

Alzheimer's Disease in Down Syndrome:

Modifying Risk Factors & Supporting Communication for Optimal Functioning



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Outline

1. What is Alzheimer's Disease (AD)?
2. How are Down syndrome (DS) and AD related?
3. What is communication? Why is it important?
4. How can you support communication with an individual with DS and AD?

Presentation Goals

- For family members and other caregivers to recognize:
 - How to minimize risk factors
 - Symptoms & associated signs
 - General strategies to support communication
 - Community resources for individualized information

Outline

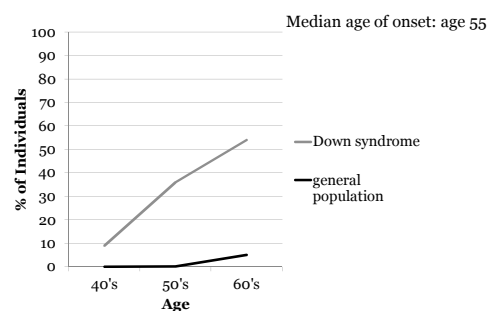
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What is dementia?

- A clinical syndrome
 - Deterioration of memory and at least one other cognitive function
 - Severe enough to interfere with ability to function in usual activities
 - *Not* an inevitable aspect of growing old¹
- Can be due to a variety of diseases, trauma, etc. – not by delirium or major psychiatric disorder

¹British Psychological Society (2009)

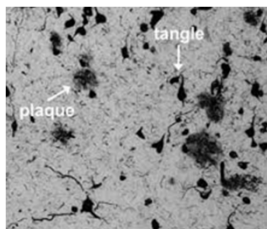
Dementia Statistics



Raffi; ¹Brosch & Farlow (2015)

What is Alzheimer's Disease?

- Leading cause (75%) of dementia¹
- Degenerative neurological (brain) condition
 - Not due to other conditions = “diagnosis of exclusion”
- Gradual onset + long term development
 - Progressive = worsens over time



¹Raffi

Outline

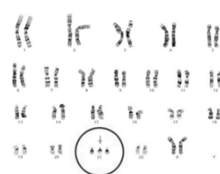
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3. How are DS and AD related?

- There are many genes that contribute to the onset and development of Alzheimer's disease in Down syndrome.
- Genetic and environmental factors can both contribute.



The 21st Chromosome and the Brain



- Amyloid deposits **plaques** in the brain
 - Plaques are a buildup of amyloid protein between neurons
- The **gene** that produces amyloid is on the 21st chromosome
 - People with DS have 3 copies of chromosome 21
 - Therefore, plaques are abundant in DS¹
 - DS = increased risk, earlier onset, and faster decline²

¹ Mufson
² Evenhuis (1997)

Diagnosis

Primary Care for Adults with DD
Canadian Consensus Guidelines
(Canadian Family Physician, 2011)



Diagnosis based on pattern of decline in neurological and psychological functioning (Dr. Chicoín)

“Diagnosis [of dementia] might be missed because changes in emotion, social behaviour, or motivation can be gradual and subtle.”

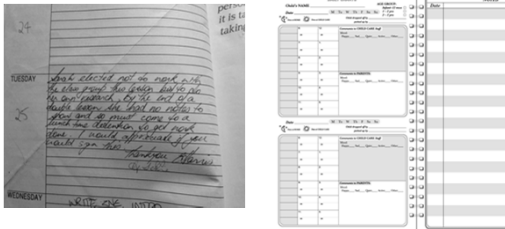
“A **baseline** of (cognitive, adaptive, and communicative) **functioning** against which to measure changes is needed.”

Establishing a baseline

- Caregiver report: talk to people who know the person well, and for a long time
 - Find out about life experiences, communication and speech characteristics, personality, preferences, skills, abilities, level of independence, daily life
- Talk to the individual
 - Formally assess skills with specialists over time
- Watch old videos, look at old examples of work, past reports, etc.

Establishing a Baseline - Log Book

Use a log book to track behaviour, health, physical, cognitive, and communication changes.



Primary Care for Adults with DD

Canadian Consensus Guidelines

- If you suspect dementia, check health status first!
 - Individuals may not be able to describe health symptoms, pain, or functional changes.
 - Other conditions or decline might be mistaken for AD
- Refer to specialists to rule out other treatable/reversible conditions.

Consider other changes in aging that may mimic AD...

- Life changes, environmental stressors
- Hearing or vision changes (min. 2 years)
- Celiac disease, diabetes, arthritis, **seizures**
- Low thyroid function
- Sleep apnea
- Mental health
- Vitamin deficiency
- Urinary tract problems
- GI problems
- Medication side effects (iatrogenic)
- **Pain**
 - Compare to previous behaviour and skill level (caregiver report of daily functioning)



Pain and Behaviour

“Pain recognition and management for people with intellectual disabilities and dementia is often very poor.”
 - British Psychological Society (2015)

- Can cause global decline in function
- Often expressed unusually (emotions, behaviour)

= It is up to caregivers to monitor health and behaviour to help identify and solve pain

Pain and Behaviour

Too often, people are treated for “behaviour” or psychological/psychotic conditions that are actually manifestations of pain



Pain and Behaviour

Difficult to communicate, so *you* can watch carefully for changes in:

- Mood (eg. angry, depressed, anxious)
- Affect (eg. crying, moaning, distressed)
- Behaviour and Participation (eg. refusal)
- Unusual physical signs (eg. rocking)
- Physical aggression (eg. lashing out)

Family Doctor: To Do...

- Review existing lab results and follow up on out of range values
- Recent **blood work** if not done within 3 months that includes:
 - Liver panel (especially if on psychotropic medications)
 - Kidney function (GFR)
 - CBC
 - Thyroid (TSH)
 - B 12
 - Vitamin D
 - Ferritin
 - Fasting Blood Sugar
 - Lipid panel – if risk factors, family history or if considering or already on anti-psychotic medication
 - Hormone levels in women over 30 if there are concerns
- If a **sleep disorder** or symptoms of sleep apnea exist, please consider an overnight oximetry test
- Celiac **screening** (total serum IgA if not done previously, and tTg)
- Consider mental health, sensory abilities, environmental changes, polypharmacy

Health Supervision in DS

Canadian: **Surrey Place Centre**
<http://www.surreyplace.on.ca/documents/Primary%20Care/Down%20Syndrome.pdf>

Health Watch Table — Down Syndrome <small>Foster-Gibson and Berg 2011</small>	
CONSIDERATIONS	RECOMMENDATIONS
1. HEENT (HEAD, EYES, EARS, NOSE, THROAT) <small>Children and Adults: Vision: ~10% have cataracts.</small>	<small>Neonatology: refer immediately to an ophthalmologist if the red reflex is absent or if strabismus, nystagmus or poor vision is identified.</small>

American Academy of Pediatrics
[http://www.ndss.org/Global/Health_Care_Information_for_Families_of_Child_rep_with_Down_Syndrome%20\(1\).pdf](http://www.ndss.org/Global/Health_Care_Information_for_Families_of_Child_rep_with_Down_Syndrome%20(1).pdf)

Health Care Information for Families of Children with Down Syndrome

Child's Age: 13 to 21 Years or Older

Regular well-care visits (check-ups)

It is important to have yearly well-care check-ups. These visits will assist in checking your child's health, giving shots, and answering questions about your child's health.

Monitor growth

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4. What is communication?

• How people communicate

- Spoken words
- Facial expressions
- Body language
- Gestures
- Voice, sounds
- Pictures
- Sign language
- Writing



• Why people communicate

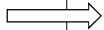
- Meeting needs (getting/refusing things), safety
- Social interaction
- Exchange information
- Build/maintain relationships



Communication Deficits in AD

Cognitive Deficits

- Memory
- Attention
- Problem solving
- Reasoning
- Initiation (starting)
- Inhibition (stopping)



Communication Deficits

- Word-finding
- Paying attention to conversations
- Processing, organizing, remembering information
- Starting conversations
- Expressing needs

Conversations gradually decrease in coherence, focus, quality, and accuracy



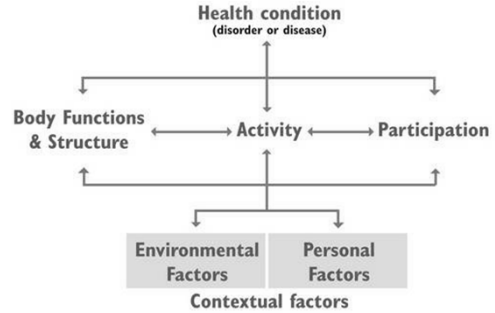
Impact of Communication Deficits

- Unmet needs
 - E.g., pain, hunger, safety
- Confusion
- Distress
- Withdrawal
- Depression
- Behaviour changes
 - E.g., aggression
- Deterioration of relationships

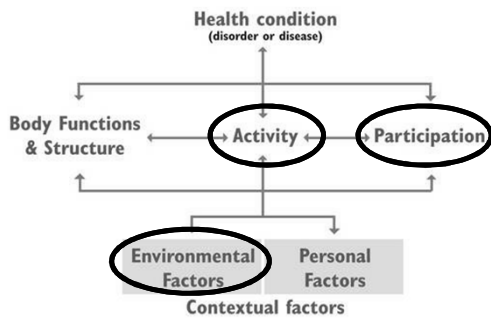
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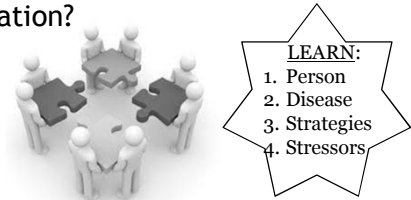
World Health Organization's International Classification of Functioning, Disability, and Health (ICF: WHO, 2011)



World Health Organization's International Classification of Functioning, Disability, and Health (ICF: WHO, 2011)



What is your Role in Supporting Communication?

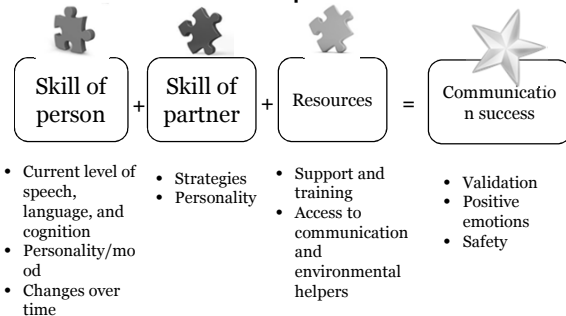


LEARN:

1. Person
2. Disease
3. Strategies
4. Stressors

- Individual can have medical and behavioural intervention
- Family needs support, education, and coping strategies
- Staff needs training and expertise
- Peers also need education and support

Communication Equation:

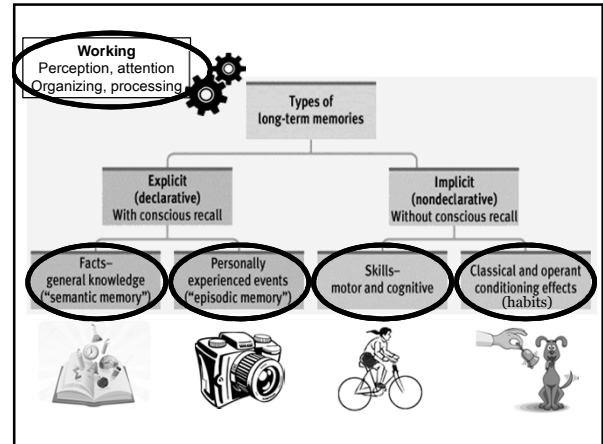
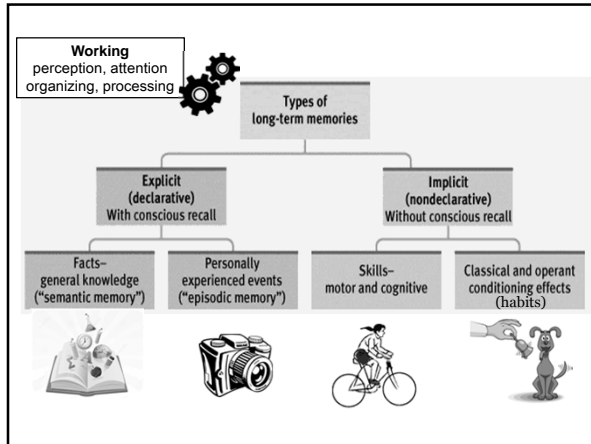


Adapted from Kagan, 1998

Communication at each stage:

What to expect = how to help

Early	Middle	Late
<ul style="list-style-type: none"> • Word-finding issues • Repetitive* • Talk more/less • Following complex conversations • Confusion • Personality changes 	<ul style="list-style-type: none"> • Struggle to speak + understand • Impaired pragmatic skills • Decreased speech clarity 	<ul style="list-style-type: none"> • Severely limited communication • Minimal orientation <p>*swallowing issues</p>



Supported Conversation

- Emphasizes competence of the adult
- Integrate supportive techniques into natural talk
- Only use strategies that are helpful to the specific individual

Information and suggestions are based on Supported Conversation for Adults with Aphasia (SCA) by Kagan et al.

APHASIA INSTITUTE

building communication ramps

Supported Conversation

1. Help get your message IN
2. Help get their message OUT
3. Evaluate

Supported Conversation

1. Help get your message IN
2. Help get their message OUT
3. Evaluate

Supported Conversation Strategies

- Help get the message IN
 - Identify yourself – say your name
 - Use the person's name
 - Minimize distractions
 - Be relaxed and patient
 - Sit still, close enough, face-to-face
 - Eye contact, smile

Adapted from Kagan, 1998

Supported Conversation Strategies

- Help get the message IN
 - Speak clearly, slowly, loudly, gently
 - Use a natural** voice
 - Manageable content + language level
 - 1 message at a time
 - Short, simple sentences
 - Pause frequently between phrases



Adapted from Kagan, 1998

Supported Conversation Strategies

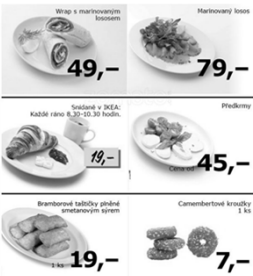
- Help get the message IN
 - Repeat and rephrase
 - Break down instructions into small steps
 - Be specific
 - Avoid negatives
 - Augment words with visuals + gestures



Adapted from Kagan, 1998

Don't just say it, show it

With visuals:



Without visuals:

501	Polievka	29,-
502	120 Vytvar s masovym knedlikom, zelenou a nudliem	49,-
503	120 Smetanova krasavicka s krutom a opeklou slaninou	49,-
504	makrela	
505	120 Hovädí carpaccio s rukolou, parmezánom, limetkou a bagetkou	99,-
506	lamb	
507	120 Udobrá salát s dravcom, kuracím masom, parmezánom a krutom	59,-
508	Salát	
509	120 Sopsky salát	59,-
510	Marinada	
511	120 Smažený sýr, hranolky, domáci tatarka	49,-
512	120 Hrádky s bryndzou, zakysanou smotanou a opraženou slaninou	49,-
513	120 Kufel Gordon blue	129,-
514	120 Smažený vepřový flek s kotlemy, majonézou a bramborovými salát	129,-
515	120 Tostika s kuracím masom, slaninou, čedarom, rajčatami a kuskusom	129,-
516	120 Kufel lung - pao	129,-
517	120 Domáci chrenoburger, americká brambory, salát celerové	129,-
518	120 Anglický roastbeef, hranolky	129,-
519	120 Chili con carne, nachos, zakysaná smotana	129,-
520	120 Hovädí gúľe s krmom, kuskusový knedlík	129,-
521	120 Hovädí sviečka, karľovský knedlík	129,-
522	120 Šalát W&B restaurant (ovce, rukola, vlašské orechy, kukuřičný	89,-
523	120 Steaková fólia, domáci hranolky, sopský salát, bagetka	129,-
524	120 Hovädí celeroburger, kukuřičná omáčka, kuskus	129,-
525	120 Steak s vepřovými kotletami a omáčkou z hrášku	129,-
526	120 Steak s vepřovými panenkami, glazovaná klobása, sladená vlnová omáčka	129,-
527	120 Steak s hovädí sviečkou a omáčkou zo zeleného papry	129,-
528	120 Ruský plnený špenátom a riccou podávaný s mäsom a rukolou	129,-
529	120 Špagety Aglio olio s peperoncino	89,-
530	120 Hřibová rožnica s parmezánom	129,-

Don't just say it, show it

What do you want for breakfast?

Do you want oatmeal or fruit?



Visuals: Demonstrations

Show what to do



Visuals: Objects



Visuals: Pictures

- Washing hands
- Water on
- Hands wet
- Rub hands with soap
- Rinse
- Water off
- Dry

Visuals: Choice Boards

My Outings Choices

park

beach

Visuals: Schedules

Visuals: Schedules

good morning

awake

toilet

breakfast

grooming

get dressed

Visuals: Schedule with Objects

Show steps in routines

Use clear pictures - does your picture make sense to the individual?

Visuals should be large enough for people to see and pay attention to

3cm X 3cm

5 cm X 5cm

7 cm X 7cm

it's your turn Practice sharing information

- An individual with DS and AD is in bed. It is time to get up and ready for an appointment.
- **What would you say and do to communicate this plan and to prepare him for the transition?**

Supported Conversation

- ✓ Help get your message IN
- 2. Help get their message OUT**
- 3. Evaluate

Supported Conversation Strategies

- Help get their message OUT
 - Include the person in conversation
 - Ask one question at a time (vs. bombardment)
 - Ask choice or yes/no questions
 - Reduces demands on episodic memory
 - Encourage discussion with some open-ended questions
 - Calls on semantic memory

Ask questions the individual can answer

Harder

How?

Why?

When?

Who?

Where?

What?

Yes-or-no questions

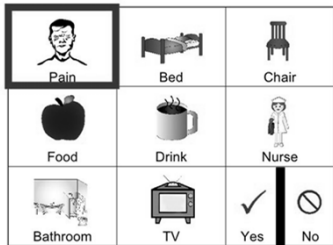
Choice questions

Easier

Supported Conversation Strategies

- Help get their message OUT
 - Give sufficient time to respond
 - Give nonverbal ways to respond
 - Pointing, pictures, gesture, written key words, etc.

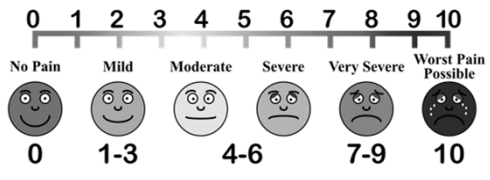
Choices: Basic Needs



Practice getting information

- How can you find out an individual's...
 - Meal preference
 - Need for a break
 - Level of pain

PAIN ASSESSMENT TOOL



Supported Conversation

- ✓ Help get your message IN
- ✓ Help get their message OUT



3. Evaluate: did your strategies work?

Supported Conversation Strategies

validation > accuracy

Look at person's reactions, sounds, body language, facial expressions, mood, behaviour

GOAL: Quality of Life

Ongoing communication is important

- Support functioning, enjoyment, and participation in daily life activities
- Tasks/conversations need to be at the right level
- Social & emotional experience > content accuracy

Ongoing communication is important!

- Cognitive-stimulation programs have beneficial effects for Alzheimer's disease¹
 - Slow the decline for activities of daily living (ADLs)
 - Minimize fear, agitation
 - Maximize participation and social access
- Focus on recognition and procedural aspects of tasks
 - Memory books
 - Errorless learning
 - Sensory cues
 - Priming
 - Spaced-Retrieval Training (SRT)
 - Montessori activities³
 - Breakfast Club
 - Stuffed animals²



¹Quayhagen et al. (1995); Bach et al. (1995); ²Bailey, Gilbert, Herveyer (1992); ³Camp, 1999

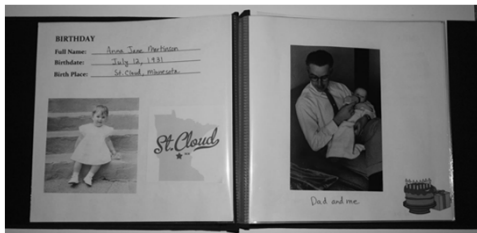
Memory Books

- Birthday
 - Where you lived
 - Family names
 - Likes/dislikes
 - Activities
 - Jobs
 - Trips
 - Timeline
- + life record, preserve identity
 - + recognition, rehearsal
 - + engaging
 - + prompts interactions
 - + reduce demands, anxiety

* Label all photos with specific details
 * Start young + participate as much as possible

Examples of Memory Books

Large pages, pictures with labels, and a small amount of text as captions



Examples of Memory Books

- Too much text
- Visually busy



Examples of Memory Books

- Containing objects, textures, and keepsakes = multisensory






Memory Books

Hopper, T. (2017)

DO	DON'T
Suitable content, font Simple labels/captions	Cluttered Heavy text
Smile, show interest Guide topics Help when stuck	Quiz Frequently redirect topic Contradict


Sharing Information	Supporting Expression	Managing Behaviour
<ul style="list-style-type: none"> Reduce distractions Make yourself visible Speak slowly + clearly Simplify language 1 message at a time Concrete and specific words Emphasize key words Repeat, rephrase Gestures, demos VISUALS 	<ul style="list-style-type: none"> Be calm + attentive Body language Give time to process and respond Offer choices Avoid bombardment Do not speak for the person 	<ul style="list-style-type: none"> Prevention (triggers) Make yourself visible Reassure Use calm and normal voice level Offer prompts/choices Reduce demands Break tasks into steps Distract from situation

Modify Lifestyle Risk Factors

- Manage health issues
- Regular physical activity
- Healthy, balanced diet
- Quality sleep
- Cognitive stimulation
- Social stimulation


Resources



- Please email jillian@dsrcf.org to request handouts regarding:
 - Associations and organizations
 - Free information resources
 - Recommended books and DVDs
 - Online options for memory books and pictures symbols


Finding an SLP

- Alberta College of Speech- Language Pathologists and Audiologists
 - <http://acslpa.ab.ca/>




Finding an OT

- Alberta College of Occupational Therapists
 - acot.ca/
 - Look for OT's who specialize in 'Geriatrics' and/or 'Mental Health'



Alzheimer's Society of Alberta

- <http://www.alzheimer.ca/ab>



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