

## Aging with a Developmental Disability

*Veronique Baril, M.A., Psychometrist  
Twin Lakes Clinical Services, Thorold, Ontario  
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What's in the bag?



## Training Outcome

You will learn:

1. About Dementia
2. Symptoms that may suggest Dementia
3. Other issues to rule out
4. Procedures for establishing diagnosis
5. Strategies to provide support

## Overview

- According to the DSM-5:
  - Dementia = Major or Mild Neurocognitive Disorder
- Not part of normal aging
- No cure
- Prevention not well understood
- Diagnosis of exclusion

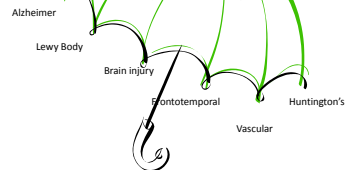
## Atrophy of the brain

Healthy Brain    Severe AD



## Dementia

(Major or Mild Neurocognitive Disorder)



## Signs of dementia

	Difficulties in/with:
Executive skills	Organising and completing tasks
Memory	Remembering: <ul style="list-style-type: none"> <li>- Answers to questions asked</li> <li>- What they did in the morning or day before</li> <li>- Already done something</li> <li>- Where they put things/ people's names</li> </ul>
Language	<ul style="list-style-type: none"> <li>- Finding familiar words</li> <li>- Participating in conversations</li> <li>- Understanding and following what has been said</li> <li>- Reading and writing</li> </ul>

## Signs of dementia

	Difficulty in/with:
Recognizing	- Recognizing people, objects, places
Visual-spatial skills	<ul style="list-style-type: none"> <li>- Telling left from right</li> <li>- Knowing where parts of the body are</li> <li>- Finding their way along familiar areas</li> <li>- Finding their way to the toilet</li> <li>- Complexity and detail in drawing</li> <li>- Stairs, curbs, patterned floors</li> <li>- "Sundowning"</li> </ul>
Learned motor skills	<ul style="list-style-type: none"> <li>- Doing up shoe laces, zips and buttons</li> <li>- Folding clothes</li> <li>- Hygiene (i.e., bathing, shaving, hair)</li> <li>- Walking</li> <li>- Swallowing (minced diet)</li> </ul>

## Signs of dementia

	Difficulty in/with:
Psychological/behavioural	<ul style="list-style-type: none"> <li>- Loss of motivation</li> <li>- Sleep disturbance (sleep/wake pattern)</li> <li>- Wandering</li> <li>- Agitation</li> <li>- Resisting/ oppositional</li> <li>- Anxiety</li> <li>- Irritability and aggression</li> <li>- Mood changes</li> <li>- Apathy</li> <li>- Withdrawal</li> <li>- Delusions/Hallucinations</li> <li>- Paranoid</li> </ul>
Seizures	<ul style="list-style-type: none"> <li>- Onset or worsening</li> <li>- Development of little motor jerks</li> </ul>
Other	- Incontinence

## Facts

- Some syndromes have particular health risks and are at greater risk than the general population.
  - Down syndrome - average life expectancy is age 60.
- Other individuals with an Intellectual Disability are at similar risk.
  - If in mild range with no significant health issues - life expectancy close to general population.
- Having strokes, seizures, and brain injuries also at greater risk than the general population.
- Family history.
- **Do not assume that changes are due to dementia.**

## Facts

- Out living parents and natural supports.
- Lack of access to appropriate services.
- Alzheimer's disease is the most common form of dementia - 64%

## Case 1

- 54-year-old woman with Down syndrome
- Limited verbal skills
- Cognitive level, mild to moderate
- Hip surgery, two years ago
- Moved to a new 24-hour supported home, one year ago
- Enjoys playing the cello, and piano
- Enjoys being social and going out
- She is very independent (i.e., likes making her breakfast, cleaning her room)

## Case 2- Dementia? Or not?

### Presenting symptoms

- Decline in energy
- Not interested in previously enjoyed activities
- Does not want to go outside and stays in her pyjamas all day
- Sleeps most of the day, everyday
- Is not interested in playing her cello or piano (played for 30 years)
- Says "I want to take my belly button out"
- Cannot focus
- More irritable
- Requires more attention from staff
- More emotional and crying

## Case 2

- 64-year-old man diagnosed with mild ID
- Diagnosis of schizophrenia - he has been stable for a few years
- Same case worker, same medications
- History of suicidal ideations and attempts
- Poor coping skills with day-to-day stressors
- Moved to a new apartment a year a half ago, but with the same housemate
- Enjoys arts, learning how to read

## Case 2- Dementia? Or not?

### Presenting symptoms

- Decline in energy
- Not interested in previously enjoyed activities
- Outside at night with slippers
- Asking more questions
- Cannot perform task/understand as he used to
- Confusion with staff names
- More irritable and angry
- Calls in sick at work more often
- Loses and misplaces items, even his favorite
- Staff find his favorite clothes in the garbage
- Does not take public transportation independently and gets lost

## Case 3

- 64-year-old man
- Lived in institutions for most of his life
- Lives with three male housemates
- Always has a coffee in his hand, from morning to night
- Awake at night but does not seem confused
- Makes his coffee and toast independently
- He is mostly non-verbal
- Limited eyesight
- Recent medical, everything in the normal limits

## Case 3- Dementia? Or not?

### Presenting symptoms

- Sleep disturbance, up at night
- Irritable/aggressive
- Confusion
- Incontinence
- Hiding toast crusts every where (i.e., behind toilet seat, in his pants pocket)
- Restless

## Assessment

- Where to start?

## Rule out

- Because of communication problems and lack of expertise among health professionals, some preventable conditions of diseases may become chronic.
- Individuals with disability may lack basic knowledge of healthy life styles.
- Degree of impairment may be more severe (i.e., hearing, vision, etc.).
- May be prone to more severe arthritis and developing arthritis at a young age.

## Rule out

- Psychiatric Disorder
  - Depression
  - Grief
  - Adjustment disorder
  - Psychosis
  - Delirium
- Sensory impairments
  - Hearing (loss, ear wax, infections)
  - Vision
- Musculoskeletal Problems
  - Arthritis (spine, hip, knees)
  - Muscle weakness
  - Lack of physical fitness
  - Bone fractures
- Life changes
- Medical Conditions
  - Hypothyroidism
  - Sleep apnea
  - Heart problems
  - Chest infections
  - Urine infection
  - Constipation
  - Epilepsy
- Medications
  - Need to adjust? New?
- Pain
  - Hemorrhoids
  - Teeth
- Others
  - Hormones (menses)
  - Vitamins (Iron, B12, Folic acid)

## Rule out

- Depression
  - Insomnia, fatigue, loss of appetite, weight loss, constipation, loss of interest in people and activities.
- Delirium (acute)
  - Variety of conditions can impair circulation to brain and cause disturbances in cognitive function.
- Dementia
  - Clinical syndrome of usually progression cognitive deterioration that eventually causes functional impairment.

## Recognizing Delirium, Depression and Dementia (3D's)

Individuals may have more than 1D present at the same time and symptoms may overlap

	Delirium	Depression	Dementia
Definition	Delirium is a medical emergency which is characterized by an acute and fluctuating onset of confusion, disturbance in attention, disorganised thinking and/or decline in level of consciousness.	Depression is a term used when a cluster of symptoms are present most of the time, most days, for at least two weeks and are of such intensity that they are out of the ordinary for the individual	Dementia is a gradual and progressive decline in mental processing ability that affects short-term memory, communication, language, judgement, reasoning, and abstract thinking.
Onset	Sudden onset, hours to days	Recent unexplained changes in mood for a period of at least two weeks	Gradual deterioration over the months and years
Course	Often reversible with treatment Often fluctuates 24hours and worse at night	Often reversible with treatment Often worse in the morning	Slow, chronic progression, and irreversible

## Diagnostic Criteria

- Diagnosis requires evidence of a definite change in areas of cognitive functioning known to deteriorate.
  - Memory
  - Language ability (aphasia)
  - Ability to perform complex tasks (apraxia)
  - Orientation in time and place
  - Everyday skills
  - Personality

## Challenges to diagnose with DD and ID

1. Pre-existing cognitive impairment
  - Marked range of ability
  - Decline may be misattributed to ID
  - Requires knowledge of person over the previous years and months (gaps in background information)
2. Person may be misdiagnosed due to reversible dementias
3. Lack of baseline
4. Individual unresponsive or uncooperative to testing



# Test Battery

## BACKGROUND INFORMATION

### 1. Cognitive measures (one of the following):

- Stanford–Binet Intelligence Scale, Fifth Edition
- Wechsler Adult Intelligence Scale
- Kaufman Brief Screening Test-R

### 2. Language- Based tests:

- Expressive Vocabulary Test, Second Edition
- Peabody Picture Vocabulary Test, Fourth Edition

### 3. Memory

- Name and Face Recall Task
- What's in the Bag?
- Dyspraxia Scale for Persons with Developmental Disabilities

## Test Battery- 3<sup>rd</sup> Party Rating

### 4. Adaptive Measures (one of the following):

- Vineland Adaptive Behavior Scale, Second Ed.
- Adaptive Behaviour Assessment System, Second Ed.

### 5. Psychiatric/Behaviour Checklists

- PIMRA
- Reiss Screen for Maladaptive Behavior
- EPS

### 6. Dementia/Older Adults specific tests

- Dementia Scale for Down Syndrome
- Dementia Scale for Mentally Retarded Persons
- Multi-Dimensional Observation Scale for Elderly Subjects (MOSES)

## How to best support?

- Personal Preferences and Values  
What would you want staff to know about you so that what you value most is preserved and you would receive wonderful care?

## How to best support?

What adaptations have you tried?

- Safety
- Sensory
- Orientation/confusion
- Memory
- Health
- Social and communication

## Keep Person Safe



Use personal door alarms for resident rooms



Stove/door knob covers



Place door lock high, at unusual height.



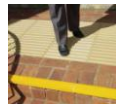
## Keep Person Safe

Stairs and clutter



Adjust hot water thermostat

Use warning strips to alert person to change in: elevation, texture, height, routes

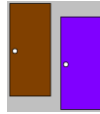


## Reduce confusion

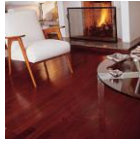


Use younger photograph on door

If possible, paint doors different colours



Keep person's the same colour



Furniture arrangements to remain the same

## Reduce confusion

Find the hearts in this picture

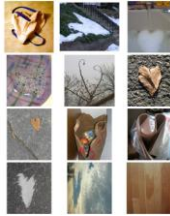


Figure - ground discrimination



Ability to distinguish items from a background of visual "clutter"

## Reduce confusion

- Ensure contrast between food and dishes.
- Use coloured dishes.
- Place dishes on coloured placemats and/or tablecloths.
- Improve lighting in room.



## Strategies - Environment

- Eliminate appliances that produce sound.
- Uniform floor surfaces.
- Good and uniform lighting, to avoid shadows.
- Post person's photograph on bedroom (use younger photo).
- Avoid using multiple electrical appliances at the same time.



## Strategies- Memory/Orientation

- Post family photographs (use younger photos).
- Review family album.
- Post daily schedules and review frequently, including visitors.
- Label/picture doors according to function.
- **Develop life story book!**



## Strategies- Memory/Orientation

- Use written or picture cues to assist memory depending on the individual's ability
  - Display steps in routine daily activities
  - Document trips/holidays (make picture album with them)
  - Write stories accompanied by photographs about events in which the individual was involved
  - Develop life books
  - Pictures of family members (with their names)
  - Record familiar voices

Most useful in early to middle stages, with variable usefulness in final stages.

## Strategies- Communication

- Positive interactions
  - Use shorter statements, concrete language
  - Visual supports
  - Be patient
  - Pay attention to individuals body language, it is a form of communication
  - Show warmth through appropriate touch
- \*\*Pay attention to your own body language

## Strategies- Communication

- Harmful Interactions
  - Do not treat like a child (infantilize)
  - Label
  - Outpace
  - Impose
  - Ignore

## Strategies to support

- Need for professional support
- Long term plan
- Adapting supports
  - Safety issues
  - Mobility and dexterity issues
  - Medical conditions
  - Self-care
  - Create a history book

Planning ahead

**Advanced care planning**

We need to be good  
detectives  
and  
not good judges.

What's in the bag?



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