



Introduction to Dementia in Individuals with Intellectual/Developmental Disabilities



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Dementia: What is it?



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What is Dementia?

- Loss of cognitive functioning serious enough to interfere with daily life.
- Causes changes in two or more of the following:
 - memory
 - language
 - executive function (planning, organizing, and attention)
 - visual spatial skills
 - judgment/reasoning
 - personality/mood

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Dementia: Quick Facts

- ...is NOT normal aging
-is different from an intellectual or developmental disability
- ...is an umbrella term
- ...symptoms vary from person to person
- ...risk increases with age
- ...is progressive



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I/DD vs. Dementia

- **Intellectual/Developmental disabilities:** The existence of impairment in physical, learning, language, or behavior areas. These conditions begin during the developmental period (before age 22) and usually do not decline noticeably with age.
- **Dementia:** A widespread decline in mental or intellectual skills and existing abilities – declines occur in memory, language skills, orientation, activities of daily living (ADLs), and/or personality.

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TYPES OF DEMENTIA

Dementia is an umbrella term for loss of memory and other thinking abilities severe enough to interfere with daily life.

- Alzheimer's
- Vascular
- Lewy body
- Frontotemporal
- Other, including Huntington's
- * **Mixed dementia:** Dementia from more than one cause

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**Intellectual/
Developmental Disability**

an umbrella term for differences usually present at birth and that uniquely affect the trajectory of the individual's physical intellectual and/or emotional development.

Types of I/DDs

- Autism
- Down Syndrome
- Fetal Alcohol Syndrome
- Cerebral Palsy
- Fragile X

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Rates of Dementia

General Population

Age	Percentage
40+	
65+	11%
85+	33%

Down Syndrome

Age	Percentage
By age 40	9%
By age 50	33%
60+	50%+
80+	

https://www.alz.org/documents_custom/2024-facts-and-figures.pdf
Ances, 2025 with data from the ABC- DS

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Prevalence of Dementia in Individuals with I/DD vs DS vs General Population

Age	General population (%)	Intellectual disabilities (%)	Down's syndrome (%)
30	0	0	0
40	0	0	10
50	0	0	25
60	0	5	45
70	5	15	75
80	15	35	-
90	30	50	-

Society Dementia and People with Intellectual Disabilities, BPS Explore 2015

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Why would people with I/DD have higher risk for dementia?

Higher rates of:

- Heart disease
- Diabetes
- Seizures
- Depression/anxiety
- Other chronic medical conditions
- Anticholinergic medication use

Lower rates of:

- Baseline cognitive reserve
- Educational attainment
- Activity level

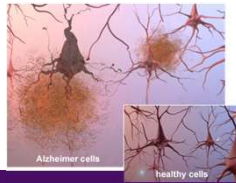
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Why do people with DS have higher risk for dementia?

- 21st chromosome is where amyloid precursor protein, the protein that clumps together to form the plaques of Alzheimer's disease, are made.

- By age 40, nearly all people with Down syndrome have the brain pathology of Alzheimer's disease



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Alzheimer's Disease



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What is Alzheimer's Disease?

- The most common form of dementia
- A disease of the brain that destroys brain cells, causing problems with memory, thinking, and behavior
- A progressive disease with no cure that is eventually fatal

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10 Warning Signs of AD

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

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A Conceptualization



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Moving Backward in Time here



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Changes in Communication



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Cognitive Changes Affecting Communication

- Memory loss
 - Remembering what words mean
 - Remembering what was said
- Executive dysfunction
 - Decision making
 - Planning
 - Attention
 - Initiating actions
- Impaired judgement

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Communication Tips

- Allow for more processing time
- Use shorter sentences
- Use concrete, familiar terms
- Give limited choices
- Avoid yes/no questions or asking “do you want to” when appropriate
- Make things their idea
- Turn negatives into positives
- Use nonverbal communication!

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The 3 R's

- **Right**
 - The person with memory loss is always right. Always.
- **Reassure**
 - Respond to the emotion, not to the words
- **Redirect**
 - Change the subject to something else

* Note: Use these tips when attempting to re-orient the person to reality doesn't work or causes the individual to become upset or agitated.

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The 3 R's vs. Attempting to Re-Orient to Reality



From HBO's The Alzheimer's Project: The Memory Loss Tapes, 2009

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From HBO's The Alzheimer's Project: The Memory Loss Tapes, 2009

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Changes in Self-Care Abilities



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Cognitive Changes Affecting Self-Care Abilities

- Memory loss
- Impaired judgment/reasoning
- Impaired attention/distractibility
- Poor sequencing/organization abilities
- Poor sensory perception

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Tips to Facilitate Independent Self-Care

- Give fewer steps at a time/break steps down into smaller sub-tasks
- Add cues to the environment
- Provide standby assistance/cues
- Simplify environments/limit distractions
- Ensure good lighting

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Changes in Behavior



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Behaviors in Dementia

- Changes in the brain from dementia can erode intentionality of behavior and ability to appreciate consequences.
- Behavior often becomes more instinctual as the disease progresses.

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Common Distressing/Disruptive Behaviors

<ul style="list-style-type: none"> • Asking repetitive questions • Neglecting personal hygiene • Anger/Aggression • Crying • Pacing/Wandering • Wanting to go home 	<ul style="list-style-type: none"> • Rummaging • Self-talk • Resisting care • Delusions/False beliefs
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Common Causes of Distressing/Disruptive Behaviors

- Person
 - Examples: pain, hunger, being too hot or cold, fatigue, illness, etc.
- Environment
 - Examples: noise, clutter, flashing lights, etc.
- Task
 - Examples: task too complicated, task unfamiliar
- Caregiver
 - Example: Inappropriate communication patterns

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What Behavior Can Look Like



From Supporting Derek, 2010

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Thank you for listening!

For more information
 please contact Kristi Davis
 at krdavis@alz.org or the
 24/7 Helpline at
 1(800) 272-3900

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