


**Module 4:  
Introduction to  
ID and Dementia**



ntg  
National Task Group  
on Intellectual Disabilities  
and Dementia Practices

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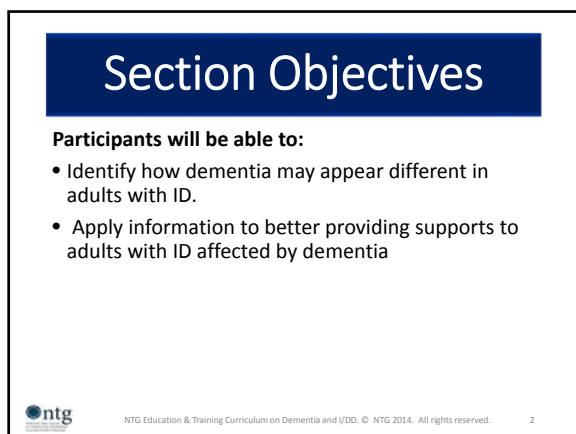
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## Section Objectives

**Participants will be able to:**

- Identify how dementia may appear different in adults with ID.
- Apply information to better providing supports to adults with ID affected by dementia



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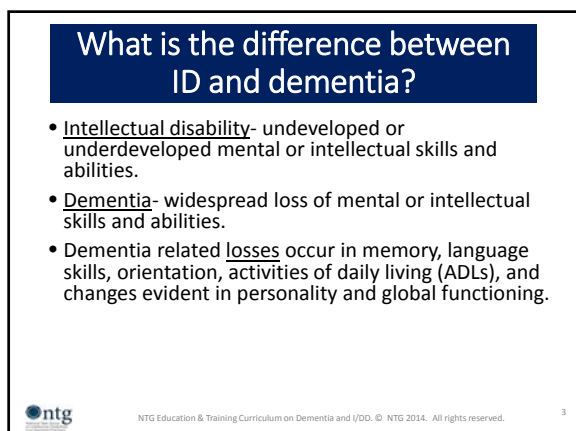
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## What is the difference between ID and dementia?

- **Intellectual disability**- undeveloped or underdeveloped mental or intellectual skills and abilities.
- **Dementia**- widespread loss of mental or intellectual skills and abilities.
- Dementia related **losses** occur in memory, language skills, orientation, activities of daily living (ADLs), and changes evident in personality and global functioning.



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## Dementia and ID

- Most adults with ID are typically at no more risk than the general population.
  - However, as indicated earlier, adults with Down syndrome are at increased risk.
  
- In the USA, an estimated 9,000+ adults with ID may be affected.
  - This number is expected to at least triple in the next 20 years.

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## Why is Diagnosis More Difficult in Adults with ID?

- **Inability to report** - Individuals with ID may not be able to report signs and symptoms.
- **Habituation** - Subtle changes may not be noticed.
- **Assessment tools lacking** - Most generally used dementia assessment tools are not relevant for people with ID as the measures often test for skills or knowledge not often possessed by adults with ID.
- **Measuring change** - Difficulty of measuring change from previous level of functioning.
- **Mistaken identity** - Conditions associated with ID, such as lifelong cognitive impairment, may be mistaken for signs of dementia.

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## Looking for Changes

Dementia is a term used for when an older adult who has been able to function begins to change and loses skills.

There is a standardized early detection screening instrument that can be used for this purpose: NTG-EDSD.

We use early detection as a means to see if we can identify those changes and raise concerns to others who may request a more detail review of the person's functioning.

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## Indicators of Onset of Dementia in Adults with ID



- Notable memory loss
- Personality changes, irritability, or apathy
- Change in language skills
- Confusion
- Changes in self care skills
- Outward behavior changing



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## Dementia: Challenge for Location and Movement

**Context processing:** *Taking in and processing sensory information in environment.*

- One must have memory to know what to do with the sensory information in your environment.
  - Path integration is essential for movement. You must remember where you were previously to determine the next movement.
  - Our location determines our behavior; behavior changes within specific locations.
  - Cells of the brain may no longer be able to adapt to environmental changes.
  - Dementia is often described as being “lost in space and time,” not knowing who you are, where you are, or where to put your foot next.



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## Dementia’s Effect on Way-Finding (Proprioception)

- The proprioception system integrates the input from the five senses to create meaning of the environment and your place in it.
- Think of dementia as a problem of *location in space*.
- You cannot perform functions of daily living if you cannot locate yourself in space.
  - Ex. Could you solve a complex math word problem while free falling on a roller coaster?



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## Dementia's Effect on Movement (Vestibular)

- The vestibular system Includes the parts of the inner ear and brain that control balance.
- Vestibular sensory information is represented in the medial temporal lobe and these brain regions deteriorate first in dementia (usually Alzheimer's type).
- Humans develop a cognitive map for movement using landmarks that may now be forgotten or misinterpreted.



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## What other Reasons (Besides Dementia) May Cause Someone to be Unable to Find His or Her Bedroom?

Would you have trouble finding your bedroom?

Can you suggest adaptations or modifications that might make it easier to navigate?



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## Diagnosis of Dementia in Individuals with ID

- Most first noticed signs of change (suspected early dementia) or 'onset of dementia' occur in early 50s in adults with Down syndrome and in the late 60s and early 70s in other adults with ID.
- Generally signs are more noticeable among adults with Down syndrome and diagnosis usually occurs within 3 years of 'onset.'
- Alzheimer's disease tends to be the most prevalent cause of dementia in adults with Down syndrome. Among adults with other kinds of ID, the causes are varied.



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## Preparing for Dementia

<p><b>Knowns...</b></p> <ul style="list-style-type: none"> <li>People with ID have same rate of dementia as general population</li> <li>Some people with ID have higher rates (e.g., Down syndrome, head injury)</li> <li>Some % of any adult client pool will be affected</li> </ul>	<p><b>Unknowns...</b></p> <ul style="list-style-type: none"> <li>Who will be affected</li> <li>How long will person live after dx</li> <li>What other diseases or medical conditions may be co-incident</li> <li>What particular dementia-related behaviors will become more prominent</li> </ul>
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## Effectively Addressing Dementia

- Know when 'onset' might be noticeable
- Know how dementia progresses and what to expect at various stages
- Know expected durations so care planning can be effective and efficient

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## Be Aware of Vision Changes for Adults with Alzheimer's Disease

**The following may all be affected by AD:**

- Depth perception
- Color contrasts
- Acuity
- Motion versus stationary objects
- Object identification
- Delayed recall to visual stimulation
- Figure-ground differentiation
- Size and shape
- Visual memory

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## Be Aware of Behavioral and Psychological Issues Caused by Dementia

There may be instances of

- distorted and confused thinking
- verbal and physical aggressiveness
- suspiciousness and paranoia
- delusions or hallucinations
- wandering
- hoarding
- disturbed sleep patterns
- disinhibition



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## Prevalence of Behavioral Symptoms in Dementia\*



NPI Item	Dementia (%) n = 329	No Dementia (%) n = 873
Apathy	27.4	3.1
Depression	23.7	7.0
Agitation / aggression	23.7	2.8
Irritability	20.4	4.5
Delusions	18.5	2.4
Anxiety	17.0	5.6
Aberrant motor behavior	14.3	0.4
Hallucinations	13.7	0.6
Disinhibition	9.1	0.9
Elation	0.9	0.3

\*Significant differences (P<01) between study participants with and without dementia for all 10 NPI items.

NPI = Neuropsychiatric Inventory  
Source: Lyketsos CG, et al. *Am J Psychiatry*. 2000;157:708-714



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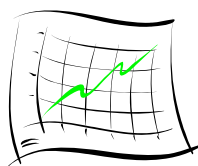
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## Higher Prevalence of Alzheimer's in People with Down Syndrome

Studies suggest that more than 75 percent of those with Down syndrome aged 65 and older have Alzheimer's disease, nearly 6 times the percentage of people in this age group who do not have Down syndrome.



[www.alz.org/dementia/down-syndrome-alzheimers-symptoms.asp](http://www.alz.org/dementia/down-syndrome-alzheimers-symptoms.asp)



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### Symptoms of Dementia in Individuals with Down syndrome

- In people with Down syndrome, changes in overall function, personality and behavior may be more common early signs of Alzheimer's than memory loss and forgetfulness.
- Memory loss also may occur.
- Look for signs and symptoms in adults when they are in their late 40s or early 50s.



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### Symptoms of Dementia in Individuals with Down syndrome

**Early symptoms may include:**

- Reduced interest in being sociable, conversing, or expressing thoughts
- Decreased enthusiasm for usual activities
- Decline in ability to pay attention
- Sadness, fearfulness, or anxiety
- Irritability, uncooperativeness, or aggression
- Restlessness or sleep disturbances
- Seizures that begin in adulthood
- Changes in coordination and walking
- Increased noisiness or excitability

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### Dementia: ID vs. Down syndrome

Intellectual disabilities	Down syndrome
<ul style="list-style-type: none"> <li>• Older adults with ID have dementia at same rate as the general population.</li> <li>• All other causes of age-associated decline should be ruled out before dementia is assumed.</li> <li>• Useful to know of signs and keep track of capabilities after age 50.</li> <li>• Dementia etiology varies.</li> </ul>	<ul style="list-style-type: none"> <li>• Older adults with Down Syndrome are at high risk of Alzheimer's disease, but not every adult will show clinical signs of dementia as he or she ages.</li> <li>• All other causes should be ruled out before assuming change is due to dementia.</li> <li>• Useful to know signs and keep track of capabilities after age 40.</li> <li>• Dementia etiology is mostly Alzheimer's type.</li> </ul>

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## Ruby



Courtesy: A.J. Dalton (2000)



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Sign or Symptom	Age
<b>Early</b>	
Impaired memory function	54.7
Impaired learning abilities	56.7
Hearing loss	57.0
Disorientation	58.0
Hypothyroidism	59.0
<b>Middle</b>	
Personality changes	60.5
Deterioration of ADL skills	63.0
Abnormal reflexes	64.5
<b>Late</b>	
Hallucinations	64.5
Seizures	65.0
Incontinence	65.4
Has to be fed	65.4
Apathy	65.4
Complete care required	65.4
Death	65.5

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## Summary

- Dementia is different from an intellectual disability (although dementia is considered a cognitive disability, or a thinking impairment).
- Generally, dementia affects people with intellectual disability at the same rate as with other people.
- Adults with Down syndrome are at much higher risk for dementia.
- Determining if dementia is present can be difficult in people with intellectual disability because of their varying behavioral and functional abilities.



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## Take-Away Points

- Dementia in people with ID typically presents in the same way as it does in other people – memory problems are generally obvious first.
- As adults with Down syndrome are at high risk for Alzheimer’s disease, if changes are observed, dementia onset should be investigated.



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**Module 5:**  
**Dementia**  
**Characteristics**  
**and Types**



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**Section Objectives**

**Participants will be able to:**

- Describe different dementias
- Recognize the symptoms of various dementias
- Describe the benefits of knowing the types of dementia
- Describe the different stages of Alzheimer’s dementia



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**What is Dementia?**

**Dementia is an age-associated condition that affects and diminishes quality of life.**

- Dementia causes a loss of cognitive function severe enough to interfere with daily functioning.
- Dementia is not a disease.
- Dementia describes clinical/ behavioral symptoms associated with certain diseases or conditions.
- Dementia is NOT part of normal aging.



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## What is Dementia?

Know the Warning Signs  
These problems must be notable and usually occur in a cluster

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## Why is it Important (or Useful) to Know Type of Dementia?

1. It will determine 'course of treatment' and expectations of staging and rate of decline.
2. It will help with determining best ways to handle 'challenging behaviors' and organize staffing patterns.
3. It will help in understanding what behaviors are to be expected in the future.
4. It will tell you how to best interact and communicate with the person affected.

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## Incidence of Types of Dementias

Type of Dementia	Percentage
Alzheimer's	47%
Mixed Alzheimer's	28%
Mixed & Others	9%
Vascular	9%
Frontotemporal	5%
Parkinson's	2%

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## Clinical Features of Various Dementias

Alzheimer Disease	Frontotemporal Dementia	Lewy Body Dementia	Vascular Dementia
Memory, visual-spatial and language disturbances Indifference Delusions Agitation Behavioral changes	Personality changes Executive dysfunction Disinhibition Impulsivity Progressive loss of speech	Visual hallucinations Delusions Falls Syncope Parkinsonism Fluctuating memory Sensitivity to antipsychotic medications	Abrupt onset Stepwise deterioration Prominent aphasia Motor dysfunction Mood or behavior changes Severe depression symptoms

Although the brain neuropathy will differ, caregivers need to note the nature of the behaviors exhibited.

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## Changes Over Time and Cognitive Decline by Type of Dementia

Dementia type	Defining characteristic	Effect on cognitive changes over time
Alzheimer's dementia [AD]	<i>Slow onset and steady decline, loss of memory and eventual dysfunction</i>	Leads to decline in all cognitive domains (memory, language, attention, executive, and visual-spatial functioning). General and prolonged progression (losses) and eventually catastrophic dysfunction
Vascular dementia [VaD]	<i>Sudden changes in function, then static</i>	Cognitive function remain stable over time – [no decline evident]; if other vascular injuries, then step-wise progression
Lewy body dementia [DLB]	<i>Hallucinations and confusion</i>	Cognitive decline in all domains <b>except</b> language; eventual deterioration with brain changes
Frontotemporal dementia/ behavioral variant (bvFTD)	<i>Personality changes and loss of judgment, memory stays intact</i>	Cognitive changes evident in <b>rapid decline in memory, language, attention and executive functioning, except</b> visual-spatial functioning); progressive deterioration with brain changes
Frontotemporal dementia/ language variant (lvFTD)	<i>Personality changes and loss of judgment, memory stays intact</i>	Cognitive decline mostly in attention and executive functioning; progressive deterioration with brain changes

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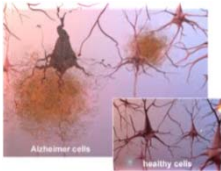
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## Alzheimer's disease



- Most common form of dementia.
- Gradual onset.
- Unable to remember new information.
- Impaired daily activities.
- Generalized brain atrophy.
- Amyloid plaques and neurofibrillary tangles.

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## How Alzheimer's disease Changes the Brain

- Damage to the brain starts 10 or more years before symptoms present.
- Abnormal deposits of proteins form amyloid plaques and tau tangles form throughout the brain, and once-healthy neurons begin to work less efficiently.
- Over time, neurons lose their ability to function and communicate with each other, and eventually they die.
- Before long, the damage spreads to a nearby structure in the brain called the hippocampus, which is essential in forming memories.
- As more neurons die, affected brain regions begin to shrink.

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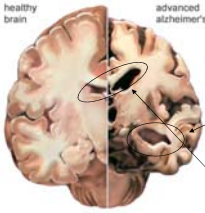
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## Alzheimer's disease



In the Alzheimer brain:

- The **cortex shrivels up**, damaging areas involved in thinking, planning and remembering.
- Shrinkage is especially severe in the **hippocampus**, an area of the cortex that plays a key role in formation of new memories.
- **Ventricles** (fluid-filled spaces within the brain) grow larger.

Source: Alzheimer's Association

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## Stage Related Changes in Alzheimer's Dementia

Early Stage	Middle Stage	Late Stage
<ul style="list-style-type: none"> <li>• Confusion and memory loss</li> <li>• Disorientation in space</li> <li>• Problems with routine tasks</li> <li>• Changes in personality and judgment</li> </ul>	<ul style="list-style-type: none"> <li>• Difficulties with ADLs ["activities of daily living"]</li> <li>• Anxiety, paranoia, agitation and other compromising behaviors</li> <li>• Sleep difficulties</li> <li>• Difficulty recognizing familiar people</li> </ul>	<ul style="list-style-type: none"> <li>• Loss of speech</li> <li>• Loss of appetite, weight loss</li> <li>• Loss of bladder and bowel control</li> <li>• Loss of mobility</li> <li>• Total dependence on others</li> <li>• Death</li> </ul>

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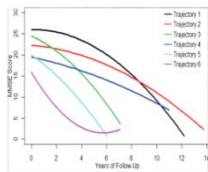
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## Progression Patterns in Alzheimer's disease

Alzheimer's disease has a particular pattern of decline. The decline is downward and progressive, or 'linear.'

Everyone will go through the various stages of Alzheimer's dementia, some quickly and some slowly.



Duration of life after diagnosis will vary and is a factor in planning for care.




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## Behavioral Changes in Early Stage Alzheimer's disease.

- No longer interested in taking part in activities.
- Unable to do tasks or activities they used to do easily.
- Asks the same question repeatedly or tells the same story over and over.
- Loss of interest in personal appearance.
- Unable to follow a new routine or learn a new task.
- Not able to follow a conversation or TV show.
- Difficulty following multi-step directions.
- Gets lost in familiar surroundings.
- Becomes suspicious of other people.
- Appears angry or agitated.




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## Forgetfulness or Alzheimer's?

	A Person with Age-Associated Memory Problems	A Person with Alzheimer's Disease
<i>Forgets</i>	Parts of an experience	Whole experiences
<i>Remembers later</i>	Often	Rarely
<i>Can follow written or spoken directions</i>	Usually able	Gradually unable
<i>Can use notes</i>	Usually able	Gradually unable
<i>Can care for self</i>	Usually able	Gradually unable




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## What Causes Alzheimer's (cont.)?

- Most people with Alzheimer's disease have "late-onset" Alzheimer's, which usually develops after age 65.
- Early-onset Alzheimer's is a rare form of the disease. It occurs in people age 30 to 60 and represents less than 5 percent of all people who have Alzheimer's disease.
- Individuals with Down syndrome develop Alzheimer's at a younger age than the general population.




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## DSM-IV Criteria for a Diagnosis of Dementia.

**NOTE:** Although the DSM-5 replaced the term "dementia" with *major neurocognitive disorder* and *mild neurocognitive disorder*, "dementia" is still universally used.

DSM-IV Criteria for Dementia
1. Memory impairment 2. At least one of the following: Aphasia Apraxia Agnosia Disturbance in executive functioning 3. The disturbance in 1 and 2 significantly interferes with work, social activities, or relationships 4. Disturbance does not occur exclusively during delirium
<b>Additional criteria for dementia type</b> Dementia of the Alzheimer's type: Gradual onset and continuing cognitive decline Not caused by identifiable medical, psychiatric, or neurologic condition
<b>Vascular dementia</b> Focal from history, physical exam, or laboratory findings of a specific medical condition
<b>Dementia due to other medical conditions</b> Evidence from history, physical exam, or laboratory findings of a specific medical condition causing cognitive deficits (HIV disease, head trauma, Parkinson's disease, Huntington's disease, Pick's disease, Creutzfeldt-Jacob)




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## Take-Away Points

- Dementia (change in functioning) is the behavioral presentation of a brain disease or injury.
- Dementia comes in various forms and each form has specific characteristics.
- Knowing the different dementias and how they affect adults helps better plan and provide services.




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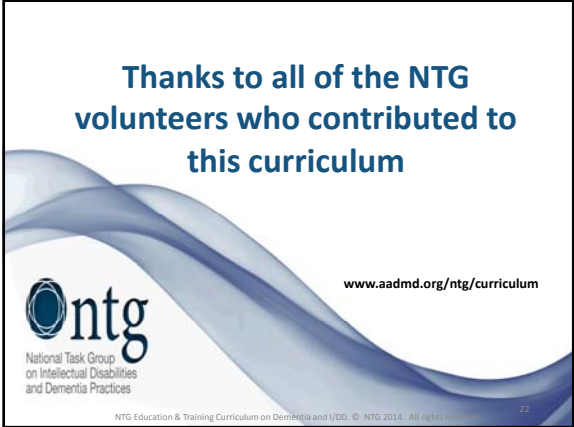
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