

**Dementia Capable Care of Adults with Intellectual Disabilities & Dementia**

**Dr. Ritabelle Fernandes**  
Associate Professor, JABSOM

**HADI** Hawaii Alzheimer's Disease Initiative  
A PROJECT OF THE UH CENTER ON AGING  
www.hawaii-agingprhiain

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**National Task Group on Intellectual Disabilities & Dementia Practices (NTG)**

- Coalition of interested persons and organizations.
- Mission: Ensuring that the needs and interests of adults with intellectual and developmental disabilities who are affected by Alzheimer's disease and related dementias – as well as their families and friends – are taken into account as part of the National Alzheimer's Project Act (NAPA).
- To access resources, visit [www.aadmd.org/NTG](http://www.aadmd.org/NTG)

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**NTG Activities**

- **An early detection-screening instrument (NTG-EDSD) & manual**
  - Various language versions available
  - Access at [www.aadmd.org/ntg](http://www.aadmd.org/ntg)
- **Practice guidelines**
  - Community supports guidelines
  - Health practitioner assessment guidelines
  - Health advocacy guidelines
  - Community dementia care setting guidelines



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## Developmental vs. Intellectual Disability

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|--|---|
| <p><b>Developmental Disability</b></p> <p><b>Umbrella Term:</b> Can be cognitive or physical or both.</p> <p><b>Severe &amp; chronic.</b> Disability occurs prior to birthdate of age 19 or 22 (depending on the state).</p> <p>May or may not have low IQ.</p> <p>Some developmental disabilities are largely physical.</p> <ul style="list-style-type: none"> <li>• Example - cerebral palsy or epilepsy.</li> </ul> <p>Can include a physical and intellectual disability.</p> <ul style="list-style-type: none"> <li>• Example - Down syndrome or fetal alcohol syndrome.</li> </ul> | <p><b>Intellectual Disability</b></p> <p>Disability related to cognitive (thought) processes.</p> <p><b>Severe &amp; chronic.</b> Disability occurs prior to birthdate of age 19 or 22 (depending on the state).</p> <p>Low IQ</p> <p>The term intellectual disability covers the same population of individuals who were diagnosed previously with mental retardation.</p> |
|--|---|

*Developmental disabilities and intellectual disabilities can co-occur.*

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## Health Care Disparities for Adults with ID

No required training on ID in medical schools

No required training on aging unless you are going into the field of geriatrics

No medical textbooks on aging and ID  
• No references in most textbooks on ID

Little available research

Few practitioners with expertise

Few patients in health care providers caseload with ID diagnosis

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## Challenges to Healthy Aging in Adults with ID

**Medical history is often incomplete or unknown**

- Staff turnover
- Family not available for information, historical documentation unavailable
- Health care provider turn over
- Providers not understanding baseline functioning of the presenting older adult with ID
  - IDEA: Video can provide a visual of the person over their lifespan.

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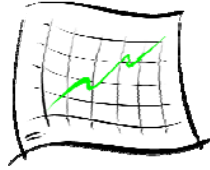
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## Risk of Dementia in ID

Most adults with ID are typically at no more risk than the general population.

**Exception:** Adults with Down syndrome are at increased risk!

- Younger (40's and '50's)
- More rapid progression.



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## Dementia Prevalence: ID vs. DS

| Intellectual Disability |            | Down Syndrome |            |
|-------------------------|------------|---------------|------------|
| Age                     | Percentage | Age           | Percentage |
| 40+                     | 3%         | 40+           | 22%        |
| 60+                     | 6%         | 60+           | 56%        |
| 80+                     | 12%        |               |            |

Matthew P. Janicki and Arthur J. Dalton (2000) Prevalence of Dementia and Impact on Intellectual Disability Services. *Mental Retardation*: June 2000, Vol. 38, No. 3, pp. 276-288.

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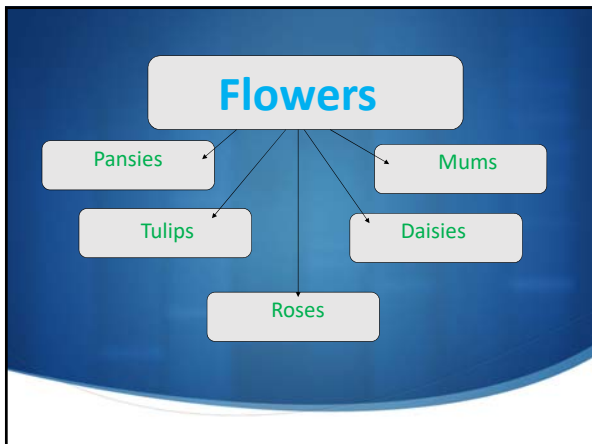
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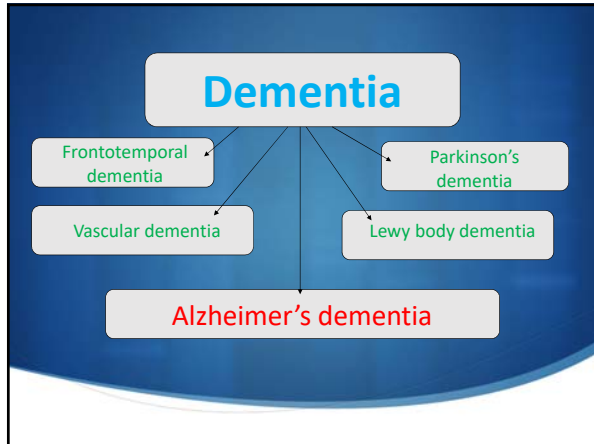
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### Key Hallmarks of Dementia

- Memory Loss
- Communication difficulties
- Behavior or mood changes

Intelligence, judgement, and behavior  
Memory  
Language

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### What is Down syndrome (DS)?

- First accurate description of a person with DS was published in 1866 by an English physician - John Langdon Down.
- DS is a developmental disability – intellectual impairment and physical abnormalities.
- DS occurs 1 in 750 live births.
- DS is caused by a genetic abnormality – an extra full or partial copy of chromosome 21 (Trisomy 21).
- Extra copy of genetic material alters the course of development and causes the characteristics associated with Down syndrome.
- common physical traits of Down syndrome are:
  - low muscle tone, small stature,
  - an upward slant to the eyes,
  - and a single deep crease across the center of the palm
  - each person with Down syndrome is a unique individual and may possess these characteristics to different degrees, or not at all

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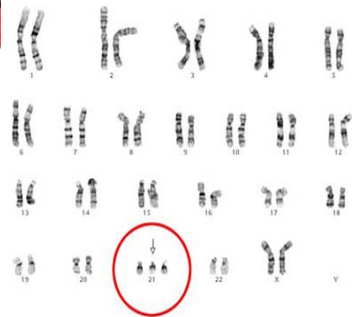
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## Premature Aging in Down Syndrome

- Life expectancy has continued to increase for people with Down syndrome.
- Aging increases risk for physical and cognitive changes for people with DS.
- Many individuals with DS age prematurely (age in their 50s).
- Adults with DS are at risk for diseases and changes about 20 years earlier than the general population.

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## Why a Focus on Alzheimer's?

Alzheimer's often presents differently in people with Down syndrome.

- Abrupt onset of seizure activity when there had been none in the past.
- Incontinence when an individual has always been independent in toileting.
- Short-term memory loss may depend upon the previous level of memory demands and reliance on memory in everyday life.
- Sleep/wake cycle disruptions.



*\*Just as in the general population, the course and symptom presentation is unpredictable and unique to the individual.*

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## Traditional Screening Tools Not Useful

Traditional screening instruments for detecting dementia in the general population are designed for people with average baseline intelligence and are not useful for detecting cognitive impairment in adults with DS.

**Example:**

- Mini-Mental Status Exam (MMSE)

**Alternative:**

- NTG – EDSD

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## NTG Early Detection Screen for Dementia (EDSD)

**Adapted from:**

- Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (Deb et al., 2007), and
- Dementia Screening Tool (adapted by Philadelphia Coordinated Health Care Group from the DSQIID, 2010)

Down Syndrome begin age 40 then annually.

Non-DS begin at age 50.

Tool & manual available online in multiple languages: [www.aadmd.org/ntg/screening](http://www.aadmd.org/ntg/screening)

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## Continued

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

Usable by support staff and caregivers to note presence of key behaviors associated with dementia

- ✓ Picks up on health status, ADLs, behavior and function, memory, self-reported problems
- ✓ Available in several languages

Pages ① ②: Basic information

Pages ③ ④: Information about function and indicators of problem areas associated with dementia

Page ⑤: Coincident conditions

Page ⑥: Medications & Comments

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## NTG-EDSD: 4 Key Sections

Demographics

Ratings of health, mental health and life stressors

Review of multiple domains including

- Activities of Daily Living
- Language & Communication
- Sleep – Wake Patterns
- Ambulation
- Memory
- Behavior & Affect

Chronic Health Conditions

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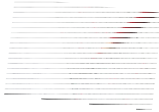
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## Who Can Complete the NTG-EDSD?



- Any caregiver, either family or staff who is familiar with the person can complete the NTG-EDSD if they:
  - Have known person for a minimum of 6 months
  - Have access to information in the person's record

### How to best complete the form?

- Combine perceptions of function offered by several staff or family members.
- Use best judgment when responding to questions asking for impressions (e.g., health, function).
- Be truthful – don't 'hide' problems to make a good impression

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## Sources of Information

- Speak with:
  - family members
  - other staff who know the person
- Look through available medical records.
- Look through program plans and personal files.
- Get consensus among care team members on behaviors and other performance factors.
- Ask the person who is being screened.
- Ask friends or other close persons.

*A short digital video of the person performing certain tasks can also be helpful.*

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## Essentials of a Diagnostic Workup

- **History and physical** (including psychiatric, personal, past medical and family histories and mental state assessment)
- **Lab tests**
  - Evidence supports the following tests:
    - Complete blood cell count
    - Serum electrolytes
    - Glucose
    - BUN/creatinine
    - Serum B12 levels
    - Thyroid function tests
    - Liver function tests
    - Celiac screening if DS (tTG-IgA test)
- **MRI and/or CT scan**

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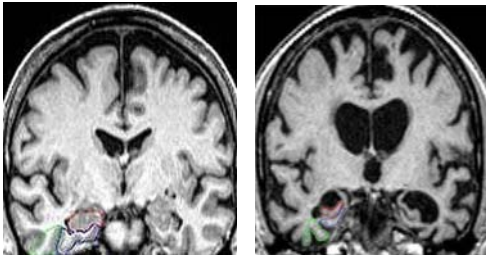
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## CT Scan



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## Common Conditions to Rule Out through Differential Diagnosis.

- |  |   |
|--|---|
| <ul style="list-style-type: none"> <li>• CVA/Stroke</li> <li>• Parkinson's disease</li> <li>• HIV/AIDS</li> <li>• Multiple Sclerosis</li> <li>• Huntington's disease</li> <li>• Lewy Body dementia</li> <li>• Frontotemporal dementia</li> <li>• Syphilis</li> </ul> | <ul style="list-style-type: none"> <li>• Creutzfeldt-Jakob disease</li> <li>• Traumatic brain injury</li> <li>• Toxic exposures(industrial strength solvents/chemicals)</li> <li>• Chronic hypoxia</li> <li>• Brain tumors</li> <li>• Normal pressure hydrocephalus</li> <li>• Wernicke-Korsakoff's Syndrome</li> </ul> |
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**Irreversible Dementias**

**The symptoms we call "dementia" can have many different causes.**

**Alzheimer's disease is the most common.**

**DEMENTIA**  
 Defined: An umbrella term used to describe the symptoms of a group of more than 100 conditions that cause memory, behaviour and thinking. The most common causes of dementia are outlined below.

**Vascular dementia (VAD)**  
 is the second most common form of dementia accounting for 20% of cases. VAD occurs through a reduction blood supply to the brain, usually due to stroke.

**Parkinson's disease (PD)**  
 accounts for 5% of dementia cases. PD is a degenerative disorder of the central nervous system.

**Frontotemporal dementia (FTD)**  
 accounts for 5% of dementia cases. FTD is associated with misfolded and tangled bundles of protein in brain nerve cells.

**Alzheimer's disease (AD)**  
 is the most common form of dementia accounting for 50-70%. AD is a degenerative disease that attacks the brain resulting in impaired functioning.

**Dementia with Lewy bodies (DLB)**  
 accounts for 15% of dementia cases. DLB is associated with Lewy bodies which are abnormal brain cells.

Image: Dementia Forward

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**Dementia Affects All Aspects of Functional Ability**

|                                    |                           |
|------------------------------------|---------------------------|
| Memory                             | Language skills           |
| Ability to focus and pay attention | Reasoning & judgment      |
| Sensory perception                 | Ability to sequence tasks |

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**Stage Related Changes in Alzheimer's**

| 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</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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## Medications for Alzheimer's

- **Aricept\*** (Donepezil)
- **Namenda\*\*** (Memantine)
- **Exelon\*** (Rivastigmine)
- **Razadyne\*** (Galantamine)
- **Namzaric – NEW 2015.** Extended release.
  - Namenda + Aricept
  - Approved for the treatment of moderate to severe dementia of the Alzheimer's type
  - Capsule can be opened to sprinkle onto food

- Often used together for moderate to severe AD.
- Statistically significant improvement in cognition and global function for patients treated with NAMENDA XR 28 mg plus an AChEI compared to placebo plus an AChEI

\* Cholinesterase inhibitors are prescribed to treat symptoms related to memory, thinking, language, judgment and other thought processes in early to moderate AD. Delay worsening of symptoms for 6 to 12 months, on average, for about half the people who take them.  
 \*\* Regulates the activity of glutamate, a different messenger chemical involved in learning and memory. Delays worsening of symptoms for some people temporarily.

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## Pain Assessment IN Advanced Dementia- PAINAD

- Nurse, CAN
- For behavioral symptoms suggestive of pain, assess at least every 8 hours
- Observe the older adult for 3-5 minutes during activity/with movement (such as bathing, turning, transferring).

**Pain Assessment IN Advanced Dementia PAINAD**

|   | 0  | 1   | 2   | Score |
|---|--|---|---|-------|
| <b>Respiratory</b><br>Respiration or vocalization | Normal   | Occasional wheezing or rattling, chest sounds, hyperinflation | Moist rattling (wheezing), long periods of hyperinflation, chest sounds hyperinflated |       |
| <b>Registries</b><br>Mouthfeel                    | None   | Occasional moist or dry                                       | Registries (bristles)   |       |
| <b>Facial</b><br>Expression                       | Low level squint or a neutral or slightly smiling face | Low level squint with a neutral or slightly smiling face      | Low level squint or smiling   |       |
| <b>Body</b><br>Language                           | Smiling or receptive                                   | Smiling   | Smiling   |       |
| <b>Body</b><br>Language                           | None   | Tense   | Single Fick (stiffness), frowning, grimacing or pulling or avoiding body              |       |
| <b>Comprehensibility</b>                          | Not asked to respond                                   | Responded to verbal or touch                                  | Unable to comprehend verbal or touch  |       |

Wolke, Rieker, Yilmaz. (2008). 3891. doi: 10.1177/0898010108319111

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## Key Concepts in Dementia Care

Adapted from *Habilitation Therapy in Dementia Care*. Paul Raia, PhD. 2011.

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Key Concept in Dementia Care #1  
**Maintenance Support**

- Generally accepted as the **best practice** in dementia care.
- **Proactive** approach
  - A few minutes of pro-action can eliminate hours of reaction.
- Focus is on **support of remaining abilities**.
  - Respect changing needs of the person
  - Provide meaningful, failure-free activity.
  - Allow the person to do as much as they can for themselves but...be aware that as the disease progresses the need for assistance will increase.
- Can **reduce or eliminate difficult behaviors** at all stages by reducing frustration, boredom, anxiety, fear, etc.
- Can be done in **all settings by all staff**.

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Key Concept in Dementia Care #2  
**Life Stories**

Everyone has a life story that needs to be honored and respected.

- The story is the *essence* of each person and should be documented over the lifespan.
- When a person can no longer tell their own story, activities related to storytelling can still be used to inform caregiving and plan activities.



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Key Concept in Dementia Care #3  
**Validation Approach**

- Focuses on **empathy and understanding**.
- Based on the general principle of **validation**...the acceptance of the reality and personal truth of a person's experience... no matter how confused.
- Can **reduce stress, agitation, and need for medication** to manage behavioral challenges.
- Forcing a person with dementia to accept aspects of reality that he or she cannot comprehend is cruel.
- Emotions have more validity than the logic that leads to them.

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**Key Concept in Dementia Care #4  
To Reorient or Not Reorient**

- Best practice in dementia care: Do not correct or try to “reorient” the person.
- Requires staff to shift their care philosophy...

**Example:**

“What time is my mother coming?” (You know Ken’s mother died 20 years ago.)

**Which response is better:**

- “Your mother is dead, Ken. Your sister will pick you up at 4:00.”
- “She’ll be here in a little while. Let’s get a dish of ice cream while we wait.”

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**Key Concept in Dementia Care #5  
REDIRECTION**

**Distract AND Divert**

- Distract and redirect to minimize or avoid outbursts and challenging behaviors.
  - Redirected with gentle distraction or by suggesting a desired activity.
    - Providing food, drink, or rest can be a redirection.
- Smile, use a reassuring tone.

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**Behavior is Communication**



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## 4 Communication Strategies

Adapted from: *Habilitation Therapy in Dementia Care*. Paul Raia, Ph.D., Alzheimer's Association. MA/NH Chapter. 2011.

1.

Difficult behaviors cannot be changed with words.

- Technique: Change your:**
  - approach to the person
  - reaction to the behavior
  - the environment
- Individuals with dementia have impairments in short term memory as well as an inability to learn new information.
- A person with dementia cannot be told to do, or not do, something and be expected to remember.



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## Communication Strategies


Continued

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Don't say "No" and NEVER ARGUE!

- You cannot reason with a person who has lost the intellectual ability to process thoughts in a logical and rational manner.
- Arguing will encourage frustration, fear, and anger.
- The goal is not to be correct!
- Remember – the person is experiencing a decline in their reasoning skills at the same time they are experiencing an increase in their emotional reactions.
- Feelings are more important than facts.

**Example:** Donna tells you she is a movie star. Agree with her. It hurts no one to let them live in a reality that may be more reflective of their dreams than the life they actually lived.



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## Communication Strategies


Continued

3.

It's their reality and you must enter it.

- Technique: Validation**
- Builds empathy and creates a sense of trust and security that reduces anxiety.
- Enter their reality and reminisce with them.
- Match their emotions.

**Example:** Tom tells you that his mother was here today (but you know his mother died last year). You say, *"That's wonderful. You must love your mother very much."*



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## Communication Strategies

Continued



**4.**  
**Reduce fear by acknowledging underlying emotions.**

- As the disease progresses the person loses the ability to express and cope with their fears.
- A person with dementia cannot “self soothe” if their fears become overwhelming.
- Reassure the person and respond to their emotion.

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## Caring for Someone with Dementia Requires a Shift in Thinking.



**Rehabilitation**      **Maintaining function, safety, and comfort (Habilitation\*)**

\*Habilitation is the term used by dementia professionals to describe the non-medical interventions considered best practices in day-to-day care, in creating good environments for ADRD patients, and within all their relationships and activities.

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Focus on remaining abilities... not the losses.



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**Adapt activities so they are "failure free."**

**Adapt activities to suit the needs and capacity of the person.**

**Focus on simple activities which reinforce self-esteem while relieving boredom and frustration.**

**Emphasis is on remaining abilities, not losses.**

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**"Right-sizing" Activities**



Adapted from the Savvy Caregiver Program.

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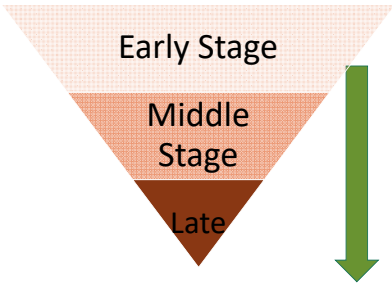
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**Task**

- Complex
- Simple steps
- Modified for increased impairment



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## Environment

- New or unfamiliar setting, change in routine
- Change in staff
- Noise
  - TV, radio, overhead paging system, people talking
- Lighting
  - People with dementia need 30% more light than we do.
  - Glare, shadows
- Large number of people
  - Over stimulating
- No orienting cues for way finding.
  - Bedroom, bathroom



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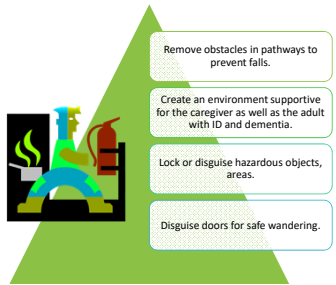
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## Dementia, Environment, & Safety



- Remove obstacles in pathways to prevent falls.
- Create an environment supportive for the caregiver as well as the adult with ID and dementia.
- Lock or disguise hazardous objects, areas.
- Disguise doors for safe wandering.

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## Environmental Considerations

- Dementia alters visual perception as well as intellectual functions.**
- People with the disease may be unable to shut out extraneous stimuli.**
- Both under- and over-stimulating environments can increase confusion and trigger problem behaviors.**



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## Maximizing Location & Function

Environmental cues:

Ex. Pictures on door

Familiar textures for matching.

Ex. On the seat for meals.

Lighting.

Contrasting colors.

Reduce unnecessary stimuli.



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## Wandering: What can you do?

- Promote as exercise. Do not prevent the movement.
- Keeping the landmarks the same as much as possible.
- Create safe wandering spaces with opportunities for sitting, drinking water and juices, snacks.
- Disguise doors, locks, knobs of doors, use signaling devices when door is opened,
- Add meaningful activity within the wandering as much as possible:
  - Music
  - Dance
  - Rhythm



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## Dementia & Vision

Factors that may be affected by AD:

- Visual field reduced about 3 feet from the floor
- 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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## Suggestions for Modifications

Reduce visual clutter.

Organize visual clutter into specific appropriate places.

Clearly identified walking paths.

Reduce glare.

- Use matted and low gloss surfaces.
- Floors with texture and not shiny surfaces.
- No-gloss waxes and cleaning products.

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## 'Sundowning'



- Sundowning – An increase in confusion and agitation that traditionally occurs in late afternoon
- Response to change of shift, transition times, fatigue, lack of light.
- Increase full-spectrum lighting especially at 3 – 6 PM. (Ex. Full-spectrum light bulbs, daylight, light box.)
- Reduce stimuli and confusion.
- Close curtains to reduce shadows and reflections.
- Try to increase supports during transition times.

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## Example of a Residence for Adults with ID

Lack of color contrasts, significant shadowing, and glare increase likelihood of difficulty functioning for the adult with ID and dementia.



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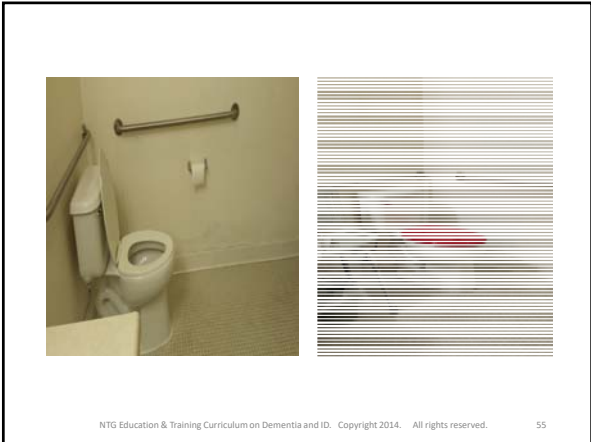
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**Suggestions for Hearing Impairment**

Reduce background noises (fans, radios, TVs, appliances).

Add soft materials such as carpeting whenever possible.

Visual and/or physical cueing along with auditory information.

**Staff awareness:**

- Simple, short, one direction or piece of information at a time.
- Speak at eye level after gaining eye contact.
- Wait longer for the response than in the past.

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## Touch (Tactile) Defensiveness

**Characterized by the following behaviors:**

- Avoidance of touch, hugs.
- Avoidance of textures, preference for certain clothing (refusing to wear anything else).
- Avoidance of activities or places where there are many people and possibilities of touch.
- Avoidance of baths, daily living tasks, hair care, etc.
- Avoidance of dental care.
- Responding with aggression to light touch.
- Increased stress when close to people.
- Pulling away or withdrawal.

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## Suggestions for Reducing Touch (Tactile) Defensiveness

Definite marking of territory and personal space.

Chairs with arms.

Clearly marked personal space in bedroom.

Areas in program and residence to get away from others, noise and visual pollution.

Placemats at the table.

Pay attention to materials and objects (including foods) that appear to irritate the individual and remove them from the environment.

If a person likes a particular outfit let them wear it! Buy two or three of the same or wash when sleeping.

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## Caregivers



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## Extent of Family Caregiving for People with ID (Braddock, 1999).

From the 1930s until the 1990s, the mean age at death for persons with ID rose from 18.5 years to 66.2 years.

- 75% live with a parent, spouse, or other family caregiver,
- 13% live alone, and
- Only 12% live in a residential facility.
- Approximately 25% of those caregivers are aged 60+ with 35% aged between 41 and 59.
- The projected population growth in the 65+ age group, due to the aging baby boomer generation, will significantly increase the number of aging caregivers in the years ahead.

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## Unique Challenges Caring for an Adult Child with ID (and Dementia)

### General Population

Average period of time that a caregiver provides assistance to a spouse or older family member with a chronic illness:

*4.5 years*

### Parents with Child with ID

Caregiving can last for 60 years or more.

For a vast majority of family caregivers...

*lifelong career*

(National Alliance for Caregiving & AARP, 1997).

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## ID & Dementia: A Special Risk

Aging caregivers for people with ID may be at special risk because of:

- age-related health and behavioral declines in the aging care recipient and caregiver,
- extensive duration of the caregiving role, and
- concerns about the long-term care of the care recipient
  - Who will care for their child if/when they die?
  - How will they pay for care?
  - Who will provide it?

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## A role for health professionals

The findings suggest that health professionals must be prepared to assist family members with:

- Anticipatory grieving of losses that accrue with the changing relationship with the relative and health care staff.
- Ways of helping and supporting family caregivers so that they can develop a sense of satisfaction and accomplishment in their care giving role.

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