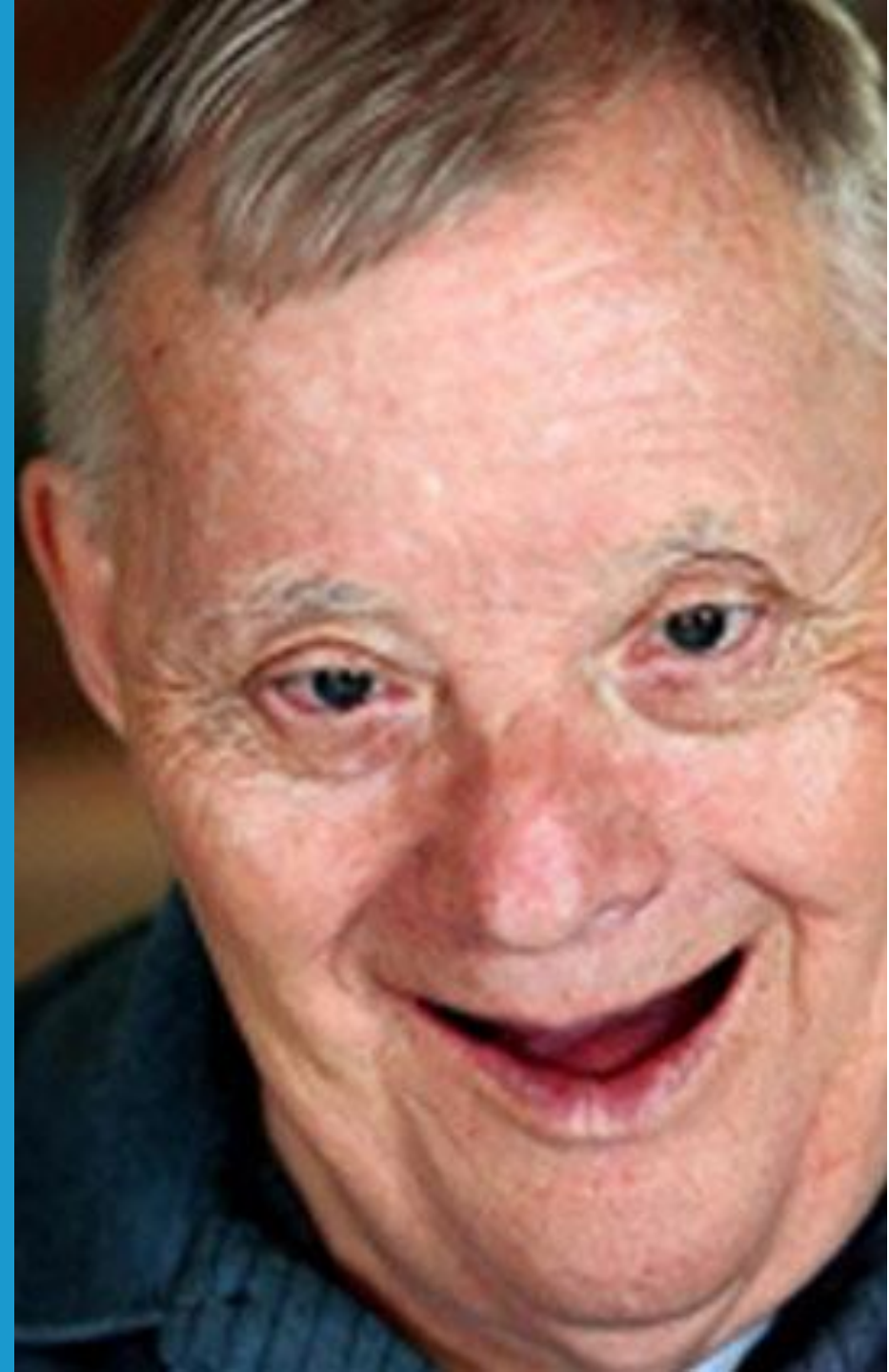


Down syndrome and Aging



Jennifer van Gennip
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A few facts about Down syndrome:

- Trisomy 21: 3 copies of 21st chromosome
- 1 in 800 live births in Canada, universal across race and gender.
- Not a disease or disorder

Down syndrome:

Named after John Langdon Down who described it as a distinct set of characteristics in 1866, and thus it is referred to as Down syndrome (*not Down Syndrome or Downs Syndrome or Down's Syndrome*).

Person 1st:

Client with Down syndrome,
not a Down's client.





**Life Expectancy
in 1982**



**Life Expectancy
in 2016**

VARIABILITY

An individualized approach is needed.



SUCCESS STRATEGIES

Related to the **individual** person (and family) needing services

- ✓ Medical comorbidities, behavioral/mental health issues, level of intellectual functioning

Related to the **providers** of services

- ✓ Education/knowledge, attitudes, support

Related to the **institutions** within which people receive and provide services

- ✓ Collaboration, resources, philosophy of care



Accelerated Aging



Accelerated Aging: Medically, physically, functionally

→ **Sensory Loss** (Vision and Hearing)

At higher risk for cataracts, conductive hearing loss, and ear wax impactions.

Can be mistaken for stubbornness, confusion, or disorientation.

Recommendation: ear cleaning, vision and hearing screening.

→ **Hypothyroidism**

Symptoms of fatigue, sluggishness, weight fluctuation and irritability.

Recommendation: test for thyroid abnormalities.

→ **Obstructive Sleep Apnea**

Common and often undetected in adults with Down syndrome. Symptoms of snoring, daytime sleeping fragmented sleep, irritability, poor concentration, behaviour changes.

Recommendations: Monitor sleep patterns, and consult primary care doctor to discuss need for a sleep study.

→ **Osteoarthritis**

People with Down syndrome are often hyperflexible. Over years this can lead increased risk of osteoarthritis. Is painful and can lead to decreased mobility, decreased willingness to participate in activities.

Recommendation: Pain can be under-reported and/or expressed in negative behaviour. Discuss possibility of underlying arthritis with primary care doctor.

→ **Osteoporosis**

People with Down syndrome are at a higher risk for this disease, especially if there is family history or immobility.

Recommendation: Bone density screening.

→ **Atlantoaxial Instability and Cervical Spine Concerns**

Increased instability between the “atlas” and the “axis” spinal bones. Also at risk for gradual narrowing of the spinal canal.

Recommendation: Watch for weakness in arms or hands, walking instability, or incontinence.

→ **Celiac Disease**

Recommendation: Consider a screening test if weight loss, poor nutrition, or persistent change in bowel habits.

→ **Alzheimer's Disease**

Down syndrome and Alzheimer's disease share a genetic connection.

Estimated that 30% of adults with Down syndrome in their 50s will get Alzheimer's disease, 50% of adults in their 60s. Never does it reach 100%.

Adults with Down syndrome are at an increased risk for Alzheimer's disease, but Alzheimer's is not inevitable.

A thoughtful approach to diagnosis is needed, ruling out other medical issues.

Recommendation: establish a baseline, and undertake formal memory screening.

ALZEIMER'S DISEASE

Traditional incentives no longer work, ability to learn and recall new rules is no longer possible, logic- or reason-based negotiations will lead to frustration.

Positive nonverbal communication (tone of voice, facial expressions body language), use positive or neutral language to redirect, short simple words and sentences, provide choices vs. open ended questions, be patient.





Quality of Life in LTC



BEING

BELONGING

BECOMING



FITTING IN

Identified as the biggest issue (48%) in a survey.

Transition with worker from previous care facility.

Look to maintain similar types of activities.

Action Item: prioritize having a familiar staff from the previous facility involved in the transition.



MEANINGFUL RELATIONSHIPS

Same survey suggests opportunity for meaningful relationships among residents goes up when grouped with other residents with intellectual disabilities.

Action Item: work to facilitate a meaningful relationship. If a suitable pairing cannot be made in the facility, consider the internet.



Maintain friendships and contacts.

Community integrations and connections.

Allow for “retirement” or reduced hours.



INCLUSION

Not just in the big things, but the little things as well.

Importance of Perception, Personal Control, Self Image, Empowerment.

Action Item: make a list of the small things that could be changed to increase opportunities for choices and feeling of personal control.

**CHOICE +
INCLUSION +
OPPORTUNITIES=
WELL BEING**



ENVIRONMENT

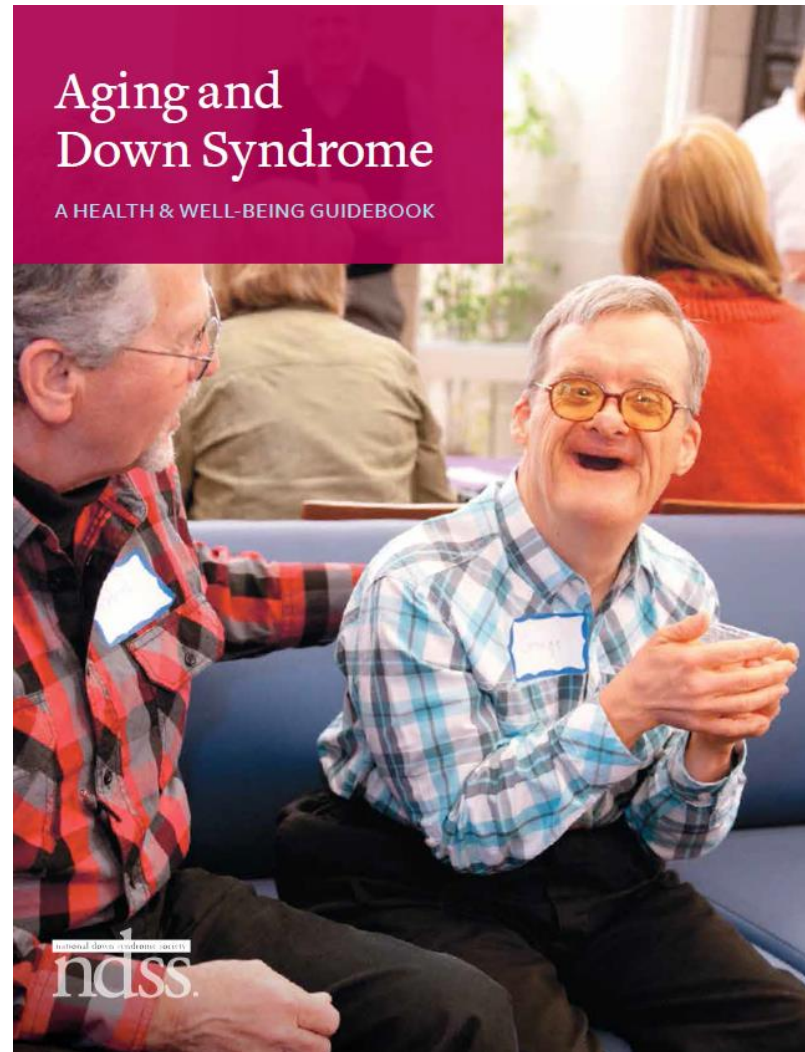
Finding the balance between a calming environment, which still offers appropriate levels of stimulation and community.

“Dementia-friendly” institutions.



RESOURCES

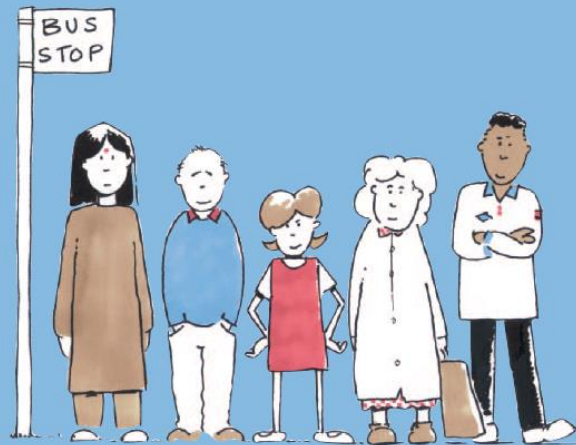




www.ndss.org/Resources/Aging-Matters



What is DEMENTIA?



A booklet about dementia
for adults who have a learning disability

Down's Syndrome
SCOTLAND helping people make their potential

VS-draft



National Task Group on Intellectual
Disabilities and Dementia Practices

The NTG FAQ: Some Basic Questions about Adults with Intellectual/Developmental Disabilities Affected by Alzheimer's Disease or Other Dementias

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Alzheimer's and related dementias

**Q1. What is
cognition?**

A1. "Cognition" is a term used to describe our mental processes and activities, such as attention, memory, language understanding and expression, solving problems.

**Q2. What is
dementia?**

A2. "Dementia" is a term used to describe cognitive decline from any cause (e.g. brain disease, head injury, stroke, or loss of oxygen to the brain) that results in impaired personal, social, or occupational adaptation. It is persistent and progressive and is associated with a chronic generalized brain disorder, such as Alzheimer's disease, or a multifocal neurological condition, such as multiple strokes involving several discrete areas of the brain.

Dementia resulting from Alzheimer's disease is the most common type

Down syndrome and Aging



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