

AGING and INTELLECTUAL DISABILITY



Haldimand & Norfolk Seniors Partnership

A training presentation
for caregivers and those involved
with persons who have an intellectual disability
and who are experiencing the effects of aging.

Table of Contents

Background and Partnership – 3 to 7

Goals – 8

Our case in Ontario – 10 to 11

Evolution of language – 12 to 13

Life expectancy – 14 to 18

Double disadvantage – 20 to 21

Diagnostic overshadowing – 23 to 27

Complicated management – 28 to 29

Biopsychosocial model – 30 to 34

Case study – 35 to 36

Vision – 38 to 42

Hearing – 43 to 47

Sleep – 48 to 52

Medication – 53 to 60

Constipation – 61 to 65

Oral health – 66 to 69

Malocclusion – 70 to 72

Muscles and bones – 73 to 76

Osteoporosis – 77 to 80

Circulation – 81 to 84

Psychiatric – 85 to 86

Dementia – 87 to 92

Alzheimer's disease – 93 to 111

Eight As – 112 to 121

Dementia and Downs – 122 to 123

General principles of care – 124 to 133

Positive behaviour approach – 134 to 143

Functions of behaviour – 144 to 146

Biopsychosocial approach – 147 to 148

Behaviour overshadowing – 149 to 150

ABCs of behaviour – 150 to 154

Interventions – 155 to 159

Create opportunities for success – 160 to 162

Communicating effectively – 163 to 165

Cloak of competency – 166 to 167

Give attention to desired behaviours – 168 to 170

Reduce reliance on power and control – 171 to 173

Crisis management – 174 to 175

Data collection – 176 to 179

Care for the caregiver – 180 to 182

Resources – 183 to 184

Contributors – 185



Background

The Haldimand & Norfolk Seniors Partnership (HNSP) is a network of support agencies from across Haldimand and Norfolk Counties that works to build region-wide capacity on aspects of aging and intellectual disability. In 2014, this partnership was awarded an Ontario Trillium Foundation (OTF) grant to support a project that would facilitate an increased education and awareness about the changes someone, with an intellectual disability, may experience as he or she ages.

These materials cover the changes that may be experienced by a person following a “Biopsychosocial Model.” Because of medical advancements, people in our society are (on the whole) living longer. With aging, unfortunately, comes the increased risk factor that those with an intellectual disability, especially someone with Down Syndrome, may develop a dementia, more commonly, Alzheimer’s disease.

The workshop was established to provide health care professionals who will be supporting these individuals with the effective knowledge and tools based on current best practices. This curriculum on aging, dementia and intellectual disabilities can be taken back to your respective agency or long-term care home to ensure best practices will be utilized. The goal of this project is to improve awareness and education with the hope that attitudinal barriers and reluctance in supporting these individuals will be reduced.



Organizations of the Haldimand & Norfolk Senior Partnership

Alphabetically, the organizations of this partnership are:



- Alzheimer Society of Haldimand & Norfolk

- Community Addiction and Mental Health Services of Haldimand & Norfolk



CAMHS
Community Addiction and Mental Health
Services of Haldimand & Norfolk



Hamilton Niagara Haldimand Brant
CCAC CASC
Community Care Access Centre
Centre d'accès aux soins communautaires

- Community Care Access Centre (Hamilton, Niagara, Haldimand, Brant)

- Community Living Access (Norfolk & Haldimand)



continued . . .

Organizations of the Haldimand & Norfolk Senior Partnership

... continued

- Community Living (Haldimand)



Haldimand-Norfolk
REACH

- Haldimand-Norfolk REACH

- Norfolk Association for Community Living



revera[®]
Long Term Care

- Revera Long Term Care

- Southern Network of Specialized Care



The Partnership

The Haldimand & Norfolk Seniors Partnership (HNSP) consists of these nine agencies.

Contributors

We appreciate the contribution of the following people who have drawn from their experiences and expertise in the field.

Also, we acknowledge the involvement of Dr. Kerry Boyd (MD, FRCPC, Psychiatrist) and Ms. Sandra Buckle who reviewed and approved this curriculum.



Acknowledging support for this project that comes from the . . .

Ontario Trillium Foundation



Fondation Trillium de l'Ontario

An agency of the Government of Ontario.
Un organisme du gouvernement de l'Ontario.

This presentation will help you to achieve these GOALS



- **GOAL** – to better understand how aging affects adults with Intellectual Disabilities (ID)
- **GOAL** – identify tools and resources that you can use in your work, and share with your team members, that will optimize the lives of the persons you support.
- **GOAL** – to better understand reactive behaviour and how to best respond to it



Adapting this resource to group work

This PowerPoint presentation has been adapted from a classroom training program that offered opportunities for small group discussion.

You may be viewing it on a computer workstation for an individual learning experience.

The graphic at the lower right-hand corner indicates where you can to include other people in discussion of the materials. It will appear on those slides where small group discussion had been planned for the original training.



An example from our history



History of Care in Ontario

People with Intellectual Disabilities are a diverse group of individuals with varying abilities and needs. In Ontario, not long ago, most were dependent upon custodial care provided in large institutional settings with few choices or rights. On birth, parents were actively encouraged to give up their children. However, beginning in the 1960s there was a shift to integrate individuals into the community. It was a slow process but, because of legislation such as the “Social Inclusion Act” and the “Excellent Care for All Act,” people with ID are now considered full citizens entitled to receive services and supports of their choosing to maintain a good quality of life and inclusion in society. Unfortunately, despite these positive trends and changes in philosophy, older adults with ID are still an under served and often marginalized group.



The Evolution of Language

- 
- Moron
 - Mentally Retarded
 - Mentally Handicapped
 - Developmentally Handicapped or Challenged
 - Cognitive Delay or Impairment
 - Developmental Delay
 - Developmental Disability
 - Intellectual Disability

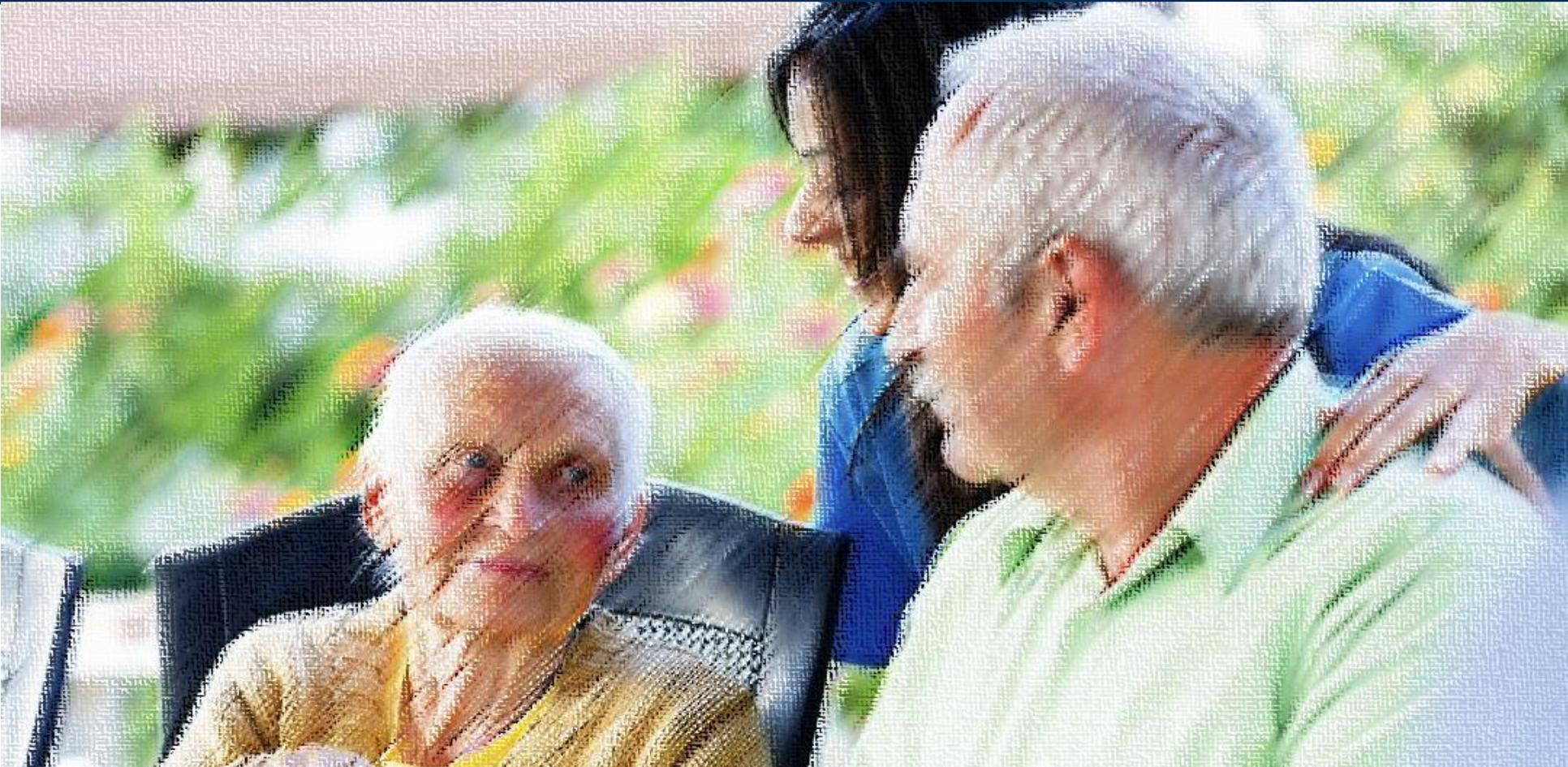


The Evolution of Language

Historically, people with Intellectual Disabilities have been described by many terms. Some terms, in our day, are considered extremely offensive. The most recent term used by professionals for diagnostic purposes is “Intellectual Disability.”



Living better. Living longer.



Life Expectancy

Just like we are seeing in the general population, people with an ID are living longer. What does this mean? It means that new things have to be considered by people who provide support to people with an ID.

- Since the 1980s, we have begun to see a shift toward an increase in studies about aging.
- In the 1930s, the average life expectancy of people with ID was around 20 years.
- The median age of death of a person with DS in the USA was only 25 years in 1983. This almost doubled to 49 in 1997.

Note: Although the statistics are from the USA, it was felt by Dr. Boyd that they would be about the same in Canada.



Life Expectancy

- The study of aging remains a relatively new theme. It was not, generally featured in journals, conferences, workshops or research until the 1980s. Today, shifts in population demographics and the consequences of an aging population have shone new light on aging.
- In the 1930s the average life expectancy of people with ID was around 20 years. By 2002 it had risen (but remains lower than general life expectancy—5 years lower for those with a mild ID and 20 years lower for those with severe ID).
- Great gains have been made in the life expectancy of people with Intellectual Disabilities. The median age of death of a person with Down Syndrome (DS) in the USA was only 25 years in 1983. This almost doubled to 49 in 1997.



Life Expectancy (continued)

People with moderate to severe intellectual disabilities are 50 times more likely than the general population to die before the age of 50 years (with respiratory failure being the most recorded cause of death).

Life expectancy depends upon:

- The quality of the person's primary care
- Severity of intellectual disabilities
- Physical disability
- Epilepsy and other medical comorbidities
- Cerebral palsy
- Down Syndrome or other syndrome related biomedical factors



Factors affecting life expectancy of those with an ID

Increasing numbers of people with an ID, especially women, are living into old age. Demographically, women tend to live longer than men. Older people with an ID endure higher rates of illness than the general population and often experience health care “issues.”

- Regular screenings for diseases that could be prevented (i.e., mammograms, colonoscopy are not typically done)
- Health issues have an atypical presentation (few professionals are able to make accurate diagnoses)
- 77% of adults with an ID live in poverty
- 70% of adults with an ID do not have a friend or any family—only paid support
- 50% of people with an ID have related genetic condition, both physical and mental health
- 25–33% people with an ID report sexual abuse. Children with an ID are 5 times more likely to experience this abuse
- 40–50% of our homeless population have both mental health and unrecognized intellectual disabilities
- People with an ID have more than twice the medical conditions than the population



For discussion



- What are some negative stereotypes about people who are aging?
- What are some negative stereotypes about people with intellectual disabilities?



The Double Disadvantage

“Although as a society today we may seem to have moved forward towards being more caring and inclusive, there is still an underlying unconscious attitude, which excludes, isolates and ignores the needs of people with intellectual disabilities (ID), we know also that society marginalises older people, therefore to be an older person with a intellectual disability (ID) is a ***double disadvantage.***”

Noelle Blackman in *People with Learning Disabilities – An Ageing Population*
The Journal of Adult Protection (2007)



Two factors affecting health care

Defining the issues, they are:

- **Ageism** – prejudice or discrimination against a particular age-group and especially the elderly (negative stereotypes and discrimination)
- **Ableism** – discrimination or prejudice against individuals with disabilities (negative stereotypes and discrimination)

Together, **Ageism** and **Ableism** will affect the person's health care. This is known as the "**Double Disadvantage.**"



Key issues related to health care and aging

- People with intellectual disabilities have had an historic lack of involvement in their health care
- Carers lack knowledge of health issues for this population
- Information is often not available about the individual
- There is limited expertise and access to specialists in this area
- Negative stereotypes of people who are aged and have a disability
- Often more than one health issue is presenting at a time
- Cooperation and collaboration are often difficult



Diagnostic overshadowing

The presenting problem is assumed to be related to the person's intellectual disability.



Diagnostic Overshadowing

Example: Bill is seen in the ER by a doctor who does not know Bill. Bill is yelling and threatening and grinding his teeth. All of this behaviour is new for Bill. The doctor attributes this behaviour to his intellectual disability. But Bill has an impacted wisdom tooth.

The presenting problem is assumed to be related to the person's intellectual disability.

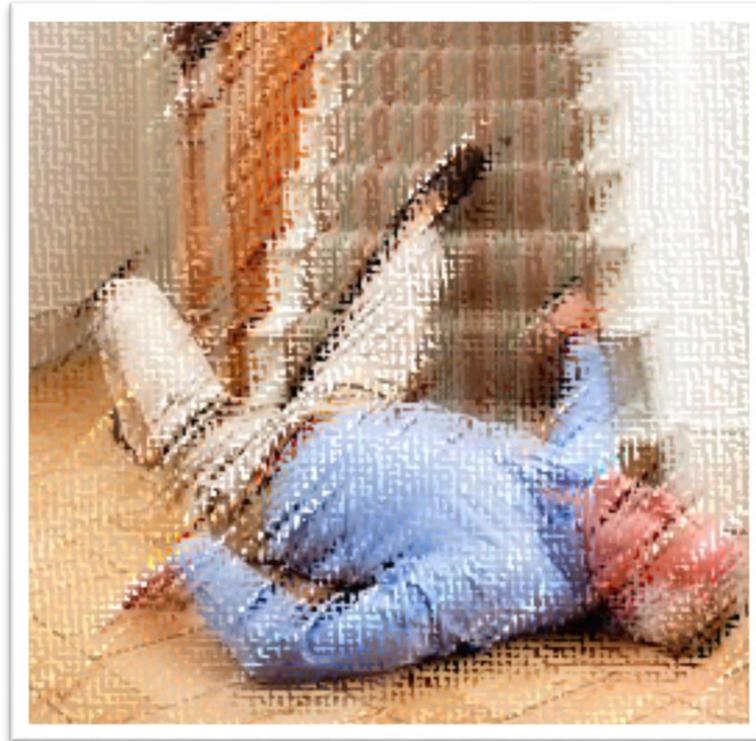
Example: 72-year-old Carl has experienced two witnessed falls in the last two months. He appears weak and confused. His family doctor tells his staff that the falls and confusion are likely due to old age. But blood tests reveal that his antiepileptic medication levels are very high.

The presenting problem is assumed to be related to the person's age.



Diagnostic overshadowing

The presenting problem is assumed to be related to the person's age.



For every complex problem there is an answer that is clear, simple and . . . wrong.

H.L. Mencken



Jumping to conclusions

Medical professionals were often quick to jump to conclusions based on attitudes about ageism and ableism. However, in the past, physicians were taught that way. All people are at risk when there is jumping to conclusions prematurely and excluding relative information. Issues can be around attitude, around approach to clients or around the presenting problem.

“There is no drive-thru approach.” – Dr. Kerry Boyd



Complicated Management



Responding to the health needs of aging individuals with ID requires collaboration and combined input from:

- the individual
- family members
- support persons
- medical providers
- non-medical providers
- allied health professionals



Complicated Management

A comprehensive approach to clinical assessment of those with ID requires **more thought and time** as the individual ages. Support persons often accompany a person with ID to appointments with health professionals. Support persons are an invaluable source of information and assistance especially when the individual they support has **difficulty in expressing their concerns and problems** to a health professional. Aged individuals with ID who present with changes in behaviour, function or both require a **comprehensive assessment**. Understanding the changes that you observe may be difficult because individuals often have **more than one issue affecting the change**. It is not uncommon for multiple care providers to have **differing opinions or ideas** about the cause of a person's problems. Aged individuals with ID are often **not able to fully explain their problems** in ways that are readily understood by others.

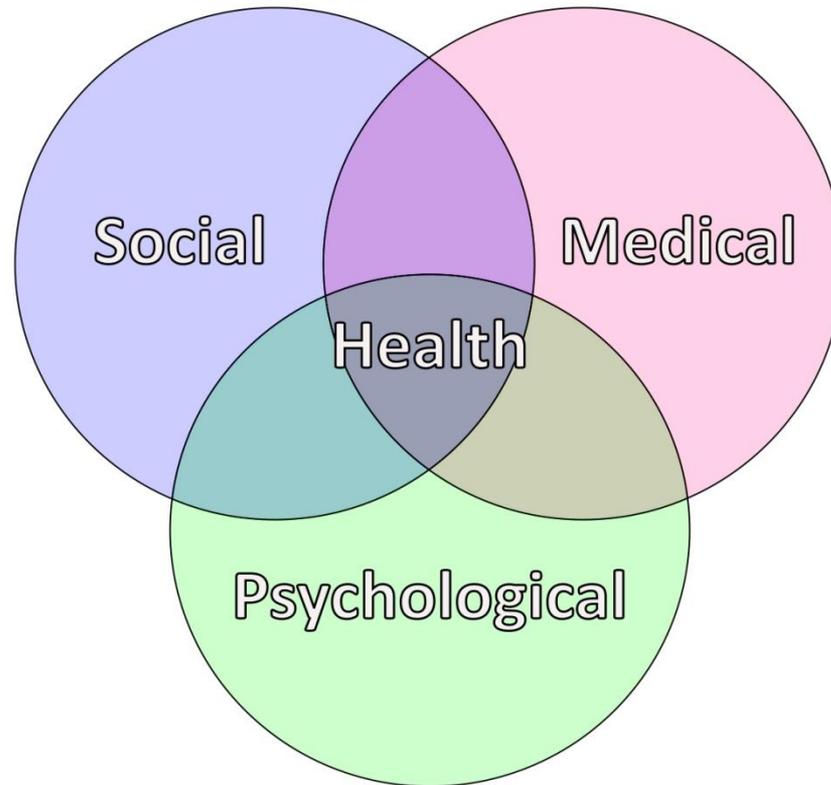
Unfortunately, illnesses that are identified in aged individuals with ID are often in **advanced stages**. It is essential to objectively identify the causes of the changes in behaviour and function so that the necessary solutions can be provided. This assessment process is often referred to as a **biopsychosocial assessment**. In this process we are looking at "just the facts." We are collecting relevant information about what you see (observational) and not making conclusions.

Tools to Help

- Cumulative Patient Profiles
- Essential Info for Emergency Department
- Today's Visit
- Caregiver Health Assessment



Biopsychosocial



Video — Dr. Yona Lunsky — “No Quick Fixes: Comprehensive Assessment” — CAMH

Explaining “Biopsychosocial”

- **Biomedical** means relating to, or involving biological, medical, psychiatric and physical science.
- **Psychological** means of relating to the mind or the study of the mind.
- **Social** means a tendency to form cooperative and interdependent relationships with others of one's kind. Here we need to consider family and other relationships. Environmentally, “fit” example could be too much sensory information or too much expectation for cognitive ability (e.g., talking to a person when visual cues will better meet the cognitive need).



BIO (medical)

- Cause of intellectual disabilities (e.g., brain injury or genetics)
- Medical – (e.g., endocrine/hormones, cardiac)
- Neurological – epilepsy, stroke
- Physical (e.g., cerebral palsy) and age-related changes (e.g., arthritis, dementia)
- Psychiatric – depression and PTSD
- Substances – drug and alcohol, prescription and non-prescription
- Side effects – too many medications
- Medication side effects



PSYCHO (logical)

- Intellectual Profile (i.e., cognitive strengths and weaknesses—Is there a fit between ability and expectations?)
- Coping skills
- Emotional responses / regulations
- Speech language capabilities
- Attitudes / beliefs
- Personality
- Learning abilities / strength
- Resiliency



SOCIAL

- Social (family and relationships)
- Resiliency
- Environmental (cognitive fit, stimulation and routines)
- Residential
- Programmatic
- Supports



Video — “Supporting Derek: Intellectual Disabilities and Dementia”



Preparation for Doctor and ER Visits

- It is important to optimize the doctor's time
- Complete the appropriate tool "Today's Visit" for each visit to the doctor (see "Tools" section)
- Ensure regular health care screens are completed (i.e., colonoscopy, mammogram)

SECTION I: Tools for General Issues in Primary Care

TODAY'S VISIT	
<p>Main Reason for Today's Visit to the Physician or Nurse (To be filled out by the Patient with DD and Caregiver)</p> <ul style="list-style-type: none"> • Please bring an updated form for each visit to the physician's office. • Bring an updated medication list, or all medications being taken. • Bring any monitoring forms being used (i.e., sleep or bowel/visit charts). • Keep a copy of this completed form for the patient's home medical files. 	<p>Name: _____ Gender: _____ (last, first)</p> <p>Address: _____</p> <p>Tel. No: _____</p> <p>DOB (dd/mm/yyyy): _____</p> <p>Health Card Number: _____</p> <p>Date of Visit: _____</p>
Up-to-date Medication List attached? <input type="checkbox"/>	
<p>What is the main health problem the patient with DD or caregivers are concerned about? When did it start? List any new symptoms. List possible contributing factors.</p>	
<p>Circle or list other needs – e.g., prescription renewals, test results, forms to be filled out, appointment for annual exam</p>	
<p>Any Recent Changes or Stressors? <input type="checkbox"/> No <input type="checkbox"/> Yes: _____ (e.g., staff changes, family illness or stress, changes in living or social environment)</p>	
<p>Any recent visit to the dentist or other doctor? <input type="checkbox"/> No <input type="checkbox"/> Yes: _____</p>	
<p>Any recent medication changes or additions? <input type="checkbox"/> No <input type="checkbox"/> Yes: _____ (include antibiotics, creams or herbal medicines)</p>	
<p>Caregiver Needs – Write down or tell doctor or nurse whether there are issues regarding caregiver fatigue or burnout</p>	
Name/Position:	Contact #: Signature:
<p>PHYSICIAN / NURSE TO COMPLETE, KEEP COPY FOR CHART, AND GIVE COPY TO THE PATIENT / CAREGIVER</p>	
<p>Assessment:</p> <p>Treatment Plan including Medication Changes:</p> <p>Advice to Patient and Caregivers:</p>	
Next Planned Visit / Follow-Up: _____ MD / RN Signature: _____	

© 2011 Sunny Place Centre



Video — Dr. Yona Lunsky – "Use of ER services by people with Developmental Disabilities" – CAMH



Case study

Read the
case study
about Don



A Case Study: Don

You can read about Don in the PDF file and discern different factors under the three categories of the “Biopsychosocial Model.”

Biomedical	Psychological	Social
-	-	-
-	-	-
-	-	-
-	-	-
-	-	-
-	-	-
-	-	-





Vision

Vision Concerns

Like most physical problems, the individual may not be able to verbalize accurately that they are experiencing vision problems. With age, it becomes difficult to tell colours apart, especially greens and blues. This happens because the lens of the eye becomes yellow and less flexible. It becomes harder for the eyes to adjust to changes in light. Older people may have to take time to adjust to the light in a room after coming in from outside. It is also difficult to adjust to sunlight after being inside because of glare. If there isn't enough light, it is very easy for an older person to trip over or run into things they cannot see. Sometimes, older people can't see things as sharply as they once could. It is sometimes difficult for older people to judge distances. Older persons may not recognize objects until they are quite close to them. They may not have enough time to move out of the way before they trip over the object or run into it. People with an ID experience a much higher prevalence of visual impairments and eye disorders than do the general population. Some studies have found that 50% of people with an ID have unrecognized or inadequately managed visual or hearing impairments and may have both.



Changes

- Changes in lens, pupil size, depth perception
- Loss of acuity of vision
- Decreased light transmission
- Changes in colour perception, especially blues, green and violets
- Decreased visual field
- Increased risk of eye disease
- Adults with Down Syndrome may be at a higher risk for eye disease (e.g., keratoconus) and may be at risk earlier
- Older adults with diabetes are at increased risk for diabetic retinopathy (i.e., damage to the retina leading to blindness)
- Dry eyes



Watch for

- Sitting closer to the TV
- Holding objects closer to their eyes
- Not recognizing people, signs
- Self Injurious Behaviour (SIB; e.g., poking at eyes)
- Rubbing eyes, squinting
- Isolating, withdrawing
- Hesitancy when walking
- Clumsiness, bumping into things, tripping
- Not participating in activities that require good vision
- Loss of ability to read, refusing to read



Support

- Schedule regular eye examinations
- Ensure adequate lighting
- Reduce environmental glare
- Provide contrast
- Blurred vision is a common side effect of many meds
- Organize belongings
- Keep environments consistent
- Ensure proper eyeglass wear and care



Hearing



Hearing Concerns

Changes in hearing can cause difficulty for older people. Talking may sound muffled because it is more difficult to hear high-pitched, consonant sounds like th, sh, s, f, and p, to name a few. Vowel sounds (a,e,i,o,u) are low-pitched sounds, so they are easier to hear. This type of hearing loss makes it difficult to hear in noisy places (such as in a restaurant or a mall), to use a telephone or watch television with others because the volume may be too high for people who can hear normally.

Shouting at a person who is hearing-impaired only makes problems worse. Shouting raises the pitch of your voice, which makes it even harder to hear what you are saying.



Changes

- Harder to hear high-pitched sounds
- Tinnitus (ring in the ears)
- Increased wax (cerumen) buildup (people with Down Syndrome have narrower ear canals that can become easily blocked)
- Decreased tone discrimination



Watch for . . .

- Speaking louder than usual
- Turning up the volume on radio / TV
- Inappropriate responses to questions
- Confusion or agitation in noisy environments
- Isolation and withdrawal
- May look apathetic, depressed
- Self Injurious Behaviour (SIB) – slapping head or inserting objects in ears



Support

- Schedule regular hearing examinations
- Encourage use of hearing aids if indicated and tolerated
- Use visual aids if necessary
- Use visual images
- Make communications brief and clear at a normal rate
- Make sure your face can be seen
- Reduce background noise and distractions (e.g., TV)
- Repeat communications by others





Sleep

Sleeping Concerns

Aging is associated with changes in sleep amount, sleep quality, and specific sleep pathologies and disorders. For instance, increased age is associated with increased prevalence of insomnia complaints, daytime sleepiness, Sleep-Disordered Breathing (SDB), Restless Legs Syndrome (RLS), and Periodic Limb Movement Disorder (PLMD) . Insomnia alone affects about a third of the older population in the United States. Nocturnal sleep difficulties can result in excessive daytime sleepiness, attention and memory problems, depressed mood and lowered quality of life. Evidence also suggests that SDB has been associated with dementia and cognitive deficits in the elderly.

Other factors associated with aging, including medical and psychiatric disorders, changes in environment, and psychosocial stressors such as bereavement, can also be independent contributors to sleep problems. According to Dr. Jean Duffy of Harvard Medical School, Division of Sleep Medicine, the most common causes of sleep disruption in older adults is medication, medical conditions that have accompanying pain (i.e., arthritis as well as respiratory problems and heartburn and acid reflux.



Changes

- Decreased sound sleep
- More likely to wake during the night
- Sleep apnea. Increased incidence with Intellectual Disability in general and specifically in Down Syndrome (DS; small upper airway, large tongue, poor muscle tone, overweight)
- Symptoms of sleep apnea include: excessive day time sleeping, behaviour issues, declining skills, disruptive sleep patterns, depression, snoring and breathing irregularities while sleeping, irritability, headache
- Medication effects



Watch for . . .

- Day-time napping
- Declining skills
- Decreased attention
- Irritability
- Depression
- Headache
- Snoring and breathing irregularities while sleeping



Support

- Sleep hygiene (i.e. night time routines) such as: avoid stimulating activities before bedtime and promote calm and relaxation prior to bedtime (e.g., dim lighting, quiet music) and no vigorous activity after 2 pm
- Reduce use of caffeine after lunch hour and no caffeine after 2 pm
- Restrict fluids before bedtime
- Establish a regular time for going to bed and waking
- Avoid spicy foods before bedtime
- Encourage regular exercise
- Schedule a health review



Age-Related Effects

- Decreased renal (kidney) clearance of drugs
- Decreased hepatic (liver) blood flow and drug clearance
- Basically speaking, older people have a harder time eliminating medications from their system.
- Weight loss
- An increase in medical conditions may lead to multiple medications, medication interactions and problems with monitoring and evaluating medication. The more medication a person takes (and the higher the dosage) the more potential there is for serious side effects.



Age-Related Effects (continued)

- People with intellectual disabilities seldom complain about side effects verbally. May not be told in a way that they can understand about potential side effects.
- Support persons often do not know about side effect monitoring.
- Older people become more sensitive to the neurological effects of medication.
- Narrow therapeutic index – the difference between a helpful and harmful dose is small.
- Historic overuse of psychotropic medication for people with ID.

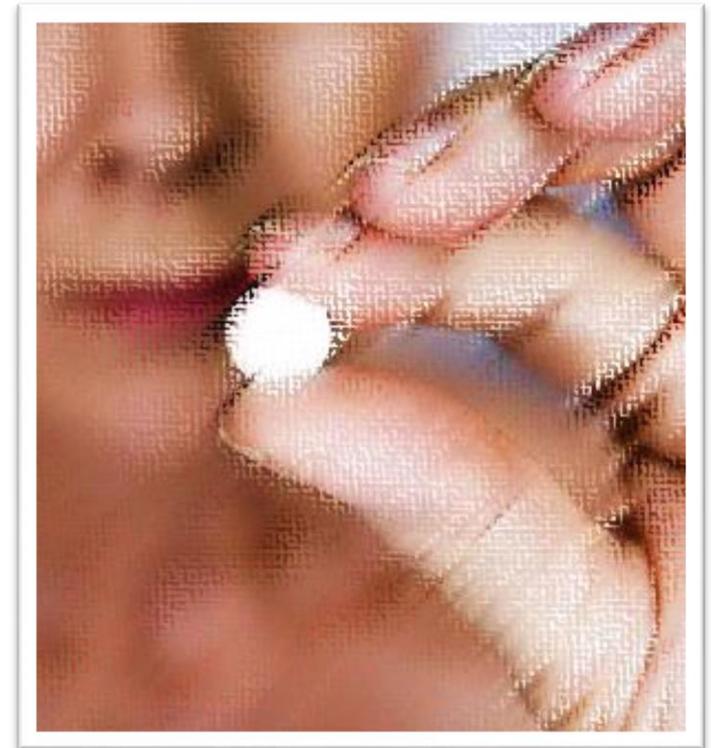


Risk Factors

- Individuals with intellectual disabilities that are taking medications no idea what they are taking or why they are taking it
- Support staff who administer medications report a lack of knowledge about medications, side effects and monitoring practices
- Therapeutic dose calculations are often based on trials of young, healthy adults



In too many instances, individuals with intellectual disabilities who were taking psychotropic medication, and their support staff who were giving it, did not know the historical reasons for the prescription or what it was meant to treat.



Support

- Ensuring that all medications are reviewed at each medical appointment and that all doctors are aware of medications being used. Its always a good idea to let the pharmacist review.
- Have knowledge of the medications that are given and the potential for side effects. Have a plan in place to monitor for side effects.
- Promote lowest effective doses of medication on initiation—
“start low—go slow.”
- Discourage use of medication unless it is needed.
- Medication reviews are recommended every year for people over the age of 75 and every six months for people taking more than 4 medications.
- Discontinuation or reduction of medications that are no longer needed.
- Careful monitoring of psychotropic medications and pain medication



**Complications from medication use
in the elderly account for
20% of hospital admissions.**



Medications

This statistic is suspected to be much higher in persons with ID.
According to Dr. Tom Cheetham's advice, "Check the medications FIRST"

Too often the response to medication side effects is to add another medication: e.g., a person develops a tremor from a low-dose antipsychotic and is prescribed an antiparkinson medication. Antiparkinson medication is poorly tolerated by elderly people because of it has anticholinergic side effects that may cause blurred vision, urinary retention, constipation, cognitive impairment, confusion, drowsiness.

A Resource

Ten Medications Older Adults Should Avoid or Use with Caution



Constipation

Constipation

Bowel motility (the way stool moves through the digestive system) tends to be diminished in the aging process. Chronic constipation occurs in 50% to 85% of older people with ID. It is a more common problem with people who are, or become non-ambulant. Severe constipation can result in serious behaviour and physical problems. In some cases, it can lead to death—usually from obstruction. Constipation prevention warrants vigorous attention.

A significant number of individuals with ID are taking one or more medications on a routine basis to promote regularity but few are monitored for fluid and fibre intake—two important factors for regularity. Add to this that it is often difficult to find individuals who get regular physical exercise—another important factor in regularity. You can see why constipation is such a big problem in this population.



Changes



- Decreased physical activity
- Increased medication use
- Decreased bowel motility
- Decreased gastric emptying
- Problems with chewing
- Decreased production of saliva (saliva is important for digestion)



Risk Factors

- Poor food and fluid intake (lack of dietary fibre is common)
- Lack of regular exercise
- Motility issues, especially those with significant mobility impairments
- Severe intellectual disabilities
- Psychotropic medication use
- Toileting habits
- Weakness



Support

- Ensure adequate fluid intake especially for individuals who do not access their own fluids (8 cups or 2000 cc/ml per day)
- Regular, safe exercise
- Medication reviews
- Specialist consults especially if constipation is chronic.
- Regular toileting schedule (individualized)
- Routine monitoring for regularity (poop chart).
- Careful attention to medications for constipation





Oral Health

Oral Health

People with ID are at a considerable risk of developing dental disease. Thinking about such individuals that you support over the age of 50, how many of these individuals have a complete, healthy set of teeth?

Poor oral health increases the risk of aspiration pneumonia, complicates the management of diabetes and is a risk factor for heart disease. Nutritional status is greatly affected by oral status.



Changes

- Reduction in tooth enamel
- Decreased saliva (many medications cause dry mouth)
- Dental disease (cavities and abscesses)
- Gum disease
- Loss of teeth
- Sores (especially with dentures)
- Dental erosion—This is common in individuals with GERD (Gastro Esophageal Reflux Disease) is caused by stomach acid in the oral cavity. Identifying and treating GERD is important to prevent this problem.



Risk Factors

- Dental care assisted or provided by support person, as needed. The quality of care varies from one person to another.
- Address resistance to dental care and examination
- Tooth extraction vs. tooth restoration
- Teeth grinding (bruxism)
- Increased risk of GERD with advancing age
- Medications that dry out the mouth
- Nutritional deficits
- Beware of abscessed tooth!



Malocclusion

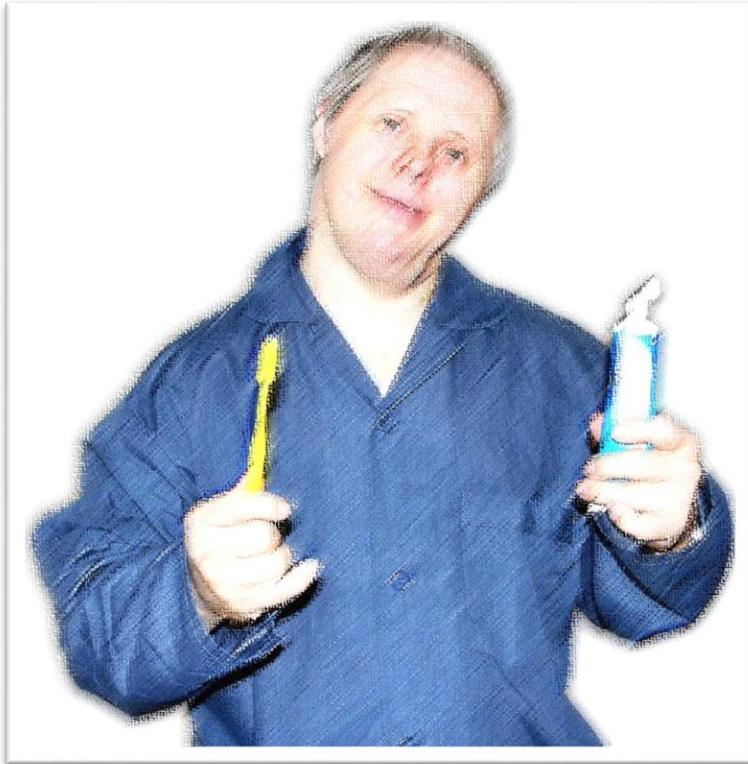


Malocclusion

Malocclusion means the teeth will not line up and grinding is effected. This is very common in persons with Down Syndrome and Cerebral Palsy.



Support



- Daily brushing and oral care (may include oral rinsing and flossing)
- Regular dental examinations
- Reduce number of sweets (sweetened cereals, candy, sugary drinks)
- Medication review (reduce or discontinue unnecessary medications)



A young girl with dark hair, wearing a white lab coat, is examining the arm of an elderly woman with white hair, also wearing a white lab coat. The girl is looking down at the woman's arm, which is resting on a surface. The woman is looking towards the girl. The background is a plain, light-colored surface.

Muscles and Bones

Muscles and Bones

The skeleton provides support and structure to the body. Joints are the areas where bones come together. They allow the skeleton to be flexible for movement. In a joint, bones do not directly contact each other. Instead, they are cushioned by cartilage in the joint, by synovial membranes around the joint and by fluid.

Muscles provide the force and strength to move the body. Coordination is directed by the brain but is affected by changes in the muscles and joints.

Changes in the muscles, joints, and bones affect the posture and gait, and lead to weakness and slowed movement.



Age-Related Changes

- Aged persons may be at risk for falls. Factors contributing to this include lack of regular exercise, pre-existing genetic or medical conditions (e.g., CP, vision loss, balance issues, hazardous environments like stairs, slippery surfaces, balance issues)
- Muscle mass decreases and muscles lose their strength and endurance
- Increase risk of joint problems
- Decreased heart rate
- Loss of elasticity in blood vessels with build up of fat (cholesterol in the artery walls)
- Bones become more brittle and may break more easily
- Overall height decreases, mainly because of shortening of the trunk and spine
- Movement slows and may become limited



Joint Problems

- Joint problems can happen to anyone with advanced age and will cause pain and interfere with functioning
- The risk factors for arthritis are increased with age, obesity and previous joint damage

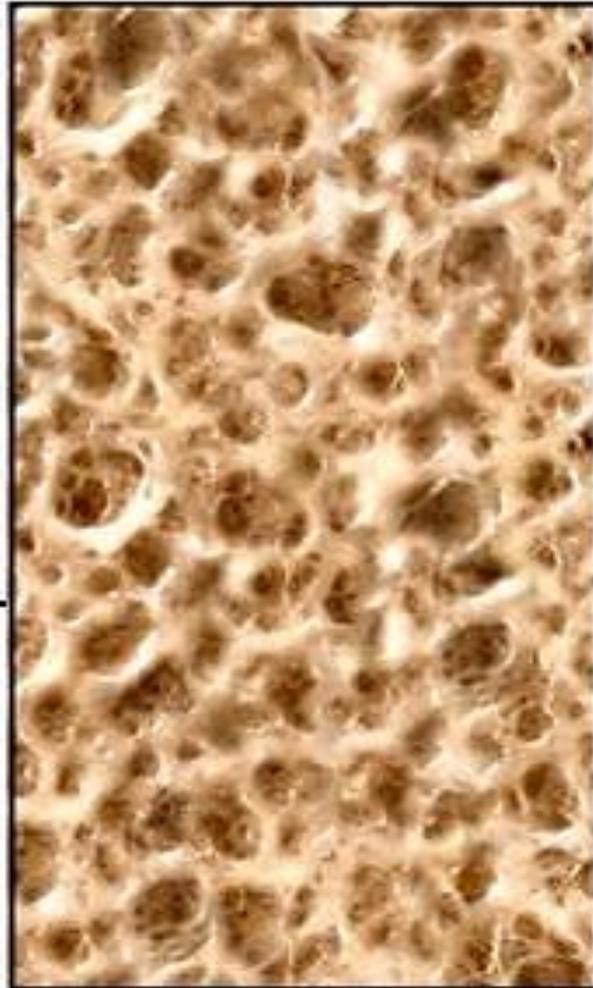
It is important to:

- Obtain specialist consultation
- Encouraging independence and activity if tolerated

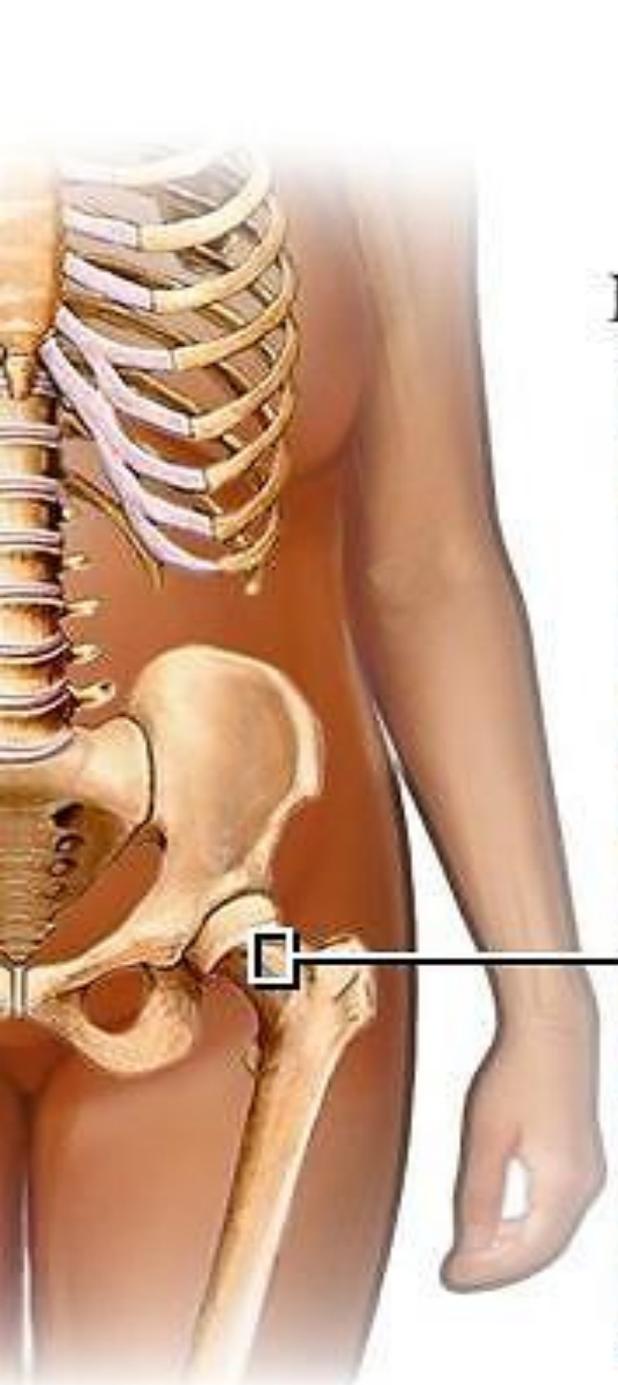
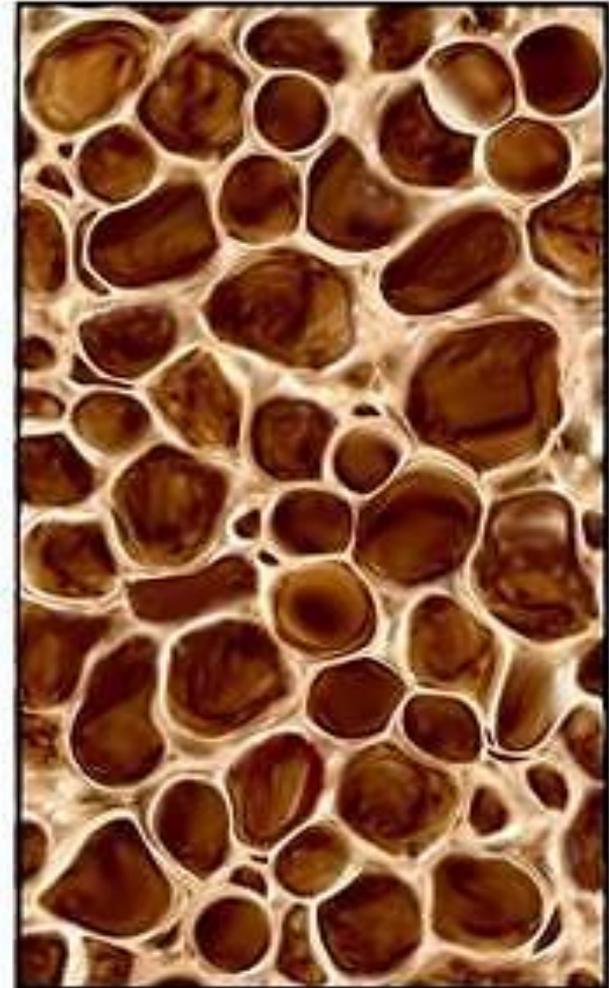


Osteoporosis

Normal bone matrix



Osteoporosis



Osteoporosis

Osteoporosis is a bone disease in which the bones become very porous, break easily and heal slowly. It is especially common in women of menopause age.



Risk Factors

- Bones become more porous and easier to break
- Women are at a much greater risk because of the loss of estrogen that occurs after menopause
- Nutritional deficits, limited muscle activity and certain medication usage can place people with intellectual disability at risk for osteoporosis
- A combination of impaired mobility and osteoporosis increases the risk of falls and fractures
- This can be further compounded by medication, certain medical neurological and age-related changes (i.e., vision impairment or social-environmental factors like loose rugs or stairs)



Support



- Obtain appropriate health care
- Implement safeguards to prevent falls while encouraging suitable levels of independence
- Promote regular individualized exercise, as prescribed (weight bearing if possible)
- Occupational therapy and physiotherapy assessment for safety and mobility aides



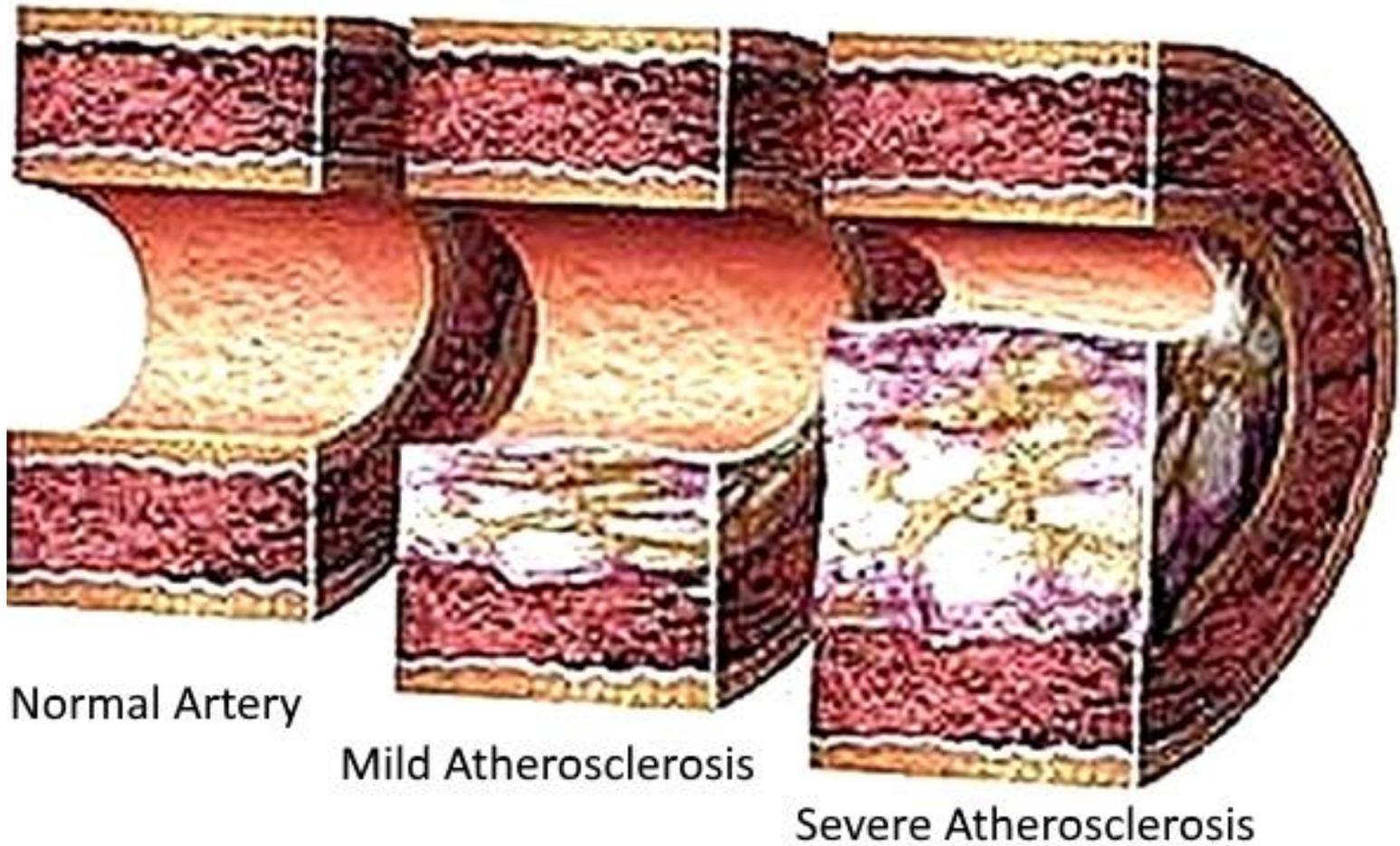


Circulation

Risk Factors

- Advanced age
- Family history
- Lack of exercise
- Smoking
- Obesity
- High salt intake (high levels of sodium often found in prepared foods)
- Excessive pressure from blood pressure on artery walls can lead to heart attack and stroke
- Adults with ID living in community based settings have the highest risk of developing cardiovascular disease of all adults with ID (30-60% of people with Down Syndrome have heart problems)
- Loss of elasticity in blood vessels with build up of fat (cholesterol or the artery wall)





Support

- Undertake activities at appropriate pace for individual
- Watch for signs of fatigue, dizziness, decreased endurance
- Allow enough time between position changes
- Avoid heavy lifting and exertion
- Regular exercise geared towards the individual's capability
- Reduction or cessation of smoking
- Healthy eating (low sodium diets and decrease fatty foods)
- Adequate calcium amounts
- Postmenopausal women/men over 65 benefit from 1,200mg of calcium and 400 – 800 international units of vitamin D per day
- Women need vitamin D as they age
- Regular tolerable exercise



Psychiatric



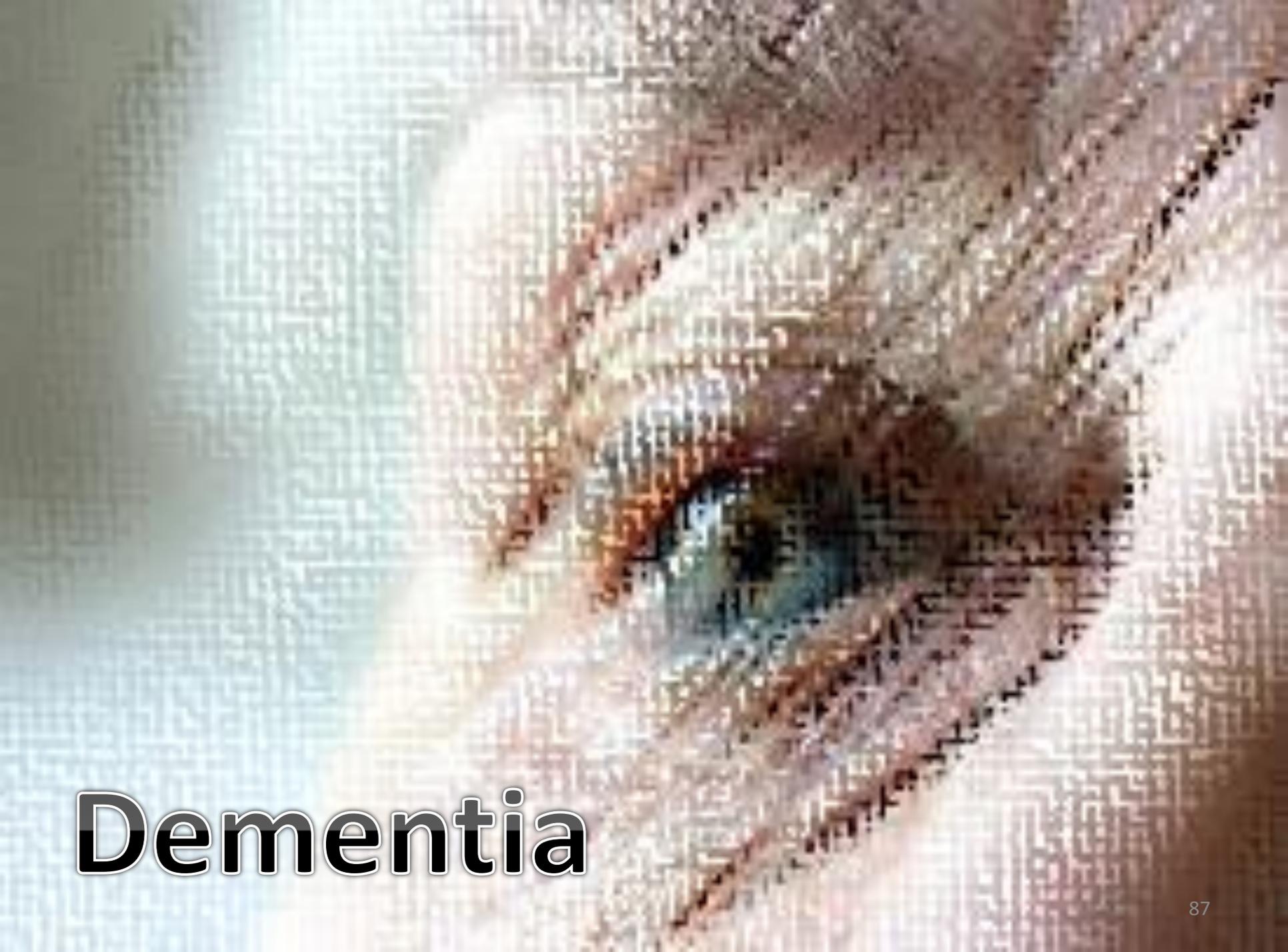
Psychiatric Conditions

The major psychiatric conditions to be considered in older people with ID are **Delirium**, **Depression** and **Dementia** (3 D's). People with intellectual disabilities can experience bio/psycho/social stressor or psychiatric condition shared by the general population. **Delirium** is a syndrome, or group of symptoms, caused by a disturbance in the normal functioning of the brain. Delirium is noted by sudden or acute changes in behaviours. The delirious patient has a reduced awareness of and responsiveness to the environment, which may be manifested as disorientation, incoherence, and memory disturbance. Delirium is often marked by hallucinations, delusions, and a dream-like state.

Delirium affects at least one in 10 hospitalized patients, and is a common part of many terminal illnesses. Delirium is more common in the elderly than in the general population. While it is not a specific disease itself, patients with delirium usually fare worse than those with the same illness who do not have delirium.

It is very important to rule out depression and delirium before assuming it is a dementia. The person may have one, two or all three of the 3 D's.





Dementia

Dementia

- The inability to think clearly
- The inability to think rationally
- The inability to think logically
- The inability to reason
- Dementia is a set of symptoms not a disease in itself
- Dementia can be either reversible or irreversible



**Not a disease . . . but a set of symptoms
that accompanies a disease**

Alzheimer's Disease

Mixed Dementia

Lewy Body Disease

Vascular Dementia

Frontotemporal Dementia

Under the Umbrella

Dementia is not a disease in itself. It is an “umbrella” or categorical term that describes a group of symptoms and is not the name of a specific disease. Dementia can be reversible or irreversible. It is estimated that there are between 90 and 100 types of diseases that can cause dementia.

Compare the word “Automobile” to the word “Dementia.” There are a lot of different automobiles . . . a lot of things make them similar but each automobile is unique in it’s own way. Dementia—all the dementias—look the same at the end of the disease process but there may be a lot of differences or symptoms of the various dementias early in the disease process. Treatment plans and medications can be different depending on which dementia the individual has.

This is not an exhaustive list of all the disease under the umbrella of dementia.



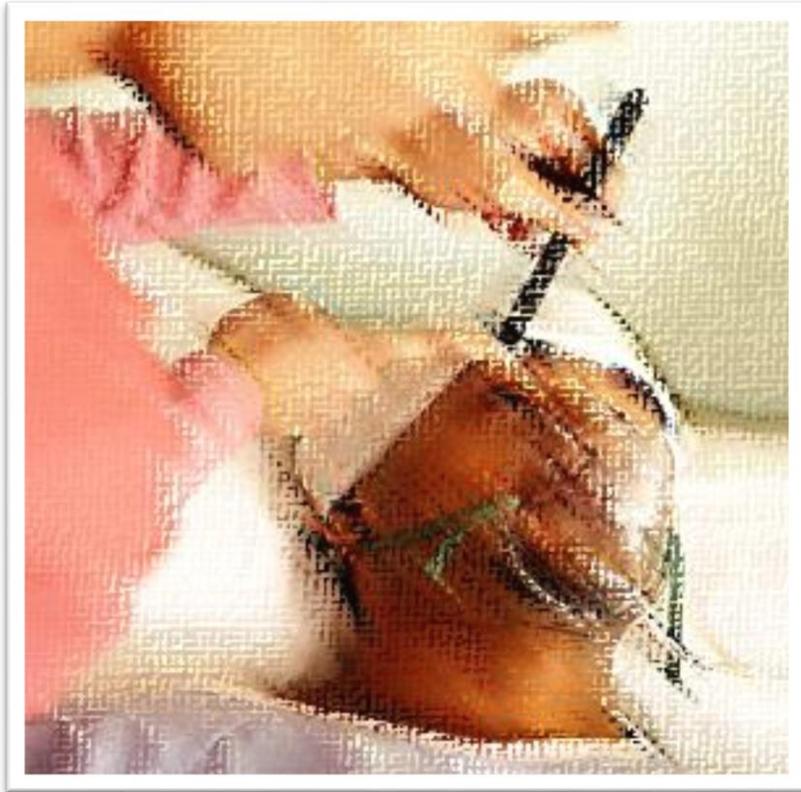
Reversible Dementias



- Depression
- Delirium
- Drugs
- Nutritional Disorders
- Metabolic Disorder
- Infection (UTI, urinary tract infections)



Irreversible Dementias



- Progressive disorders
- Vascular dementia
- Subcortical dementia
- Head trauma
- Infectious diseases



Alzheimer's disease is . . .

PROGRESSIVE:

damage from the disease increases over time

DEGENERATIVE:

brain cells degenerate or break down

IRREVERSIBLE:

damage cannot to be repaired;
at present there is no known cure



Alzheimer's Disease

Alzheimer's disease is the most common form of irreversible dementia accounting for about 64% of cases. It has a gradual onset and progression. Alzheimer's disease is a progressive, degenerative disease of the brain that leads to a loss of mental functioning that affects day-to-day activities.

Although the onset is gradual, Alzheimer's disease eventually affects all aspects of a person's life including mental abilities, emotions and moods, behaviour, and the ability to carry out daily activities like eating and grooming. Symptoms can include memory loss that affects day-to-day functioning, difficulty performing familiar tasks, problems with language, disorientation of time and place, poor or decreased judgement, problem with abstract thinking and misplacing things.

Several changes occur in the brain. Dense irregularly-shaped spots ("plaques") appear outside of brain cells and thread-like "tangles" develop inside brain cells, both affecting brain cell functioning.



Genetics

Two forms of Alzheimer disease

Sporadic (90-95% of cases)

- Late onset
- Gene variant called ApoE4 increases the risk of developing AD (chromosome 19)

Familial (5-10% of cases)

- Symptoms begin in 40s and 50s
- Gene mutations on chromosome 1, 14, 21

Genetics

Scientists have identified two kinds of genes that are associated with the genetic risk factor. The first is thought to be a “risk gene,” ApoE 4, that increases the likelihood of developing Alzheimer’s, but does not guarantee it. ApoE4 is one of the three variants of the apoE gene, the others being the benign apoE2 and apoE3 genes. If a person's pair of apoE genes include one apoE4, they have three times the normal risk of developing Alzheimer's disease, but if they carry two apoE4 genes the risk increases to ten times. It is important to note, however, that people with no apoE4 genes can still develop Alzheimer's disease, and people with two apoE4 genes may not.

In addition to ApoE 4, scientists think there could be up to a dozen more risk genes yet to be discovered. How these genes interact or may be triggered by environmental risk factors is also important. Even in the sporadic form of Alzheimer’s disease having a close relative (a parent or sibling) with the disease does increase the chances of a person developing Alzheimer’s disease by a small percentage.

The second kind of gene is a “deterministic gene” and is much rarer than risk genes. Deterministic genes are only found in a few hundred extended families around the world. If a deterministic gene is inherited, the person will undoubtedly develop Alzheimer’s, probably at a much earlier age. Persons with Down Syndrome have one such mutated gene.

The more common form of Alzheimer's disease is called Sporadic Alzheimer’s disease and accounts for 90 to 95% of all cases. Persons with this type may have what is called a high risk gene.



Risk Factors for Alzheimer's Disease

- Age
- Sex (female)
- High blood pressure
- Diabetes
- Brain / Head injury
- Late onset depression
- Smoking
- Poor eating habits
- Lack of exercise
- Decreased socialization
- Low education
- Genetics (Sporadic and Familial Alzheimer's disease)
- Down Syndrome (Familial Alzheimer's disease)



Video — "Inside the Brain: Unraveling the Mystery of Alzheimer's"



Risk Factors for Alzheimer's Disease

Risk Factors are factors that appear to be linked to the development of a disease. If a risk factor is present, there is an increased chance but not a certainty that the disease will develop. Also, those without any risk factors may develop the disease.

Age – The older a person is, the higher the risk for Alzheimer's disease.

- 1 in 11 Canadians over age 65 and
- 1 in 3 Canadians over age 85 have Alzheimer's disease

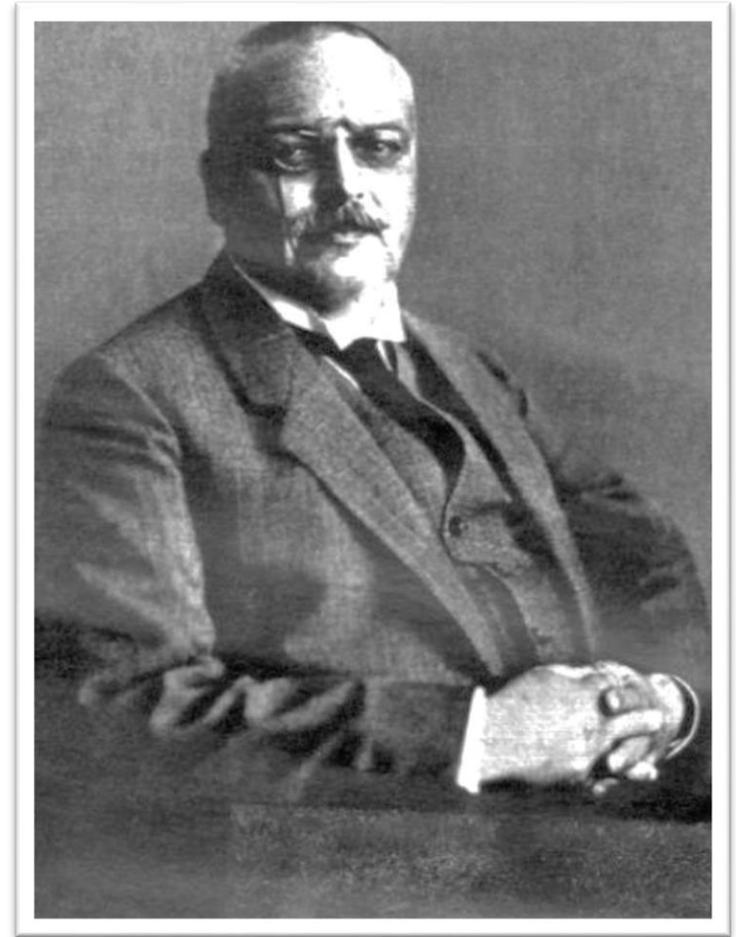
Family History – A person with a family history of Alzheimer's disease has a higher risk of developing the Disease than someone without a family history.

A rare form of the disease, **Familial Autosomal Dominant** (FAD) Alzheimer's disease, accounts for approximately 5 to 10% of all cases and is known to be inherited—the disease will occur if the gene is present. This form of Alzheimer's disease is usually associated with an early onset (before the age of 65).



Dr. Alois Alzheimer

In the period 1901 to 1906, Dr. Alois Alzheimer treated a 51-year old woman with dementia symptoms. Upon her death he autopsied her brain and discovered the relationship of physical damage to the brain (plaques and tangles) to the symptoms of dementia.

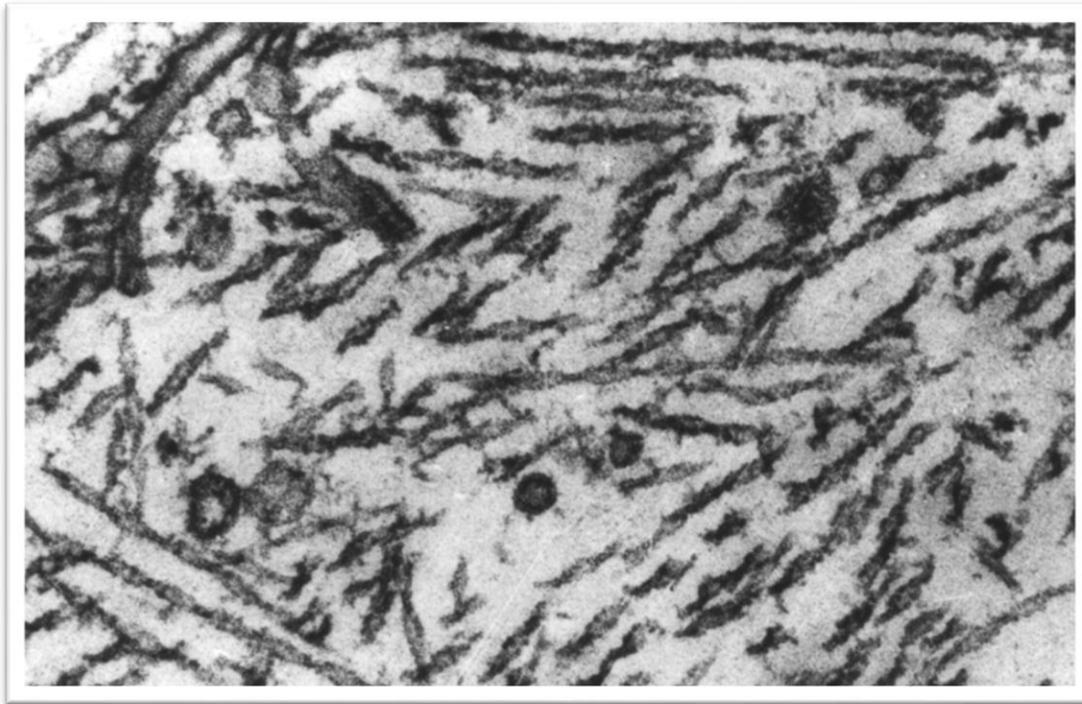


Origins of Alzheimer's Research

The German physician Alois Alzheimer, a pioneer in linking symptoms to microscopic brain changes, describes the haunting case of Auguste D., a patient who had (1) profound memory loss, (2) unfounded suspicions about her family, and (3) other worsening psychological changes. In her brain at autopsy, Dr. Alzheimer saw dramatic shrinkage and abnormal deposits in and around nerve cells. The pathological changes Dr. Alzheimer identified are **Amyloid Plaques** and **Neurofibrillary Tangles**.



Neurofibrillary Tangles



Neurofibrillary Tangles

Inside cells damaged by Alzheimer's Disease are twisted filaments or strands of fibres, called neurofibrillary tangles, one of two hallmarks of Alzheimer's Disease.

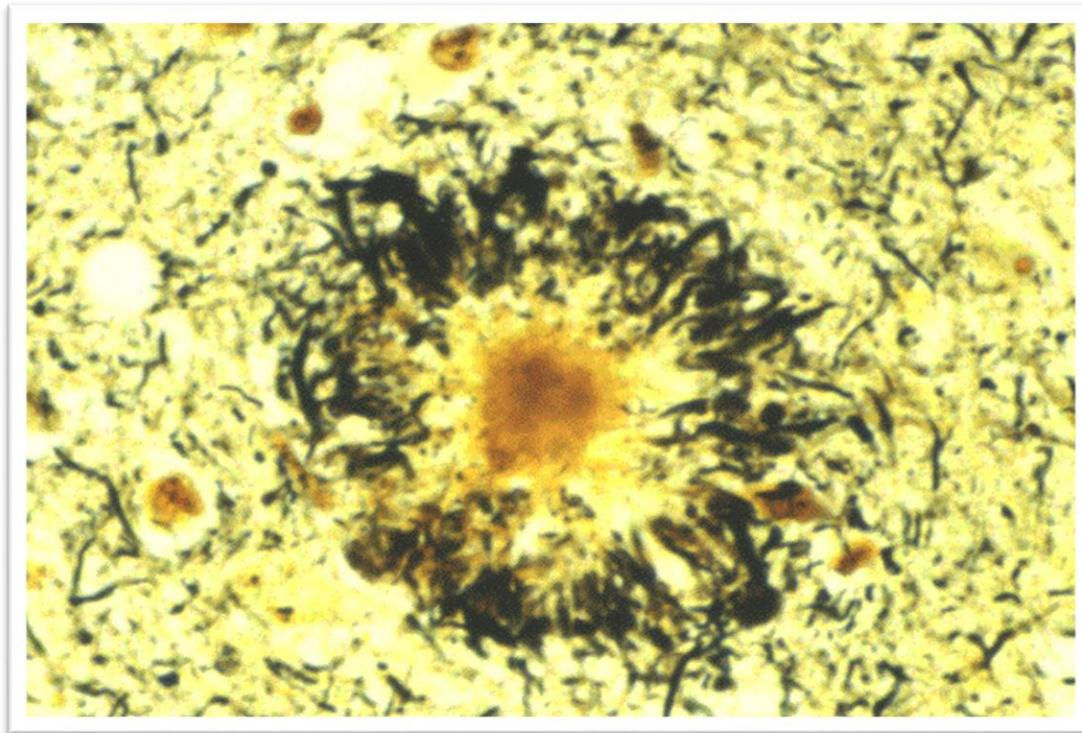
The structure that holds the cell together can be pictured as railway tracks with crosspieces formed of protein. The tau protein that normally forms the crosspieces twists into what are called paired helical filaments, like two threads wound around each other. This is the basic formation of neurofibrillary tangles. Without the protein crosspieces the cell loses its structure leading to cell death.

This slide shows paired helical filaments inside of a neuron as seen through electronic microscope.

As cells die, they lose the ability to communicate and the brain shrinks in size.



Amyloid Plaque



Amyloid Plaque

On the previous slide, amyloid plaque is the brown spot in centre surrounded by cells that have died.

Amyloid plaque is the second hallmark feature of Alzheimer Disease. Beta amyloid protein builds up in the brain and forms what are called “amyloid plaques” outside the brain cells. It isn’t yet known whether this is a cause or an effect of Alzheimer’s Disease. Regardless, this protein plaque causes surrounding neurons to die.





Normal Brain



A brain affected by
Alzheimer's disease

Comparison of Brains

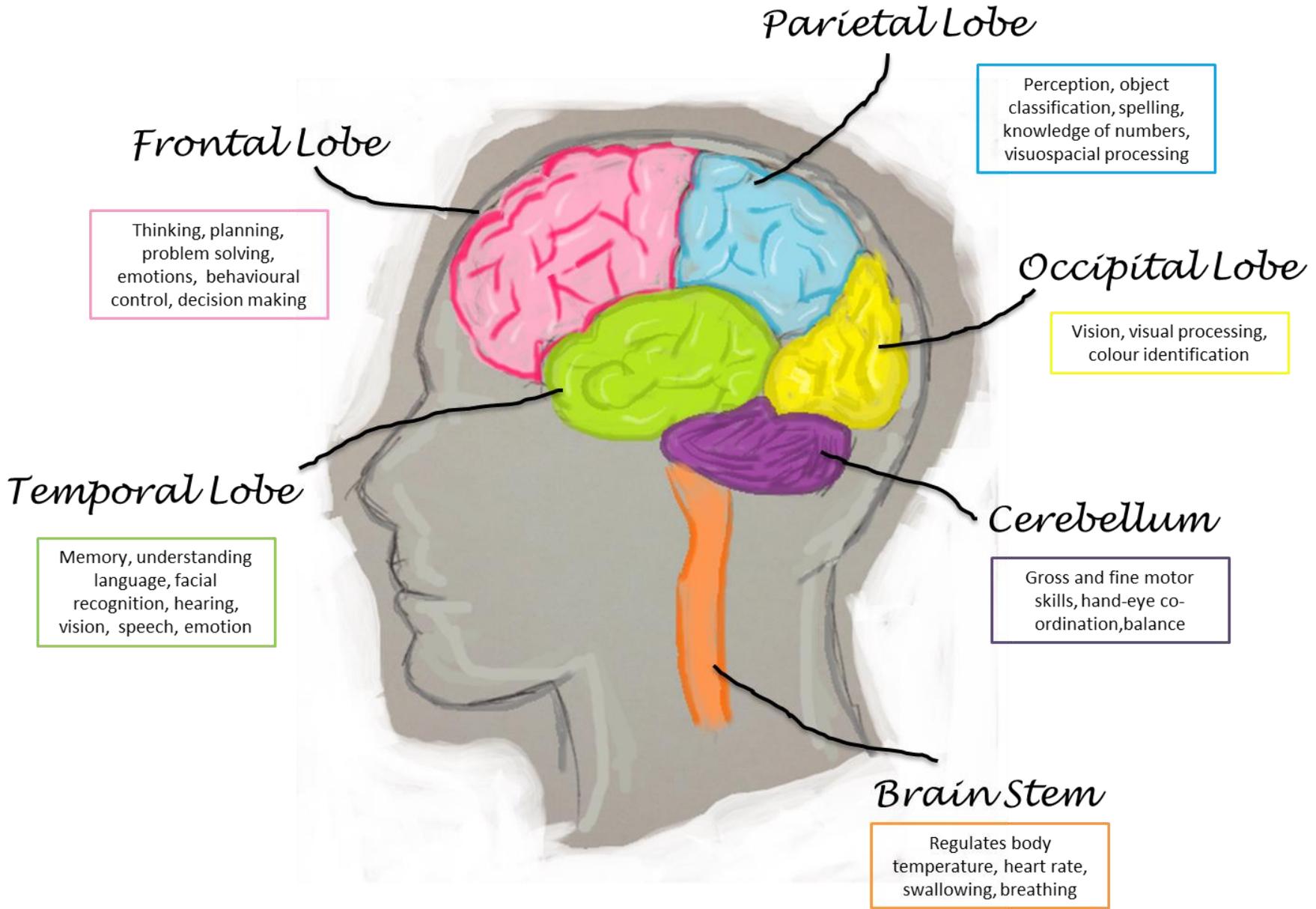
The brain is an organ weighing 3 to 3½ lbs (1.5 kilo) 2½ per cent of the body's weight. It needs 15% of the blood and 25% of the oxygen available to the body. The brain is where the illness originates—that is, where the degeneration of cells occurs. Notice the difference between the two brains in the previous slide. An Alzheimer's Disease brain can weigh as little as a pound. Consider the difference between 3 pounds of butter versus 1 of butter.

As the disease progresses, the brain shrinks, affecting brain functioning. As seen on this slide, there are physical differences between a brain that is healthy and a brain affected by Alzheimer's disease.

The brain on the right is from a 70-year old person who died of Alzheimer's disease. We see it is smaller than the healthy brain on the left.

Note that the brain damaged by Alzheimer's disease has large gaps between the folds of the brain, caused by shrinkage. As the brain shrinks it loses its ability to function properly.





Alzheimer's Disease and Down Syndrome

- Related by Chromosome 21
- Studies have confirmed that dementia is common in older adults with Down Syndrome and that the prevalence increases sharply from the age of 40 until the age of 60 (Coppus, et al., 2006; Holland, Hon, Huppert, Stevens, & Watson, 1998)
- Brain changes of AD (plaques and tangles) are found in almost all people with DS by the age of 40
- Most studies report 80% of people with DS will develop AD by the age of 60
- Adults with developmental disabilities, other than Down Syndrome, similar to the general adult population (6% of persons age 60 and older)



Alzheimer's Disease and Down Syndrome

Most people with Down Syndrome (95% of cases) have 3 copies of Chromosome 21 (people without DS have only 2 sets). The specific brain protein, Amyloid Precursor Protein (APP) is the protein thought to be associated with Alzheimer's Disease. The gene that codes the APP is located on Chromosome 21 and having 3 copies of Chromosome 21 results in excessive amyloid plaque in the brain.

Adults with Down Syndrome are about 60% of the adults with developmental disabilities who have dementia. Most adults with a developmental disability are at the same risk for Alzheimer's disease (or other forms of dementia) as are individuals in the general population.

This does not necessarily mean Alzheimer's Disease will occur, however, it is important to anticipate the probability of this.



Baseline

- Observe a well-documented progression of symptoms
- Evaluate to determine a baseline level of function and repeat assessments to establish decline
- Diagnosis of exclusion (3 D's)
- Monitor changes by videotaping the individual in activities of daily living (ADLs) for a baseline.



Alzheimer's Disease and Down Syndrome

Early stage tends to be missed in Down Syndrome. There may be difficulty in obtaining a good history and many medical problems may manifest as behaviours. Usual tests for diagnosis do not take into account existing disabilities.

It is recommended that a baseline of activities of daily living (ADL), behaviour, memory and cognitive function for individuals with DS be established at age 30 and evaluated repeatedly annually to determine any deterioration in these functions.

A good way to monitor their baseline is the tool from the National Task Group on Intellectual Disabilities and Dementia Practice (NTG-EDSD).





Eight A_s

8 As of Dementia

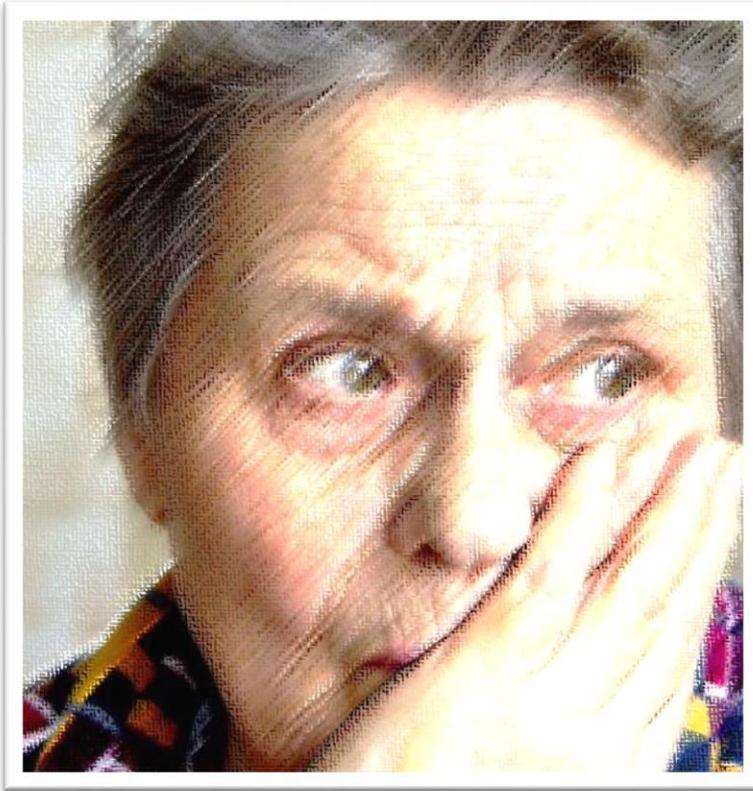
One way to understand the changes in the brain and resulting behaviour is to look at the **8 As of Dementia**. These 8 major cognitive losses may occur in people with a progressive dementia. It is important to understand that the whole brain is affected and the we may also see changes in insight, judgement and executive functioning.



Anosognosia

A preceding “A” in Greek indicates something without (for example, A + mnesia = without memory)

Anosognosia (a compound of **nosos**, meaning “disease” and **gnōsis**, meaning “knowledge”)



- Loss of knowledge of the illness
- Unaware of deficits in cognitive abilities
- Forget they forget so blame others when things go wrong

In the case study,
is Don demonstrating
any of these indicators?



Attention Deficit



- Short attention span
- Easily distracted, tendency to drift away (although at times can be hyper focused)
- Restlessness, constant motion, legs moving, fidgetiness

In the case study,
is Don demonstrating
any of these indicators?



Amnesia

A preceding “A” in Greek indicates something without (for example, A + mnesia = without memory)

Amnesia (mnesia, meaning “memory”)



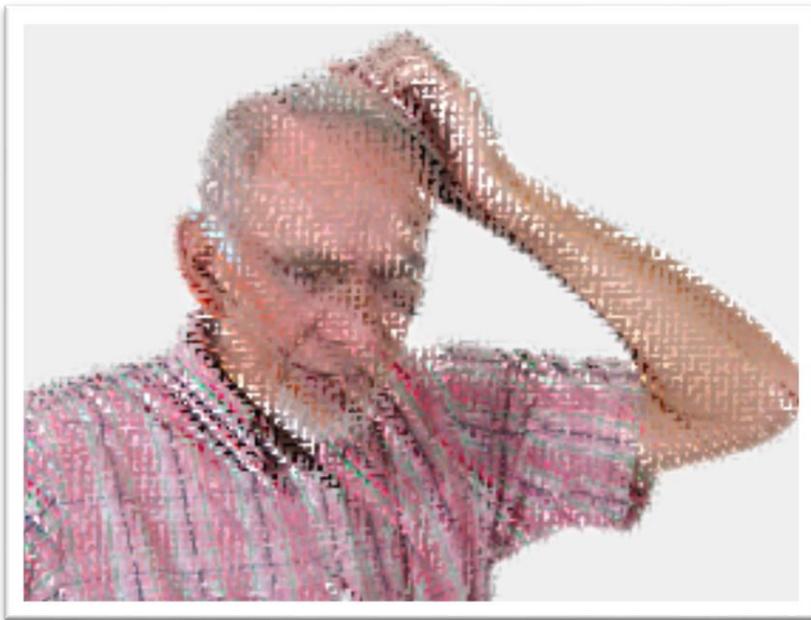
- Memory loss
- May not remember recent conversations, comments, questions
- Access to information is from the past
- Difficulties with sequencing activities (what happened before, what happens next?)



Aphasia

A preceding “A” in Greek indicates something without (for example, A + mnesia = without memory)

Aphasia (**phásis**, meaning “speech”)



- Loss of language (both speech & comprehension)
- Word finding difficulties
- May not participate in conversations
- May revert to first language

In the case study,
is Don demonstrating
any of these indicators?



Altered Perception



What do you see?

- Misinterpretation of sensory information
- May lead to illusions and/or delusions
- Loss of colour and visual perception
- Loss of depth perception

In the case study,
is Don demonstrating
any of these indicators?



Apraxia

A preceding “A” in Greek indicates something without (for example, A + mnesia = without memory)

Apraxia (**praxis**, meaning “action”)



- Difficulty initiating purposeful movements
- Difficulty directing body parts to do familiar tasks
- Difficulty understanding directions—
up, down, back, front, left, right

In the case study,
is Don demonstrating
any of these indicators?



Apathy

A preceding “A” in Greek indicates something without (for example, A + mnesia = without memory)

Apathy (**pathos**, meaning “suffering”)

- Loss of drive
- Reduced or no initiation of activity
- Little or no emotional response



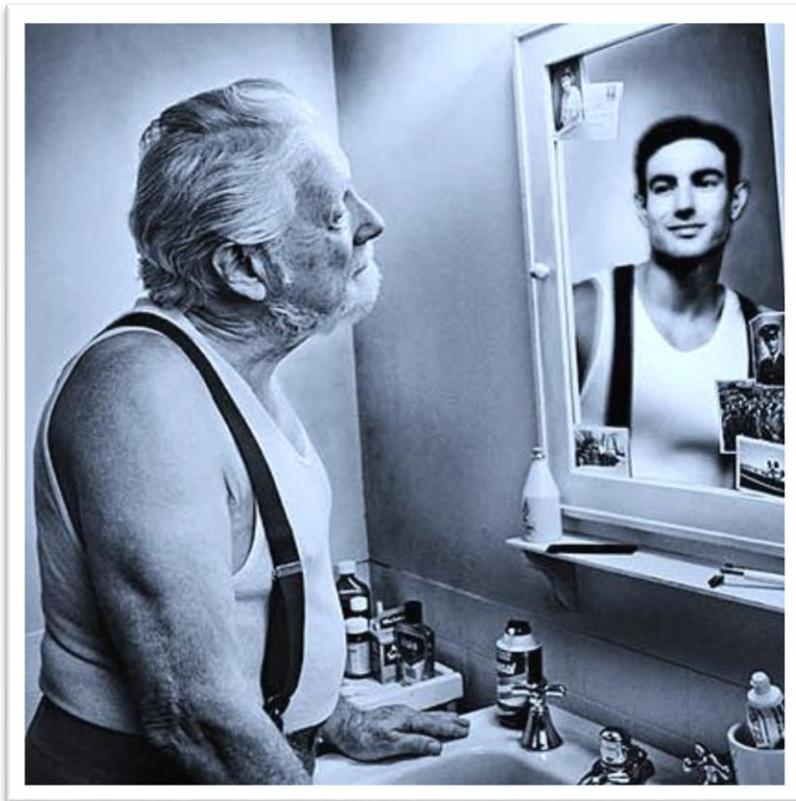
In the case study,
is Don demonstrating
any of these indicators?



Agnosia

A preceding “A” in Greek indicates something without (for example, A + mnesia = without memory)

Agnosia (gnōsis, meaning “knowledge”)



- Loss of recognition of sensory information (sight, sound, taste, touch, smell)
- May misinterpret what is seen / heard, etc.

In the case study, is Don demonstrating any of these indicators?



Recognizing Dementia in Adults with Down Syndrome

It is widely accepted that people with Down Syndrome are more likely than the general population to develop Alzheimer's dementia as they age. However, the diagnosis can be problematic in this population for a number of reasons. These include: the large intra-individual variability in cognitive functioning, the different diagnostic and methodological procedures used in the field and the difficulty in obtaining baseline levels of cognitive functioning in this population with which to assess cognitive and behavioural change.

“Diagnostic overshadowing” (Reiss et al, 1982) means the attribution of changes in behaviour or ability to learning disability. For people with Down's Syndrome, diagnostic overshadowing can mean that they are referred to specialist services late or not at all.

Generally speaking, there is no single test for the diagnosis of Alzheimer's Disease. Alzheimer's Disease is diagnosed through a process of elimination. A complete history and physical is done.

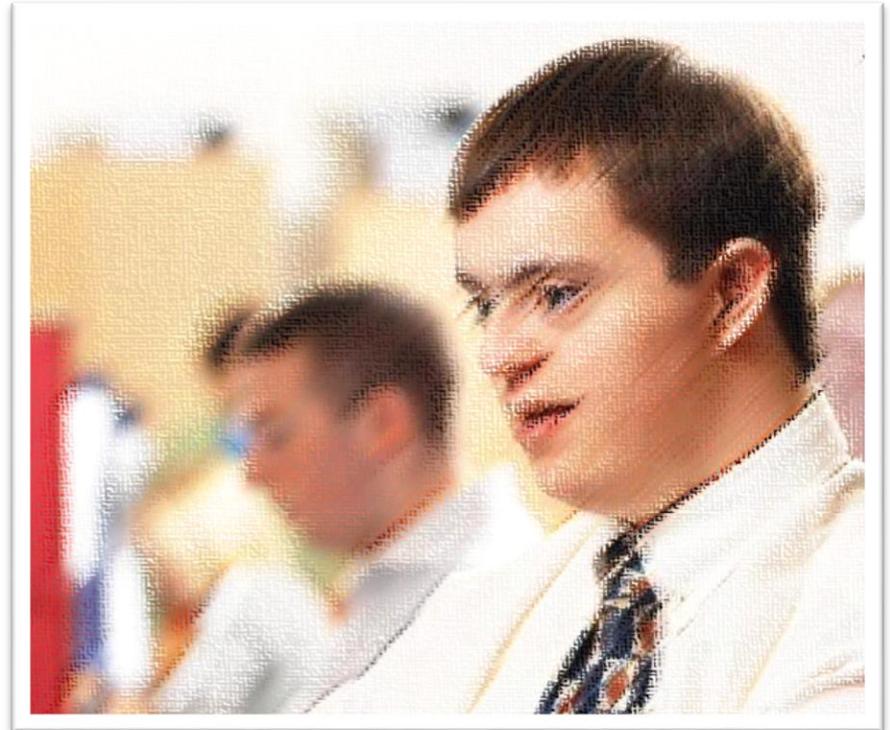
Early stage tends to be missed in Down Syndrome because old behaviours have a tendency to emerge. Staff tend to focus on behaviours rather than the cause. There may be difficulty in obtaining a good history and more difficult to get accurate information from lower-functioning individuals.

Medical problems may manifest as behaviours. Usual tests for diagnosis do not take into account existing disabilities.



Recognizing Dementia in Adults with Down Syndrome

- Observe a well-documented progression of symptoms
- Evaluate to determine a baseline level of function and repeat assessments to establish decline
- Diagnosis of exclusion—medical and psychiatric issues have been investigated



General Principals of Care

- Care should be person centred
- Support the individual to feel safe and secure
- Emphasize maintaining abilities rather than teaching new skills
- Simplify routines and reduce choices
- Use patience and redirection and offer supportive care



Person-centred Care

Once Alzheimer's disease has been clinically confirmed, changes need to be made in the person's daily routine. Person-centred care includes knowing what the person can still do and what they can no longer do. Person-centered care includes working in partnership with staff and the family to understand as much as we can about the person behind the illness.



Warning Signs

- Unexpected changes in routine behaviours
- Difficulty with functional activities (i.e., cooking, dressing, washing)
- Changes in mood / attitude / personality
- Long periods of inactivity or apathy
- Hyperactive reflexes
- Loss of job or social skills



Warning Signs

- Visual retention deficit
- Loss of speech
- Disorientation
- Increase in stereotyped behaviour
- Night time awakenings
- Onset of seizures



Pseudo Dementias

Aging issues that may appear as Dementia in adults with DS:

- Sensory impairments
- Thyroid disorders
- Mental illness
- Depression
- Infection
- Medication interactions
- Other: Sleep Apnea, B12 deficiency



Support – Early Stage

Primary impact is loss of communication skills:

- Maintain routine and familiar environment
- Ensure safety considerations
- Simplify or modify task to enable independence and self esteem
- Optimize the person's sense of success



Support – Middle Stage

Primary impact is increased behaviours:

- Use good communication skills
- Acknowledge and validate what the person is saying
- Modify ADLs to provide support while enabling independence
- Ensure safety
- Create facilitative environment
- Respond to behaviours through a person-centred care approach
- Provide for caregiver support



Support – Late Stage

By late stage will require full bed care—long term care maybe most appropriate:

- Meet the need for constant attention and supervision
- Ensure nutritional needs are met
- Attend to personal care, bladder and bowel incontinence, skin integrity
- Special consideration for caregiver support



The Importance of Understanding

All behaviour has meaning.

The person has a reason for doing
what they are doing

The person is not intentionally
trying to be difficult



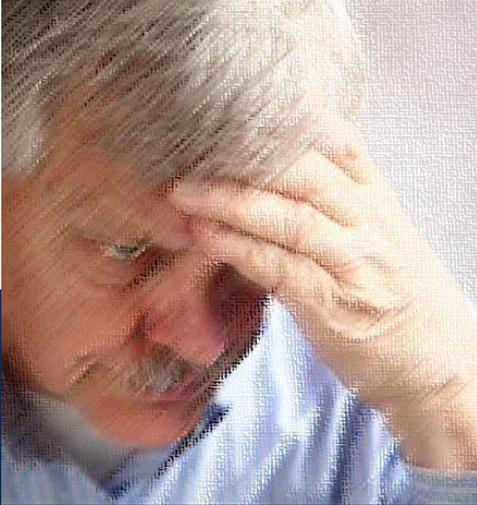
The Importance of Understanding

It is important to understand that all behaviour has meaning. Understanding what may be behind a behaviour is the first step in finding possible solutions that will address what is happening. One thing to keep in mind is that there are things you can do to prevent these behaviours and there are strategies that you can learn to help you cope with them.

We first need to determine who is having the problem. Some behaviours may be distressing to one person and not another (e.g., drumming fingers, pacing, strange noises). A challenging behaviour is usually seen as a problem if it causes distress to or puts others at risk or is a safety concern for the person or those around them.

Because of the disease, this person's way of seeing the world is different. Learning more about this person will help you to understand the behaviour and positively influence care.





The Positive Behaviour Approach: A Brief Introduction

The Positive Behaviour Approach: A Brief Introduction, Whittingham, L. (2014).



Goals of Presentation

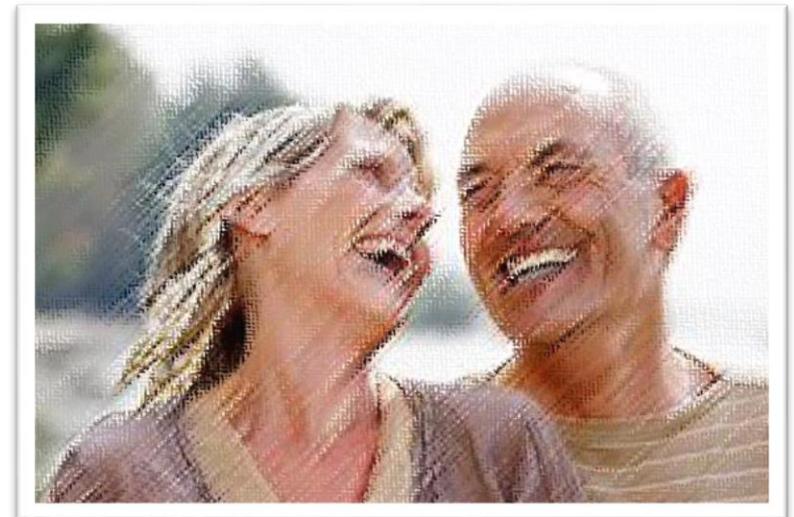
- Know what the functions of behaviour are and how to assess for them.
- Define behaviour and know how to describe them.
- Develop basic ideas for changing behaviour based on the identified function.
- The importance and role of data collection.



What is Behaviour?

Behaviour is:

- A response to an action, situation, or person that comes before or after the behaviour
- May be a response to an unmet need
- Is observable
- A form of communication



What is Behaviour?

Behaviour is a response. There is always something that precedes the behaviour that cues it to happen in spite of whether it is obvious or not. For example, if a person is punched in the head and he cries, it is obvious that the crying is response to the punch. Whereas, if a person starts to cry and you don't observe anything, there is still something that caused it, it's just less obvious such as pain or a sad memory.

One of the most critical difference between behaviourists and other clinicians in psychology is that they focus on what is observable or seen (instead of things that cannot be directly observed like thoughts and feelings). For example, we do not talk to people about how they know they're in love or what they can change to get more love. Instead we focus on what behaviours can be observed that indicate someone is in love and change the circumstances around this behaviour.

Finally, behaviour is a form of communication. It communicates something to other people. This means that it is functional.

It is important to distinguish between adaptive and maladaptive behaviour. The word "maladaptive behaviour" will be used to describe any behaviours that are considered dysfunctional, bad or wrong. The word "adaptive behaviour" will be used to describe any behaviour that is desirable and considered appropriate for the situation.



The Positive Behaviour Approach

- The Positive Behaviour Approach Values:
 - The Individual (Dignity and Respect): reduced reliance on power/control, opportunities for success and to build on strengths
 - Antecedent Management: Changing what happens before the behaviour instead of responding to it
 - Enhancing Quality of Life: When people feel valued and respected, they are motivated to make good choices.



The Positive Behaviour Approach

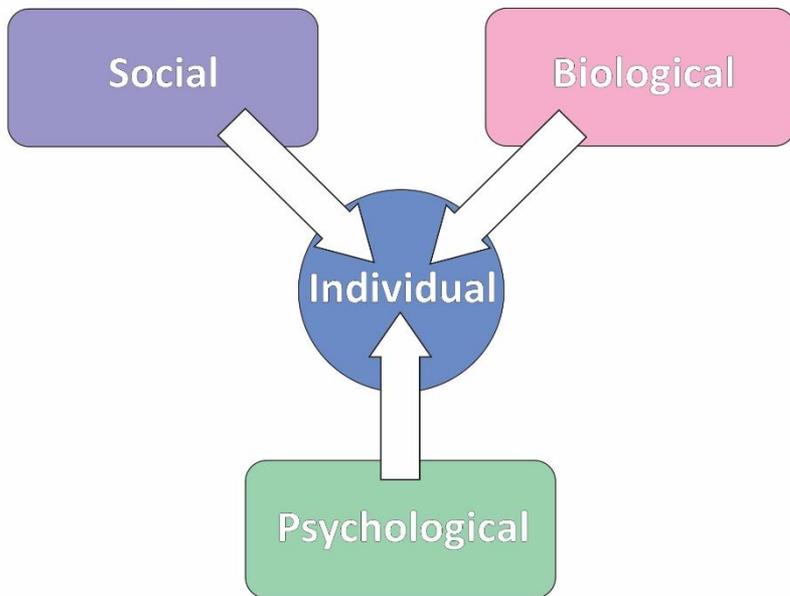
The positive behaviour approach is part of Applied Behaviour Analysis (ABA) that ensures these principles are incorporated into practice. It focuses on changing the conditions so the behaviour of concern is less likely to occur. This means there is less focus on reactive strategies to change behaviour and more focus on what can be done before the behaviour occurs to reduce its necessity.

It also ensures that the individual is at the centre of all interventions. Nothing is done without the individual's consent (to the best of their ability). The approach respects their rights for choice and risk as well as enhancing what the person can naturally do well or is interested in.

For example, Mr. Smith engages in physical aggression every time he is at a session of arts and crafts. The question is not what can we do to address his behaviour, but "Is he interested in this activity?" or "Is he able to sit for the length of time needed to complete the craft?" (i.e., maybe he finds the chair uncomfortable, maybe his attention span has reduced as a result of plaque on the brain from Alzheimer's).



The Biopsychosocial Model



- Recognizes there are many influences on behaviour
 - Focuses on the entire individual, not just the behaviour
- Bio** – What is physically happening to the person?
- Psycho** – What are the cognitive and emotional factors influencing well-being/behaviour?
- Social** – Are the person's needs being met to promote health?



The Positive Behaviour Approach

Historically, the belief regarding health and behaviour was that there was an illness or behaviour and then a subsequent treatment that caused a desired outcome. For example, in medicine, if you had a cold (which is the illness), you took a pill (the treatment), and then felt better (which is the desired outcome); or with behaviour, if someone was physically aggressive (the behaviour), you restrained the person (the treatment), and then they stopped (which is a desired outcome).

We have since come to the conclusion that health and behaviour is much more complex than that. We have come to the realization that many factors influence the success of a treatment and getting the desired outcome.

Going back to the example of the cold and taking a pill, there are biological, psychological, and social factors that may or may not influence how successful this treatment is. For example, **biological factors** include the severity of the cold, medication interactions, the food that is consumed, or the amount of sleep the person gets. **Psychological factors** may include: cognitive abilities (i.e., can the person read the label of the medicine bottle to take the pills correctly, does the person feel that it's a good idea to take pills for colds, is the person motivated to get better (i.e., maybe they have a job they hate and want to avoid going to, so they want to be sick longer).

Finally, there are **social factors** influencing whether they are compliant with treatment. For example, do they have a drug plan at work? *or* do they have someone to remind them to take the medications? *or* do they go into environments with high risk of contracting another cold virus?



Examples of Biopsychosocial Factors

Biological	Psychological	Social
Brain Damage	Executive functioning and IQ	Dependence on other people
Sensory Impairments	Self-esteem	Inadequate support
Genetic Disorders	Coping Skills	Reduced social network
Medications	Trauma	Limited access to resources
Nutrition	Mental Health	Discrimination
Epilepsy	Bereavement/Loss	Institutionalization
	Learned Helplessness	

All factors can influence behaviour!

Functions of Behaviour

- A behaviour persists because it meets a need
- It is an attempt to communicate something
- Possible functions include:
 - Tangible: “Give me”
 - Escape: “Run Away”
 - Attention: “Look at me”
 - Sensory: “It feels good”
 - Biological / Medical: “It hurts”
- Is one of these functions happening before or after a behaviour?



Functions of Behaviour (1)

Someone continues to use a maladaptive behaviour because it works for them—it gets their desired outcome, whatever that may be.

It is important to ensure that we do not assign intent to the behaviour. This means that people may not always be aware that they are doing the behaviour to get a specific need met. For example, laughter when told something that is sad or extremely stressful (i.e., laughing at a funeral). This is not an intentional behaviour (i.e., people are not trying to be insensitive), but the function is to reduce internal tension from being in a very sad or stressful situation.



Four Functions of Behaviour (2)

There are four functions of behaviour:

Tangible: The person wants to access to an object or activity. For example, when you're hungry, you may take food or cook a meal.

Escape: The person wants to escape or avoid something they find less desirable. For example, if a person does not want to clean up after themselves, they may go to the bathroom to get out of having to do this.

Sensory/Medical: Is anything that is an internal state that we may not directly see, but someone may do a behaviour to meet get or communicate. Sensory and medical are separated on the slide, but they are actually one category. The reason for the separation is to show the importance of ensuring that we take into account medical causes when looking at behaviour. Sensory includes anything that is directed by the five senses (e.g., massages, pleasant surroundings, flowers, flashing lights, good food).

Biological/medical: Is something that reduces the internal sensations (e.g., hunger, tiredness, pain). Before we decide how we are going to respond to the behaviour, we need to understand the function of the behaviour. There are many of ways to determine the function, but the quickest and easiest way is to do a questionnaire entitled the "Questions About Behaviour Function."



The Biopsychosocial Approach

- Because there are a variety of reasons that a person may exhibit maladaptive behaviours, it is important to ensure that medical and sensory needs are first assessed and addressed.
- Socially mediated interventions will not be effective if these needs are not being met.
- Examples include: infections, hearing/vision loss, constipation, medication side effects, sleep disturbances.



The Biopsychosocial Approach

It is important to look into the medical causes of behaviour before trying to use an intervention. This is especially true for a person who may have limited communication skills (i.e., has lost language skills due to Alzheimer's Disease or has a developmental disability). They may hit the area that hurts if there is pain or there may be a change in behaviour because they are not well.

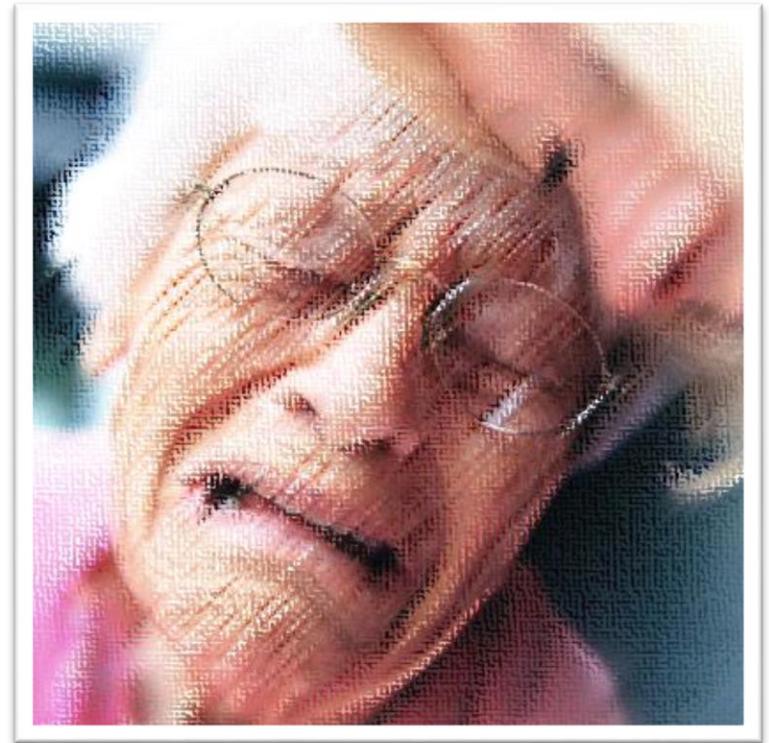
For example, if you injure your foot (i.e., sprained ankle). What might change about your behaviour in general? You may sit more often to get off it. If you're not able to communicate that your foot is injured, I might assume that you're being lazy. If I ask you to walk home instead of getting a ride, you might swear to communicate distress about my request. If I physically try to get you up to walk, you may hit me to stop. Also you are not likely to change any of these behaviours (i.e., physical aggression, swearing) if I offer to give you a chocolate bar for walking home or standing more often because the need to reduce pain is greater than the desire for a chocolate bar.



Behaviour Overshadowing

- Changes in behaviour are attributed to a “learned” response instead of an underlying medical or psychiatric disorder.

For example, crying is seen as an attempt to get your attention instead of a response to an ear infection.



Behaviour Overshadowing

Behaviour overshadowing is the tendency to point to an environmental cause of a behaviour rather than something that is actually causing the behaviour to occur. We tend to do this with medical or psychiatric disorders, especially in people who have developmental disabilities.

For example, any time you try to clean Ms. Smith's ears, she starts to cry. You assume this is to avoid having to get her ears cleaned or to continue watching TV (because you asked her when she was watching TV), instead of the fact that she has an ear infection and it hurts to have someone clean her ears.

or

For example, you assume that Jim does not follow through on your suggestion to eat dinner because he is trying to get your attention rather than the fact that he is terrified to follow through because he has delusions that people are putting razors in his food.



The ABCs of Behaviour

- **Antecedent**: Anything that happens immediately before the behaviour that maintains it.
Setting Events: Anything that can change the behaviour momentarily (e.g., illness, temperature)
- **Behaviour**: An observable event that everyone is able to recognize.
- **Consequence**: Anything that happens after the behaviour that maintains it.



The ABCs of Behaviour

Antecedents are anything that happen in the environment before the behaviour occurs. Setting events (also known as modifying operations) are not always directly observed but happen before the behaviour to increase the likelihood of the behaviour occurring. You may or may not be aware of these factors and the role they play in the behaviour, therefore they may not be reported all the time when asking about behaviour or collecting data about behaviour.

Behaviour is an observable event that everyone is able to recognize. It is important to ensure there is a description of the behaviour that everyone agrees upon so they know what to look for and report. For example, what is included in physical aggression? Should staff include spitting or is that something different? Again, no intent should be given to the behaviour. For example, “Marc hit the staff with an open hand” is a good description of behaviour. “Marc hit me because he hates me” is a is not a good description of behaviour.

Consequence is anything that happens after the behaviour. In the case of behaviourism, consequences is used to describe ANYTHING that happens after the behaviour. This could be positive (i.e., reward) or negative (i.e., punishment).

We look for answers regarding how events within the environment maintain the maladaptive behavior—something that happens before or after the behaviour that increases the likelihood that it is going to happen again.



ABC Examples

ANTECEDENT	BEHAVIOUR	CONSEQUENCE
Jim is asked by staff to take a shower.	Jim screams and throws the items in his room on the floor.	Staff stop asking him to take a shower and let him watch TV
The function of behaviour is avoidance – Jim has effectively avoided taking a shower.		
Cindy is asked to participate in a craft with the group.	Cindy bangs her head on the tray of her wheelchair.	The instructor gives her a hug and cuddles her until she stops.
The function of behaviour is attention – Cindy has effectively maintained the instructor’s attention.		

Setting events may increase the intensity or frequency:

Temperature (for Jim) — If he is cold, he may engage in more intense behaviour to avoid a shower than if he is warm.

Christmas (for Cindy) — The value placed on this holiday may increase the need for attention from caregivers.

Following the case of Jim under the ABCs of Behaviour

He is an example of **Antecedent**, **Behaviour** and **Consequences**, and how by looking at the information you could guess at the function of behaviour.

Looking at the example of Jim, we can see that he was given a task demand (“take a shower”).

We know that Jim does not want to take a shower based on his response to the request (i.e., screaming and throwing items).

We are not able to tell from this information why he does not want to (e.g., feeling sick, hates water, etc).

We can see that in response to his behaviour, staff backed off and he didn’t have to take a shower.

If we see this pattern of behaviour every time, Jim is asked to take a shower, we could guess with confidence that the function of behaviour is escape/avoidance because he has effectively gotten out of taking a shower.

It is important to note that we would not guess the function of behaviour on one event, and that we would collect ABC data about behaviour over a period of time (i.e., a week or a month) depending on how often the behaviour happens. For something that happens regularly (i.e., daily), you may only want to take data for a week, if it happens less frequently (i.e., once per week), you may want to gather data for a month.

At the bottom of the slide, possible setting events are listed. Again, these events may or may not be obvious. Looking at the first example with Jim, if he was cold or the temperature of the room is cold (which is a different experience for everyone), it may alter the intensity of the behaviour or increase the likelihood of the behaviour. For example, he may be more willing to tolerate the shower if the temperature in the room is increased before he takes a shower.



Following the case of Cindy under the ABCs of Behaviour

He is an example of **Antecedent**, **Behaviour** and **Consequences**, and how by looking at the information you could guess at the function of behaviour.

Looking at the example of Cindy, we can see that she was asked to do something in a group (this means there is more than one person present).

We can guess that she does not like sharing staff's attention because she bangs her head on the tray of her wheelchair.

Again we are not able to tell from this information why she does not want to share staff's attention (e.g., fear, poor self-esteem).

We can see that in response to her behaviour, staff gave her a hug and attention until she stops.

If we see this pattern of behaviour every time she is in a group, we could guess with confidence that the function of behaviour is maintaining attention because she has effectively gotten staff to focus on her rather than the group.

With regards to setting events, Cindy may not have a family to see her at Christmas and therefore may desire more comfort from staff on this holiday. This will increase the likelihood of the behaviour happening in the month of December than July.



Positive Behaviour Approach Interventions

- Once the function of a behaviour has been determined, interventions can be developed to change the frequency or intensity of maladaptive behaviour.
- We can influence behaviour by changing what happens before (antecedents) or after it (consequences).
- We cannot “control” the behaviour.



Positive Behaviour Approach Interventions

It is important to know the function of behaviour before developing interventions. If the intervention is not paired properly to the function, it will not work. For example, if the function of behaviour is to maintain attention and we suggest giving a reward, this could make the behaviour worse because we are still responding to the behaviour with more attention (i.e., staff interaction AND a rewarding object).

It is also important to note that the focus is on changing the conditions to reduce the likelihood of the behaviour occurring and not changing the individual. We cannot modify anything about the individual, only their actions. Again, the Positive Behaviour Approach puts the individual and quality of life in the center. Strategies that focus on power and control do not promote a good quality of life (because it disempowers the individual) and does not respect the individual's right to make choices.

Once data has been collected about the behaviour and what is happening before or after, we can develop strategies to change these events and decrease the frequency of behaviour. For example, in Jim's case, we would see that every time he yells and breaks items when asked to take a shower, staff stop. We would know to look at the variables related to shower taking (e.g., ask Jim what it is that he doesn't like about the shower), investigate water temperature, look at history of involvement with staff and look at changing these variables to increase the likelihood that he will want to take a shower. We would also make recommendations to staff about how to respond to these behaviours if they occur (e.g., increase personal space). Reactive strategies can NOT be recommended without the preventative strategies – this is unethical and not following the principles of positive behaviour approach.

The following slides have some basic ideas for interventions that could be used to prevent the likelihood of behaviour. The goal is to give you some ideas regarding what to recommend. They can also be used while waiting for a referral to a behaviour service as well.



Change the Environment

- Everything outside of the individual is the environment (even staff!).
 - Change the physical environment (e.g., lighting, temperature)
 - Provide more opportunities to do desired activities
 - Provide structure and routine to increase predictability
 - Provide an escape route and opportunities for breaks
 - Change the staff (e.g., approach, increase skill)



Change the Environment (1)

Change the physical environment: this includes any modifications to building (e.g., furniture layout, adding/removing walls or clutter, paint colour), seasonal changes (e.g., appropriate dress for weather, the availability of heat and air conditioning), and the amount of sensory stimulus (e.g., noise, crowding, smells), adding visuals to the environment (e.g., signs, instructions), moving (e.g., moving from a location with stairs to no stairs if someone has mobility concerns)

Provide more opportunities to do desirable activities: Find out what the person likes and make sure they have access to it. Suggest people think about how they feel if they work a lot of hours without a holiday or breaks? What happens to their mood? What happens to the quality of their work? Are they more likely to swear? More likely to avoid certain tasks and change their behaviour to avoid it?

Pair desirable activities with less desirable activities. For example, the “first . . . then . . .” principle puts the more desirable activity after a less desirable activity as a reward for getting through the less desirable activity.

continued . . .



Change the Environment (2)

Provide structure and routine to increase predictability: Some people feel stressed when they do not have a routine to follow. For example, think about how your behaviour changes when you are not working (i.e., on vacation) – your eating habits might change (e.g., don't eat as healthy), you may shift around your sleep schedule (e.g., stay up later and sleep in). Predictability reduces fear because people know what to expect.

Provide an escape route and opportunities for breaks: We need to take into account someone's attention span. If we ask them to do something for longer than what they are capable of (e.g., ask them to wait for an hour, when they can only wait for 10 minutes), we risk that they may find a way to communicate boredom or entertain themselves. You can reduce the likelihood of observing maladaptive behaviour by reassuring them that they can have a break if they ask or keep a clear path for leaving a room. We need to be aware of ensuring the person completes the task so we don't unintentionally cause a new behaviour to escape.

Change the staff: This can include actually changing the staff, but it can also include changing the staff's ability with training and supervision, improving the relationship someone has with the person, or choosing the right staff for the right task. For example, ensure a familiar staff helps with intimate routines, while building rapport with newer staff so one day the person feels comfortable accepting help from them one day as well.



Create Opportunities for Success

- We are more able to make good choices when we feel good about ourselves. For example:
 - Offer simple choices whenever possible (e.g., towel colour)
 - Set realistic goals for the individual
 - Provide warnings for changes
 - Build momentum by starting with tasks you know the person can complete



Create Opportunities for Success (1)

Offer simple choices whenever possible. This is an easy way to empower someone in an environment they may not have a lot of opportunity for control. We tend to focus on the big choices when we think about it, but a series of little choices over the course of a day can be very empowering. It can be as simple as choice regarding order of tasks, choosing what to wear, or offering condiments at meal times. It can also be a way to avoid a power struggle about a task that is not optional. For example, taking medications: do you want water or applesauce with your medications? Instead of are you ready for your medications? What happens if the person says 'no'? Then you have to increase forcefulness to get the person to follow through; whereas if you offer choice about something else related to the task, they may be more willing to be agreeable.

Set realistic goals for the individual: Ensure that the goals are within the person's capabilities and interests. This will help to avoid making requests that the person cannot follow through on and potentially engage in a maladaptive behaviour to avoid the request. It can also be helping the individual to set realistic goals for themselves. For example, they may expect that family can come and visit them every day, you may have to help them understand that this is not a possibility and find another desirable thing to look forward to.

continued . . .



Create Opportunities for Success (2)

Provide warnings for changes: If someone is not able to predict what is going to happen, they may become fearful and then use maladaptive behaviours as a way to avoid doing something. It can also be angering if someone interrupts what you are doing, especially if it is something you really like. Therefore, it is helpful to provide reminders and warnings when there is going to be change. For example, change in staff that typically does a task (e.g., hygiene-related) or change in routine (e.g., family always comes on Sunday, but are going to come on Monday).

Build momentum for more difficult tasks: Doing a sequence of a few successful tasks will increase the likelihood that the person will at least attempt to do what is accessed of them. The best tasks to build momentum are often VERY simple (e.g., “Give me high five,” “Show me a smile,” “Pick up the book”). It also gives the opportunity to build rapport with the person because you can smile or give words of praise quickly between each task.



Communicating Effectively

- The person needs to understand you. For example:
 - Use simple, concrete words
 - Speak slowly, quietly and calmly
 - Keeping things simple, but do not “talking down” to the person
 - Pause between statements
 - Be sensitive to person’s non-verbal cues and adjust accordingly (e.g., If the person seems fearful, address before continuing)
 - Use concrete cues (e.g., visual communication and/or gestures)



Communicating Effectively (1)

Use simple, concrete words: Try to keep your language basic and avoid using “dress up words” like adjectives (e.g., lovely, fresh, tidy, engaging). Some people can only remember or understand as few as 2 to 3 words given at a time and you want them to have the words that are going to help them find an answer, not the descriptors in between. Avoid using abstract words and phrases such as “quiet as a mouse” or “free as a bird.” The person may not understand the meaning behind these statements.

Speak slowly and calmly: Try to be mindful of the speed in which you say things. If something is said fast, someone may not hear all the words and not be able to express that they haven't hear you.

Also important to speak calmly, regardless of how you are feeling. If a person notices that you are nervous about something, they may become nervous as well. For example, children's emotions tend to imitate that of their parents. This is because they rely on their parents (like clients rely on their staff) to read the situation for them (e.g., what is scary, what is safe) and respond accordingly. If you appear fearful to the client and they don't know why, you are going to increase their agitation and subsequently increase the risk of maladaptive behaviour.

Finally the tone and pitch of a voice tends to change when we yell or raise our voice. If someone is tone deaf or hard of hearing, this may alter their ability to hear you.



Communicating Effectively (2)

Pause between statements: Some people hear well, but there is a bit of a delay in their ability to process what is heard. Therefore it is beneficial to make a statement or request and then count slowly to three to ensure the person has the opportunity to process what has been said. If they do not respond, repeat what was said or ask them to repeat back to you what you said in their own words to ensure they understood it.

Be sensitive to the person's non-verbal cues and adjust accordingly: We may all be familiar with the statistic “80% of communication is non-verbal.” We do tend to get more information from a person's body language than what they are saying. For example, if someone says “I'm fine” but their body is tense, they're shouting, and their eyes are darting around the room—they're probably not fine. Therefore, we need to focus on what is not being said as well as what is being said and provide the opportunity to address what may be bothering the person before moving ahead. A good statement that may be helpful is “You appear (label the emotion). Would you like me to _____?”

Use concrete cues: When possible show the person what it is that you want them to do by showing them pictures, pointing, or demonstrating how something is done. For example, if the person is asking about the weather, instead of just saying, “It's raining,” show them it's raining outside the window. Or if there's more than one closet in their room, point to the closet that their shoes are in.



Cloak of Competency

- It is when an individual appears to understand more than they actually do (e.g., can talk the talk).
- This tends to lead caregivers to believe the person is more able than they are.
- Some individuals have 'splinter skills:' extreme abilities in one area (e.g., math, music)



Cloak of Competency

This is most relevant with regards to verbal communication. Often, people who experience some form of decrease in ability or a developmental disability want to cover it up because they don't want to appear stupid or want to be "socially desirable" (i.e., have been taught that people like them when they do what they say). This is called the **cloak of competency**.

This can lead us to believe that a person is more capable than they actually are. For example, they use complex words (e.g., anger management, empathy, complex) but they don't really know what they mean. This leads the people around them to believe that they have better skills than they actually do. For example, "He uses words like empathy, but can't understand when I ask them how they are doing." This difference leads people to believe that the person is faking their inability to avoid a task instead of changing their communication strategy.

Some people have extreme abilities in one area (e.g., math, language, or music). We used to call this a "savant" ability (an "idiot savant" was an individual who had an intellectual disability, but was considered a genius on area), but now we call this a "splinter skill." If someone has a splinter skill, this could be an opportunity for creating success for them. It may also lead someone to believe that someone is more capable than they are if they only interact with them in relation to their splinter skill or because they have an extreme ability in one area.



Give Attention to Desired Behaviours

- It is important to provide praise and reward for good choices.
 - Identify effective reinforcers (e.g., items, words)
 - Be specific when giving praise (e.g., “Adam, I like the way you did the dishes”)
 - Try to get into the habit of providing praise once per hour
 - Minimize response to undesirable behaviour (e.g., avoid eye contact, talking about behaviour, rolling eyes, smiling, etc.)



Give Attention to Desired Behaviours (1)

Identify effective reinforcers: It's important to do a good investigation of what the person really likes in order to find effective reinforcers. This can be items or words or activities. There are a lot of preference assessments online that have lists of items that are commonly reinforcing for people. You can use these assessments to help find a reinforcement for someone. If we offer something that the person likes but doesn't necessarily LOVE, they may not be willing to work for it.

Be specific when giving praise. We want to ensure that people are aware of what they are being praised for. We tend to shorten our praise to "Good job!" or "Awesome work!" which may not be meaningful to the individual (i.e., good work doing what? Taking a shower? Getting wet? Standing? Keeping their hands to themselves?). Therefore we have to ensure that we identify the target behaviour to the individual so they know which part of the task is getting them the praise.

continued . . .



Give Attention to Desired Behaviours (2)

Try to get into the habit of providing reinforcement at least once per hour. This could include praise, but it could also include positive attention, depending on the individual. Positive attention is a sense of connection. This could include: asking how they are doing, asking if they need anything, making a comment about what they are doing, and/or smiling with eye contact. It ensures the person feels that you are aware of them and available without being completely engaged in an activity with them. It may also reduce agitation or fear, and provides the opportunity to ask for help before they become frustrated.

Minimize response to undesirable behaviour. Behaviour tends to persist because it gets attention from people in the environment. Many people who are ignored tend to become indifferent to whether the attention they are getting is considered good or bad (i.e., attention is attention). Therefore any response to the behaviour can increase the likelihood of persistence. We need to be aware of how we respond when someone does the behaviour we are concerned about and be mindful to reduce all of the outward responses to the it. Sometimes this might include leaving the room if it is safe to do so.



Reduced Reliance on Power/Control

- Pick your battles wisely. For example:
 - Can the request be done at another time, by another person?
 - What is the risk associated if you do not respond to the behaviour?
 - Set firm consistent boundaries and allow free movement within those boundaries
 - Being too reliant on power and control can create / increase hostility



Reduced Reliance on Power/Control (1)

Be aware of power and control. We need to be aware that we are inherently in a position as staff of power and control because often we have more access to resources (e.g., freedom to leave, food, attention). Therefore it is important to ensure that we are empowering people as much as possible. This is a large part of maintaining dignity and respect (that is the cornerstone of Positive Behaviour Approach). Therefore we need to ask ourselves: Is this important? Could it be done at another time? Can only part of it be done? Can another person do it? What will happen if the person doesn't do it?

We also need to consider the risk associated with not responding to the behaviour at that moment? For example, what is the risk if the person misses a shower one day? Three days? One week? What is the risk if they miss one meal? A day of meals? Two days of meals? This needs to be discussed as a team and a plan that everyone is comfortable with is developed. Also, there is need to consider whether the person has the capacity to make these decisions of risk. This is an issue bigger than this presentation and therefore the right people should be consulted about capacity.

continued . . .



Reduced Reliance on Power/Control (2)

Set firm and consistent boundaries: Environments that encourage adaptive behaviour often have rules and limits set up front and then allow the person to work within them. It reduces the number of negative interactions with staff (e.g., it's not staff saying you have to do something, it's the rule of living here). It is also important that everyone understands and applies the rules the same to create predictability and reduce tension on staff team (i.e., people can become resentful if one staff is always bending the rules in their favour).

Being too reliant on power and control can create/increase hostility: People become fearful and angry in environments that they have little control or power over. It can lead to the opposite effect of what is desired. For example, people refuse more in an effort to feel some level of control instead of complying with requests. It also reduces trust and predictability between the staff and the client.



Crisis Management

- The goal of crisis management is to maintain safety and should be a last resort
- There is no therapeutic value for crisis management
- Should not be used without an accompanying intervention plan



Crisis Management

Sometimes, in spite of our best efforts, the maladaptive behaviour occurs. This could be because of a setting event (e.g., didn't sleep the night before) or we misjudge the cause of the behaviour (i.e., we thought it was because they were avoiding leaving the building, but it was actually to get a chocolate bar).

If this happens, the goal is to maintain everyone's safety and not to teach alternative behaviours. This is because we have not shown an alternative for them to use. For example, if someone is using physical aggression to get out of arts and crafts, we have to teach them an alternative way to communicate their desire not to participate (e.g., sign language, a statement). Restraint and punishment do not teach a person alternative strategies.

All employees that are potentially going to respond to a crisis need to be well-informed of the organizations policies and ministry's legislation regarding crisis management: for example, reporting, approved restraints, what constitutes a crisis.



Data Collection

- All interventions should be “data driven”
- Need to ensure that everyone is very clear about what they are looking for and tracking

Example: What is lazy?

- It is also important to collect data regarding when the behaviour is not happening



Data Collection (1)

One of the key components of applied behaviour analysis is data collection. Data informs what interventions we choose (i.e., based on the function of behaviour) and it also lets us know if the selected intervention is effective in reducing the behaviour of concern. Therefore, we need to collect information about the behaviour before the interventions are introduced (this is called “baseline data”) so we have something with which to compare the data after the intervention has been introduced.

It also increases the accountability to the individual and their support network regarding the interventions being selected. For example, if a family does not feel that increases opportunities for choices will change behaviour, collecting data will demonstrate whether it is effective or not. We also need to be clear about what is included in the definition of the behaviour of concern. This means focusing on what is observable and what is included in the definition. For example: What is “lazy”? This is not an observable behaviour therefore we need to find behavioural indicators of it (e.g., refusing to do chores, refusing to get out of bed). We also need capture what is included in the definition. For example, what does physical aggression include—hitting, punching, kicking, biting, scratching? Descriptions need to be as complete as possible.

It is also important to collect data regarding when the behaviour is NOT happening. This tells us the factors that lead to success and recognize that people do not engage in the maladaptive behaviour all the time (e.g., if someone is picking fights for 2 hours per day, what are they doing for the other 22 hours a day? What is preventing behaviour for those 22 hours?)



Data Collection

- There are two forms of data:
 - Direct data collection: observations, asking the person questions
 - Indirect data collection: questionnaires, interviewing staff
- Data should be collected at the following times:
 - Before recommending interventions (i.e., to determine the frequency/ intensity, to determine the function of the behaviour)
 - After recommendations have been made to ensure they are effective



Data Collection (2)

There are **two forms of data collection**: direct and indirect.

Direct data collection is anything that requires direct investigation of the behaviour that can be evaluated. For example, the ABC chart is an example of direct data collection. We are observing the behaviour and writing down details about what happens before, during and after the behaviour.

Indirect data collection comes from another source and not necessarily from seeing the behaviour directly. For example, the “Questions About Behaviour Function” is indirect data collection. You are not seeing the behaviour, but asking staff to report on what they see (i.e., their opinion about when the behaviour happens).

We need to collect information about the behaviour before the interventions are introduced to determine the function of behaviour and to ensure we have information about the prior behaviour so that there is something by which to compare the numbers after the interventions are introduced.



Care for the Caregiver

- Know your limit
- Maintain a healthy balance in your life: good sleep and nutrition, exercise
- Seek help for symptoms that are interfering with your daily life
- Maintain positive supportive connections with others
- Implement regular mini-escapes in your life (e.g., hobbies, creative therapies or recreation)
- Don't medicate yourself with drugs or alcohol!
- Get professional help for yourself if needed to get back on track



Care for the Caregiver

Knowing your limit is knowing when to take breaks or knowing when to ask someone for help. We need to create team environments in which people can ask for help and remain feeling competent.

Maintain a healthy balance in your life. This can be difficult to achieve, even when you are not working with someone with challenging behaviours. A healthy balance will prevent you from becoming ill or burn out.

Seek help for symptoms that are interfering with daily life. For example one of the symptoms of stress disorders is excessive sleep. If you find there is an increase in the amount of sleep you need, seek assistance from your physician or a counselor.

Maintain positive supportive connections with others. Do not isolate. Keep good relationships within your team. Often we are not able to talk about what happens at work with our loved ones, therefore our team members may be a good source of brainstorming and/or comfort.

Implement regular mini-escapes in your life—that is recreation.

With our clients, we need opportunities for success because it makes us feel good and increases our willingness to do things that we find difficult.

Don't medicate with drugs and alcohol. This creates more problems than it solves.

Get professional help for yourself if needed to get back on track. If you feel you are at a point where you can't recover (i.e., always tired, always worried about what is going on at work), look for assistance from a counselor or a physician.



Getting Help for Your Client

- Our source of information in the province of Ontario is Developmental Services Ontario:
 - www.dsontario.ca
 - This is the gateway to developmental services in Ontario
 - Referrals to all services funded by the Ministry of Community and Social Services (e.g., behaviour supports)



Helpful Resources

- Behaviour Analyst Certification Board
www.bacb.com
- Ontario Networks of Specialized Care
www.community-networks.ca
- National Association for Dual Diagnosis
www.thenadd.org
- American Association on Intellectual and Developmental Disabilities
www.aaidd.org
- Applied Behaviour Analysis International
www.abainternational.org



Helpful Resources

The previous slide indicates sources that may be helpful to find information and resources about positive behaviour approach or applied behaviour analysis including fact sheets, journal articles, and worksheets (i.e., more information about how to collect data).

There is a lot of information available on the Internet, but the suggested sites are likely to produce the most reliable results.





Contributors

- **Susan E. Cuming** – Public Education Coordinator, Alzheimer Society Haldimand Norfolk
- **Beth-Ann Currie** – Research Facilitator, SNSC
- **Al Fewster** – retired Registered Nurse, and Community Consultant
- **Nancy Hall** – Facilitator for Niagara, Haldimand and Norfolk, The Southern Network of Specialized Care (SNSC)
- **Kathie Poitras** – RPN, Psychogeriatric Resource Consultant, Alzheimer Society Norfolk
- **Katherine Rankin** – retired Manager of Education, Alzheimer Societies of Brant, Haldimand Norfolk, Hamilton Halton
- **Susan Wavell** – Executive Director of Community Living Haldimand
- **Lisa Whittingham** – B.A. (Hons), Behaviour Consultant, Hamilton Brant Behaviour Services





Reviewed and Approved by

Dr. Kerry Boyd (MD, FRCPC, Psychiatrist)

Dr. Boyd is an Associate Clinical Professor for the Department of Psychiatry and Behavioural Neurosciences at McMaster University. She is a clinician and Chief Clinical Officer for Bethesda. She also works with the Autism Spectrum Disorder Service at McMaster Children's Hospital.

Sandra Buckle

Since 2010, Ms. Buckle has served as an Intensive Geriatric Services Worker in Specialized Geriatric Services, Community Addiction Mental Health Services of Haldimand–Norfolk. Her experience includes 11 years as a Counsellor with the Alzheimer Society of Haldimand–Norfolk and 5 years as a Developmental Service Worker.



AGING and INTELLECTUAL DISABILITY



Haldimand & Norfolk Seniors Partnership

We hope that this training presentation has been informative and beneficial for your activities.

We welcome your feedback in order to improve our website and the associated resources. Thank you!