DEMENTIA

An Increasing Challenge: Early Recognition & Support

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1

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4

Dementia – An Increasing Challenge

Today, we will look at….

- What is dementia?
- Different types of dementia
- Alzheimer's Disease
- Challenges in Recognizing AD
- Dementia Responsive Program
- Strategies for Support, Adaptations and Accommodations

5

NORMAL FORGETFULNESS
(The Difference Between Alzheimer's And Typical Age-related Changes - the Alzheimer's Association)

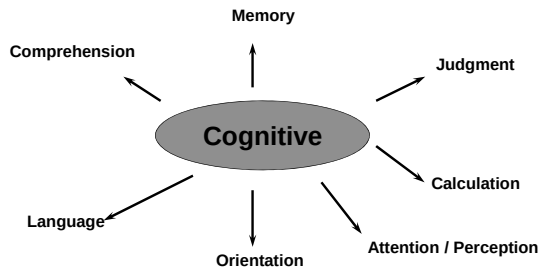
Signs of Alzheimer's	Typical age-related changes
Poor judgment and decision making	Making a bad decision once in a while
Inability to manage a budget	Missing a monthly payment
Losing track of the day, date or the season	Forgetting which day/date it is and remembering later
Not recognizing familiar people you see frequently	Recognize people & places, even if cannot remember names

6

NORMAL FORGETFULNESS (The Difference Between Alzheimer's And Typical Age-related Changes) (From the Alzheimer's Association)	
Signs of Alzheimer's	**Typical age-related changes**
Difficulty having a conversation	Sometimes forgetting which word to use
Misplacing things and being unable to retrace steps to find them	Losing things from time to time
Forget having participated in a recent activity/event – morning to afternoon	Forget details of a recent experience/event, but not experience/event
Difficulty completing a routine Functional Task	Difficulty remembering infrequent tasks (e.g. how to reset TV controller)

7

What is Dementia?



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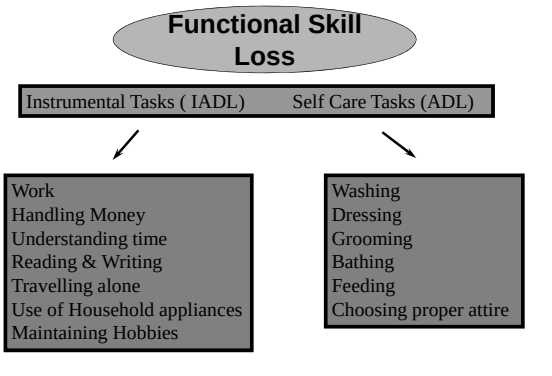

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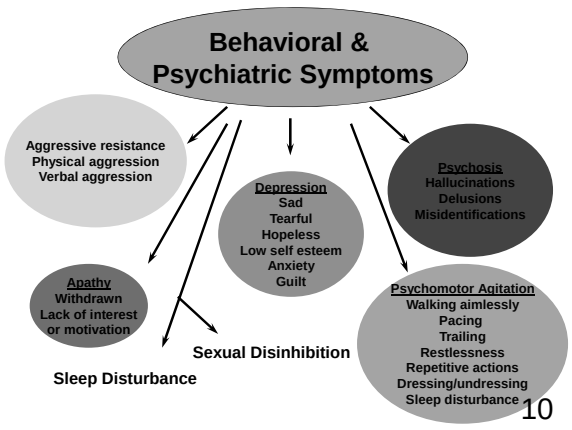


10

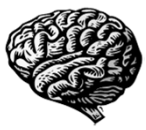
Types of "Reversible" Dementia OR "What can be mistaken for Alzheimer's"

- Depression
- Medication Side Effects
- Nutritional disorders
- Metabolic disorders
  Sensory Loss – vision, hearing
- Other – Intoxicants, Infections, Brain Tumors, Brain Injury, other neurological disorders

11

Irreversible Dementias

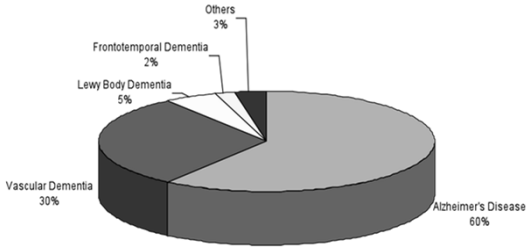
- Alzheimer's disease
- Multi-infarct or vascular dementia
- Parkinson's disease
- Lewy Body disease



- Creutzfeldt-Jakob disease
- Pick's disease
- Huntington's disease
- AIDS dementia complex
- Progressive aphasia

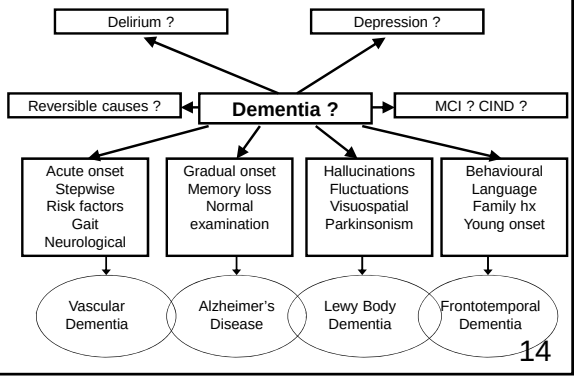
12

Dementia - Types



13

DIFFERENTIAL DIAGNOSIS OF DEMENTIA



14

Alzheimer's Disease is . . .

Progressive:

damage from the disease <u>increases</u> over time

Degenerative:

brain cells degenerate or <u>break down</u>

Irreversible:

damage <u>cannot be repaired</u>;

at present there is no known cure

15

Challenges in Recognizing Alzheimer's in Persons with Down Syndrome

- Alzheimer's disease is a diagnosis of exclusion in persons with Down syndrome, just as it is in the general population.
- Clinicians rely largely on informant reports
- May be more difficult for those who see people daily, than those who see them weekly or monthly

16

Challenges in Recognition

- Mental health disorders often present differently in persons with Down syndrome and other disabilities because of cognitive and expressive language limitations in this population.
- Traditional testing less helpful for assessing, making diagnosis and monitoring declining abilities in persons with an intellectual disability
- Lack of definitive **biological tests or markers** for AD

17

When to Suspect Alzheimer's in a Person with Down Syndrome

- Loss of memory which impairs daily function
- Difficulty performing familiar tasks / daily living skills <u>despite intact sensory & motor function</u>
- Increased difficulty learning new tasks
- Reduced language skills
- Decrease in judgment
- Misplacing items consistently
- Loss of orientation / Disorientation
- Loss of initiative / apathy / longer periods of inactivity
- Deterioration in adaptive social skills
- Onset of seizures for the first time

18

Dementia Responsive Program "Effective" Practice Guidelines

- Early Screening & Diagnostics
- Person Centred Care Plans
- Environmental Modifications
- Program Adaptations
  - o Modified Interaction Techniques
  - o Specialized Activities
  - o Intervention for Behavioural / Mood Changes
- Specialized Care

19

Dementia Responsive Program "Effective" Practice Guidelines

1) Regular Medical Examination: (Health Watch Table)

a. Annual Physical (vision, hearing, orthopedic, thyroid, menopause)
b. Regular medication **review** (dosage and side effects with changes in weight & age)
c. Mental Health Evaluation (depression, delirium)

2) Establish a Personal Ability Baseline

a. Living Arrangements
b. Community Involvement
c. Academic Achievements
d. Volunteer & Vocational Achievements
e. Social Relationships

20

Dementia Responsive Program "Effective" Practice Guidelines

3) Monitor & Evaluate changes that can occur. (Research indicates that changes will likely occur in the following order):

① Changes in Personality & Behaviour
② Decline of Cognitive Abilities
③ Decline in Memory Skills
④ Decline in Orientation
⑤ Loss of Adaptive (everyday) skills
⑥ Decline in Self-Care (Instrumental) skills.

21

Dementia Responsive Program "Effective" Practice Guidelines

4) Complete a comprehensive evaluation:

- Cognitive ability
- Adaptive Skills
- Interview with parents / caregivers
- Behavioural indicators of dementia

22

Dementia Responsive Program "Effective" Practice Guidelines

5) Evaluate the Model of Care being provided

Person Centred Plan	**Versus**	Person Centred Care Plan
Developmental	**vs**	Support
Increases Choice	**vs**	Limits Choice To Avoid Confusion
Maximizes Potential	**vs**	Maintains Existing Abilities Whenever Possible

23

Implications of Person Centred Care

- The **focus of care-giving activities change** at different stages of dementia
- Should identify the changing roles of the caregivers and **specific educational and training programmes**, which are tailored to meet the needs of persons at different stages of dementia
- Should identify appropriate **environmental supports and modifications**
- Identifies that changing care requirements, particularly for persons within the moderate range of intellectual disability, needs to be planned for from an **economic and resource perspective**

24

Strategies for Support: Changes in Program Practices

- Provide closer supervision to be able to more closely monitor and document (data) increased episodes of confusion, disorientation or memory lapses
- Maintain present levels of independence by increasing staff supervision, prompts and hands-on care
- Modify the individual's support plan to anticipate changing ADL needs
- Increased communication amongst family, residential and day-program staff

25

Strategies for Support: The Person

- Medical Treatment
- Lifestyle
- Environmental Considerations
- Structure & Routine needs
- Interaction Tips
- Conversation Tips
- Modify Leisure Activities
- Consider daily activities **AS** activities
- Consider Behaviour as Communication

26

Strategies for Support: Medical Treatment of Alzheimer's Disease

- Prevention of disease
- Delay onset
- Slow rate of progression
- Treat primary symptoms (cognitive)
- Treat secondary symptoms (behavioural)

27

Medications Used for Dementia

Anticholinergic Medications
(Aricept, Razadyne and Exelon)

- Used in the early to mid stage of the disease to reduce memory loss
- These drugs have shown to decrease in effectiveness over time and do not help all individuals diagnosed with Alzheimer's

Anitglutametergic medications
(Namenda)

- Usually anticholinergic medications are prescribed during the mid to later stage of the disease
- Long term effectiveness is not clear at this time.

28

Efficacy of Use of Medications

- Controversial research on effectiveness of medications in the general populations and very limited data to show treatment outcome results for adults with intellectual disabilities.
- Risk of Adverse Drug Reactions: presumed to be higher in adults with intellectual disabilities because of:
  1) Higher concentration of medications
  2) Higher prevalence of chronic health issues
  3) Interactions of the underlying disorder with medications used to treat other symptoms
  4) Exacerbations of reactions with the early age related changes experienced.

29

Strategies for Support: Lifestyle & Activity

- **Maintain cognitive function during aging**
  - Increase Omega 6 intake
  - Increase fruit & vegetable intake
  - Maintain social contacts
  - Maintain hobbies/interests
  - Regular physical exercise – 2 to 3 times per week

PICKLES, Deaf Seniors USA

30

Strategies for Support: Environmental Considerations

- Keep changes to an absolute minimum
- Maintain consistency in personal space
- Eliminate clutter and distractions
- Minimize ambient noise (loud and multiple conversations, TV, radio)
- Keep traffic paths clear
- Good lighting, non-glare glass, attention to figure ground contrast
- Use symbols, signs & colours in the environment
  - Personalization of bedroom doors
  - Special markings for bathrooms
- Outdoor Safety
  - Door Alarms, Fenced Yards, Special "wandering" paths

31

Strategies for Support: Structure & Routines

- Maintain regular, predictable schedules
  - Add visual supports as required
- Consistent approach to each activity of the day
- Simplify routines as needed
- Reduce choices, but continue to offer them
- DO EVERYTHING POSSIBLE to maintain skills
- Maintain community programs – vocational, recreational, church, sports
- Maintain social opportunities – individual & group activities, friends, family

32

Strategies for Support: General Interaction Tips

- **ALWAYS** approach from the front, **THEN**
  - Get low to maintain eye contact, offer your hand & say his/her name, **AND** introduce yourself (every time) & **WAIT**
- Speak slowly, quietly and clearly
  - Keep verbal requests simple, combined with exaggerated facial expressions, clear body language and gestures
- Incorporate symbols or signs familiar to the person
- Use the person's name frequently

- **Always tell the person what you are going to do before you start any action or activity**
- **Always explain when you are leaving the person!**

33

The Don’ts of Interactions

- Call or shout from a distance
- Argue or confront
- Initiate interactions ‘on the go’ (Drive-by Interactions)
- Abandon people (drop a person off or leave a person even for a few minutes without explanation**)**

34

Strategies for Support: Conversation

(Help the person recall the Past)

- Get to know the person’s history
- Use photos and mementos to stimulate conversation
- Create a life story book or video
- Invite conversation by making suggestions (“This looks like you in this picture” or “You looked happy when this picture was taken”)
- Don’t play 20 questions (Say “Did you enjoy the trip to Tim Horton's this morning?” VS “So, what did you do this morning?”

35

Strategies for Support: Leisure and Social Activities

- Being with the person is more important than the actual activity (spending time together provides reassurance and combats confusion and fear)
- Simplify activities and focus on individual interactions
- Use fewer materials, fewer steps, forget about rules and outcomes
- Make every moment count

36

Strategies for Support:
Self-Care becomes Person-Centered-Care

- Personal Care and Meals ARE Social Activities
- Slow down
- PATIENCE
- Support INDEPENDENCE to preserve dignity
- Use simple instructions, do one step at a time
- Simplify - smaller steps or portions, fewer choices
- Minimize distractions and clutter

37

Strategies for Support:
Understanding the world of the individual living with dementia ….

- The **"7 A's" + Executive Functioning**
  - Encountering stressors is a normal part of daily existence
  - The cognitive losses of dementia
    - Affect an individual's interpretation of new stressors,
    - Influence the person's internal response to stimuli and
    - Compromise previously (limited) coping mechanisms
- **Thus resulting in challenging behaviours**

38

Amnesia
(Trouble with Memory)

Examples of Behaviour	Strategies to Compensate
Repeating	Treat all repetitions as if it were the first time
Misplacing/losing things	Provide cues & gentle reminders
Insisting a recent event hasn't occurred	Don't assume a recent event can be recalled
Disorientation	Provide visual cues and reminders
"Living in the past"	Reminisce about the distant past – use photos and "life book"

39

Agnosia

(Trouble Recognizing – people, places, objects)

Examples of Behaviour	Strategies to Compensate
Misidentifying familiar people & family	Introduce yourself every time
Not recognizing regular caregivers	Don't assume they will remember
Misusing common objects	Identify objects and places
Eating unusual things or mixing foods up	Prevent unfortunate mixtures and foods that shouldn't be eaten until cooked

40

Aphasia

(Trouble Using & Understanding Language)

Examples of Behaviour	Strategies to Compensate
Word finding difficulty	Accompany words with visuals and gestures
Not using the right words	Patience!
Repetitive sounds or words	Allow more time for a response
Failure to report distress/pain	Be mindful of facial expressions
Reverting back to a First language	Use key words from individual's first language when possible
Needing more time to respond and/or not responding appropriately	Speak slower and clearer than usual

41

Apraxia

(Trouble with Purposeful Movement)

Examples of Behaviour	Strategies to Compensate
Deterioration of the ability to perform activities of daily living	Provide short, simple directions
Not getting the steps of a task right	Add in visuals and gestures
	Assess capabilities regularly
	Refrain from assuming capability based on physical range
	Demonstrate (model) the actions required

42

Anosognosia

(Lack of Awareness that you have a problem)

Examples of Behaviour	Strategies to Compensate
Refusing assistance or care	Normalize assistance (i.e. "I do this for Everybody")
Insisting that the task has "already been done!"	Avoid arguing
Lack of awareness of risk	Be aware of individual's reality & recognize strengths
Appearing stubborn	Offer help as if it were temporary (i.e. "I will help you just this once")
NOT DENIAL!!!	

43

Altered Perception

(Trouble Perceiving the world accurately)

Examples of Behaviour	Strategies to Compensate
Delusions (false beliefs)	Avoid arguing or trying to convince someone of the reality
Hallucinations (experiencing something that isn't there)	Respond to the feelings rather than the facts being expressed
Illusions (mistaking something for something else)	Alter the environment to minimize misinterpretation
Poor depth perception	Provide increased lighting and colours to distinguish height differences

44

Apathy

(Lack of Motivation or Initiative)

Examples of Behaviour	Strategies to Compensate
Appearing to not care or withdraw	Help the person initiate or get something started
Failure to initiate activities – conversations, eating	Connect with them on a regular basis
Appearing to be "stuck"	Gently persuade the person to join in activities they formerly enjoyed
Sitting in the same place	

45

Executive Functioning

(Necessary planning for ADL's)

- Planning
- Organizing
- Sequencing (doing things in the right order)
- Initiating (knowing when to start something)
- Ceasing (knowing when to stop)
- Judgement
- Abstraction

46

Day-to-Day Management of Challenging Behaviour:

(All Behaviour has Meaning)

- Changes in behaviour and mood often occur in people with Alzheimer's disease and similar conditions that alter brain function.
- What we experience as disturbing, agitated or challenging behaviour might be an individual's way of showing that he/she is in distress.
- Cognitive losses prevent the individual from coping with the distress. **We must always do our best to address the root cause of the behaviour.**

47

Agitation

Possible Causes/Meaning	Possible Solution
• Gap between capacity & demands	• Use nonverbal calming – music, touch
• Misperception of reality, uncertainty, fear	• Keep a calm tone of voice, remain supportive
• Needs – washroom, constipation, pain, discomfort	• Adhere to routine
• Sensory – noise, light, overstimulation, boredom	• Reduce noise, clutter
• Inability to communicate	• Use short yes/no sentences
• Situational changes	• Offer reassurance

48

Verbal/Physical Aggression

Possible Causes/Meanings	Possible Solutions
• Poor impulse control	• Refrain from correcting – instead validate emotion and offer to help • If necessary, distract them
• Frustration – unable to communicate	• Keep calm and remain supportive
• Sense of loss of control	• Offer concrete, limited choices
• May not understand need for personal care	• Be aware of body language, tone of voice, facial expression
• May not recognize people around them	• If possible, give person space and approach later

49

Repetition

Possible Causes/Meanings	Possible Solutions
• Often linked to memory	• Look for reason & emotion
• Can reflect anxiety about forgetting something	• If repetition is an action – make an activity that uses that action
• Fear, insecurity, worry	• Do NOT tell person they have already asked/said/done • Instead… answer & redirect to another activity
• Person looking for something comforting & familiar	• Use visuals to remind person of upcoming activities, appointments, etc..

50

Hallucinations/Altered Perception

Possible Causes/Meanings	Possible Solutions
• Sensory experiences that seem real	• Try to understand what is causing misperception
• Altered depth perception	• TV & radio can cause confusion
• Confusing objects or reflections	• Increase lighting, use colour to distinguish areas
	• Eliminate clutter

51

Hoarding

Possible Causes/Meanings	Possible Solutions
• Can be response to isolation	• Remove items gradually
• Response to loss of control	• Try to negotiate amount kept
• Often associated with anxiety	• Don't try to use logic
	• Re-organize & clear paths if needed

52

Social/Sexually Inappropriate

Possible Causes/Meanings	Possible Solutions
• Impaired impulse control	• "Pardon my Companion" cards
• Unable to communicate hot/cold, tired, uncomfortable	• Don't take it personally
• Under-stimulation	• Increase appropriate physical attention
• Misinterpret cues seen on TV	• Provide personal space and direct to private area

53

Sundowning / Shadowing

Possible Causes/Meanings	Possible Solutions
• Changes to person's circadian rhythm	• Discourage napping • Provide calming, repetitive tasks during agitated times • Listen to calming music
• Hormonal factors	• Encourage appropriate levels of exercise • Restrict consumption of caffeine products to ONLY early morning
• Reduced vision at lower light levels	• Keep areas well lit • A night-light can be reassuring and help orient person
• Tiredness after a full day	• Reduce extraneous stimulation – TV, radio, too many visitors • Plan challenging activities for early in the day
• Boredom / lack of activities	• Scheduled outings and social events

54

Other Behavioural Strategies

P.I.E.C.E.S. - A "Best Practices" Framework for Looking for Possible Causes: (Alzheimer's Society of Manitoba)

- **P** – Physical (basic needs, medications, senses)
- **I** – Intellectual (memory loss, poor judgment, loss of initiative, language loss)
- **E** – Emotional (depression, anxiety, boredom, multiple losses)
- **C** – Capabilities (inability to meet own needs)
- **E** – Environment (noise, temperature, clutter, etc.)
- **S** – Social/Cultural (loss of meaningful relationships, loss of control/choice)

55

Person Centered Care Plans for Hospital Stays

- Continuous cueing about the new environment
- Explain procedures and apologize each time discomfort is caused
- Watch for non-verbal signs of pain
- Try to maintain routine and regular activity level
- As much as possible, maintain consistent staff
- Avoid groups of staff or visitors
- Avoid restraints - falls are not prevented and sometimes result from restraint
- Avoid room changes
- Keep television off unless requested by the person
- Continue to provide dentures and glasses

56

End of Life Issues

- The right and opportunity to acknowledge the end of life
- Making deliberate choices and plans
- Receiving the same array of services and supports as everyone else (palliative care / comfort measures)
- Affirming the value of each life
- Grieving the end of each life, the loss of each friend

57

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58

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59

Questions?

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60