cerebral palsy, hypoxic episodes, etc.) and resulting dementia later in life, which may be overlooked (28). PCPs and medical specialists rarely explore, review, or consider birth history or birth records when evaluating an adult diagnosed with IDD. As a result, we can assume PCPs and medical specialists rarely establish the connection between early birth injuries (EBIs) and dementia in community settings.

Traumatic Brain Injury (TBI)

- TBI is a well-established, modifiable risk factor that can lead to dementia. The risk scales with injury severity (moderate-to-severe TBIs carry much higher risk than isolated mild concussions) and cumulative number of head injuries (2).
- Repetitive, mild brain impacts from contact sports, falls, vehicle accidents, etc. can lead to cumulative neurodegeneration and progressive dementia syndromes manifesting years or decades later (2) (29).
- A TBI combined with subsequent epilepsy creates a compounding risk, drastically raising 5-year dementia incidence rates (5) (6).

Compounding Effect

- Individuals diagnosed with IDD who have also experienced birth injury, a traumatic brain injury (TBI), or those diagnosed with epilepsy face elevated and/or accelerated risks of developing dementia (6) (15).
- When conditions like Intellectual and Developmental Disabilities (IDD), cerebral palsy, or chronic epilepsy stem from birth injuries, they do not just cause static, lifelong challenges; they actively change how the brain handles the wear and tear of aging.

Down Syndrome

- Down syndrome is the strongest genetic and biological risk factor for dementia; roughly 2 in 3 people with Down syndrome over age 60 develop Alzheimer's disease due to the triplication of the 21$^{st}$ chromosome (24).
- Key risk factors include the severity of intellectual disability, duration/level of education, and age for IDD without Down syndrome. The prevalence of dementia ranges from about 8.8% to 19.6% among individuals without Down syndrome who are between 60–79 years (27).

Severe and Profound IDD

- Individuals with severe and profound IDD are at a much higher risk for dementia. (27; 34; 33). More research is needed in this area.

Epilepsy and Post-Traumatic Epilepsy (PTE).

- Epilepsy alone
  - Active epilepsy or chronic seizure disorders independently increase long-term dementia risk by roughly 1.84 to 2.6 times higher than the general population.

Middle-aged females, ages 55–64, with epilepsy show a particularly pronounced risk elevation for dementia (5).

- Post-Traumatic Epilepsy (PTE)
  - Developing epilepsy following a head injury dramatically multiplies vulnerability. Research from studies like the Atherosclerosis Risk in Communities (ARIC) cohort indicates PTE is associated with a 4.5- to 4.56-fold higher risk of dementia compared to individuals with no head injury or epilepsy, surpassing the risk of head injury alone or epilepsy alone. Younger individuals who develop PTE often experience a strong relative increase in long-term cognitive decline (5).
- The pooled risk of dementia among individuals with varying forms of epilepsy is estimated to be as high as 17% (5).

## Resources

### DBHDS Resources

- **OIHSN Dementia Caregiver Training:** The DBHDS Office of Integrated Health Supports Network (OIHSN) offers dementia caregiver training for those supporting individuals with intellectual and developmental disabilities who are aging or experiencing dementia-related changes. The training incorporates NTG dementia-capable care principles and provides practical strategies for recognizing changes from baseline, using the NTG-EDSD, adapting communication and the environment, responding to changing needs across the stages of dementia, and advocating for appropriate healthcare. The training emphasizes person-centered support that promotes safety, independence, dignity, and quality of life.

  For information about Dementia Caregiver Training, upcoming training opportunities, or dementia consultation and technical assistance, contact the OIH Registered Nurse Care Consultants: **communitynursing@dbhds.virginia.gov**
- **Mobile Rehab Engineering (MRE)** OIH's Mobile Rehab Engineering program provides consultation and technical assistance related to positioning, mobility, and adaptive equipment needs for individuals with developmental disabilities. Mobile Rehab Engineering - Virginia Department of Behavioral Health and Developmental Services (DBHDS)
- **Customized Rate Information** is for individuals whose support needs have significantly changed, teams may explore available DBHDS resources and processes for addressing exceptional support needs. Eligibility and approval requirements apply. Customized Rates - Virginia Department of Behavioral Health and Developmental Services (DBHDS)

**National Task Group (NTG) Resources**

- National Task Group on Intellectual Disabilities and Dementia Practices (NTG) Information and resources related to aging, intellectual disabilities, and dementia.
- NTG-Early Detection Screen for Dementia (NTG-EDSD) Early detection screening tool for documenting changes in function, behavior, cognition, and health.
- Physician's Quick Guide for Using the NTG-EDSD Guidance for physicians and other healthcare professionals on using information from the NTG-EDSD.
- Quick Guide for Using the NTG-EDSD by Families Family-friendly guidance for completing the NTG-EDSD and sharing observed changes with healthcare providers.
- Quick Guide for Using the NTG-EDSD by Support & Care Staff Guidance for support and care staff on documenting changes and using the NTG-EDSD.
- NTG-EDSD Resource Flyer Additional information and resources related to the NTG-EDSD.

**General Dementia Caregiver Resources**

- Alzheimer's Association

  Information, education, support, and resources for individuals living with dementia, families, and caregivers.
- Dementia in Adults with I/DD – ONEcaregiver Resource Center

  Resources for caregivers supporting adults with intellectual and developmental disabilities who are experiencing dementia-related changes.

**Down Syndrome Resources**

- Improving Alzheimer's Diagnosis and Care for Adults with Down Syndrome – Virtual Forum

  Educational resource addressing Alzheimer's disease diagnosis and care for adults with Down syndrome.
- Vitamin B12 and Folate – Dr. Brian Chicoine

  Information from the Adult Down Syndrome Center regarding vitamin B12 and folate.

**Virginia Resources**

- Virginia Department for Aging and Rehabilitative Services (DARS)

Provides information, resources, and support for Virginians living with Alzheimer's disease and other dementias, as well as their families and caregivers.

- Virginia Department of Health (VDH) – Healthy Brain Virginia

  Provides information and resources related to brain health, Alzheimer's disease and related dementias, early detection, caregiver support, and dementia-capable care in Virginia.

## References

1. American Geriatrics Society Beers Criteria® Update Expert Panel, 2023. American Geriatrics Society 2023 updated AGS Beers Criteria® for potentially inappropriate medication use in older adults. *Journal of the American Geriatrics Society*, *71*(7), 2052-2081.
2. Attwood, J. E. (2025). *Long-term outcomes of traumatic brain injury: an epidemiological, neuropsychological, and neuropathological study* (Doctoral dissertation, University of Oxford (United Kingdom)).
3. Brodaty, H., & Connors, M. H. (2020). Pseudodementia, pseudo-pseudodementia, and pseudodepression. *Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring*, *12*(1), e12027.
4. Chow, K. H. M., & Abel, T. (2026). Neurodevelopmental origins of age-related neurodegenerative diseases. *EBioMedicine*, *124*.
5. Chen, L., Yang, W., Yang, F., Yu, Y., Xu, T., Wang, D., ... & Han, Y. (2024). The crosstalk between epilepsy and dementia: A systematic review and meta-analysis. *Epilepsy & Behavior*, *152*, 109640.
6. Chu, S. F., Liao, K. H., & Wei, L. (2024). Increasing Risk of Dementia Among Patients with Subsequent Epilepsy Within 2 Years Post-Traumatic Brain Injury: A Population-Based Case-Control Study. *Journal of Multidisciplinary Healthcare*, 1447-1457.Intellectual and Developmental Disabilities (IDD)
7. Ernstmeyer, K., and Christman, E. (2021, January) Nursing Fundamentals: Chapter 4 Nursing Process. *Chippewa Valley Technical College Open Access* [Internet]
8. Fann, J. R., Ribe, A. R., Pedersen, H. S., Fenger-Grøn, M., Christensen, J., Benros, M. E., & Vestergaard, M. (2018). Long-term risk of dementia among people with traumatic brain injury in Denmark: a population-based observational cohort study. *The Lancet Psychiatry*, *5*(5), 424-431.
9. Funayama, M., Kurose, S., Takata, T., Sato, H., Izawa, N., Isozumi, K., & Abe, Y. (2025, March). Identifying reversible psychiatric dementia mimics in new memory clinic outpatients. *Journal of Alzheimer's Disease Reports*, 9: 1–14.
10. Helvik, A., S., Haugan, G., & Eriksson, M. (2021, March). Health promotion in health care – vital theories and research: Chapter 25 coping and health promotion in persons with dementia. *Springer* [Internet].
11. Jokinen, N., Janicki, M. P., Keller, S. M., McCallion, P., Force, L. T., & National Task Group on Intellectual Disabilities and Dementia Practices. (2013). Guidelines for structuring community care and supports for people with intellectual disabilities affected by dementia. Journal of Policy and Practice in Intellectual Disabilities, 10(1), 1–24.

12. Kadaba Sridhar, S., Dysterheft Robb, J., Gupta, R., Cheong, S., Kuang, R., & Samadani, U. (2024). Structural neuroimaging markers of normal pressure hydrocephalus versus Alzheimer's dementia and Parkinson's disease, and hydrocephalus versus atrophy in chronic TBI—a narrative review. *Frontiers in Neurology*, *15*, 1347200.
13. Khodyakov, D., Ochoa, A., Olivieri-Mui, B. L., Bouwmeester, C., Zarowitz, B. J., Patel, M., ... & Briesacher, B. (2017). Screening tool of older person's prescriptions/screening tools to alert doctors to right treatment medication criteria modified for US nursing home setting. *Journal of the American Geriatrics Society*, *65*(3), 586-591.
14. Kim, N.G., and Lee, H.W. (2021, February). Stereoscopic depth perception and visuospatial dysfunction in Alzheimer's disease. *Healthcare*, 9, 157.
15. Kreimer, S. (2024). Post-traumatic Epilepsy Is Associated With a Higher Risk for Dementia: What and When to Screen for It. *Neurology Today*, *24*(7), 8.
16. Mouta, S., Fonseca Vaz, I., Pires, M., Ramos, S., & Figueiredo, D. (2023). What do we know about pseudodementia?. *General Psychiatry*, *36*(4), e100939.
17. National Institute on Aging (NIA). (2026, January). Tips for Caregivers and Families of People With Dementia. Alzheimers.gov [Internet]
18. National Institute on Aging (NIA). (2020, November 30). Alzheimer's disease in people with Down syndrome. U.S. Department of Health and Human Services, National Institutes of Health.
19. National Task Group on Intellectual Disabilities and Dementia Practices. (2023). NTG education and training curriculum on dementia and intellectual/developmental disabilities: Behavioral and psychiatric symptoms of dementia [Training curriculum].
20. National Task Group on Intellectual Disabilities and Dementia Practices. (2014). NTG education and training curriculum on dementia and intellectual/developmental disabilities [Training curriculum].
21. National Task Group on Intellectual Disabilities and Dementia Practices. (n.d.). NTG-Early Detection Screen for Dementia (NTG-EDSD).
22. Paiva, A.F., Nolan, A., Thumser, C. & Santos, F.W. (2020, November). Screening of cognitive changes in adults with intellectual disabilities: A systematic review. *Brain Sciences*, 10(848), 1-26. Doi:10.3390/brainsci10110848
23. Pears, K. (2026, June). The coming wave: Aging, intellectual disabilities, and dementia care. *National Task Group on Intellectual Disabilities and Dementia Practices* (NTG) [Internet]
24. Qu, H. Q., Liu, Y., Connolly, J. J., Mentch, F. D., Kao, C., & Hakonarson, H. (2025). Risk of Alzheimer's disease in Down syndrome: Insights gained by multi-omics. *Alzheimer's & Dementia*, *21*(4), e14604.
25. Reiss, A. B., de Levante Raphael, D., Chin, N. A., & Sinha, V. (2022). The physician's Alzheimer's disease management guide: Early detection and diagnosis of cognitive impairment, Alzheimer's disease and related dementia. *AIMS Public Health*, *9*(4), 661.
26. Snowden, T. M., Hinde, A. K., Reid, H. M., & Christie, B. R. (2020). Does mild traumatic brain injury increase the risk for dementia? A systematic review and meta-analysis. *Journal of Alzheimer's disease*, *78*(2), 757-775.
27. Takenoshita, S., Terada, S., Inoue, T., Kurozumi, T., Yamada, N., Kuwano, R., & Suemitsu, S. (2023). Prevalence and modifiable risk factors for dementia in persons with intellectual disabilities. *Alzheimer's Research & Therapy*, *15*(1), 125.

28. Tarkowska, A., Furmaga-Jabłońska, W., & Pluta, R. (2026). Long-Term Consequences of Perinatal Asphyxia in the Development of Alzheimer's Disease. *Current Alzheimer Research*.
29. Thomas, A. (2025). Alzheimer's Disease Risk in Older Adults With a Concussion History (*Doctoral dissertation, Azusa Pacific University*).
30. Tsou, A. Y., Bulova, P., Capone, G., Chicoine, B., Gelaro, B., Harville, T. O., Martin, B. A., McGuire, D. E., McKelvey, K. D., Peterson, M., Tyler, C., Wells, M., & Whitten, M. S. (2020). Medical care of adults with Down syndrome: A clinical guideline. *JAMA*, 324(15), 1543–1556.
31. Weil, Z. M., & Karelina, K. (2019). Lifelong consequences of brain injuries during development: From risk to resilience. Frontiers in neuroendocrinology, 55, 100793.
32. Wilson, L., Stewart, W., Dams-O'Connor, K., Diaz-Arrastia, R., Horton, L., Menon, D. K., & Polinder, S. (2017). The chronic and evolving neurological consequences of traumatic brain injury. The Lancet Neurology, 16(10), 813-825.
33. Wissing, M. B., Hobbelen, J. S., De Deyn, P. P., Waninge, A., & Dekker, A. D. (2024). Dementia in people with severe/profound intellectual (and multiple) disabilities, and its natural history. *Journal of mental health research in intellectual disabilities*, *17*(1), 1-28.
34. Wissing, M. B., Ulgiati, A. M., Hobbelen, J. S., De Deyn, P. P., Waninge, A., & Dekker, A. D. (2022). The neglected puzzle of dementia in people with severe/profound intellectual disabilities: A systematic literature review of observable symptoms. *Journal of Applied Research in Intellectual Disabilities*, *35*(1), 24-45.
35. Xu, J., Patassini, S., Begley, P., Church, S., Waldvogel, H. J., Faull, R. L., ... & Cooper, G. J. (2020). Cerebral deficiency of vitamin B5 (d-pantothenic acid; pantothenate) as a potentially-reversible cause of neurodegeneration and dementia in sporadic Alzheimer's disease. *Biochemical and biophysical research communications*, *527*(3), 676-681.

*To the best of the OIHSN Nursing Team's knowledge the information contained within this alert is current and accurate. If the reader discovers any broken or inactive hyperlinks, typographical errors, or out-of-date content please send email to communitynursing@dbhds.virginia.gov to include the title of the Health & Safety alert with specifics details of concern.*