

AGING WITH A DEVELOPMENTAL DISABILITY PLANNING FOR SUCCESS

Aging with a Developmental Disability



AN INFORMATIVE GUIDE
THAT MAKES IT EASIER AND
FASTER TO ACCESS HEALTH
AND SENIOR SERVICES
ACROSS ONTARIO.

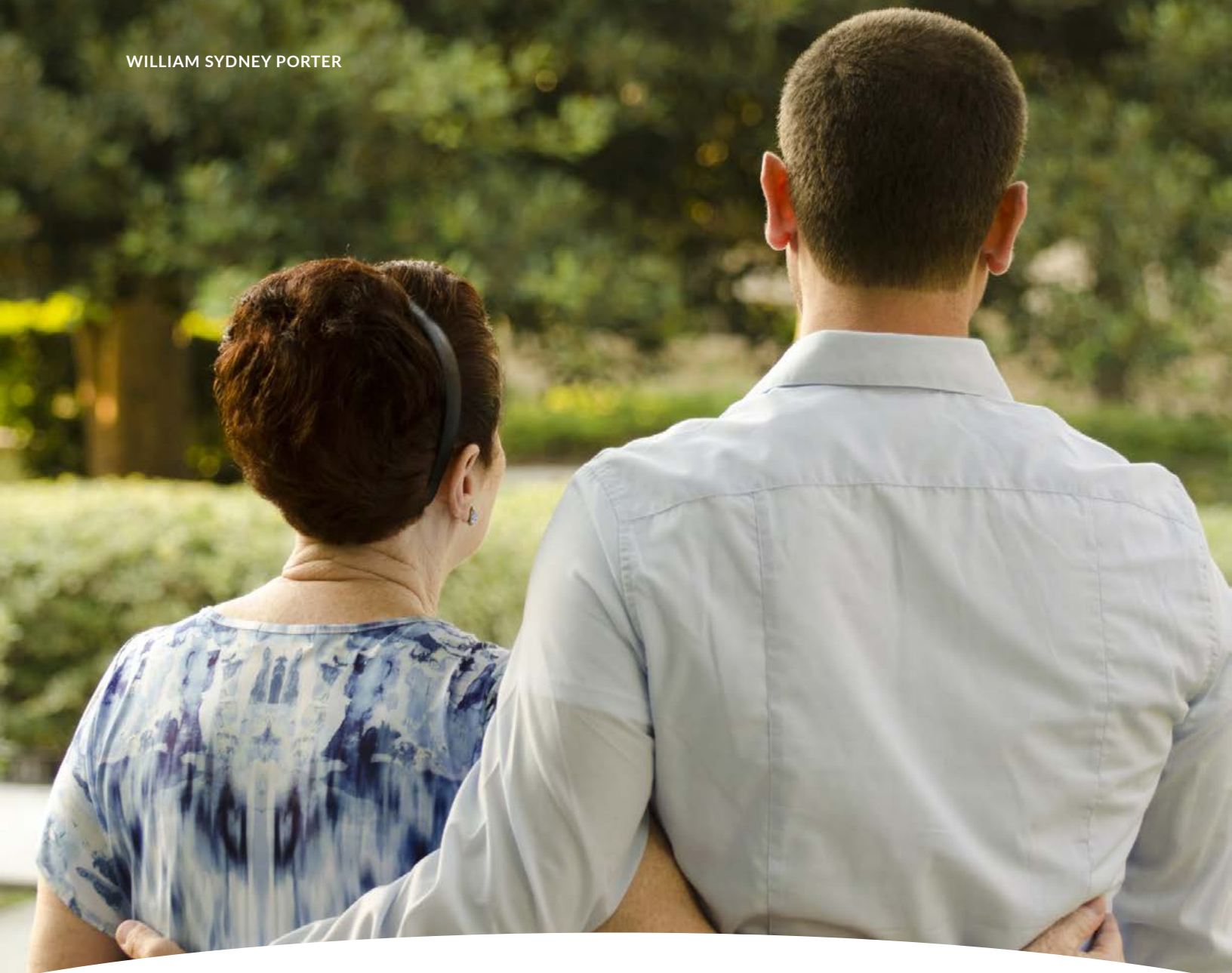
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No friendship is an accident.

WILLIAM SYDNEY PORTER



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Support



Reena was established as a practical alternative to institutions to provide support for individuals with developmental disabilities and their families.



Mary Centre assists people in building a good life by creating new opportunities for adults with developmental disabilities, their families and the community.

The Guide

The focus of the Guide is to increase awareness of the aging process for persons with a DD (and their caregivers), promote healthy lifestyles and early planning to aid in successful aging, and to include related resources.

Contact Us

If you'd like more information or have any questions, let us know how we can help.

Email support at
info@agingdd.com

We would be
happy to assist.

AGING WITH A DEVELOPMENTAL DISABILITY (DD)

Overview and Definitions



In this section, aging with a DD from a historical perspective, and insights about current research and aging with a DD are discussed. The aging process, and strategies to manage changes, including self-assessments, checklists and screening tools will be introduced.

It is important to first clarify what is meant when using the term aging, developmental disability (DD) and intellectual developmental disability (IDD). In some cases, service providers use the term developmental disability, developmental delay, or learning disability, on an interchangeable basis. When using the term intellectual developmental disability, some service providers mean a diagnosis of both intellectual disability and mental health challenges (e.g., depression). In addition, some persons with a developmental disability prefer the term intellectual disability, or “labelled with an intellectual developmental disability”, as they may not find the terminology useful or appropriate.

For the purposes of this section of the *Guide*, here is what is meant when using the following terms:

“**Aging**” is a developmental process that starts at birth and involves gradual changes in body structures and systems (Nochajski, S., 2000). In this *Guide*, the term aging refers to someone who is 55 years of age or older and who is younger than 55 and beginning to experience age related changes.

“**Adults with a Developmental Disability (DD)**” in this *Guide* includes adults with intellectual and developmental disabilities including learning disabilities and autism spectrum disorder. Consistent with the definition used in the *Primary Care of Adults with Intellectual and Developmental Disabilities: 2018 Canadian Consensus Guidelines (2018 p. 254)* DD refers to “...various lifelong limitations in intellectual functioning and conceptual, social, or practical skills that develop in persons before the age of 18 years”. Limitations may differ in severity and type among persons with a DD and can vary during the lifespan.

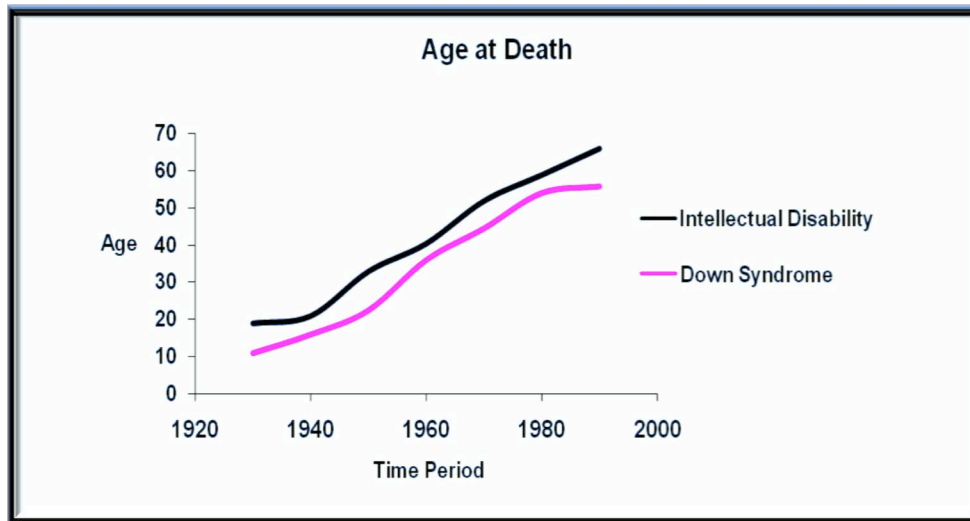
A growing population of persons with a DD, along with their caregivers and families, are living much longer than previously expected. As they age, these individuals will experience diverse medical, functional, independent living and social needs in a range of settings including home, long - term care homes, and group homes.



Historically, the average life expectancy of persons aging with a DD and living in Canadian institutions in 1976 – 1978 was 36.6 years for males and 37.9 years of age for females. This is not the case today! According to MAPS (Multidimensional Assessment of Providers and Systems) the number of older adults with a DD in Ontario (45-84 years of age) is projected to increase by as much as 20.5% between 2010 and 2021. Advances in

health care, new technology, improved environments and living conditions, and access to community health and social service supports likely account for this significant rise in life expectancy. See the comparison of the average age of death and time period for persons aging with a DD in the graph below.

COMPARISON OF AGE OF DEATH & TIME PERIOD FOR PERSONS WITH A DEVELOPMENTAL DISABILITY



Carter & Jancar, (1983) and Janicki, Dalton, Henderson, & Davidson (1999)

Today, many persons with a DD can enjoy the same life expectancy as the general population. At the same time, evidence suggests that for persons with a DD, the effects of aging begin earlier, progress more quickly, and/ or present differently, which can pose a challenge when making assessments. For example, many persons aging with a DD have existing hearing and vision impairments that may become exacerbated with age or experience early onset of vision and hearing loss. As well, genetic predisposition to develop Alzheimer Disease (AD) for persons with Down Syndrome and diabetes with Prader-Willi Syndrome has also been linked, which may result in the caregiver and/or family struggling to be able to provide the necessary supports in the community. Additionally, it has been noted that the combined experience of aging and disability may result in extra discrimination and/or isolation for the person aging with a DD. This knowledge adds to the complexity of the aging process and increases the challenges facing caregivers and families of persons aging with a DD. The necessity to start planning early with caregivers and family members, can't be emphasized enough!



Plan Early

Historical Background– The End of an Era

In Ontario, having persons aging with a DD residing in institutions away from their families and communities was the trend spanning over 133 years, from the opening of the first institution in 1876 to the closing of the final three facilities in 2009 (Brown & Radford, 2015).

On March 31st, 2009, Ontario closed the last institution. This was a historic event, which spoke to the philosophy of “normalization” for persons with a DD, and the right to live safely in the community with the support of caregivers, family, community services, and housing options. Brown and Radford (2015 pg. 25) claimed that,

“The closing of the last institutions takes away this physical representation and offers us an opportunity to re-conceptualize disability in another way. Today, this opportunity has emerged as a set of values that support the overall goals of social inclusion & enhanced quality of life: respect for the place of a full range of abilities and skills within our broader culture; the value and dignity of each person’s life; the right to participate fully in the community life of our choosing; opportunities from which to choose and the freedom to make choices; and the celebration of one’s individuality in concert with social and cultural participation”.

The picture below is the first institution built and one of the last institutions closed. It was renamed in 1973 as the Huronia Regional Centre (Oosterom, 2013).

THE ASYLUM FOR IDIOTS AND FEEBLE-MINDED, ORILLIA, 1876



Courtesy Archives of Ontario

Since the closures of the institutions and the creation of the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008* (Government of Ontario, 2009), persons with a DD are “increasingly becoming empowered, asserting their rights, and working to create social networks” (Brown & Radford, 2015 pg. 24).

Research on Aging with an Intellectual and Developmental Disability (IDD)

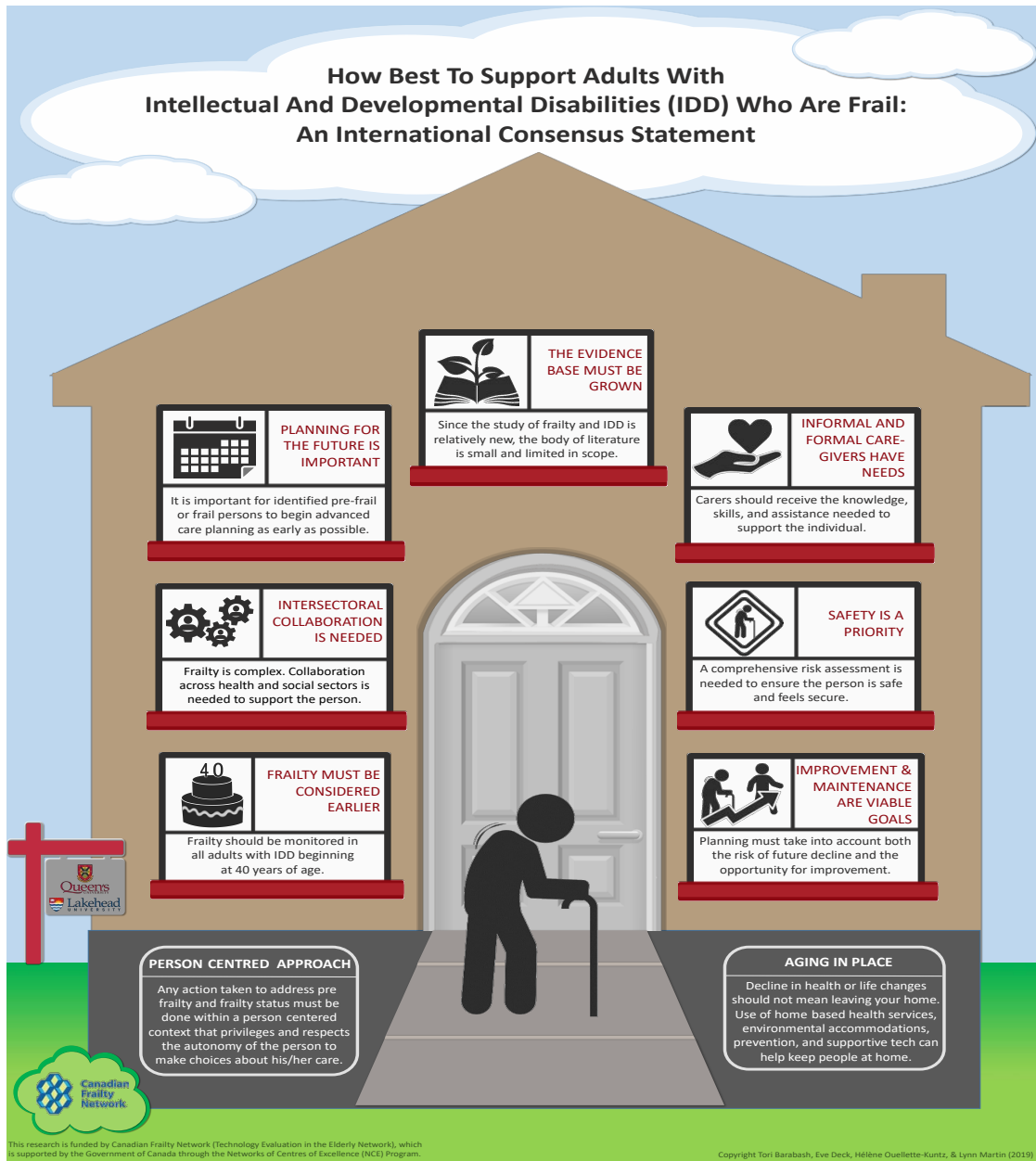
Canadian research on aging among adults with a DD is limited. Evidence - based best practice guidelines to support persons aging with a DD and their caregivers and families are beginning to emerge. In particular, an international consultation was undertaken with the aim of producing an “*International Consensus Statement of the Best Approaches to Supporting Individuals with Intellectual and Developmental Disabilities*” as they age and/or become frail. According to researchers McKenzie, Ouellette-Kuntz, and Martin, (2019), the purpose of the statement was two fold:

- I. Promote awareness of frailty in the field of DD with “**frailty**” defined as:

“...a multi-dimensional state of vulnerability, with cognitive, social, psychological & biological deficits, as well as environmental aspects associated with aging and adverse outcomes (e.g., falls, hospitalization, institutionalization, and mortality)”- Ouellette-Kuntz, H. et al (2018).
- II. Guide support and care planning considerations when a person is identified as frail or pre-frail.

The *International Consensus Statement* (2019) includes two core principles and seven recommendations to consider using when supporting persons aging with a DD and their caregivers/families.

The illustration below reflects the purpose of the statement and seven core principles/ recommendations.



Used with permission by Ouellette-Kuntz, H., Martin, L., Burke, E., McCallion, P., McCarron, M., McGlinchey, E., Sandberg, M., Schoufour, J., Shoostari, S., & Temple, B. (2019). How best to support individuals with IDD as they become frail: development of a consensus statement. *Journal of Applied Research in Intellectual Disabilities*, 32(1), 35-42.

Core Principles

1. *Apply a person-centered approach to planning*, which respects the autonomy of the person with a DD to make choices about their care.
2. *Aging in place is a priority*. Utilize home - based health and social services, environmental adaptations, and use of technology as ways to maximize independence

and safety within the community of choice.

Summary of Study Recommendations

The seven recommendations below are derived from the study with supplemental case scenarios, checklists, etc., to support the recommendations.

1. Frailty must be considered earlier than in the general population.

Persons with a DD experience higher rates of frailty and earlier onset of aging. Researchers McKenzie, Ouellette-Kuntz, and Martin, (2017) found that the presence of frailty is three times higher among adults with intellectual and DD. Their study recommends that frailty and aging should be monitored in *all* persons with an intellectual and DD “beginning at 40 years of age, and possibly earlier in some sub-groups (e.g., Down Syndrome), given that they accumulate frailty deficits more quickly”.

Furthermore, in their study, the researchers noted that “when issues related to frailty are identified, this knowledge leads to actions that have the potential to improve the individual’s status and functioning over time” (Ouellette-Kuntz & Martin, June 2019, p.1). Improving a person with a DD’s status over time may include earlier interventions such as: participation in adult day programs (which emphasizes memory improvement and socialization), rehabilitation and exercise programs, and linkages to other health and social services. The Table below reflects key physical differences in aging with a DD as compared to general aging.

Note: Additional information about general aging and aging with a DD, including screening and recommendations, will be discussed further in this section.

TABLE: PHYSICAL AGING WITH A DEVELOPMENTAL DISABILITY

SYSTEM/ ORGAN/CELL	EARLY ONSET WITH A DD	COMMENTS*
Central Nervous System <ul style="list-style-type: none"> • <input type="checkbox"/> Brain • <input type="checkbox"/> Neurons 	X	Epilepsy occurs in about 1 in 5 persons with a DD compared with 1 in 100 persons without a DD. The prevalence increases with the severity of a DD. It contributes to early mortality. It can be difficult to diagnose. Choice of medications and importance of regular monitoring are the same as for those in the general population.

		Increased incidence of developing Alzheimer's Disease in persons with Down Syndrome.
<p>Cardiovascular</p> <ul style="list-style-type: none"> • <input type="checkbox"/> Heart 	X	<p>Cardiovascular disease is prevalent among people with DD, especially those with Down, 22q11del, and Prader-Willi syndromes. Risk factors for cardiac disorders are also increased owing to physical inactivity, smoking, obesity, and prolonged use of certain psychotropic medications.</p> <p>Congestive Heart Failure (CHF) is three times higher than in the general public.</p>
Respiratory	X	<p>Respiratory disorders (e.g., asthma, Chronic Obstructive Pulmonary Disease (COPD), aspiration leading to lung infections) are more common in adults with a DD.</p> <p>Respiratory disorders (e.g., aspiration pneumonia) are among the common causes of death for people with a DD. Swallowing difficulties can increase the risk of aspiration or asphyxiation. Such difficulties are prevalent among people with neuromuscular dysfunction (e. g., cerebral palsy) or those</p>

		who are taking medications with anticholinergic effects.
<p>Sensory</p> <ul style="list-style-type: none"> • <input type="checkbox"/> Eyes • <input type="checkbox"/> Ears • <input type="checkbox"/> Chewing & Swallowing 	X	<p>Impairments in hearing, vision, and dental health among adults with DD are often underdiagnosed and can result in changes in behaviours and adaptive functioning.</p> <p>Ear wax build up is more common with persons with a DD.</p>
<p>Muscular Skeletal</p>	X	<p>Musculoskeletal disorders (e.g., scoliosis, contractures, spasticity, and ligamentous laxity) are possible sources of unrecognized pain and occur frequently among people with DD, especially those with cerebral palsy.</p> <p>14% of persons diagnosed with Down Syndrome have spinal column instability and joint problems of the neck, knees, and hips, which may cause neck and joint pain, loss of balance, and gait changes contributing to a greater risk of falls.</p> <p>Osteoporosis and osteoporotic fractures are more prevalent and occur at a younger age among people with DD than those in the general population. Potentially, this is attributed to impaired mobility/lack of weight bearing and long-</p>

		<p>term use of specific medications (e.g., psychotropic, and anti-seizure medication).</p> <p>Risk is often compounded by limited physical activity and diets low in calcium and Vitamin D.</p>
<p>Cognitive/Mental Health</p>	<p>X</p>	<p>Persons with a DD have increased vulnerability to mental stress compared to those in the general population.</p> <p>Developmental challenges, transitions, greater exposure to adversity and traumatic life events, limited coping skills, and insufficient supports contribute further to this vulnerability.</p> <p>Dementia (major neurocognitive disorder) is more prevalent among adults with a DD compared with the general population (age of onset 60-65 years), with a statistically significant increased risk in adults with Down Syndrome and at an earlier age (50-55 years). A diagnosis might be missed because changes in emotion, social behaviour, or motivation can be gradual and subtle.</p> <p>Differentiating dementia from depression and</p>

		delirium can be especially challenging in adults with a DD.
Endocrine	X	<p>Endocrine disorders can be challenging to diagnose in persons with a DD. They have a higher incidence of thyroid dysfunction compared with those in the general population.</p> <p>The prevalence of diabetes is higher among persons with a DD compared with those in the general population and slightly higher among women than men.</p> <p>Persons with Prader-Willi Syndrome are predisposed to developing Type 2 Diabetes.</p>

*Comments are based on the *Primary Care of Adults with Intellectual and Developmental Disabilities: 2018 Canadian Consensus Guidelines* (Canadian Family Physician, Volume 64(4): April 2018, p254-279) and Health Check (Surrey Place)

2. Improvement and maintenance are viable goals.

Improvement opportunities (e.g., rehabilitation) and maintenance are viable goals for those identified as frail. Planning must take into account both risks of future decline and opportunities for improvement.

Using the study recommendation, consider how the case study below reflects how important rehabilitation can impact quality of life outcomes.

What Went Wrong – The JR Story?

John R. a 56- year old man with a DD, lived on the third floor of a triplex group home in an urban area. John was able to manage his activities of daily living (ADLs) with verbal prompting. He attended a day program five days per week and was independent with his ambulation. John also enjoyed participating in many group activities in the community.

In January, John was admitted to the hospital for bowel obstruction and underwent bowel surgery for the removal of part of his colon. After a short period of time, the hospital staff were anxious to discharge John, as he was now deemed medically stable - despite some new limitations e.g., with mobility, toileting, eating, etc., after the surgery.

The group home manager and supervisor attended a discharge planning meeting at the hospital. John's two sisters were also present. The hospital staff that attended the meeting were John's physician, nursing staff, the Occupational Therapist (OT), Physiotherapist (PT), plus the hospital Social Worker.

The group home manager and supervisor explained who John had been prior to hospitalization. They both raised concerns with hospital staff that it would be impossible in John's current condition for him to return to his home, in particular based on the layout and staffing model. The group home manager advocated for convalescent care at this point.

All the hospital staff remained firm in their assessment that John would not be eligible for convalescent (rehabilitation) care as he could not self-propel to get to the Physiotherapy Department. John's sisters looked to the hospital for advice and direction, as would be expected given the differing recommendations.

The group home manager explained that they could assist and support John in the convalescent care setting with hours of support including providing an independent Physiotherapist. The group home manager reinforced the underlying rationale - that she was hoping for some additional time and opportunity for John to continue improving so that he could return to his own home.

The hospital staff insisted that John was not eligible, focusing on how they would physically get him back to his home. Their plan was to physically carry him into his apartment on the third floor, which was not accessible, and where he would have been a virtual shut in.

Three weeks later, a visiting Registered Nurse (RN) from Home and Community Care came to assess John. The RN raised some serious concerns about John's health status and current care at home, and determined that John was dehydrated, due to 7-10 loose stools/day (due to the removal of some of his colon), not eating, was suffering from a urinary tract infection, that catheterization had not been done at all in the last day (the order was for catheterization three times/day), and that John was in pain during his care due to an intense raised rash in his groin area. He also had the early stages of developing a pressure ulcer as he rarely managed to get out of bed.

It was recommended that John return to the hospital and have a permanent G-tube inserted to supply him with necessary nutrients, a permanent catheter

inserted, appropriate and effective pain killers, and treatment for his groin area and developing pressure ulcer.

Eight months later, John was admitted to a Long - Term Care Home.

3. Inter- sectorial collaboration is needed to coordinate comprehensive, multidisciplinary assessments and actions.

Collaboration among health and social service sectors is complex and often fragmented with duplication of assessments, communication barriers etc. There is an urgent need to work together, maximizing services and supports. The researchers recommend that, "...advocacy, care coordination, case management, and planned follow-up are required to ensure that plans are implemented, actions are monitored, and supports/services are responsive to new and emerging needs".

Based on their findings, the researchers also recommend:

1. Training to build capacity in the developmental sector related to frailty.
2. Development of a formal data sharing agreement.
3. Development of intersectoral collaboration protocols.

Note: Resources for forming inter-sectorial partnerships identified by the researchers are listed below:

Partnership Self-Assessment Tool

The Partnership Self-Assessment Tool is a questionnaire that various partners can complete to examine the strengths and weakness of the partnership. Answers can help guide organizations and individuals to make the partnership increasingly successful. The tool measures a key indicator of a successful collaborative process: synergy (partnership synergy).

https://atrium.lib.uoguelph.ca/xmlui/bitstream/handle/10214/3129/Partnership_Self-Assessment_Tool-Questionnaire_complete.pdf?sequence=1&isAllowed=y

The Partnership Handbook

This tool provides practical tips, checklists, stories and strategies to help develop, sustain and evaluate a partnership. For instance, the guide includes checklists and questions to assess individual and organizational skills for partnering, partnership readiness and steps for closing a partnership.

<http://publications.gc.ca/site/eng/245551/publication.html>

Self-Evaluation Tool for Action in Partnerships

This tool allows members of partnerships to evaluate themselves and learn about the requirements for effective partnership work.



<https://en.healthnexus.ca/>

Note: As part of creating the guide, *Aging with a Developmental Disability: Planning for Success (2020)*, health and social service sectors met to discuss how to work together to support persons aging with a DD. High-level Cross-Sector Planning and a Partnership Framework was developed. In addition, a sample Integrated Care Plan was developed and is included within the *Guide* to assist with communication and care planning across the sectors, and to promote discussion and early planning among persons aging with a DD, their caregivers/families.

4. Safety is a priority.

A proactive approach is required to ensure that the person is safe and secure in their chosen environment. A comprehensive risk assessment, which takes into account the persons autonomy (e.g. choice of risk), is required. Action plans related to safety risks should be developed and revised as the situation changes in collaboration with the person aging with a DD, their caregiver and family.

The following checklist may be helpful when reviewing safety risks in a home or apartment.

SAMPLE HOME SAFETY & RISK CHECKLIST

Date: _____

CATEGORY/LOCATION	YES	NO/NA	HAZARD/ACTION
EXTERIOR OF HOME/APARTMENT/GROUP HOME /OTHER	YES	NO/NA	HAZARD/ACTION IN COLLABORATION WITH PERSON WITH A DD
Home/Housing Building: <ul style="list-style-type: none"> • <input type="checkbox"/> Location (e.g. in high crime/unsafe area) • <input type="checkbox"/> Controlled entry • <input type="checkbox"/> Designated public entry doors • <input type="checkbox"/> Clear sightlines to entrance (landscaping, layout, & 			

bushes blocking entrance) • <input type="checkbox"/> Maintained landscape (e.g. grass cut, bushes trimmed) • <input type="checkbox"/> Well - marked address • <input type="checkbox"/> Security cameras • <input type="checkbox"/> Accessible transportation • <input type="checkbox"/> Other			
Outdoor lighting in place with motion/movement detectors			
Driveway & paths in good condition, easily accessed & free of slip & trip hazards (e.g. leaf litter, small twigs, weeds, moss, ice/snow, excess shrubbery, overhanging branches)			
Entrance, basement and/or second story steps have handrails that are: • <input type="checkbox"/> Securely in place • <input type="checkbox"/> On both sides			
Steps in good condition: • <input type="checkbox"/> Non slippery surface • <input type="checkbox"/> Steps in good repair, elevator in good working order			
Other			
GENERAL INTERIOR OF HOME/APARTMENT/GROUP HOME / OTHER	YES	NO/NA	HAZARD/ACTION IN COLLABORATION WITH PERSON WITH A DD
Room temperature suitable (e.g. not excessively cold/hot/humid conditions & heater/air conditioner in place Other environmental issues:			
Working smoke & carbon monoxide detectors in place			
Floor surfaces & coverings: • <input type="checkbox"/> In good condition • <input type="checkbox"/> Free from excessive wear, loose boards, and • <input type="checkbox"/> Free of trip hazards (clutter,			

scatter rugs, throw carpets, loose tiles).			
Furniture arranged so persons can move easily & safely <ul style="list-style-type: none"> • <input type="checkbox"/> Waste management in place • <input type="checkbox"/> No evidence of “hoarding” 			
Furniture stable, sturdy, at height so persons can easily sit, transfer & stand			
Sufficient space to accommodate persons: equipment, furniture (Kitchen, Living Room etc.)			
Electrical leads, plugs, socket & power points/cords free from obvious defects, not overloaded, accessible & safe			
Adequate lighting to perform Activities of Daily Living			
Evidence of pests, bedbugs, & other infestation			
Pets: <ul style="list-style-type: none"> • <input type="checkbox"/> Evidence of suitable care (feeding, hydration & elimination) 			
Evidence of satisfactory: <ul style="list-style-type: none"> • <input type="checkbox"/> Emergency contact list • <input type="checkbox"/> Cleanliness (e.g. vacuuming, dusting, washing dishes etc.) • <input type="checkbox"/> Laundry services • <input type="checkbox"/> Food management (e.g. shopping, meal preparation, nutritional choices) • <input type="checkbox"/> Transportation to appointments/social activities 			
BATHROOM/SHOWER AREA	YES	NO/NA	HAZARD/ACTION IN COLLABORATION WITH PERSON WITH A DD
Clear path between bedroom &			

bathroom			
Floor surfaces suitable: non-slip mat, slip resistant surfaces			
Bath & toileting safety equipment in place (if required): <ul style="list-style-type: none"> <input type="checkbox"/> Grab bars <input type="checkbox"/> Tub clamps <input type="checkbox"/> Bath seat/ transfer bath seat <input type="checkbox"/> Raised Toilet Seat <input type="checkbox"/> Saska Pole (stationary lift pole) <input type="checkbox"/> Bathmat 			
Hot water temperature is easy to regulate			
Other			
MOBILITY	YES	NO/NA	HAZARD/ACTION IN COLLABORATION WITH PERSON WITH A DD
Wears shoes with good support, non-slip soles			
Mobility devices (cane, walker, wheelchair, lifts, transfer equipment etc.) in good working order			
History of falls or frequent falls <ul style="list-style-type: none"> <input type="checkbox"/> A Falls Risk Assessment should be completed if falls are reported (See section below for sample Falls Risk Assessment). 			
Other			
MEDICATION MANAGEMENT	YES	NO/NA	HAZARD/ACTION IN COLLABORATION WITH PERSON WITH A DD
Medication compliance system in place (e.g. dosette, blister pkg. or original container)			
Medication expiry dates reviewed and if expired disposed of			
Sharp box in place (if required)			

and is it disposed of safely			
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Adopted from Quality Healthcare Management (2019)

5. Planning for the future is important.

Early and continuous advanced care planning is critical with the person aging with a DD. Documentation of the person’s preferences and wishes for the future is essential, and should include supported decision-making, advanced care directives, living arrangements, and financial security (See Aging and Financial Planning section --- & other sections TBD).

Surrey Place has additional information, guidelines, recommendations, tools and resources to access for transition planning. See attached link below:

<https://ddprimarycare.surreyplace.ca/>

6. Informal and formal caregivers also have needs.

Informal and formal caregivers are often challenged by the need to balance the complex needs of caring for a person aging with a DD and their own needs. Caregiver and family member needs should be included in the planning process with attention to health and wellness, emotional, spiritual support and respite care (See next section related to health promotion . As the needs change with the person aging with a DD, caregivers and families require appropriate and timely education on the skills and care required.

“I’m not sure what you mean by a plan? We plan to deal with events or change as they occur”.
Caregiver Survey Respondent

Note: During the consultation process of developing the *Guide*, caregivers were asked in the Caregiver Survey (2018), “What are the biggest barriers” they have encountered in caring for a person with a DD? The response was:

1. 64% experienced difficulties balancing caregiver responsibilities with other life responsibilities.
2. 45% finding time/space to care for themselves.
3. 45% access to knowledge and what is available.

An additional question was asked from the Caregiver Survey (2018), “Have you completed a plan” for when you are no longer able to care for the person with a DD? The response was:

- 14% had completed a plan and shared it with their service providers.
- 31% had not begun a plan.
- 14 % partially completed a plan.
- 33% in various stages including not knowing where to locate a template or send a plan to.

7. The evidence base must be grown.

The study of aging and frailty with persons aging with a DD is limited. Additional research should be given priority to support the development of evidence - based best practice guidelines.

Frailty Assessment in Persons Aging with a DD and Additional Research

Recognizing that persons with a DD often show signs and symptoms of aging earlier than those without a DD, a research team co-led by Drs. Hélène Ouellette-Kuntz and Lynn Martin. (2015) developed a valid frailty index for adult home care users with intellectual and DD.

The research team tested the newly developed “Home Care-Intellectual and Developmental Disabilities Frailty Index (HC-IDD FI)”. The purpose of the project was:

- to determine how knowledge of persons with IDD’s frailty status would affect care planning decisions, and
- whether care planning decisions would result in changes in frailty.

Several key findings were identified during the four year study:

1. For the assessment tool to be implemented in practice, a frailty measure must be brief, relevant, and inform care decisions.
2. The prevalence of frailty is three times higher among adults with IDD.
3. The frailty index predicts admission to long-term care from home care among adults with IDD, independent of age, sex, rural status, caregiver inability to continue supporting the individual, living situation and level of cognitive function.
4. Strong ties between frailty researchers, practitioners and policymakers are important to successful implementation of measures developed.

Other findings have been incorporated in the section above in the *International Consensus Statement of the Best Approaches to Supporting Individuals with Intellectual and Developmental Disabilities (IDD.)*

For additional information about frailty research see the attached link below:

<https://www.mapsresearch.ca/projects/aging/>

Other Research/Statistics

According to Statistics Canada (2012), the average age at which persons with a DD reported starting to have difficulty associated with their main DD condition and aging was 43. Men reported an earlier age of onset of aging symptoms (e.g. vision, decreased

strength and mobility changes) than did women: 41.5 years versus 44.5 years. About half of seniors (65 years or older) with disabilities reported that they began having difficulties or activity limitations before age 65.

Additional research supports the concept that the overall impact of aging with a DD can be affected by:

- heredity and genetics,
- overall health and wellness,
- lifestyle,
- environment,
- number and status of chronic conditions associated with DD and aging, and
- disease processes.

As previously mentioned, measuring aging and frailty can be difficult to assess with a person aging with a DD. Behavior has meaning and therefore should always be considered when determining potential causes. Using a series of risk factors and identifying and measuring the level of need may assist persons with a DD and their caregivers and families in planning. The sample assessment tool below provides examples of risk factors associated with general aging and frailty.

RISK FACTORS RELATING TO AGING & FRAILITY WITH A DEVELOPMENTAL DISABILITY: A SAMPLE ASSESSMENT TOOL

A person aging with a DD may be experiencing an increasing number of priority needs or safety risks (or even a high need in one or two critical areas) and may need additional supports and/or a change in plan of care/services. Consider the following risk factors and potential related supports in planning in the Table below.

TABLE: SAMPLE RISK ASSESSMENT TOOL AND CARE PLANNING

RISK FACTOR	NEED: YES/NO NEED LEVEL:	SAMPLE SUPPORTS REQUIRED
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	HIGH – H MEDIUM – M LOW- L	
Hearing Impairment		<input type="checkbox"/> Schedule Audiologist appointment <input type="checkbox"/> Physician/ Primary Care Provider & Follow-Up <input type="checkbox"/> Schedule ear wax cleaning <input type="checkbox"/> Contact Canadian Hearing Society for arranging test/ information
Unintentional Weight Loss/Decline/Loss in Appetite/Trouble Swallowing		<input type="checkbox"/> Physician/ Primary Care Provider & Follow-Up <input type="checkbox"/> Local Ontario Health Team (OHT) Home & Community Care Support Services – (Speech Therapist, Dietician) <input type="checkbox"/> Regional Geriatric Outreach Team or other geriatric assessment team <input type="checkbox"/> Provide educational material /resources (e.g. Nutritional information) <input type="checkbox"/> Community Support Services Agency (e.g. MOW)
Activities of Daily Living Decline: Mobility in bed		<input type="checkbox"/> Physician/ Primary Care Provider & Follow-Up <input type="checkbox"/> Local Ontario Health Team (OHT) Home & Community Care Support Services – (Physiotherapist, Occupational Therapist) <input type="checkbox"/> Regional Geriatric Outreach Team or other geriatric assessment team <input type="checkbox"/> Equipment vendor/supplier <input type="checkbox"/> Community exercise programs <input type="checkbox"/> Community Support Services Agency (e.g. Personal Support Program)
Activities of Daily Living Decline: Transfers/ In-Home Locomotion		<input type="checkbox"/> Physician/ Primary Care Provider & Follow-Up <input type="checkbox"/> Local Ontario Health Team (OHT) Home & Community Care Support Services – (Physiotherapist, Occupational Therapist) <input type="checkbox"/> Regional Geriatric Outreach Team or other geriatric assessment team <input type="checkbox"/> Equipment vendor/supplier <input type="checkbox"/> Community exercise programs <input type="checkbox"/> Community Support Services Agency (e.g. Personal Support Program) <input type="checkbox"/> Personal Emergency Alarm System (e.g., Lifeline)
Activities of Daily Living Decline: Locomotion Out of Home		<input type="checkbox"/> Physician/ Primary Care Provider & Follow-Up <input type="checkbox"/> Local Ontario Health Team (OHT) Home & Community Care Support Services – (Physiotherapist, Occupational Therapist) <input type="checkbox"/> Regional Geriatric Outreach Team or other geriatric assessment team <input type="checkbox"/> Equipment vendor/supplier <input type="checkbox"/> Community Support Services Agency (e.g. Personal Support Program) <input type="checkbox"/> Personal Emergency Alarm System (e.g. Lifeline) <input type="checkbox"/> Community exercise programs
Activities of Daily Living Decline: Ability to Dress		<input type="checkbox"/> Physician/ Primary Care Provider & Follow-Up <input type="checkbox"/> Local Ontario Health Team (OHT) Home & Community Care Support Services – (Physiotherapist, Occupational Therapist), Personal Support Worker)

		<input type="checkbox"/> Regional Geriatric Outreach Team or other geriatric assessment team <input type="checkbox"/> Community Support Services Agency (e.g. Personal Support Worker) <input type="checkbox"/> Equipment vendor/supplier
Mobility Decline: Stair Climbing/ General Mobility		<input type="checkbox"/> Physician/ Primary Care Provider & Follow-Up <input type="checkbox"/> Local Ontario Health Team (OHT) Home & Community Care Support Services – Physiotherapist, Occupational Therapist <input type="checkbox"/> Regional Geriatric Outreach Team or other geriatric assessment team <input type="checkbox"/> Equipment vendor/supplier (stair climber, mobility Equipment, safe bath equipment) <input type="checkbox"/> Community exercise programs <input type="checkbox"/> Community Support Services Agency (e.g. Personal Support Worker) <input type="checkbox"/> Personal Emergency Alarm System (e.g., Lifeline)
Activities of Daily Living Decline: Ability to Manage Routine Hygiene & Bathing		<input type="checkbox"/> Physician/ Primary Care Provider & Follow-Up <input type="checkbox"/> Local Ontario Health Team (OHT) Home & Community Care Support Services (Physiotherapist, Occupational Therapist), Personal Support Worker <input type="checkbox"/> Regional Geriatric Outreach Team or other geriatric assessment team <input type="checkbox"/> Community Support Services Agency (e.g. Personal Support Worker) <input type="checkbox"/> Equipment vendor/supplier (safe bath equipment)
Irregular Sleep Pattern/Problems Sleeping		<input type="checkbox"/> Physician/ Primary Care Provider & Follow-Up <input type="checkbox"/> Sleep Study as ordered by physician /primary care Provider
Activities of Daily Living Decline: Preparing Meals/Eating		<input type="checkbox"/> Community Support Services Agency (e.g. Meals On Wheels, Personal Support Worker) <input type="checkbox"/> Local Ontario Health Team (OHT) Home & Community Care Support Services – (Speech Pathologist, Dietician, Personal Support Worker) <input type="checkbox"/> Provide educational material /resources (e.g. Nutritional information) <input type="checkbox"/> Regional Geriatric Outreach Team or other geriatric assessment team
Decline in Stamina/Energy		<input type="checkbox"/> Physician/ Primary Care Provider & Follow-Up <input type="checkbox"/> Local Ontario Health Team (OHT) Home & Community Care Support Services – (Occupational Therapist) <input type="checkbox"/> Exercise programs <input type="checkbox"/> Nutritional assessment
Increase in Frequency of Falls/Fear of Falling		<input type="checkbox"/> Physician/ Primary Care Provider & Follow-Up <input type="checkbox"/> Local Ontario Health Team (OHT) Home & Community Care Support Services – (Physiotherapist, Occupational Therapist) <input type="checkbox"/> Regional Geriatric Outreach Team or other geriatric assessment team <input type="checkbox"/> Equipment vendor/supplier <input type="checkbox"/> Community exercise programs <input type="checkbox"/> Personal Emergency Alarm System (e.g., Lifeline) <input type="checkbox"/> Foot Care Clinic <input type="checkbox"/> VON SMART Program (if available in the region)

Unsteady Gait		<input type="checkbox"/> Physician/ Primary Care Provider & Follow-Up <input type="checkbox"/> Local Ontario Health Team (OHT) Home & Community Care Support Services – (Physiotherapist, Occupational Therapist) <input type="checkbox"/> Regional Geriatric Outreach Team or other geriatric assessment team <input type="checkbox"/> Equipment vendor/supplier <input type="checkbox"/> Community exercise programs
Diagnosis of a Stroke		<input type="checkbox"/> Local Ontario Health Team (OHT) Home & Community Care Support Services – (Occupational Therapist for home safety & risk assessment, Personal Support Worker for assistance with ADL) <input type="checkbox"/> Personal Emergency Alarm System (e.g., Lifeline) <input type="checkbox"/> Participation in Stroke Recovery Program <input type="checkbox"/> Community exercise programs <input type="checkbox"/> Regional Geriatric Outreach Team or other geriatric assessment team <input type="checkbox"/> Community Support Services Agency (e.g. Personal Support Worker, Adult Day Program) <input type="checkbox"/> Chronic Disease Self- Management Programs
Diagnosis of Coronary Artery Disease & /or Circulatory Issues e.g. Hypertension		<input type="checkbox"/> Local Ontario Health Team (OHT) Home & Community Care Support Services (Nursing, Physiotherapy) <input type="checkbox"/> Physician/ Primary Care Provider & Follow-Up <input type="checkbox"/> Chronic Disease Self- Management Programs <input type="checkbox"/> Regional Geriatric Outreach Team or other geriatric assessment team
Loss of Muscle /Strength		<input type="checkbox"/> Community exercise programs <input type="checkbox"/> Physician/ Primary Care Provider & Follow-Up <input type="checkbox"/> Local Ontario Health Team (OHT) Home & Community Care Support Services – (Physiotherapy)
Increased Alcohol/ Drug (illegal/legal) consumption & smoking		<input type="checkbox"/> Physician/ Primary Care Provider & Follow-Up <input type="checkbox"/> Community Mental Health Programs <input type="checkbox"/> Canadian Mental Health Association (CMHA) <input type="checkbox"/> Local Health Integrated Network (LHIN) Home & Local Ontario Health Team (OHT) Home & Community Care Support Services - (Mental Health Nursing, Occupational Therapy) <input type="checkbox"/> Addiction & Mental Health Ontario resources <input type="checkbox"/> Smoking Cessation Programs/Acupuncture
Diagnosis or High Risk of Developing Osteoporosis (e.g. female over 50 years of age)		<input type="checkbox"/> Community exercise programs <input type="checkbox"/> Bone Density tests <input type="checkbox"/> Annual Osteoporosis screening with physician or health care provider <input type="checkbox"/> Dietician/ Nutritionist referral
Changes in Vision (new or worsening)		<input type="checkbox"/> Physician/ Primary Care Provider & Follow-Up <input type="checkbox"/> Schedule an Optometrist appointment
Diagnosis of Dementia/ Alzheimer’s Disease		<input type="checkbox"/> Alzheimer Society of Ontario/Canada – First Link, Finding Your Way & other information & resources <input type="checkbox"/> Alzheimer Society (Region specific) – May include programs such as: Dementia Day Programs, Respite Care, Caregiver Support groups, & Education <input type="checkbox"/> Physician/ Primary Care Provider & Follow-Up <input type="checkbox"/> Regional Geriatric Outreach Team or other

		<ul style="list-style-type: none"> geriatric assessment team <input type="checkbox"/> Local Ontario Health Team (OHT) Home & Community Care Support Services - (Occupational Therapy – Home Safety & Risk Assessment, Personal Support Worker – Caregiver Respite) <input type="checkbox"/> Wandering/ Vulnerable Person's Registry <input type="checkbox"/> Personal Emergency Alarm System (e.g., Lifeline) with GPS capability <input type="checkbox"/> Community Support Services – (e.g., Transportation) <input type="checkbox"/> Behavior Support Ontario – Assistance with Education & support for responsive behaviors <input type="checkbox"/> Local Ontario Health Team (OHT) Home & Community Care Support Services -Placement applications and/or respite care applications
Diagnosis of Diabetes		<ul style="list-style-type: none"> <input type="checkbox"/> Physician/ Primary Care Provider & Follow-Up including regular lab tests e.g. (A1c) <input type="checkbox"/> Local Ontario Health Team (OHT) Home & Community Care Support Services – (Nursing, Dietician) <input type="checkbox"/> Optometrist- Annual eye examination <input type="checkbox"/> Outpatient Diabetes Education Program <input type="checkbox"/> Chronic Disease Self-Management Program
Respiratory Disease e.g. Emphysema, Chronic Obstructive Pulmonary Disease, Asthma, & Others		<ul style="list-style-type: none"> <input type="checkbox"/> Local Ontario Health Team (OHT) Home & Community Care Support Services – (Nursing, Physiotherapy, Occupational Therapy, Personal Support Worker may have Respiratory Therapist available) <input type="checkbox"/> Oxygen Provider & Assistive Devices Program <input type="checkbox"/> Physician/ Primary Care Provider & Follow-Up <input type="checkbox"/> Chronic Disease Self-Management Program <input type="checkbox"/> Community Support Services – (Transportation, Adult Day Programs, Personal Support Worker)
Decline in Continence (Stool &/or Urine)		<ul style="list-style-type: none"> <input type="checkbox"/> Local Ontario Health Team (OHT) Home & Community Care Support Services - (Incontinence Nurse, Personal Support Worker – Caregiver Respite) <input type="checkbox"/> Physician/ Primary Care Provider & Follow-Up <input type="checkbox"/> Community Support Services – (Transportation) <input type="checkbox"/> Supply Vendor for incontinence supplies
Worsening Pain Management (e.g. new, increased frequency, higher level, mechanisms less effective for managing pain)		<ul style="list-style-type: none"> <input type="checkbox"/> Physician/ Primary Care Provider & Follow-Up <input type="checkbox"/> Local Ontario Health Team (OHT) Home & Community Care Support Services - (Pain Management Nursing Specialist, Physiotherapist) <input type="checkbox"/> Regional Geriatric Outreach Team or other geriatric assessment team <input type="checkbox"/> Pain Clinic <input type="checkbox"/> Pharmacy MedsCheck Program
Changes in Social Activities (e.g. Social Isolation, Decline in Communication)		<ul style="list-style-type: none"> <input type="checkbox"/> Community Support Services – (Transportation, Adult Day Programs & Outreach Programs, Meals on Wheels or similar activities, Friendly Visitors) <input type="checkbox"/> Physician/ Primary Care Provider & Follow-Up
Frequent hospitalization/ unplanned emergency department visits		<ul style="list-style-type: none"> <input type="checkbox"/> Geriatric Emergency Management (GEM) nurses positioned in ER Departments <input type="checkbox"/> Local Ontario Health Team (OHT) Home & Community Care Support Services -(Nursing) <input type="checkbox"/> Consider a Supportive Housing/Senior Residence,

		which often has 24/hour supports <input type="checkbox"/> Regional Geriatric Outreach Team or other geriatric assessment team <input type="checkbox"/> Physician/ Primary Care Provider & Follow-Up
Diagnosis of Mental Health Issues (e.g. Depression, Responsive Behaviors etc.)		<input type="checkbox"/> Physician/ Primary Care Provider & Follow-Up <input type="checkbox"/> Community Mental Health Programs <input type="checkbox"/> Canadian Mental Health Association (CMHA) <input type="checkbox"/> Local Ontario Health Team (OHT) Home & Community Care Support Services - (Mental Health Nursing, Occupational Therapy) <input type="checkbox"/> Addiction & Mental Health Ontario resources
Transition Issues (e.g. Housing, Change in Caregivers/Family, Programs/Services)		<input type="checkbox"/> Local Ontario Health Team (OHT) Home & Community Care Support Services - (Placement & Case Coordinators) <input type="checkbox"/> Behavioral Support Ontario <input type="checkbox"/> MCCSS supports <input type="checkbox"/> Community Support Services (Social & Medical services)

Onset of Aging

This section describes some of the major system changes within the body with the general onset of aging. Strategies and recommendations will be available including resources at the end of the section. Given that persons with a DD show earlier signs of aging, the strategies and recommendations may have to be considered and implemented earlier. Where possible, evidence-based practice guidelines (*Primary care of adults with intellectual and developmental disabilities: 2018 Canadian consensus guidelines*) will guide the strategies and recommendations provided, acknowledging that research is limited in the study of aging with a DD at the time of the *Guide's* development.

Physical Changes with Aging

The Nervous System

As a person ages, changes occur in the central nervous system (CNS). Specifically, in the brain, there is a decrease in:

1. Blood flow and oxygen through the brain.
2. Loss of neurons and the number of cells.
3. Number of synaptic (nerve endings) connections, delays and general brain activity resulting in delays in reaction time, speed of recall and memory.

Central Nervous System (CNS) and DD

Changes with the CNS for persons with a DD and aging may impact an existing neurological disorder such as epilepsy, by increasing the frequency, severity of seizures and the risk of premature death (World Health Organization <https://www.who.int/news->

“I used to be such a safe driver. Now that I am 85, I am experiencing a delay in

[room/fact-sheets/detail/epilepsy](#),). According to WHO, one in five persons with a DD experience seizure activity and the most common causes of death due to epilepsy are:

- falls,
- prolonged seizure activity,
- drowning, and
- burns.

reacting”. I am getting nervous about driving”. (Caregiver of a person with DD)

Note: Persons with a DD diagnosed with Alzheimer Disease and/or other Dementias may experience new seizure activity as part of the disease process. Additional information is included later in this section under dementia.

Strategies/Recommendations for Persons Aging with a DD and Epilepsy:

A. Screening Recommendations

1. An *Epilepsy Health Action Plan* should be developed, in consultation with the person with a DD, primary care provider, and other care providers, caregiver, and family.
2. Review of the *Epilepsy Health Action Plan* at least annually.
3. Ensure that antiseizure medication is reviewed a minimum of annually with the primary care provider /specialist.

B. Comfort and Other Interventions

1. Implement fall prevention strategies (See Fall Prevention below).
2. Access the *Developmental Disability Primary Care Initiative (2011)* seizure tools which includes tips for caregivers, care plans, and seizure monitoring sheets. The tools and other information can be accessed at: ddpcp@surreyplace.on.ca .
3. Ensure the person with a DD is safe in their surroundings, taking the appropriate medication, and seeking the necessary medical interventions as necessary during an emergency.

Other CNS Strategies/Recommendations for Persons Aging with a DD

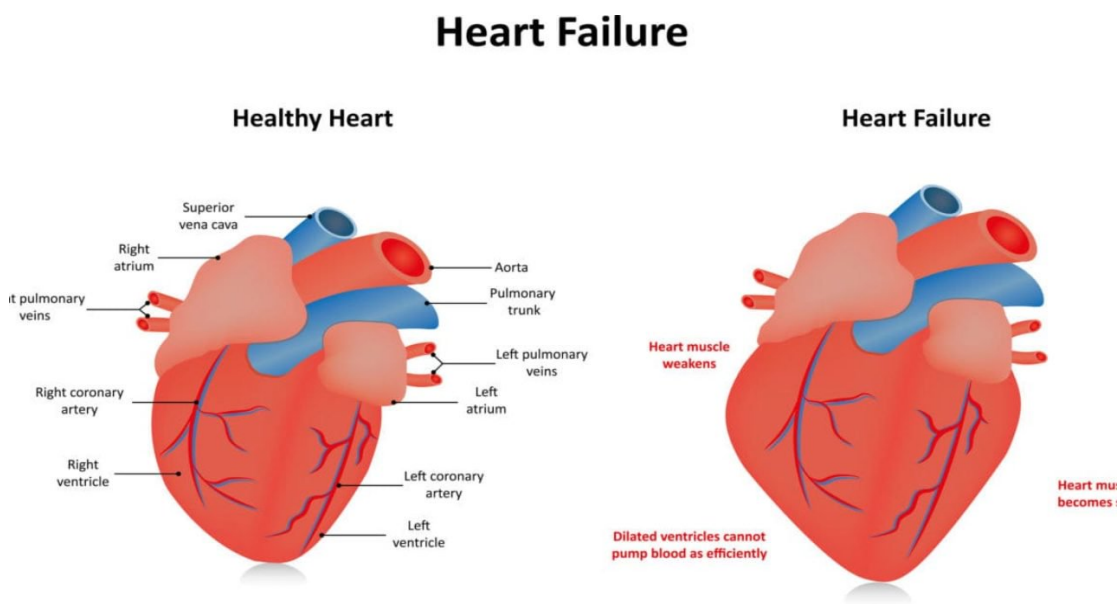
Memory loss, delays in speed of recall, and in reaction can be very frustrating to everyone as they age. However, it is important to consult a physician or other health care providers if memory loss/recall affects the ability to complete routine activities of daily living (ADL) or if memory/recall is getting worse. Treatment will depend on what is contributing to the memory loss/recall, such as illness, infection, poor nutrition, dehydration, etc.

Cardiovascular (Heart) Disease, Stroke and Aging

Age represents the largest risk factor for cardiovascular disease (Steenman & Gilles, 2017). The prevalence of cardiovascular disease increases dramatically with increasing age and has been noted to be more prevalent with persons with a DD, particularly Down Syndrome, Prader- Willi and 22Q11 deletion Syndromes. The two major age-associated cardiac diseases are: heart failure and atrial fibrillation.

Heart Failure

Heart failure (HF), also known as congestive heart failure (CHF), is when the heart is unable to pump sufficiently to maintain blood flow to meet the body's needs. Signs and symptoms of heart failure commonly include shortness of breath, excessive tiredness, and leg swelling. The Figure below illustrates the changes of a healthy heart vs. a heart experiencing heart failure.



Health Promotion is defined as “the process of implementing a range of social and environmental interventions that enable people and communities to increase control over and to improve their health” Public Health Ontario (PHO)

Atrial Fibrillation

Atrial Fibrillation (Afib) is a type of irregular heart rhythm (arrhythmia) and is due to electrical signal disturbances of the heart. Afib is the most common arrhythmia, affecting approximately 200,000 Canadians (Heart & Stroke Foundation). The risk of developing Afib increases with age and with other risk factors such as diabetes, high blood pressure, and underlying heart disease. The main complications of Afib are stroke and heart failure. In fact, one in four of all strokes after the age of 40 are caused by Afib (Heart & Stroke Foundation).

A stroke is a medical condition in which poor blood flow to the brain results in cell death. There are two main types of stroke, ischemic, due to lack of blood flow, and hemorrhagic, due to bleeding. Both result in parts of the brain not functioning properly (<https://en.wikipedia.org/wiki/Stroke>)

Cardiac Risk Factors & Interventions

Several risk factors contribute to heart disease and stroke but can be modified by medical treatment and making healthy choices (e.g., Chronic Disease Management Programs). It is especially important to identify, modify, and monitor the risk factors for persons with a DD as they are potentially at a higher risk due to lack of physical activity/mobility, smoking, obesity, and prolonged use of psychotropic medications.

In the Table below are the cardiac risk factors, which can be modified to reduce heart disease and potential resources available within the community and health services sectors.

TABLE: MODIFIABLE CARDIAC RISK FACTORS & RECOMMENDED STRATEGIES

RISK FACTOR	TYPE OF RISK	STRATEGY
1. Blood Pressure (BP)	High BP (hypertension) affects one in five Canadians. It is the number one risk factor for stroke & a major risk factor for heart disease. High blood pressure is often called a "silent killer" because it has no warning signs or symptoms.	<input type="checkbox"/> Regularly monitor BP during primary care & specialist appointments <input type="checkbox"/> Establish early baseline BP <input type="checkbox"/> Establish regular exercise regime <input type="checkbox"/> Weight control <input type="checkbox"/> Healthy diet, low in saturated fat & salt <input type="checkbox"/> Control cholesterol <input type="checkbox"/> Sleep study if sleep apnea is suspected <input type="checkbox"/> Participation in community Chronic Disease Self-Management Program
2. Cholesterol	High blood cholesterol is one of the major controllable risk factors for heart disease. As blood cholesterol rises, so does the risk of heart disease. Cholesterol can also lead to a buildup of plaque in the artery walls (atherosclerosis). The plaque makes it harder for blood to flow through the body, increasing the risk of stroke	<input type="checkbox"/> Regular blood tests <input type="checkbox"/> Diet low in saturated fats <input type="checkbox"/> Routine exercise regime <input type="checkbox"/> Medication management

3. Diabetes	Diabetes increases the risk of high blood pressure, atherosclerosis (narrowing of the arteries), coronary heart disease & stroke, especially if blood sugar levels are poorly controlled. Diabetes can cause circulatory problems by damaging the blood vessels	<input type="checkbox"/> Regular A1C lab work (minimum every 6 months) <input type="checkbox"/> Testing blood sugar with glucometer daily or as recommended by primary health care provider/specialist <input type="checkbox"/> Monitor healing of wounds and presence of infection <input type="checkbox"/> Implement a diabetic diet according to primary health care provider/specialist orders <input type="checkbox"/> Link to Home and Community Care Support Services /other- Dietician
4. Atrial Fibrillation	Atrial Fibrillation (Afib) is an irregular heart rhythm. It can cause small clots to form in the heart & travel to the brain. It increases the risk of ischemic stroke by three to five times	<input type="checkbox"/> Monitor vital signs during primary health care/ specialist appointments <input type="checkbox"/> Monitor signs & symptoms of congestive heart failure (shortness of breath, swelling) <input type="checkbox"/> Medication management
5. Sleep Apnea	Sleep Apnea is a serious medical condition that can cause breathing to stop & start many times while sleeping. There is a strong link between sleep apnea, high blood pressure & stroke. Even short pauses in breathing while sleeping are hard on the heart because they lower the amount of oxygen reaching the heart	<input type="checkbox"/> Monitor breathing during sleep <input type="checkbox"/> Observe increasing fatigue despite hours of sleep unchanged <input type="checkbox"/> Refer to sleep study <input type="checkbox"/> Purchase a C-Pap machine if compliance is not a problem
6. Lifestyle	<ul style="list-style-type: none"> • <input type="checkbox"/> Smoking Smoking triples the risk of	<input type="checkbox"/> Smoking cessation interventions as per

	<p>dying from heart disease & stroke in middle-aged men & women.</p> <ul style="list-style-type: none"> • <input type="checkbox"/> Unhealthy diet Processed foods, foods high in salt, fats & carbohydrates contribute to high cholesterol, high blood pressure and weight gain • <input type="checkbox"/> Physical Inactivity People who are not active have double the risk of heart disease & stroke as well as increased risk of diabetes, cancer & dementia • <input type="checkbox"/> Unhealthy weight Over 60% of Canadian adults are either overweight or obese. Being overweight can lead to high blood pressure, high cholesterol, diabetes & sleep apnea. Obesity can double the chance of heart disease • <input type="checkbox"/> Stress People who have high levels of stress or prolonged stress have higher cholesterol or blood pressure. Stress causes narrowing of the arteries (atherosclerosis), a stroke risk factor. • <input type="checkbox"/> Excessive alcohol and drug use Heavy drinking & binge drinking are risk factors for high blood pressure, heart disease & stroke. Alcohol may also cause 	<p>primary health care direction</p> <ul style="list-style-type: none"> <input type="checkbox"/> Acupuncture/Laser therapies <input type="checkbox"/> Referral to Dietician <input type="checkbox"/> Medication management <input type="checkbox"/> Community exercise programs <input type="checkbox"/> Participation in Adult Day Programs <input type="checkbox"/> TAI CHI <input type="checkbox"/> Referral to Dietician <input type="checkbox"/> Establish meal plan for weight reduction <input type="checkbox"/> Referral to Social Worker for counselling <input type="checkbox"/> Referral to Social Worker for counselling <input type="checkbox"/> Referral to Mental Health & Addictions Programs
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	problems by interacting with medications	
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Manage your Heart Risk of Heart Disease & Stroke by taking this seven minute risk assessment by the Heart and Stroke by accessing the link below:

<https://ehealth.heartandstroke.ca/>

Additional tools and resources are available from Surrey Place by using the link below:

<https://ddprimarycare.surreyplace.ca/>

HEALTH WATCH TABLE: DOWN SYNDROME

The Health Watch Table: Down Syndrome, developed by the Developmental Disabilities Primary Care Initiative at Surrey Place (Toronto, 2011), complements the primary care guidelines and Preventive Care Checklist and flags issues relevant to the genetic condition Down syndrome.

HEALTH WATCH TABLE: PRADER-WILLI SYNDROME

The Health Watch Table: Prader-Willi syndrome, developed by the Developmental Disabilities Primary Care Initiative at Surrey Place (Toronto, 2011), complements the primary care guidelines and Preventive Care Checklist and flags issues relevant to the genetic condition Prader-Willi syndrome.

HEALTH WATCH TABLE: 22Q11.2 DELETION SYNDROME

The Health Watch Table: 22q11.2 deletion syndrome, developed by the Developmental Disabilities Primary Care Initiative at Surrey Place (Toronto, 2011), complements the primary care guidelines and Preventive Care Checklist and addresses issues relevant to the genetic condition 22q11.2 deletion syndrome.

Skin Changes with Aging

The purpose of skin is to provide a protective buffering function from the environment (e.g. exposure to sun, pollution). As persons age, natural changes to the skin occur. The skin becomes:

- rougher,
- slack with the loss of the elastic tissue (elastin) causing the skin to hang loosely,
- more transparent caused by thinning of the epidermis (surface layer of the skin),
- more fragile due to a flattening of the area where the epidermis and dermis (layer of skin under the epidermis) come together. This effect can increase the chance of injury and infection, and
- more easily bruised due to thinner blood vessel walls.



How skin ages will depend on a variety of factors:

- □ lifestyle (e.g., smoking, weight, sleep regime),
- □ diet,
- □ heredity and,
- □ personal habits (e.g., level of stress experienced, hygiene, skin care regime).

Strategies/Recommendations for Persons Aging with a DD:

There are many strategies to minimize the overall impact of skin changes with aging. Most importantly, however, is to minimize the risk of skin breakdown and infection particularly for persons with limited mobility. Consider the following recommendations:

1. Check skin frequently for any problems (e.g., dehydration, redness, skin tears, lesions).
2. Drink plenty of water to hydrate the skin and eat healthy with a focus on choosing foods high in protein to repair tissue and fight infection.
3. Avoid extreme exposure to the environment (e.g., sun, wind, cold, pollution),
4. Reposition, a minimum of every 1 – 2 hours if mobility is limited.
5. Apply skin barrier solutions (creams, protective bandages) to areas at high-risk for breakdown (coccyx, groin, elbows).
6. Use equipment/supplies to minimize impact of pressure points on the skin (e.g., egg crate/pressure mattresses, sheepskin, seating cushions).
7. Develop a routine hygiene and skin care regime.

Sensory System Changes with Aging

Age-related changes occur in all sensory systems- visual, hearing (auditory), touch (tactile), smell (olfactory), taste (gustatory), and awareness of self and the body (proprioception- sense of the body in the environment). Often referred to the sixth sense.

Vision:

With age, structural changes in the eye affect vision and can have a significant impact on functional abilities, and on safety (particularly the risk of falls). In particular, changes from aging can lead to:

- □ reduction in tears resulting in dry eyes, itching, and soreness,
- □ yellowing of the lens of the eye making it difficult to distinguish between blue-green and yellow-white,
- □ decrease in clarity,
- □ increase in glare,
- □ changes in pupil size resulting in increased sensitivity to glare and adaptability to the dark,
- □ altered depth perception leading to an increased risk of trips and falls,
- □ narrowing of the visual field and distinguishing of colour, and

- □ slower processing of visual information.

Eye diseases commonly associated with aging are:

- □ **Cataracts:** the clouding of the lens in the eye, which leads to a decrease in vision. Cataracts often develop slowly and can affect one or both eyes. Symptoms may include faded colors, blurry or double vision, halos around light, trouble with bright lights, and trouble seeing at night. Diagnosis is found during regular eye exams and treatment is eye surgery on an outpatient basis.
- □ **Glaucoma:** A group of eye diseases, which lead to progressive degeneration of the optic nerve. This can lead to gradual irreversible vision loss and potential blindness if not detected and treated early.
- □ **Macular degeneration:** the leading cause of severe, irreversible vision loss in persons over age 60. It occurs when the small central portion of the retina, known as the macula, deteriorates. The retina is the light-sensing nerve tissue at the back of the eye.

Strategies/Recommendations for Persons Aging with a DD:

Here are just some of the suggested strategies to manage changes with vision and detection of eye disease in the early stages of aging:

A. Screening

1. Need to plan for an annual screening with a primary care provider and communicate any changes with health and vision, as some medical conditions and medicines, both prescription and over the counter (OTC), can affect the eyes and vision. Persons with diabetes are eligible for annual eye exams without additional fees.
2. A referral to an optometrist to detect glaucoma and/or cataracts every two years after the age of 40.

B. Comfort & Other Interventions

1. Use moisture or comfort strategies for eye dryness in consultation with a healthcare provider (e.g., artificial tears, lubricants, allergens, steroids, anti-inflammatory drops, warm compresses, wrap around glasses, and other technology).
2. Ensure the environment is sufficiently bright with proper lighting (consider the use of motion sensors, night lights, etc.).
3. Utilize blinds, shades, and shutters to reduce glare.

4. Healthy eating with nutritional choices of vegetables, protein, and fruit.

For an assessment of how well you may be taking care of your eyes and vision, refer to the link below:



Are you Taking Good Care of your Eyes?

<https://www.webmd.com/eye-health/eye-assessment/default.htm>



Hearing and Aging

Ears have two main jobs; hearing and maintaining balance. Balance (equilibrium) is controlled in the inner ear. Fluid and small hair in the inner ear stimulate the auditory nerve. This sends signals to the brain to help maintain balance.

With aging, the structures inside the ear start to change and their functions decline. In particular, degenerative changes result in the loss of a person's ability to hear high-pitched sounds, resulting in words becoming distorted and incoherent, and making conversation difficult. Frustration and/or withdrawal from social activities/isolation often result.

Another degenerative change with aging is a decrease in blood supply to the ear receptors. This results in a condition known as "tinnitus" (commonly known as ringing in the ears). A person experiencing tinnitus has difficulty hearing conversations, doorbells, sirens, etc.

Strategies/Recommendations for a Person Aging with a DD:

A. Screening

1. Hearing (audiology) tests every five years after the age of 45

B. Comfort and Other Interventions

General strategies to address hearing loss include:

1. Speaking face - to- face with adequate lighting, speaking slower, and reducing the pitch, and when possible, reducing background noise

- Schedule routine (every six months) appointments for removing ear wax (Cerumen)

According to the Canadian Hearing Society (CHS), most hearing loss can be effectively addressed with hearing aids. It is suggested however that once hearing loss has been established, annual testing is required to investigate and manage hearing loss ongoing.

Did you know that the Canadian Hearing Society (CHS) offers online hearing tests! CHS Hearing Healthcare has modern, state-of-the-art audiology facilities located in key CHS offices throughout Ontario, offering an array of services including hearing testing, hearing aids, tinnitus consultations and more.

For additional information and for booking an online hearing test see the attached link to the Canadian Hearing Society (CHS):

http://hearinghealthcare.chs.ca/hhc_home

If it is recommended to purchase hearing aids, there are many choices. Hearing aids are not a replacement for normal hearing, but there have been significant advances in recent years to make hearing aids work well in most situations.

Some hearing aids have features such as special noise reduction circuitry, or multiple listening programs that can be adjusted to suit certain environments. There are several different styles of hearing aids, from tiny completely in-the-canal models to behind-the-ear hearing aids. Each style has specific performance characteristics. Regardless of the type, the most important thing is to choose the right hearing aids with a trusted vendor, who will work to make sure the best possible outcome is achieved.

The price of a hearing aid will vary depending on the specific model, features, and how effective it is in various noise environments. As with many products, there are multiple levels of technology to consider, from entry to advanced levels. Funding for hearing aids may be sought from a number of sources. Refer to the Table below for more information.

6 million Canadians aged 20 - 79 had hearing loss, or 19% of the age group studied (Stats Canada, 2013)

Over age 60, hearing loss was more common for men than women". (Canadian Health Measures Survey, 2012/2013)

TABLE: ONTARIO FUNDING SOURCES FOR PURCHASING HEARING AIDS

ORGANIZATION NAME	FUNDING INFORMATION	CONTACT INFORMATION
Assistive Devices Program (ADP)	Provides a limited subsidy for hearing aids. Adults & children with a valid Ontario Health	Ministry of Health Assistive Devices Program 7th Floor, 5700 Yonge Street

	Insurance Health Card are eligible to receive 75% coverage of the cost of one or two hearing aids up to a maximum grant of \$500 can. per hearing aid.	Toronto, ON M2M 4K5 Tel: Toronto 416-327-8804 Toll-free 1-800-268-6021 TDD/TTY 416-327-4282 TDD/TTY 1-800-387-5559 Fax 416-327-8192 e-mail: adp@ontario.ca
Ontario Disability Supports Program (ODSP)	The Hearing Aid Benefit provides assistance to eligible members of ODSP benefit units for the purchase of hearing aids and hearing related items and services. The MCCSS Schedule of Fees for Hearing Aids, Devices and Services (Schedule) outlines the goods and services that are available to eligible recipients of the ODSP Hearing Aid Benefit. The Schedule is used in parallel with the Ministry of Health’s (MOH) Assistive Devices Program (ADP) policies and processes.	To locate an office in a specific region access the following link locator: http://www.officelocator.mcs.gov.on.ca/
Veterans Affairs Canada /VAC (formerly DVA)	If you qualify for the Treatment Benefits program, you will receive a VAC healthcare card. This healthcare card provides coverage for such things as home health or hospital services, nursing services, appointments with specialists (such as physiotherapists, audiologists, and mental health providers),	If you have questions about your health coverage or about VAC’s treatment benefits program, visit any VAC office or call at 1-866-522-2122. You can also contact Medavie Blue Cross.

	<p>medical equipment, prosthetics, and prescriptions. The extent of your coverage will depend on a number of factors, including how you qualified, your health needs and your individual circumstances.</p>	
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Note: The CHS has a Hearing & Donation Program. Each year a small number of donated hearing aids are available for those persons who are in need of great financial assistance.

Some insurance companies (e.g., Greenshield Canada) may have a vendor of choice that offers discounts to purchasers even if Greenshield is not the insurance company of the purchaser.

How good is your hearing? Take the hearing challenge by accessing the link below:



How Old Are Your Ears?

<https://www.youtube.com/watch?v=VxcbppCX6Rk>

For more information about aging and hearing loss, access the following links:

<https://www.nidcd.nih.gov/health/hearing-loss-older-adults#1>

Case Study – Murray A.

Murray is 62 years of age with Down Syndrome. He lives in a group home, and he participates in an adult day program three days a week. In the last month, staff at the group home have found Murray sitting in the dark during the evenings, rubbing his eyes and moving his chair close to the television set. The volume is on high. When the staff ask Murray “what is the matter” and switch on the light in the room, Murray yells, “Turn out the lights, I can’t see”.

Murray is most likely exhibiting signs and symptoms of developing cataracts. Some of

the symptoms include blurred and double vision, frequent rubbing of eyes, putting one hand over one eye to see, sitting closer to see the television, and frequent prescription changes. As cataracts develop over time, it would be necessary for Murray to see the ophthalmologist to determine the need for surgery to correct the problem or determine if there is another cause for his symptoms.

Murray may also be experiencing some hearing problems and may require an audiologist appointment and/or scheduling of extraction of wax build-up in his ears.

Smell/Taste, Oral Hygiene and Aging



Our senses of smell and taste are closely related. Research suggests that over time there is a gradual decrease in the sensitivity in taste and smell. In particular, nerves within the nose tend to degenerate at a greater rate resulting in a decreasing ability to smell and taste.

Changes affecting taste include:

- taste buds that decrease and shrink,
- gums that recede causing dental sensitivity,
- thinning of dental enamel resulting in dental decay and tooth loss, and
- less saliva being produced resulting in a dry mouth, making swallowing difficult and increasing the risk of choking (dysphasia).

Take the quick quiz below to test your knowledge about oral hygiene and health (adapted from Cunha, J. (2017) *Test Your Dental Hygiene IQ*).

1. Tooth decay is caused by cavities.

True False



2. Halitosis is the definition of having a black and spotty tongue?

True False

“Dysphasia is having difficulty swallowing meaning it takes more time & effort to move food or liquid from the mouth to the stomach (Mayo Clinic-<https://www.mayoclinic.org/diseases-conditions/dysphasia/about/overview>).

[conditions/dysphasia/symptoms-causes/20372028](#)



www.shutterstock.com - 4420044

3. The best way to prevent gum disease is to remove plaque.
True False

False
Tooth decay is caused by acid from carbohydrates (sugar & starch) left on teeth

False
Bad breath, medically called halitosis, can result from poor dental hygiene may be a sign of other health problems. It can be made worse by the types of foods eaten & other unhealthy lifestyle habits



True
Plaque removal can be easily accomplished by thoroughly brushing & flossing teeth daily. Regular dental check-ups (every 6-12 months) can detect early signs of gum disease

Changes in smell begin as early as 30 years of age and by 80, the sense of smell is often completely diminished. These changes make food unappealing and can lead to a poor appetite resulting in a low nutritional status. The loss of smell also presents safety concerns as a person may become ill when they can't smell spoiled food, food burning on the stove/oven or a dangerous gas leak.

[Strategies/Recommendations for Persons Aging with a DD:](#)

A. Screening

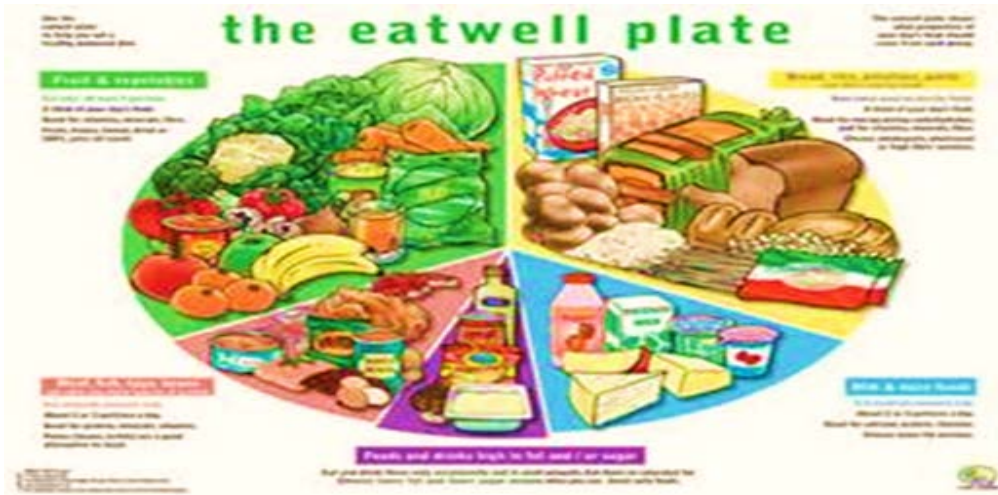
1. Annual dental, hygiene, and oral check-ups.
2. Frequent reviews and reinforcement of the principles of oral hygiene and establishing daily cleaning regimes.
3. Dry mouth, which can interfere with swallowing and cause choking can be related to the administration of diuretics, antihistamines, mood stabilizers, and neuroleptic medications, and should be reviewed frequently with the primary care provider.

B. Comfort and Other Interventions

There are many ways to stimulate and/or increase appetite. According to Elmcroft Seniors Residence (<https://www.elmcroft.com/blog/2018/july/dealing-with-loss-of-appetite-in-the-elderly/>), these tricks have been proven to be successful.

1. Create a routine. Set an eating schedule and start eating at the same time every day. This can train the body and mind to expect and even look forward to an upcoming meal.
2. Pack in those nutrients. Avoid big portions. Make sure that what is being offered is filled with vitamins, minerals, protein, and complex carbohydrates. Healthy fats like nuts, avocados, olive oil, and whole milk dairy products can also raise the calorie count without adding a lot of extra food to the plate.
3. Eat with others. Depression and loneliness are associated with loss of appetite. Encourage opportunities to eat with others.
4. Fight dry mouth. Dry mouth is a common side effect of medication and, apart from being uncomfortable, it can also affect appetite. A suggestion is to use a mouth rinse, brush teeth or chew sugarless gum before a meal.
5. Embrace finger foods. Shaky hands or loss of coordination, both of which make using utensils difficult, can cause frustration or embarrassment. Sandwiches, chicken nuggets, fruit and other items that can be eaten by hand may be more appealing.
6. Encourage healthy snacking. Provide a variety of easy-to-eat, healthy snacks to keep handy. Include high-protein, high-calorie options like meat and cheese roll-ups, full-fat yogurt and peanut butter crackers.
7. Drink meals instead. Many persons report having trouble chewing. And others just prefer liquids and softer foods such as smoothies, whole-fat milk, and soup. Bottled nutritional drinks and pudding like Ensure are also good options.
8. Make it special. Use table linens, music, etc. Creating a pleasant atmosphere may make eating more enjoyable.
9. Offer choice and empower the person by getting them involved in what they're going to eat and how it's going to be prepared.
10. Suggest appetite stimulants. These are available by prescription only and may not be compatible with other medication. The physician should be consulted prior to use.
11. Experiment with different seasonings and flavours.
12. Offer familiar, culturally appropriate, and safe foods for swallowing.

See the Eatwell Sample Plate below which takes in account the revised Canadian Food Guide.



You may wish to take a nutritional screening tool below:

The Mini Nutritional Assessment – MNA (*Adapted from Nestle Nutrition Institute, 1994, Revised 2009*), is included below.

Complete the assessment below by filling in the boxes on the right with the number from the chosen response. Add up all the numbers in the boxes and determine the risk of malnutrition. Depending upon the risk identified, consult with a healthcare provider for appropriate interventions as required.

1. Has food intake declined over the past three months due to loss of appetite, digestive problems, chewing, or swallowing difficulties?

0 = severe decrease in food intake - 1 = moderate decrease in food intake 2 = no decrease in food intake

2. Experienced weight loss during the last three months?

0 = weight loss greater than 3kg (6.6lbs) 1 = does not know 2 = weight loss between 1 and 3kg (2.2 and 6.6 lbs.) 3 = no weight loss

3. Mobility

0 = bed or chair bound 1 = able to get out of bed / chair but does not go out 2 = goes out

4. Has suffered psychological stress or acute disease in the past three months?

0 = yes 2 = no

5. Neuropsychological problems

0 = severe dementia or depression 1 = mild dementia

2 = no psychological problems



6. Body Mass Index (BMI) = weight in kg / (height in m)²

0 = BMI less than 19 1 = BMI 19 to less than 21 2 = BMI 21 to less than 23 3 = BMI 23 or greater



Screening Score (Max. Score -14 points)



12-14 points - Normal nutritional status 8-11 points - At risk of malnutrition 0-7 points: - Malnourished

For a more in-depth assessment, see the link below:

https://www.mna-elderly.com/forms/MNA_english.pdf

Touch, Sensitivity to Pain/Temperature, and Aging

With aging, there is a decrease in touch receptors. The sense of touch allows for the awareness of pain, temperature, pressure, vibration, and body position. Skin, muscles, tendons, joints, and internal organs have nerve endings (receptors) that detect these sensations. The brain interprets the type and amount of touch sensation. The brain also interprets the sensation as pleasant (such as being comfortably warm), unpleasant (such as being very hot), or neutral (such as being aware that you are touching something) and reacts accordingly. For more information and understanding of the physiology see the link below:

<https://medlineplus.gov/ency/anatomyvideos/000054.htm>

Symptoms of changed sensation vary based on the cause (e.g. general aging, deficient blood supply and circulatory changes, medications, and nutritional status).

With decreased temperature sensitivity, it can be hard to tell the difference between cool and cold, and hot and warm. This can increase the risk of injury from frostbite, hypothermia (dangerously low body temperature), and burns. As well, there is an increase in the risk of developing pressure ulcers (skin sores that develop when pressure cuts off blood supply to an area) particularly when there is decreased mobility. Furthermore, after age 50, reduced sensitivity to pain has been noted as a normal aging process and the person may not be aware of injuries developing. Problems walking may develop as well, because of reduced ability to perceive where the body is in relation to the floor. This increases the risk of falling, a common problem in the elderly.

In the person with a DD, pain and distress can be difficult to recognize. Noting changes in vital signs (e.g., pulse and respirations tend to be higher), appearance (e.g., perspiration, cold, clammy), and behaviour, including being less responsive and more withdrawn or new onset of behaviours that challenge might be the only indicators of pain and distress.

Strategies/Recommendations for a Person aging with a DD:

A. Screening

1. Systematically check all potential causes of pain beginning with common ones such as dental caries, arthritis, constipation, and gastroesophageal reflux disease (GERD).
2. Apply best practice assessment tools (See links below).

B. Comfort and Other Interventions

Specific strategies for the reduction in sensation are:

1. Ensure when going outdoors to wear the appropriate clothing for the weather and avoid lengthy exposure to extreme heat and cold.
2. Use skin blocks regularly.
3. Monitor daily or more frequently, skin integrity for early signs of skin breakdown (redness, swelling, bruising, abrasions, skin tears).
4. If mobility is compromised, change positions frequently (every hour) to prevent skin breakdown.
5. Reinforce dangers associated with stoves and other hot appliances.
6. Assess pain through other mechanisms other than through verbal expression (e.g., behavior, body language, change in routine activities).

To learn more about pain, including the different types of pain, and ways that you can help, please see the article, OUCH! How Understanding Pain Can Lead to Gain when it Comes to Supporting Those with Developmental Disabilities at:

<http://www.vitacsls.org/UserFiles/uploads/files/sss%20vol%206%20issue%205%20-%20ENGLISH.pdf>

See the Non-Verbal Pain Scale for Intellectual Disabilities and dementia clients at:

<https://www.mdcalc.com/pain-assessment-advanced-dementia-scale-painad>

Muscular Skeletal (MSK) System

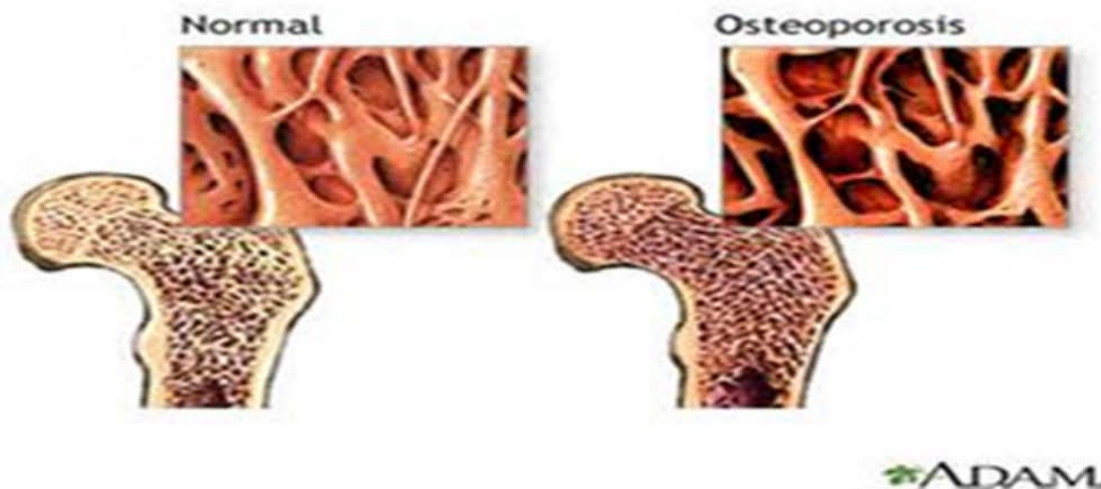
As a person ages, there are changes in skeletal components (muscle, cartilage, bones, and joints), such as a decrease in muscle bone mass, strength, and tone. In addition, there is a decrease in joint mobility resulting in joints becoming stiffer and less flexible. The

overall impact of the combination of changes to the MSK system is an unsteady gait, bone health decline, and poor balance. This is primarily due to changes in posture as a result of muscle weakening, muscles shortening (primarily due to inactivity and poor circulation), bone mass (height loss), and disruption in the center of gravity.

Some of the more common and chronic conditions associated with aging and the MSK system is osteoarthritis and osteoporosis. Osteoarthritis is the most common form of arthritis. It is a degenerative joint disease that involves thinning or destruction of the smooth cartilage that covers the ends of bones, as well as changes to the bone underlying the joint cartilage. Pain from inflammation significantly impacts quality of life and emotional health.

Osteoporosis is a disease characterized by low bone mass and deterioration of bone tissue, which can lead to increased risk of fracture. Known as the “silent thief”, bone deterioration can occur over a number of years without any symptoms. Unfortunately, by the time affected bones break or fracture, the disease is already fairly advanced and less treatable. The most common fractures associated with osteoporosis are in the hip, spine, wrist, & shoulder (Osteoporosis Canada). The Figure below illustrates the comparison of a normal physiology of a bone versus that of a bone affected by osteoporosis.

Figure: Comparison of Healthy Bone vs. Bone Affected by Osteoporosis



1.4 million Canadians are affected by Osteoporosis & another 2 million are at risk (Osteoporosis Canada)

According to research by Osteoporosis Canada, one in four women over 50 and one in

eight men over 50 have osteoporosis. Research also estimates that at least one in three women and one in five men will suffer from an osteoporotic fracture during their lifetime (Public Health Agency of Canada (2014)).

Strategies/Recommendations with Persons Aging with a DD:

A. Screening

1. Monitor foot care and ensure properly fitting shoes in consultation with a orthotist and /or podiatrist.
2. Refer to an Occupational Therapist for promoting mobility, assessing home safety, conducting seating assessments, and determining ongoing equipment needs.
3. Refer to Physiotherapy for promoting and training of effective exercise programs suitable for the unique needs of the person with a DD and their caregiver.
4. Frequent reviews of medication with the primary care provider/pharmacist (MedsCheck), which can impact bone health.
5. Screen for male and female risks for osteoporosis early and establish benchmarks in late 20s and early 30s.
6. Conduct Bone Mineral Density scans to confirm risk of fractures based upon best-practice guidelines.

B. Comfort and Other Interventions

According to Bonura (2009), strategies for the prevention and management of osteoporosis are:

1. Nutrition

Eating a balanced and nutritious diet, rich in calcium and Vitamin D is important for healthy bones. Good sources of calcium include dairy products, dark green, leafy vegetables, and calcium-fortified foods, and beverages. Also, supplements can help ensure that the calcium requirement is met each day.

Vitamin D plays an important role in calcium absorption and bone health. It is synthesized in the skin through exposure to sunlight. Individuals who do not have exposure to natural sunlight may require vitamin D supplements in order to ensure an adequate daily intake.

Note: Vitamin D supplements are contraindicated in persons with Prader Willi Syndrome. Check with the primary health care provider before starting any supplement.

2. Exercise

Like muscle, bone is living tissue that responds to exercise by becoming stronger. The best exercise for bones is weight-bearing exercise that forces the body to work against gravity. Some examples include walking, climbing stairs, and dancing.

3. Avoid Risk Factors

Smoking is bad for bones as well as the heart and lungs. Women who smoke tend to go through menopause earlier, triggering earlier bone loss. In addition, smokers may absorb less calcium from their diets. Alcohol can also negatively affect bone health. Those who drink heavily are more prone to bone loss and fracture, both because of poor nutrition and an increased risk of falling.

4. Routine Comprehensive Risk Assessments

Routine assessments (e.g. annual physical) should include an annual risk assessment and screening for osteoporosis for women 50 and over and earlier for persons with a DD.

5. Fall Prevention Strategies

Avoiding falls and fear of falling are important concepts which will be covered in the next section. Suffice it to say, falls can lead to premature placement, chronic pain, and an overall decrease in quality of life. Consequently, there is the need for early fall prevention interventions.

For additional information please see the attached link below:

https://osteoporosis.ca/about-the-disease/?gclid=CjwKCAjwwtTmBRBqEiwA-b6c_8U2FXX8rUok1U9uGT8g3xcBFRXDzJGEoMcVY0g3Wa-Xe3Y6kPfezRoCeAkQAvD_BwE



Information

Osteoporosis Canada provides a video series on exercise and osteoporosis and safe effective exercise and physical activity with osteoporosis. The videos are based on four case studies of individuals affected by osteoporosis, various risk levels, and exercise guidelines. The videos change weekly and can be accessed at:

<https://osteoporosis.ca/health-care-professionals/clinical-practice-guidelines/exercise-recommendations/video-series-on-exercise-and-osteoporosis/>



Join the Canadian Osteoporosis Patient Network (COPN)
You will receive:

- Free newsletters
- Practical Tips on nutrition, exercise and medications
- Inspiring stories

Contact Information:

- 1-800-463-6842
- www.osteoporosis.ca/copn

Fall Prevention



A fall is defined “...as a sudden & unintentional change in position resulting in an individual landing at a lower level such as on an object, the floor, or the ground, with or without injury” (WHO, 2015).

Senior Falls in Canada

Falls are a serious issue, as a fall of an older person can have an enduring and devastating impact, resulting in injury, chronic pain, reduction in quality of life and, in severe cases, death (Public Health Agency of Canada, 2016). Additional impact includes; disability, loss of confidence in physical and functional abilities, fear of falling, increased social isolation, increased dependency on caregivers, lack of independence, loss of mobility, and premature and long-term institutionalization.

Consider the following fall hospitalization data prepared for *Seniors’ Falls in Canada – Second Report* (Public Health Agency of Canada, 2014):

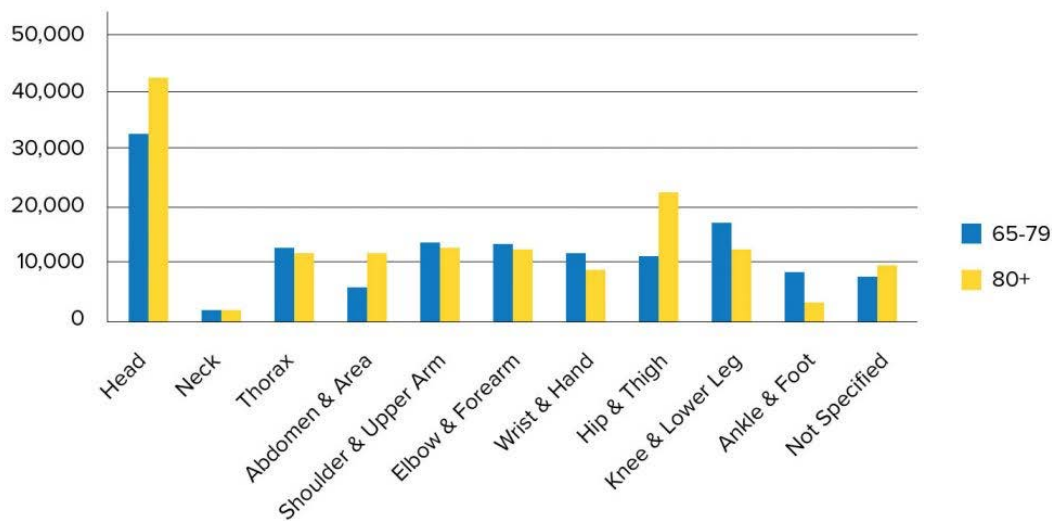
- falls remain the leading cause of injury-related hospitalizations for Canadian seniors,
- Canadian seniors who are hospitalized for a fall remain in hospital an average of nine days longer than those admitted for any other cause,
- the number of deaths due to falls increased by 65% from 2003 to 2008,
- approximately **20-30%** of seniors experience **1+** falls a year,
- falls account for **90%** of all hip fractures,
- over **50%** of falls happen in the **HOME** and can be preventable,

- health care costs associated with fall –related injuries accounted for over \$2.0 billion in spending and is predicted to rise to \$4.4 billion by 2036, and
- **35-40%** of all long-term care home admissions are due to fall related outcomes.

In 2017, there were approximately 135,000 emergency department (ED) visits for fall-related injuries for persons aged 65-79, and nearly 149,000 ED visits for individuals aged 80 and above. See the Table below for comparison of injuries obtained from falls

Fall-Related Emergency Department Visits By Injured Body Part, 2017

For Ontarians Aged 65-79 & 80+



Closing the Gap: How to Prevent Falls: A Complete Falls Prevention Guide for Seniors & Caregivers (2018).

Before continuing with fall risk factors and prevention strategies, why not take the Fall Prevention Quiz below. The answers are on the right. Don't peek!

TAKE THE FALLS PREVENTION QUIZ

1. Falls are the leading cause of injury in older adults.



True or False?

True
 Falls are the leading cause of injury & the 6th cause of death among seniors. Falls in older adults, costs \$6.2 billion a year to the Canadian health care system. (The Economic

*Burden of Injury
Canada,
SmartRisk)*

2. You should always put on your reading glasses when walking, especially on stairs, to reduce your risk of falling.



True or False?

False
Be sure you remove your reading glasses for walking or climbing up or down stairs. If you use bifocals, adjust your glasses so you can see the stairs clearly (Public Health Agency of Canada).

3. A “slip” or “trip” can result in serious injury.



True or False?

True
People who “slip or trip”, end up falling & usually do not report such an experience as a fall. Speak to your doctor or nurse about how to prevent a fall (Step Ahead to Falls Prevention).

4. If you exercise and improve your muscle strength, as well as eat a healthy diet, you can reduce your risk of falling.



True or False?

True
Regular physical activity is one of the most effective means to reduce your risk from falls & to prevent injury. Healthy eating provides energy & strength for better

*physically active
Diets low in
calcium and
Vitamin D may
increase the risk
for fracture in
seniors with
osteoporosis
(Smart Moves,
Smart Risk).*

5. Most falls happen away from home.



True or False?

False
*Up to 75 % of
falls happen in
the home.
Slipping, tripping
& stumbling from
one level to
another are the
most common
causes of injury.
The stairs &
bathroom are
particularly
dangerous
(Public Health
Agency of
Canada, 2005)*

6. Side effects of medications can contribute to falls in older adults.



True or False?

True
*20 % of falls in
older adults are
caused by
improper use of
medications (See
Ahead to Falls
Prevention: Fall
Risk Factors).*

7. Injuries from falls are predictable and preventable.

True
*Unintentional
injuries are a
leading cause of
hospitalization &
death in Canada*



True or False?

While these injuries are usually called "accidents," they often occur under preventable conditions. Some of the risks associated with these accidents are hazards in the home, misuse of medications, balance & gait problems, & blood pressure problems (www.york.ca/injury-prevention).

8. Women, especially those over 75, are at greater risk for injury due to falling.



True or False?

True
Women tend to have less muscle strength, be more prone to brittle bones (osteoporosis), and take more medications than men. Twice as many older women are admitted to hospital than men of the same age (Step Ahead to Falls Prevention).

True

9. Winter increases the risk of falls in the elderly.



True or False?

Though falls can happen at any time of the year, cold weather often exacerbates pre-existing medical conditions in the elderly, increasing the risk of falls. Environmental conditions such as ice also increase the risk of falling.

10. Head injuries are the most significant injuries from a fall.



True or False?

False
Though falls can cause other injuries in an elderly person, the most common injury is a fracture to the hip.

11. Wearing the right footwear is important. The ideal footwear is soft, flexible, and tight fitting.



True or False?

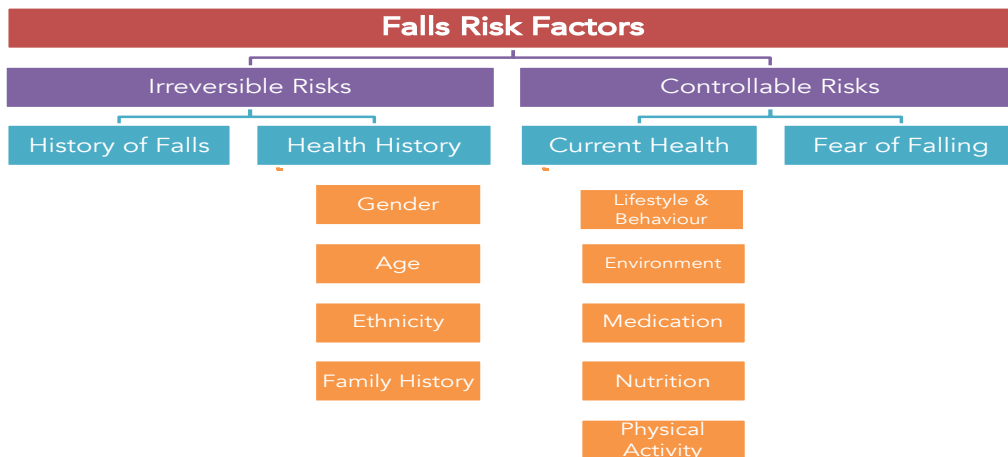
False
A firm back & cover with adjustable fastening, ankle support & non-slip sole is the best type of footwear.

How did you do? According to Parachute's Ontario Injury Data Report, 2018, the most frequent cause for falls is slips, trips and falling downstairs, and off furniture. Note in the Table below that the incidence of falls increases significantly with age.

Falls: Hospital Visits by Cause and Age Group						
	Age Group					
Injury	60-64	65-69	70-74	75-79	80+	Total
Slip/Trip General	1,258	1,632	1,951	2,599	11,356	18,796
Slip/Trip Ice/Snow	316	276	282	256	517	1,647
Stairs and Steps	653	780	811	935	2,423	5,602
Bed	125	197	235	351	2,003	2,911
Chair	68	96	116	168	800	1,248
Other Furniture	18	34	30	38	178	298
Total	2,438	3,015	3,425	4,347	17,277	30,502

Risk Factors for Senior Falls

Significant research findings point to most falls occurring as a result of a number of factors (risk factors) that combine and overwhelm an older person’s ability to maintain or regain their balance. Understanding what puts a person at risk of falling is a critical step in reducing falls and fall-related injuries among older Canadians. Examining the Figure below from Canadian Patient Safety Institute,(CPSI, 2013), fall risk factors can be categorized as irreversible or controllable risks.



When examining best practice related to fall prevention, CPSI (2013) recommends using a multifactorial fall risk assessment – The BBSE (Biological, Behavioral, Social/Economic & Environmental) Model. The Figure below depicts the Model:

BIOLOGICAL	BEHAVIOURAL	SOCIAL/ECONOMIC	ENVIRONMENTAL
<ul style="list-style-type: none"> • Impaired mobility • Balance/gait deficit • Muscle weakness • Advanced age • Chronic illness 	<ul style="list-style-type: none"> • History of falls • Fear of falling • Multiple medications • Excessive alcohol use • Lack of exercise • Poor nutrition or hydration • Inappropriate footwear • Inappropriate assistive devices 	<ul style="list-style-type: none"> • Low income • Lower level of education • Living alone • Lack of support/social interaction • Lack of transportation • Culture/ethnicity 	<ul style="list-style-type: none"> • Stairs • Obstacles and tripping hazards • Lack of handrails/grab bars • Poor lighting • Slippery or uneven surfaces

When focusing on biological changes with aging from the BBSE Model above, consider the following impact on falls:

Acute Illness

Symptoms of acute illness such as weakness, pain, fever, nausea, and dizziness can increase the risk of falling. Studies have found that urinary tract infections (UTIs) contributed significantly to falls due to the need, frequency, and urgency to reach the toilet. Furthermore, the effects of medications taken to treat the condition or symptoms can also increase the risk of falling. Similarly, foot disorders (corns, bunions, toe deformities, ulcers) and general pain can contribute to balance and gait difficulties. Studies by Leveille, S. (2009, pg. 2221) suggests that "chronic pain may serve as a distractor or, in some way, interfere with cognitive activity needed to prevent a fall".

Balance and Gait Impairment

Balance impairments result when there are changes to the normal functioning of the nervous and skeletal systems, which can involve biomechanical (impact on muscles & other mechanical systems), sensory (vision, hearing, touch etc.) and cognitive changes (confusion, dementia, delirium etc.) as discussed earlier. Research consistently shows that balance impairment is significantly linked to the risk of falling among older adults. Similarly, a number of studies have found that a person's gait (e.g., timing, placement) is a significant risk factor for falling.

Gait is defined as... "A person's way of walking" (Wikipedia)

Chronic Conditions and Disabilities:

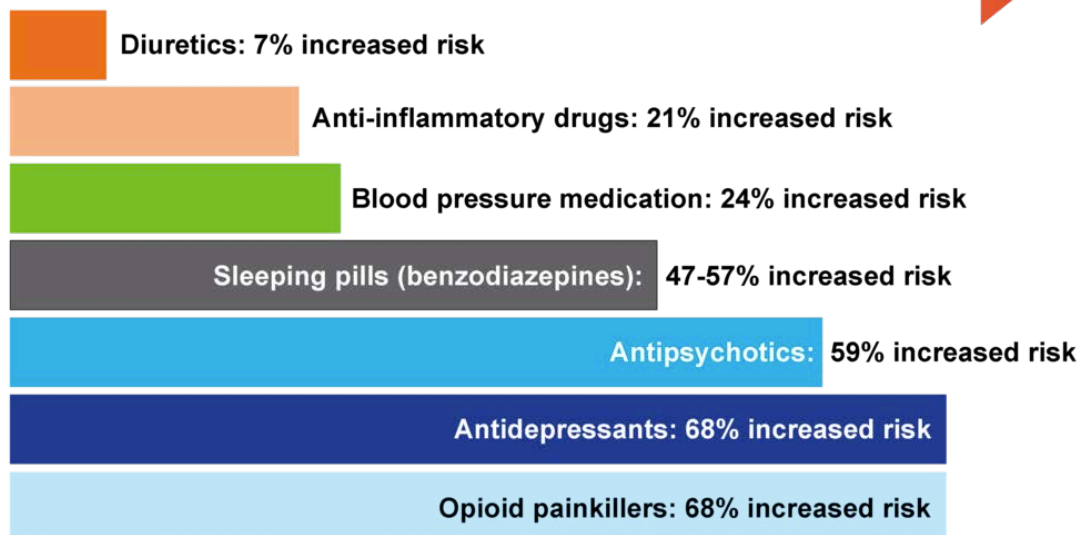
A wide range of chronic medical conditions can increase a person's risk of falls, including neurological disorders, such as Parkinson's disease, diabetes (lack of sensation in the feet leading to falls), arthritis, cardiovascular disease, end-stage renal disease, chronic obstructive pulmonary disorder, or the effects of a stroke. More than 80% of older adults have at least one chronic condition. These chronic conditions result in physical limitations and loss of function, that affect mobility, gait, and balance. In the next section, chronic disease management will be more thoroughly discussed.

Other chronic conditions include bowel or bladder incontinence, which can lead to urgency and frequent trips to the toilet. An interesting study by Bloch (2013), found a link between taking laxatives and falls. Person's taking laxatives were twice as likely to fall as those not taking them.

Cognitive Impairments:

For those older persons with dementia or other cognitive impairments, the risk of falling and sustaining a fall injury is two to three times that of older people without cognitive impairments. Cognitive impairments affect one's ability to anticipate and adapt to the environment and surroundings in order to maintain or restore balance. These symptoms may be further compounded by the side effects of medications taken to manage behavioural and chronic/acute medical problems that may exist as well (e.g., psychotropic, anti-seizure, diuretic medications). In the Figure below, provided by Canadian Deprescribing Network <https://www.deprescribingnetwork.ca/medications-and-falls>), illustrates the impact of specific medications and risk of falls with seniors.

Which medications increase the risk of falls in seniors?



Source: de Jong et al. 2013; Huang et al. 2012; Kelly et al. 2003.

A state of mental confusion or disorientation, also referred to as delirium, has also been shown to increase the risk of falls. Research has found that normal age-related cognitive changes can also affect balance. For example, through delays in switching attention from one task to another task, which can then result in an unexpected loss of balance.

Poor Vision:

Changes to vision are associated with aging and increase the risk of falls. For example, a study of fall risk factors found that older adults with poor vision were two and a half times more likely to fall than older adults without vision problems. Indirectly, changes in vision are also linked to a decrease in physical activity, which is another risk factor for falling. Poor vision can impact safety while walking because one cannot detect hazards in the environment. Poor vision can also affect the ability to maintain balance and being able to focus in unfamiliar environments thereby missing important environmental cues such as position and location of handrails or steps.

Muscle Weakness and Reduced Physical Fitness:

Decreases in muscle strength and endurance may result in slips, trips, or stumbles becoming a fall. The panel of the American Geriatrics Society, British Geriatrics Society and American Academy of Orthopaedic Surgeons found muscle weakness to be the most important risk factor, increasing the risk of a fall by four to five times. Furthermore, weakness in the lower extremities was found to be a risk factor for fall-related hip fractures.

Another major cause of falls noted by Stevens (2009), was the misuse of canes and walkers. It was noted that many falls (higher incidence with females), occurred as a person was leaving a walker to sit in a chair, or standing from a chair to use a walker. Stevens’s research also observed that over 60% of falls occur at home. Conducting environmental assessments (e.g., Home Safety & Risk Assessment – See above example) and Fall Risk Assessments can have a significant impact by identifying risks in home environments, which could be linked with falls (e.g., clutter, scatter rugs, lack of bath safety equipment).

A helpful tool in addition to the Home Safety & Risk Assessment is the Fall Risk Assessment. The tool can be used by service and care providers to identify the level of risk and recommendations such as: linking to professional resources and community supports. See the Table below:

SAMPLE FALL RISK ASSESSMENT PROFILE (HEALTH /SOCIAL SERVICE CARE PROVIDER)

<input type="checkbox"/> On Admission/Intake/1 st Assessment	<input type="checkbox"/> Post Fall	<input type="checkbox"/> Change in Medical Status
Fall Risk Category	Yes	No
1. History of two or more falls in the last 60 days • <input type="checkbox"/> If Yes , client is considered high - risk automatically	<input type="checkbox"/>	<input type="checkbox"/>
		Referral / Resources After investigation <u>consider</u> referral to: <input type="checkbox"/> Equipment Supplier <input type="checkbox"/> Ontario Health Team Home & Community Care Support Services <input type="checkbox"/> Physician/ Primary Care Provider & Follow-Up <input type="checkbox"/> Regional Geriatric Outreach Team or other geriatric assessment team <input type="checkbox"/> Provide educational material /resources (e.g. exercise programs) <input type="checkbox"/> Community Support Services Agency (e.g. MOW, Personal Care Support etc.)
2. Impaired mobility, balance and/or gait • <input type="checkbox"/> If Yes , client is considered high - risk automatically	<input type="checkbox"/>	<input type="checkbox"/>
		Referral / Resources After investigation <u>consider</u> referral to: <input type="checkbox"/> Foot Care Clinic <input type="checkbox"/> Equipment Supplier <input type="checkbox"/> Ontario Health Team Home & Community Care Support Services <input type="checkbox"/> Physician/ Primary Care Provider & Follow-Up <input type="checkbox"/> Regional Geriatric Outreach Team or other geriatric assessment team <input type="checkbox"/> Provide educational material <input type="checkbox"/> Community Support Service Agency (e.g. MOW, Personal Care Support etc.)
3. High to very high levels of pain results in a 70% chance of falls occurring. In a dementia client, pain level will be rated subjectively. The client is considered as high to very high based upon changes in behaviour (e.g. increased agitation, anxiety, aggression, facial grimacing etc.)	<input type="checkbox"/>	<input type="checkbox"/>
		Referral / Resources After investigation <u>consider</u> referral to: <input type="checkbox"/> Specific agency for pain management <input type="checkbox"/> Ontario Health Team Home & Community Care Support Services <input type="checkbox"/> Physician/ Primary Care Provider & Follow-Up <input type="checkbox"/> Regional Geriatric Outreach Team <input type="checkbox"/> Provide educational material (e.g., exercise programs) <input type="checkbox"/> Community Support Service Agency (e.g. MOW, Personal Care Support etc.)
	<input type="checkbox"/>	<input type="checkbox"/>
		After investigation <u>consider</u> referral to:

4. Medications (3 or more)			<input type="checkbox"/> Provide educational material <input type="checkbox"/> Pharmacy for in-home/on-site free consultation (MedsCheck) <input type="checkbox"/> Ontario Health Team Home & Community Care Support Services <input type="checkbox"/> Regional Geriatric Outreach Team or other geriatric assessment team
5. Impaired cognitive status In a dementia client the rating should be based on the four (4) stages of the disease process. High to very high risk is considered in the late or end stages. However, in certain situations, middle stage may result in high- risk. Use judgment to determine level of risk.	<input type="checkbox"/>	<input type="checkbox"/>	After investigation <u>consider</u> referral to: <input type="checkbox"/> Ontario Health Team Home & Community Care Support Services <input type="checkbox"/> Regional Geriatric Outreach Team or other geriatric assessment team <input type="checkbox"/> Provide educational material <input type="checkbox"/> Community Support Service Agency (e.g. MOW, Respite & Personal Care Support etc.)
6. Sensory impairment/deficits e.g. visual, hearing	<input type="checkbox"/>	<input type="checkbox"/>	After investigation <u>consider</u> referral to: <input type="checkbox"/> Encourage Follow Up with Physician/Specialist <input type="checkbox"/> Foot Care Clinic or other sensory clinics <input type="checkbox"/> Ontario Health Team Home & Community Care Support Services <input type="checkbox"/> Regional Geriatric Outreach Team or other geriatric assessment team <input type="checkbox"/> Provide educational material <input type="checkbox"/> Community Support Service Agency (e.g. MOW, Personal Care Support etc.)
7. Other (specify) e.g. low blood pressure, home & safety hazards	<input type="checkbox"/>	<input type="checkbox"/>	After investigation <u>consider</u> referral to: <input type="checkbox"/> Foot Care Clinic <input type="checkbox"/> Provide educational material <input type="checkbox"/> Encourage Follow Up with Physician/Specialist <input type="checkbox"/> Conduct a Home Safety & Risk Assessment & determine needs <input type="checkbox"/> Regional Geriatric Outreach Team or other geriatric assessment team
Fall Risk Status	<input type="checkbox"/> Normal Risk <input type="checkbox"/> Medium Risk (2 or more of identified risks) <input type="checkbox"/> High – Very High Risk (Answered yes on Questions #1, #2 and #5). *Interventions are required at this level		
Additional Comments:			
Completed by: (print)	Signature:	Date:	

Adopted from Quality Healthcare Management 2019

Strategies/Recommendation for Persons Aging with a DD:



The good news about falls is that most of them can be prevented. The key is to know the fall risk factors (e.g., changes in balance and gait, flexibility, unsafe environments, poor vision, interactions with medications etc.) and where to seek advice and assistance. According to Rubenstein (2006), significant evidence now points to the most effective (and cost-effective) fall reduction programmes have involved fall risk assessments (See Sample Falls Risk Assessment above) and targeted interventions such as:

- linking to healthcare providers for assessments and medical interventions/treatments,
- community exercise programmes and staying active,
- environmental-inspection and hazard-reduction programmes (e.g. Home Safety and Risk Assessments - See above),
- regular foot care,
- managing chronic conditions (e.g., diabetes),
- healthy eating and other wellness activities,
- medication reviews with the local pharmacist,
- using assistive devices (e.g., walkers, canes, bath chairs, tub clamps, raised toilet seats), and safety equipment where appropriate,
- home safety modifications,
- Vitamin D supplements, and
- hip protectors/fall mats.

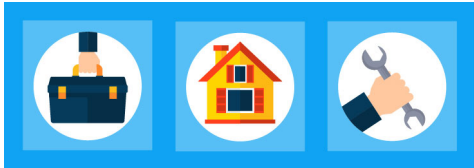
Implementing targeted interventions for fall prevention should be in consideration of the following principles when working with a person aging with a DD, their caregivers and family:

- ensure the person aging with a DD's perspective and needs are key in determining the choice of interventions,
- apply the best interventions for maintaining the highest quality of life possible while striving for a safe environment, and
- be aware that risk-taking, dignity, autonomy, and self-determination should be supported, respected, and considered during the plan of care.

Additional Fall Prevention Strategies to Consider

Keeping the above principles in mind, this next section will highlight fall prevention strategies, which have not yet been discussed; home safety modifications, Vitamin D supplements, and specific supplies/equipment such as hip protectors/fall mats. Following the discussion, there will be a list of Fall Prevention Tool Kit resources, on-line education, and other materials to support additional learning needs.

Home Modification/Adaptation.



If the plan is to continue living safely in the community and home for as long as possible, it may be necessary to configure the home to adapt to the changing needs of the person aging with a DD. It is highly recommended that before embarking on expensive renovations and equipment purchases consider contacting the Ontario Health Team (OHT) Home and Community Care Support Services for a free Occupational Therapist (OT) in-home risk assessment (Note: Private OT services can also be purchased at medical supplies and equipment vendors-See list at end of section). The OT will provide recommendations to modify the space to help reduce the risk of falling and improve quality of life as well as assisting in completing applications for financial assistance if required.

OT recommendations may include purchasing adaptations such as: ramps, extra lighting, handrails, etc. depending upon the safety needs identified. More information about adaptations and equipment may be found at the Canada Mortgage and Housing Corporation (CMHC) web-site - <https://www.cmhc-schl.gc.ca/>. CMHC also has a free step-by-step Guide, *Maintaining Senior's Independence Through Home Adaptation* available for download.

An interesting document developed in partnership by CMHA and the March of Dimes titled: *Low Cost or No Cost Home Modifications for Seniors and People with a Disability* (2017), identifies over 50 low- or no-cost modifications to make a home accessible and safe for the prevention of falls and aging in the community. These simple modifications can improve safety and accessibility for everyone, including seniors and persons with a DD. The document is included in the appendix at the end of this section.

There are various funding sources for financial assistance for home adaptation and modifications. Perhaps the most well-known is the CMHC, which has the Home Modifications for Persons with a DD and seniors (RRAP & RRAP - D) programs. Also, another program is the provincial government Ministry of Children, Community and Social Services (MCCSS), Home and Vehicle Modification Program, administered by the Ontario March of Dimes. To access additional information about the program, please

see the link below:

<https://www.mcscs.gov.on.ca/en/mcscs/programs/social/hvmp.aspx>

In addition, the web-site below provides links to over 100 potential Canadian government grants for home modifications:

<https://showmethegreen.ca/home/home-improvement/canadian-government-grants-for-disabled-homeowners-2018/>

Keep in mind the financial support that may be available through the Ontario Disability Support Program (ODSP). Another consideration is contacting a local Community Support Services Agency or Seniors Centre that may offer subsidy or low-cost senior home maintenance/adaptation support (e.g. grass cutting, window cleaning, driveway snow and walkway clearing etc.). See also, the Aging and Financial Planning section for additional financial assistance support and tax savings incentives.

Note: Remember do not purchase anything before confirming that funding supports are available! Most funders will disallow the funding grant if the purchase or adaptation is completed and paid prior to submitting the application.

Vitamin D Supplements

Osteoporosis Canada recommends that individuals with osteoporosis or with risk factors for fractures receive adequate Vitamin D, as recommended at 800-2,000 IU per day. Vitamin D is essential for bone development and maintenance throughout life. In addition, the role of Vitamin D is to assist the body to absorb calcium and act to slow down bone mineral loss. Studies have shown that Vitamin D can improve muscle strength and function, thereby reducing the risk of falls and fractures by about 20% (International Osteoporosis Foundation, 2015).

Note: Persons diagnosed with Prader Willi syndrome should not receive Vitamin D supplements. Remember to always consult your primary health care provider before administering any medication including over-the-counter medication, herbs and vitamins.

Hip Protectors

Persons at high risk of falling are also at high risk of developing a hip fracture. In an effort to reduce the risk of hip fractures, hip protectors have been used in home and long-term care settings. Hip protectors are plastic shields (hard) or foam pads (soft), usually fitted in pockets in specially designed underwear.

Recent research by Santesso et al. (2014), suggests that hip protectors probably reduce the risk of hip fractures without increasing the frequency of falls. However, hip protectors may slightly increase the small risk of pelvic fractures. Poor acceptance and adherence to consistently wear the hip protectors is seen as a barrier to their use.

Fall Protection Mats

Fall protection mats are safety features that are placed on the floor along the side of the bed in the home. Fall protection mats are made from high-impact foam and are designed to help prevent injury from potential falls. Each mat is specifically made with shock-absorbing material that resists compression under impact. They are waterproof, antimicrobial, flame retardant, and slip resistant. The mats can be purchased through any medical supply and equipment vendor. The price ranges from \$50 - \$100 depending on size and type of materials.

For additional information, please see the links below at:

Debunking the Myths of Older Adult Falls: A list of 10 myths related to falls with older adults from the National Council on Aging (NCOA):

<https://www.ncoa.org/healthy-aging/falls-prevention/preventing-falls-tips-for-older-adults-and-caregivers/debunking-the-myths-of-older-adult-falls/>

Online Module 1: Step Ahead to Fall Prevention E-Learning Module

1. Examines age related changes and modifiable risk factors associated with falls.
2. Enables caregivers to incorporate fall prevention strategies when working with older adults.

Instructions:

1. Please go to Toronto Public Health – Step Ahead to Falls Prevention E-Learning Module to register
2. Once registered, you will receive the link below:

<https://www.toronto.ca/community-people/health-wellness-care/health-programs-advice/injury-prevention/fall-prevention/step-ahead-to-fall-prevention-in-older-adults/e-learning-module-1-fall-prevention/>

Falls - http://www.phac-aspc.gc.ca/seniors-aines/publications/public/injury-blessure/seniors_falls-chutes_aines/assets/pdf/seniors_falls-chutes_aines-eng.pdf

Mental Health and Aging – The 3D’s - Depression, Delirium and Dementia

Aging is associated with an increased risk of developing minor cognitive difficulties and the development of more serious mental health problems, such as depression, delirium, and dementia, as well as physical illnesses as described above. In the general population, relatively minor cognitive difficulties in aging are common, however, the risk of such disorders increases as people live into their 70s and 80s. The most common form of dementia is called Alzheimer's Disease, named after Alois Alzheimer who, in 1906, first

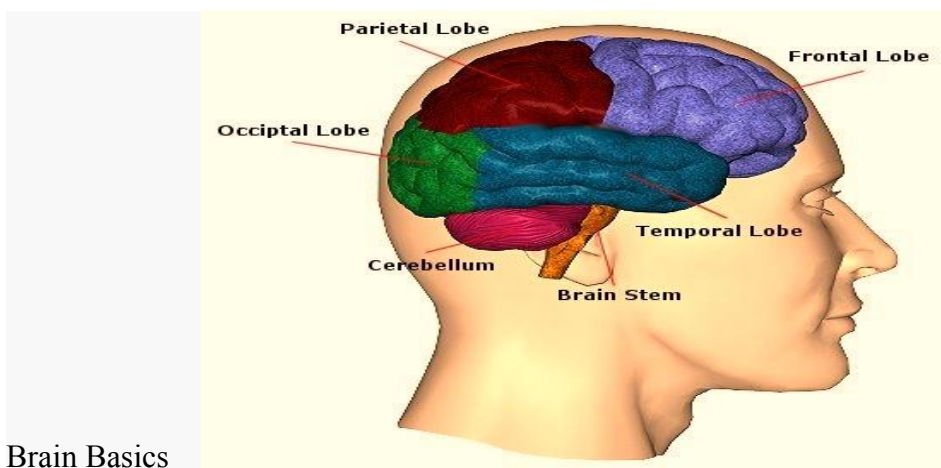
“In any given year, 1 in 5 people in Canada will personally experience a mental health problem or illness,

described the characteristic brain changes (called plaques and neurofibrillary tangles) associated with this disorder. In the past, this was often referred to as “senile or pre-senile dementia” (<http://www.intellectualdisability.info/life-stages/articles/ageing-and-its-consequences-for-people-with-downs-syndrome>).

(Canadian Mental Health Association)

According to Aggarwal (2013), mental health disturbances are considered common among adults with a DD, with a 1.5 – 2 percent higher prevalence than the general population. The cause has been attributed to sensory impairments, life events, lack of suitable supports (emotional, social, community, work, and recreational), stress, lack of capacity to cope and resolve issues, and genetic predisposition (e.g., Down Syndrome and Alzheimer Disease). Caregivers, families, and the primary health care team have an important role in recognizing mental health issues through communication, frequent assessments, and utilization of an interprofessional team approach (e.g., social workers, psychiatrists, nurses, etc.), prescribing and monitoring side effects of medication, planning early, and supporting life transitions.

In this section, depression, delirium and dementia will be highlighted focusing for the most part on general signs and symptoms and treatment. Although research continues to evolve to better understand the brain and mental health, much is unknown with persons aging with a DD. Dementia however, particularly in persons with Down Syndrome, has been well documented. Several assessment tools have been developed such as the *National Task Group – Early Detection Screen for Dementia (NTG-EDSD)* and the *Resident Assessment Instrument (RAI) Caregiver Distress Index*. The assessment tools will be illustrated in the *Guide*. In addition, the National and Ontario Dementia Strategy (2017), will be outlined to provide the reader with an overview of the planned strategies and outcomes for persons living with dementia and caring for persons with dementia with a DD. The figure below is an overview of the brain anatomy.



Brain Basics

The brain is a “three (3) pound miracle” that controls all we do and how we do it with over 80 billion neurons working together. The figure above illustrates the components of

the brain. The brain is divided into two sections or hemispheres. The left side of the brain controls such things as language and analytical thinking and the right side of the brain controls spatial relations, attention, and thinking as a whole. The cerebellum controls coordination and balance, while the brain stem connects to the brain and spinal cord and controls automatic functions such as breathing, digestion, heart rate, and blood pressure. The frontal lobe helps plan and organize and is involved in controlling motor function, problem solving, memory, language, judgement, impulse control, and social and sexual behavior. The parietal lobe integrates sensory information (touch, temperature and pain) and language processing. The occipital lobe controls vision and interpretation of visual meaning, language, and emotions. The temporal lobe controls new learning and short-term memory.

Keeping the function of the brain in mind, it is clear that diseases affecting one or more areas of the brain can impact health and functioning (e.g., stroke, diabetes, and dementia etc.).

For additional information regarding the function of the brain, please see the link below:

<https://www.youtube.com/watch?v=Ir1pY9QSGxM>

Depression

According to the American Psychiatric Association (APA) and the Centre for Addictions and Mental Health (CAMH), depression (major depressive disorder) is defined as a common and serious medical illness that negatively affects feelings, thought processes and behavior. Fortunately, for most people, it is also treatable.

Depression symptoms can vary from mild to severe and can include:

- ☐ feeling sad or having a depressed mood,
- ☐ loss of interest or pleasure in activities once enjoyed,
- ☐ changes in appetite - weight loss or gain unrelated to dieting,
- ☐ trouble sleeping or sleeping too much,
- ☐ loss of energy or increased fatigue,
- ☐ increase in purposeless physical activity (e.g., hand-wringing or pacing) or slowed movements and speech (actions observable by others),
- ☐ feeling worthless or guilty,
- ☐ difficulty thinking, concentrating, or making decisions, and
- ☐ thoughts of death or suicide.

Depression can affect anyone - even a person who appears to live in relatively ideal circumstances. For persons aging with a DD, depression can be misdiagnosed as dementia and therefore it is critical to note changes in activity level and interests, anxiety level, etc. and communicate these findings to the healthcare and social service team.

Several factors can play a role in depression:

“People often think that depression in older adults is a normal response to the losses of aging. When they say, for example, “It’s no wonder he’s depressed he’s 82,” or “If I had arthritis, I’d probably be depressed too, they may mean well, but depression is normal”.
<https://www.camh.ca/health-info/guides-a-publications/depression-in-older-adults>

1. **Biochemistry:** Differences in certain chemicals in the brain may contribute to symptoms of depression.
2. **Genetics:** Depression can run in families or specific diseases.
3. **Personality:** People with low self-esteem, who are easily overwhelmed by stress, or who are generally pessimistic appear to be more likely to experience depression.
4. **Environmental Factors:** Continuous exposure to violence, neglect, abuse, chronic illness/disability, or poverty may make some people more vulnerable to depression.

Strategies/Recommendation for Persons Aging with a DD:

A. Screening

1. Physical assessment including lab work.
2. Medication reviews.
3. Psychiatric Assessment Tools including risk assessments, depression scale tools, and other assessment tools.

B. Comfort and Other Interventions

1. Individual and group counselling as appropriate.
2. Cognitive Behavior Therapy.
3. Coping skill training.
4. Introduction of anti-depressant medications (Note: This should not be the first choice and should be reviewed every three months with caregiver input on changes in behavior and side effects).
5. Linkages to Home and Community Care Support Services (e.g., Mental Health Nursing, Occupational Therapy, and Social Work), and Community Support Services.
6. Psychiatrist and/or other specialists.

Case Study – Anne E.

Anne is a forty- nine year - old female with a busy social life who is known by everyone in the local community as an outgoing, good humoured person. She has Down's Syndrome and moderate DD. She lives at home with her parents who are both in their seventies. They have noticed a gradual decrease in her skills over the past month or two. They have reported that her memory is not as good as it has been, and she is more forgetful - so much so that they have to remind her about her usual schedule of activities. They are aware that Alzheimer Disease is prevalent with Down Syndrome persons and are very concerned.

Today, when you visit her home, you find Anne in her bed sleeping. Her parents have said that she has refused to eat breakfast.

While Anne is sleeping, you conduct a risk assessment (See Surrey Place Risk Assessment Tool below), with her parents which included a/an:

- physical and functional review including recent appointments, etc.,
- medication review,
- discussion on recent changes in environment,
- assessment on current support services and changes/challenges/barriers, and
- description of emotional issues/behavior.

During the assessment, you discover that Anne's Aunt recently passed away from breast cancer. She was close to Anne and spent a lot of time with her. As well, her parents admitted that there had been a lot of staff changes at the Adult Day Program she participated at and she just didn't want to attend anymore as she loved the games and they no longer played them anymore.

When Anne woke up, you confirmed your risk assessment findings while sharing a warm soup together and nice fresh fruit and a glass of water. Before leaving, you asked Anne if she would visit with you at the Primary Care Clinic as she may benefit from a:

- physical assessment including lab work,
- medication review with the Pharmacy/Physician,
- referral to Social Worker for grief counselling, and
- group counselling if appropriate.

And permission to speak with the staff at the Adult Day Program to better understand how the program may better meet Anne's emotional needs. You also suggested that Anne's parents begin monitoring Anne's behavior over the next month using the Surrey Place - ABC Monitoring Chart for Antecedent/Behavior/Consequences (See)Appendix to share with the Interprofessional Team at the Primary Care Clinic.

Additional information and resources are found in the links below:

Beyond Words provides books and training to support people who find pictures easier to understand than words. Whether supporting somebody with a learning disability or communication difficulty, our products empower people through pictures.

<https://booksbeyondwords.co.uk/>

Tutorials from the Centre of Addictions and Mental Health (CAMH) about mental health and older adults and depression are available to access with the links below:

http://www.camhx.ca/education/online_courses_webinars/mha101/introolderadults/Older_Adults_.htm

Depression

<https://moodle8.camhx.ca/moodle/login/index.php#dep>

BounceBack

Supported by provincial government funding, BounceBack is a program offered by the Ontario division of the Canadian Mental Health Association (CMHA) that aims to help those aged 15 and over manage mild to moderate symptoms of anxiety and depression.

The program offers two types of support through workbooks and one-on-one telephone coaching as well as a series of online videos offering practical tips available any time at bouncebackvideo.ca.

Delirium

Delirium is a sudden and severe disturbance in thinking. It can cause changes in a person’s ability to stay alert, remember, be oriented to time, or place, speak, or reason clearly.

Delirium is a common and serious condition often caused by many things including having an infection, dehydration, recent surgery, various medical conditions, untreated pain, starting, increasing, or stopping some medications, or not eating or sleeping well. It can often be prevented (D’Aniello, 2019). If not treated it can lead to death.

You may wish to take the screening tool below, while recognizing that this screening may be more suitable for persons with mild to moderate DD.

The Sour Seven: Delirium Detection Questionnaire for Caregivers

This is a questionnaire designed for caregivers to screen for delirium (acute confusion) in seniors, including those with dementia (chronic confusion), that requires no training, no prior knowledge of the person, no questions posed to the person, is independent of language, and is based on seven simple observations of the person during caregiving.

During your interaction with the person today, have you observed any of the following? Circle the corresponding value in the answer boxes. Add the total score in the box below.

- | | | |
|---|---------------|--------------------------|
| 1. Altered level of awareness to the environment in any way different than being normally awake. Yes (3 points) | No (0 points) | <input type="checkbox"/> |
| 2. Reduced attentiveness; inability to focus on you during the interaction. Yes (4 points) | No (0 points) | <input type="checkbox"/> |
| 3. Fluctuation in awareness and attentiveness, such as drifting in and out during an interaction or through the day. Yes (3 points) | No (0 points) | <input type="checkbox"/> |

4. Disordered thinking; the response (whether verbal or action) is unrelated to the question or request.
Yes (3 points) No (0 points)
5. Disorganized behaviour; purposeless, irrational, under-responsive or over-responsive to requests.
Yes (2 points) No (0 points)
6. Unexplained impaired eating or drinking (excluding appetite); unable to perform the actions to feed oneself.
Yes (2 points) No (0 points)
7. Unexplained difficulty with mobility or movement.
Yes (1 points) No (0 points)

Total Score

Scoring Information:

A score 4 – 8 is possible delirium present (89% probability).
It is recommended that potential causes be evaluated and treated accordingly (medications, dehydration, infection, etc.)

A score of 9 or greater is delirium (100% probability).
It is recommended that an immediate medical evaluation is required
(Adopted from Dr. Richard W. Shulman, Trillium Health Partners (THP), 2014)

Strategies/Recommendations for Persons Aging with a DD

A. Screening

1. Monitor for urinary tract and other infections.
2. Monitor for changes in mental awareness (time, place).
3. Review medications frequently.
4. Monitor fluid intake to prevent dehydration.

B. Comfort Measures & Other Interventions

1. Offer fluids frequently to prevent dehydration.

Note: Many hospitals now offer water in emergency departments from volunteers to decrease the incidents of delirium while waiting for assessments and other test results.

2. Treat infections and monitor for rapidly changing behaviors.
3. Consider antipsychotic drugs for short term treatment only.

Delirium & Prevention in Older Adults Guide

<https://ccsmh.ca/wp-content/uploads/2017/06/CCSMH-8.5-x-11-Delirium-R1-1.pdf>

Alzheimer Disease and other Dementias (ADOD)

Dementia is a term used to describe a variety of brain disorders that include symptoms such as loss of memory, confusion, problems with speech and understanding, and changes in mood and behavior (Alzheimer Society of Canada).

1 in 5 baby boomers will develop dementia in their lifetime

According to well-known author and professor June Andrews (2016), the key symptoms of dementia include difficulty in:

Each year, 1 in 10 seniors die with dementia (cass.acss.ca, 2019)

- remembering things,
- logically working things out (problem solving),
- learning anything new,
- coping with any physical or sensory impairments that develop as a result of normal aging or because of illness or accidents, and
- activities such as driving, way finding, and poor judgement.

What is the difference between Alzheimer Disease and Dementia?

Dementia is not a disease but a combination of symptoms that has many different causes including:

Dementia impacts more women than men. Of the over 400,000 individuals living with dementia in Canada, over two-thirds are women (PHAC 2017)

- vascular disease (e.g., stroke, diabetes)- *Second most common cause of dementia,
- medications,
- Alzheimer Disease*Most common cause of dementia,
- disease specific (e.g., Huntington, Parkinson),
- Lewy Bodies (Tiny lumps of protein in the brain that disrupt normal functioning),
- frontotemporal (motor neuron disease such as Pick's),
- deep or severe depression,
- infections (e.g., AIDS),
- vitamin deficiency,
- metabolic disorders (thyroid disease),
- head trauma, and
- others.

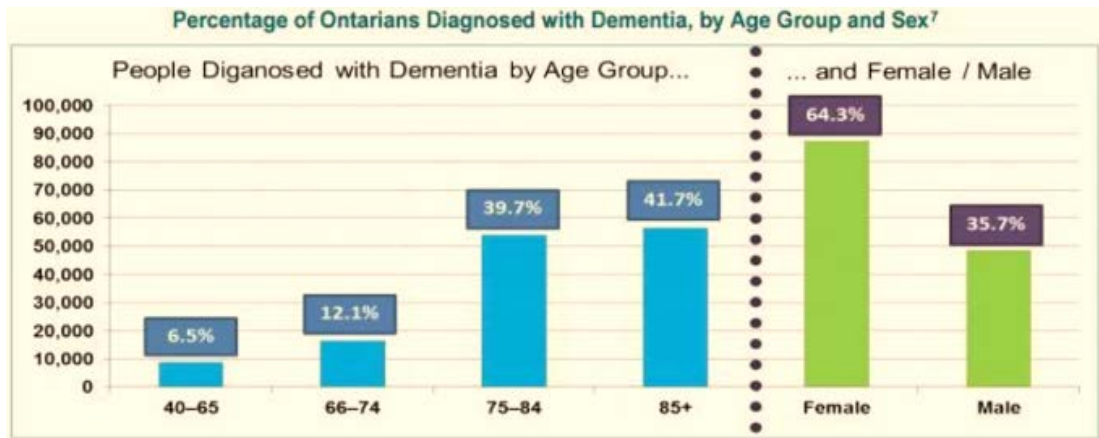
Evidence suggests that compared to the general population, the prevalence of dementia is 34% higher in First Nations populations and is increasing at a faster rate; also, dementia onset is 10 years earlier.

For additional information, please see the link below, which describes dementia:

<https://www.youtube.com/watch?v=RT907zjpZUM>

It is estimated that close to 228,000 Ontarians are currently living with dementia. As Ontario's population ages, it is expected that these numbers will rise to 255,000 people in 2020 and over 430,000 people by 2038. The Table below illustrates the rates of dementia in the population by age group and sex.

TABLE



earlier and males have higher rates of diagnosis (Jacklin, 2018),

The debilitating effects of dementia have substantial personal and financial impact on persons living with dementia, their caregivers, and families. As well, there is considerable economic impact on the Canadian health care system and in 2008, the total annual costs were estimated to be \$14.9 billion.

Dementia Strategies- Canada and the United States Approach

Recognizing the tremendous impact ADOD have, the federal government created the *National Strategy for Alzheimer's Disease and Other Dementias Act*, which passed by Parliament in 2017. The *Act* provides for the development of a national dementia strategy for Canada to ensure that people with dementia, caregivers, and providers:

- have access to information that allows them to make the best possible choices regarding their health and well-being, and
- are living well with dementia, helped by appropriate services and supports where and when they need them.

In Ontario, caregivers of seniors with dementia provide up to 75 % more hours of care than caregiver. of seniors with dementia. (Alzheimer Society of Canada)

Building on the National Dementia Strategy, Ontario released the Provincial Dementia Strategy in May 2017 with a focus on:

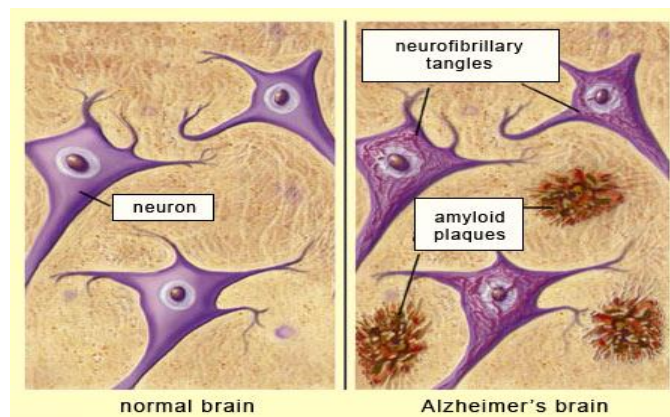
- increasing access to adult day programs for people with dementia, additional hours of care, and transportation to help people travel to their local program location,
- enhancing caregiver respite services, both in-home and/or overnight, so that caregivers can schedule breaks for rest, family commitments, or other priorities,
- expanding behavioural supports, which are tools and techniques used to address behavioural symptoms of dementia, in all long-term care homes, and providing similar support at home and in the community,
- improving the coordination of care, including building strong partnerships between primary, specialist, and community care providers that are critical to help people with dementia live well,

- continuing to invest in health care providers' education with in-person, educational resources and public awareness about the signs and symptoms of dementia to support geriatric care, and
- raising awareness about dementia risk factors and reducing stigma through targeted public awareness campaigns to inform and educate people in Ontario about dementia and how to maintain a healthy brain.

Evidence suggests that dementias affect persons with a DD in the same way as other adults in the general population. Among adults with a DD however, factors that may impact the disease process include age, evidence of significant psychotic symptoms, gait deterioration, and the presence of Down Syndrome as previously discussed. (National Task Group on Intellectual Disabilities and Dementia Practices (2013).

Specifically, with Down Syndrome, chromosome 21 plays a key role in the relationship with Alzheimer's Disease (AD) as it carries a gene that produces one of the key proteins involved with changes in the brain caused by AD. The Amyloid Precursor Protein (APP) and the Tau Protein builds amyloid plaque and neurofibrillary tangles within the brain. According to Tyrell et al. (2001), by age 40, virtually all adults with Down Syndrome develop the neuropathological signs of AD. See the illustration in the Figure below of a normal brain neuron vs an Alzheimer diseased neuron

FIGURE: A COMPARRISON OF BRAIN NEURONS WITH GENERAL AGING & WITH ALZHEIMER'S DISEASE



In the Table below, Zyman and Lott (2007), illustrate the percentage of persons with Down Syndrome affected by dementia.

TABLE: PERCENTAGE OF PERSONS WITH DOWN SYNDROME AFFECTED BY DEMENTIA BY AGE

“Dementia affects the family as much as the person living with the disease. It is critical that we respond to the needs of both patient and caregiver. That’s why we’re making sure that we’re providing more care for people living with dementia while also looking after their caregiver.”
Dr. Eric Hoskins
Minister of Health and Long-Term Care (2013)

“...dementia is not an inevitable aspect of growing old; it is a condition individually experienced that has profound

AGE GROUP	PERCENTAGE OF PEOPLE WITH DOWN SYNDROME AFFECTED BY DEMENTIA	impact on the person, their family, other caregivers and their community".
	10-25%	
50-59 years	20-50%	
60+ years	60-75%	NTG- Caregiver Guidelines (2013pg. 6)

In the United States, the National Alzheimer’s Project Act (NAPA) 2011, was created to address more specific information and best practice guidelines for providing quality care for persons with a DD affected by dementia. Three major American organizations created the National Task Group on Intellectual Disabilities and Dementia Practices (NTG) with the goals to:

1. Identify a screening instrument that would help identify characteristics of dementia-related decline.
2. Develop practice guidelines for health and social services supports.
3. Recommend models of community-based support and long- term care of persons with DD affected by dementia (National Task Group, 2012).

1. Screening Instrument - NTG-Early Detection Screen for Dementia (NTG-EDSD)

The NTG-EDSD Screening Instrument is included in the Appendix at the end of the section or is available on line at: <http://aadmd.org/ntg/screening>. The NTG-EDSD Screening Instrument is available in many languages such as French, German, Italian, Greek, Spanish, Chinese, and Japanese, etc.). An instruction manual is also available.

Note: Family caregivers, who opt to use the NTG-EDSD, should know that this is not an instrument for the diagnosis of dementia. The intent is that caregivers will use the information captured on the NTG-EDSD to begin a dialogue with health care and social services providers and that it will serve as an aid to shared decision-making.

The purpose of the NTG-EDSD Screening tool is to be:

- easily completed by family, caregivers, or direct health/social services support staff with minimal orientation or training,
- used to identify those individuals with dementia-like symptoms whose function and behavior are the results of other causes (such as thyroid disorders, medication interactions, depression, etc.),
- used to document and track changes over time,
- used to contribute to the types of behavior consistent with ‘cognitive impairment’ among adults with DD, and
- used at 40 years of age as a base line for persons with Down Syndrome and 50 for other persons with a DD.

2. NTG Community Care Guidelines

When developing the *Community Care Guidelines*, the NTG established eight principles aligned with the WHO (2012). *Dementia: A Public Health Priority*. The eight principles include:

1. Know the early signs of dementia.
 2. Early diagnosis of dementia helps people receive information, support, and treatment at the earliest possible stage.
 3. Communicate sensitively to support meaningful interaction.
 4. Promote independence and encourage activity.
 5. Recognize signs of distress and respond by diffusing a person’s anxiety and supporting their understanding of the events they experience.
 6. Family members and other caregivers are valued, respected, and supported just like those they care for and helped to gain access to dementia care advice.
 7. Managers take responsibility to ensure members of their team are trained and well supported to meet the needs of people with dementia.
 8. Multi- agency team work to support persons with dementia.
3. *Model of Care*. The NTG prescribes to the “Staging Model” to plan care and services, which is illustrated in the Table below. Recommendations for each stage follows the table:

TABLE: STAGES OF DEMENTIA & CHARACTERISITICS

Confusion & memory loss	Difficulties with activities of daily living	Loss of speech
Disorientation in space	Anxiety, paranoia, agitation & other behavioural problems	Loss of appetite/weight loss
Problems with routine tasks	Sleep difficulties	Loss of bladder/bowel control
Changes in personality & judgement	Difficulty recognizing familiar people	Loss of mobility Total dependence on others Seizures

With each stage the following care and service recommendations for persons with a DD, health and social service providers, caregivers, and families should consider:

Pre - Diagnosis & Early Stage

RECOMMENDATIONS	ACTION PLANS- CARE/SERVICE
1. Make provisions for the ongoing information needs of a person with a	<ul style="list-style-type: none"> • <input type="checkbox"/> Link to the Alzheimer Society of Canada & Ontario for information

<p>DD, friends, and families to be better able to understand the diagnostic process and progressive nature of dementia.</p> <p>2. Hold meetings with the individual, family members and others important to the person, if a diagnosis of dementia is obtained, to explain the diagnosis, prognosis, and begin to map out priorities for future support.</p>	<p>& resources (e.g., First Link/First Steps)</p> <ul style="list-style-type: none"> • <input type="checkbox"/> Contact regional Alzheimer Societies for access to support, education, counselling, etc. • <input type="checkbox"/> Consider enrollment into an adult day program for socialization, mental stimulation, good nutrition & exercise programs, etc. • <input type="checkbox"/> Work with primary healthcare and social service team(s) to develop/revise plans for transitions • <input type="checkbox"/> Plan early!
<p>3. Use a detection/screening tool on a regular basis to capture early warning signs that may or may not indicate dementia.</p>	<ul style="list-style-type: none"> • <input type="checkbox"/> Conduct baseline assessments early, in order to measure changes & conduct regular assessments annually after the age of 50 or 40 years of age with Down Syndrome • <input type="checkbox"/> Utilize dementia screening tools such as: <ul style="list-style-type: none"> - NTG-EDSD - InterRAI HC
<p>4. Assess for medication-induced adverse drug reactions or other conditions mimicking, exacerbating or masking dementia.</p>	<ul style="list-style-type: none"> • <input type="checkbox"/> Consult health care providers for assessments including medication reviews, lab work • <input type="checkbox"/> Consider using Pharmacy – MedsCheck program
<p>5. Dialogue with a healthcare professional or clinician about the screening tool results and, if the suspicions appear supported, seek a referral for a formal health assessment.</p> <p>6. Provide ongoing clinical supports to address behavioral and psychological symptoms associated</p>	<ul style="list-style-type: none"> • <input type="checkbox"/> Consider linking with a primary healthcare Interprofessional Team (e.g., nursing, social work, occupational therapist) • <input type="checkbox"/> Initiate referral to a Geriatrician • <input type="checkbox"/> Initiate a referral to a Regional Geriatric Program (outpatient and will make home visits) • <input type="checkbox"/> Create in consultation with a person with a DD, caregiver and family <ul style="list-style-type: none"> - Advance care plans - Revise /develop safety plans • <input type="checkbox"/> Consider referral to Behavioral

<p>7. Advocate that trained professionals familiar with assessment and diagnosis of adults with intellectual disabilities and cognitive / functional decline become involved.</p>	<ul style="list-style-type: none"> • <input type="checkbox"/> Assess current social and health care provider supports for level of
<p>8. Have a person familiar with the person with a DD and his or her history and communication method always accompany the person to the assessment appointment(s).</p>	<ul style="list-style-type: none"> • <input type="checkbox"/> Link to Home and Community Care, Support Services, and <ul style="list-style-type: none"> - personal support - transportation services • <input type="checkbox"/> Utilize technology as much as <p>https://www.enablingtech.ca</p>
<p>family, and / or other caregivers or (and prepare advance directives)</p>	<p>and other professionals for advance planning (e.g., arrangements of</p>
<p>10. Identify and plan to address the environmental challenges (e.g., safety risks, etc.) to help maintain community living.</p>	<ul style="list-style-type: none"> • <input type="checkbox"/> Link to Home and Community Care Support Services for Occupational • <input type="checkbox"/> May require equipment needs for (grab bars) which can be purchased

<p>11. Establish a daily regime that provides for engagement based on individual needs and preferences yet is organized so as not to cause anxiety and confusion.</p>	<ul style="list-style-type: none"> • <input type="checkbox"/> Link to Home and Community Care Support Services for services such as personal care support/respite care • <input type="checkbox"/> Consider the benefits of adult day programs for respite care and socialization for the person with dementia and a DD
<p>12. Redesign day activities and programs so that participation in activities and opportunities for interaction with others continues and respite for families and other caregivers is possible.</p>	

Middle Stage:

RECOMMENDATIONS	ACTION PLAN- CARE/SERVICE NEEDS
<p>1. Provide increased assistance with personal care and hygiene when needed.</p>	<ul style="list-style-type: none"> • <input type="checkbox"/> Link to Home and Community Care Support Services for services such as personal care support/respite care • <input type="checkbox"/> Link to community support services for additional “top up” care and respite services (fee for service)
<p>2. Secure appropriate residential supports and consider housing options to accommodate increasing losses in independent functioning.</p>	<ul style="list-style-type: none"> • <input type="checkbox"/> Link to Home and Community Care Support Services for placement & respite forms • <input type="checkbox"/> Work with social service sector (e.g., DSO) for residential and other housing alternatives
<p>3. Continue surveillance and periodic assessments to determine extent of change and progressive dysfunction as well as the possible development of co- morbid conditions.</p>	<ul style="list-style-type: none"> • <input type="checkbox"/> Monitor status through regular assessments with primary health care and social service providers • <input type="checkbox"/> Utilize assessment tools geared for DD

<p>4. Monitor any medications being taken to prevent adverse drug reactions.</p>	<ul style="list-style-type: none"> • <input type="checkbox"/> Continue with frequent monitoring of medication management and adverse drug reactions by primary health care and social service providers • <input type="checkbox"/> Consider using MedsCheck program with local pharmacist
<p>5. Enhance training of staff and family as well as consultation to caregivers around coping with behaviors and adapting routines.</p>	<ul style="list-style-type: none"> • <input type="checkbox"/> Consult Alzheimer Society of Canada & Ontario for education & resources
<p>6. Institute planning for long-term services and supports</p>	<ul style="list-style-type: none"> • <input type="checkbox"/> Referral to Home & Community Care Support Services for long-term care placement & respite care placement • <input type="checkbox"/> Utilize supports from social service providers • <input type="checkbox"/> Access <i>Ministry Guidelines For Supporting Adults With A Developmental Disability; When Applying To, Moving Into & Residing In A Long-Term Care Facility</i> (2017) • <input type="checkbox"/> Plan early!
<p>7. Ensure protections are in place to preclude abuse or harm in both formal and informal settings</p>	<p>more information and understanding</p> <ul style="list-style-type: none"> • <input type="checkbox"/> Seniors Safety Line – 1- 866-299- languages <p>http://www.elderabuseontario.com/links/</p>

	<ul style="list-style-type: none"> ☐ Discuss with service provider agencies what policies, procedures, and practices exist to preclude abuse & staff training received.
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Late Stage:

RECOMMENDATIONS	ACTION PLAN- CARE/SERVICE NEEDS
<p>1. Reorganize care services toward non- ambulatory care.</p>	<ul style="list-style-type: none"> ☐ Coordination with Home & Community Care Support Services- coordinators to review case management services and plan accordingly ☐ Frequent home visits by Home & Community Care Support Services - coordinators
<p>2. Reassign service providers to activities structured around nursing and personal care including the support of family caregivers who wish to maintain the person at home.</p>	<ul style="list-style-type: none"> ☐ Coordination with Home & Community Care Support Services: Access support from professionals (e.g., speech and language, occupational therapists) as appropriate ☐ Adjust settings to reduce safety and wayfinding challenges (Wandering Person Registry, Finding Your Way) ☐ Increase assistance with personal care, nutrition, safety, and supervision. ☐ Introduce specialized, nonpharmacological interventions to manage behavioral / psychological symptoms and reduce demands likely to result in behavioral challenges.
<p>3. Obtain support from palliative care or hospice specialists.</p>	<ul style="list-style-type: none"> ☐ Access hospice /palliative care services <p>Hospice Palliative Care Ontario</p>

<p>4. Institute procedures to maintain dignity, comfort, and address pain and symptom management.</p>	<ul style="list-style-type: none"> ☐ Coordination with Home & Community Care Support Services nursing, pain pumps, or other symptom management equipment and support

In the Table below are specific dementia focused environmental modifications adopted from *McCallion & McCarron (2005)* and *Watchman (2007)* to consider when assessing safety and risk for persons with a DD and diagnosed with mild to moderate staged dementia.

TABLE: DEMENTIA FOCUSED ENVIRONMENTAL MODIFICATIONS

Home	Action

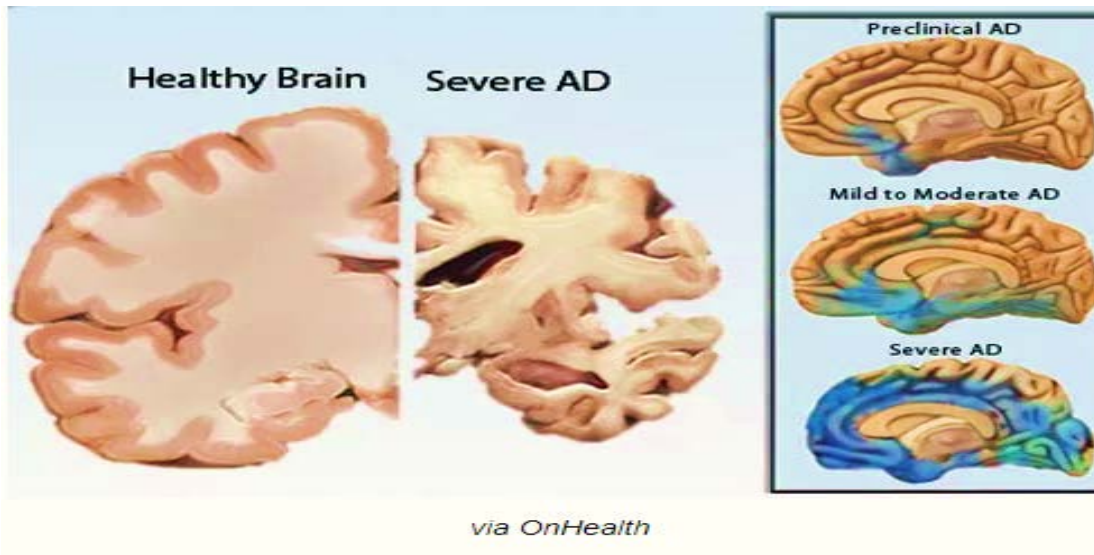
	<p>Regulate water temperature on taps. Replace standard showers or tubs with walk-in models. Widen doorways to accommodate walkers, wheelchairs, and lifts if Required</p>
Color	<p>Use colour and contrast to create visual cues or reduce attention to specific areas throughout the home.</p> <p>Contrast colours in key places to create visual cues (e.g., white light switch with a dark colored switch plate; dark colored toilet seat on a white toilet; dark handrail against a light - coloured wall; dark placemat under a light colored dinner plate).</p> <p>Use tableware that offers contrasting colors to the foods being served (e.g., milk served in a white cup will appear to be empty to the person with dementia).</p> <p>Reduce visibility of exits, cupboards, or other areas through use of colour (e.g., exits and cupboards painted the same color as surrounding walls makes them less visible).</p> <p>Colours in the red to yellow range are more accurately perceived than blues and greens. Use solid colors or simple patterns instead of complicated or highly unusual designs.</p>
Flooring	<p>Use non-patterned flooring that has a matte versus high gloss finish.</p> <p>Provide floor markers to aid with wayfinding - people with dementia may develop the habit of looking down when walking.</p> <p>Eliminate scatter rugs and other loose floor rugs as potential risks for falls.</p> <p>Reduce or eliminate changes in the levels of flooring in the home to prevent falls and ease movement when mobility aids are used.</p>
Furniture	<p>Use furniture with rounded versus sharp edges that is sturdy, simple and versatile. Contrast furniture color with floors and walls.</p> <p>Arrange furniture to create clear pathways for movement.</p> <p>Secure lightweight items such as lamps.</p> <p>Use table-tops / cloths that are smooth and pattern-free.</p> <p>Consider height and placement of objects and signage when a person is standing or seated.</p>
Lighting	<p>Use lighting to avoid shadows, a common source of visual illusions for persons with dementia.</p> <p>Disperse direct sunlight with curtains or tinted glass.</p> <p>Use indirect lighting to avoid glare as well as sudden changes in lighting levels (e.g., use dimmer switches and night lights).</p>
Kitchen	<p>Label cupboards for visual cues, pictorially not with text.</p> <p>Create an open space (e.g., shelves that slide in when not in use).</p> <p>Provide safe storage for kitchen tools, liquids and powders that are not</p>

	<p>food by using discreetly locked cabinets. Install shut-off switches on appliances. Regulate water temperature on taps.</p>
Noise	<p>Improve acoustics through use of carpeting, acoustic tiles, curtains, other sound absorbing materials. Reduce ambient sound levels associated with TV use and music. Design and encourage use of quiet spaces.</p>
Outdoor	<p>Provide access to safe outdoor space for walking and wandering (e.g., fenced yard with seating area, raised garden beds, and walking path that leads back to the house door). Install ramps or otherwise eliminate barriers to entrances / exits for people with gait difficulties or who use walking aids (e.g., walkers, wheelchairs). Install alert systems so caregivers know when someone has left the home or install door opening prevention devices.</p>

Alzheimer’s Disease

There are many different types of dementia. One of the causes of dementia is Alzheimer’s disease (AD). AD is a progressive, degenerative disease of the brain, which causes thinking and memory to become seriously impaired. You may see changes in the person’s ability to interact with the people around them and perform activities of daily living. As the disease progresses, the person with dementia often experiences challenging (responsive) behavior, such as aggression, wandering, physical resistance, or agitation. Often the person is responding to something negative, frustrating, or confusing in his or her environment. See the Figure below for changes in the brain during the course of the disease process.

FIGURE: ILLUSTRATIONS OF CHANGES IN THE BRAIN WITH ALZHEIMER DISEASE



For additional information about what is Alzheimer Disease, please see the link below and the Figure depicting the ten early warning signs of AD and examples.

<http://www.youtube.com/watch?v=9Wv9jrk-gXc>

TEN EARLY WARNING SIGNS OR SYMPTOMS OF ALZHEIMER’S DISEASE – (Alzheimer Society of Canada, 2018)

10
warning signs of dementia

Dementia is not a part of normal ageing.
 Talk to a doctor or contact the Alzheimer association in your country.

Alzheimer's Disease International
 The global voice on dementia

Sign 1 Memory Loss

It is normal to occasionally forget appointments, colleagues’ names or a friend’s phone

number only to remember them a short while later. However, a person with Alzheimer's disease may forget things more often or may have difficulty recalling information that has recently been learned.

Sign 2 Difficulty Performing Familiar Tasks

Busy people can be so distracted from time to time that they may forget to serve part of a meal, only to remember about it later. However, a person with Alzheimer's disease may have trouble completing tasks that have been familiar to them all their lives, such as preparing a meal or playing a game.

Sign 3 Problems with Language

Anyone can have trouble finding the right word to express what they want to say. However, a person with Alzheimer's disease may forget simple words or may substitute words such that what they are saying is difficult to understand

Sign 4 Disorientation in Time and Space

It is common to forget the day of the week or one's destination - for a moment. But people with Alzheimer's disease can become lost on their own street, not knowing how they got there or how to get home.

Sign 5 Impaired Judgement

From time to time, people may make questionable decisions such as putting off seeing a doctor when they are not feeling well. However, a person with Alzheimer's disease may experience changes in judgment or decision-making, such as not recognizing a medical problem that needs attention or wearing heavy clothing on a hot day.

Sign 6 Problems with Abstract Thinking

From time to time, people may have difficulty with tasks that require abstract thinking, such as balancing a chequebook. However, someone with Alzheimer's disease may have significant difficulties with such tasks because of a loss of understanding what numbers are and how they are used.

Sign 7 Misplacing Things

Anyone can temporarily misplace a wallet or keys. However, a person with Alzheimer's disease may put things in inappropriate places: for example, an iron in the freezer or a wristwatch in the sugar bowl.

Sign 8 – Changes in Mood and Behavior

Anyone can feel sad or moody from time to time. However, someone with Alzheimer's

disease can show varied mood swings - from calmness to tears to anger - for no apparent reason.

Sign 9 – Changes in Personality

Personalities can change in subtle ways over time. However, a person with Alzheimer’s disease may experience more striking personality changes and can become confused, suspicious or withdrawn. Changes may also include lack of interest, fearfulness, or acting out of character.

Sign 10 Loss of Initiative

It is normal to tire of housework, business activities, or social obligations, but most people regain their initiative. However, a person with Alzheimer’s disease may become passive, disinterested, and require cues, and prompting to become involved.

Having confirmed the diagnosis and treatment with the health care provider, it is important to establish coping and safety strategies to reduce stress and injuries. In earlier sections, we discussed risk of falls, a healthy diet, regular stimulation and socialization, medication management, and other aging strategies. These strategies apply to persons with AD. In this section, communication strategies and wandering (also known as elopement) will be detailed.

Note: Caregiver Burden and Distress will be specifically addressed in the next section .

Communication Tips

- speak slowly and clearly,
- do not ask “**why**” questions,
- avoid test questions,
- avoid correcting, confrontation,
- validate emotions,
- try distraction,
- use appropriate touch,
- find out individual responses,
- look for meaning and use repetitive sounds/rhythms/actions,
- laughter – create a sense of fun, and
- regular, frequent, one to one contact, “being there”.

Four Handy Communication Tips:

1. *Do Not Argue*
2. *Use Finess*
3. *Make It Make Sens to Them*
4. *Redirect – Change the Topic/ Activity*

(Virginia Bell & Da Troxel, 1997)

Jennifer T. Case Study

Jennifer participates every day at the local Alzheimer Society Day Program and enjoys

the program very much. Each day her mother drives her to and from the program before and after work. Within a few hours of being at the program, Jennifer begins to ask the staff, “I want to go home. Can my mother pick me up”?

The staff recognize that it will be several hours before her mother will be able to pick her up and use the four handy communication tips (Bell & Troxel, 1997), to manage her stress.

The staff explain that her mother is at work and will be coming to pick her up as soon as she is finished. Staff gently take her hand and re-direct her away from the entrance and ask her if she would like some juice or water (hydration is very important). The staff accompany her to the table and encourage her to drink and engage in the singing and exercise activities underway.

An hour late, Jennifer returns to the staff, “Where is my mother? I want to go home”. The staff repeat that the mother is at work and will be coming to pick her up soon. The staff say that they have called her on the phone to let her know that Jennifer wants to go home. The staff inquire if Jennifer needs to go to the washroom and gently guide her to the room and back to the activities.

Jennifer’s mother arrives shortly to pick her daughter up and Jennifer leaves safely with her mother. Prior to her leaving, staff inquire with the mother if there are any concerns or changes with Jennifer at home in order to ensure Jennifer’s stress level is minimized at the program.

For additional information, please see the attached video below “Supporting Derek”

https://www.youtube.com/watch?v= 0qp_cXvruc

Strategies/Recommendations for Persons Aging with a DD

A. Screening

1. Rule out other underlying conditions that may be mistaken for symptoms of dementia such as; Thyroid abnormality, urinary tract infection or other infections, vision and hearing loss, depression, general aging, arthritis, osteoarthritis and other pain (e.g., lab tests, scans, psychiatric assessments, hearing and vision tests etc.)
2. Apply the NTG- Early Detection Screen for Dementia
3. Healthcare teams rely on caregivers and families for details of the person’s current/previous history and behavior as assessment tools as diagnosis of Alzheimer Disease and Dementia. It is often difficult to diagnose as it is overshadowed in many cases with other symptoms associated with DD and/or general aging

4. Monitor medications and adverse drug reactions
- B. Comfort & Other Interventions
1. Adapt activities to suit the needs of the person.
 2. Focus on the person's continuing abilities and build on strengths.
 3. Apply "cueing" (verbal and non-verbal) strategies to assist with interactions and surroundings.
 4. Promote a nutritious diet (See Canada's Food Guide).
 5. Maintain hydration and participate in exercise programs.
 6. Avoid hospitalization.
 7. Reduce anxiety and stress.
 8. Follow established medication regime.
 9. Link to the Alzheimer Society of Canada, Ontario and regional programs for support, respite, and other resources.
 10. Register with safety registries (See Wandering below).



Wandering/Elopement

Wandering refers to a variety of behaviours that may result in a person living with dementia becoming lost. Wandering is a direct result of physical changes in the brain. Six in ten people with dementia will wander (Alzheimer Society of Ontario, Alzheimer Society of Canada). A person with AD may not remember his or her name or address, and can become disoriented, even in familiar places. Wandering among people with dementia is dangerous, but there are strategies and services to help prevent it.



Strategies

Among the many strategies listed below are also dedicated on-line courses for persons with a DD, their caregivers, families, and health and social service workers with the goal to better understand dementia.

Register online at ALZeducate and/or Finding Your Way
<http://findingyourwayontario.ca/>



The on-line courses include the following:

- 101- Dementia Basics
 - 102- Communication
 - 103- Behavior
 - Finding Your Way- Living Safely in the Community
- This online learning session consists of four modules, 15 minutes in length and completed at your own pace.



Other strategies include:

- MedicAlert® Safely Home®
<https://www.medicalert.ca/About-MedicAlert/Media-Centre/Safely-Home>
- Vulnerable Person Registry - <https://www.vulnerablepersonsregistry.ca/>
- Project Lifesaver – Bringing Love Ones Home

Project Lifesaver is a not-for-profit premier search and rescue program operated internationally by public safety agencies (including partnering with police) and is strategically designed for “at risk” individuals who are prone to the life-threatening behavior of wandering. The primary mission of Project Lifesaver is to provide timely response to save lives and reduce potential injury for adults and children with the propensity to wander due to a cognitive condition. There is a variety of products available to suit specific needs. Each region in Ontario has specific contact numbers to register. The Table below provides contact information.

REGION	CONTACT INFORMATION
York Region	Contact Community Services at projectlifesaver@yrp.ca or 1-866-876-5423
Halton	Victim Services Unit 905-825-4747 Ext. 5239 or projectlifesaver@haltonpolice.ca
Hastings-Prince Edward	https://alzheimer.ca/en/hpe/We-can-help/Living-Safely/Project%20Lifesaver or 613-962-0892/ 1-800-361-8036
Huron	https://www.oapc.ca/project-lifesaver-huron/
Niagara	www.projectlifesaverniagara.ca / info@projectlifesaverniagara.ca or 905-734-5614/ 905-735-0081 ext. 214
Norfolk	www.norfolkcounty.ca / or 519-688-0710
Simcoe	https://www.projectlifesaversimcoe.ca/ or 1-249-888-0249

Wellington/Guelph	https://www.vswguelph.on.ca/project-lifesaver-wellington/or/519-824-1212
Windsor-Essex	http://www.windsor-essexprojectlifesaver.com/or/519-728-1810

Note: Additional project lifesaver programs may exist. Please contact your local police department, Alzheimer Society or health and social services agency for additional information and registration.

- Personal Emergency Response Systems which have built in GPS devices to locate persons who may be lost.

Please see additional resources available below:

UFirst

U-First! is a training program that helps frontline staff to develop a common knowledge base, language, values, and approach to caring for people with Alzheimer’s disease and other dementias by:

- understanding the person living with dementia and associated behaviour changes, and
- working as a team to develop individualized support strategies.

For additional information please use the following link:

<http://u-first.ca/about-u-first/>

Gentle Persuasion Approaches (GPA)

GPA is an innovative dementia care education program based on a person-centred care approach. Designed for front line staff across all healthcare sectors. GPA certified coaches guide participants to fully understand responsive behaviours in order to be able to respond effectively and appropriately in a workplace setting. GPA also includes respectful self-protective and gentle redirection technique for use in situations of risk.

For additional information please use the following links:

<http://alz.to/health-care-professionals/gentle-persuasive-approaches/>

The Hartford Financial Services Group and the MIT AgeLab have developed a guide, “At the Crossroads” to help people with dementia and their families prolong independence while encouraging safe driving.

<http://hartfordauto.thehartford.com/UI/Downloads/Crossroads.pdf>

Alzheimer Society of Canada:

https://alzheimer.ca/en/Home?gclid=CjwKCAjwTO7qBRBQEiwA15WC2wdDOnhwkxBbUFdfyU0cEAQ8OpwGMweluEchtwGj_dTTEwhUPZUnUBoCK78QAvD_BwE

Alzheimer Society of Ontario- Finds supports and connects to your local/regional Alzheimer Society:

<http://alzheimer.ca/on>

Alzheimer Society of Ontario- Finding Your Way Resource Guide to lower missing (wandering) incidents. Contains a free four part online training program for professionals. Content is multi-lingual:

http://findingyourwayontario.ca/living-safely-with-dementia/?gclid=CjwKCAjwO7qBRBQEiwAl5WC28RfDRpqEi5bTxSa7epFzPCy0SEZWTGz1glrfe4KUTOgeRwOUbOnhxoC4LMQAvD_BwE

MedicAlert Safely Home Program. An identification bracelet for those with dementia living in the community.

Personal Care: Resource sheet on providing personal care to someone living with dementia:

http://alzheimer.ca/sites/default/files/files/national/brochures-day-to-day/day_to_day_personal_care_e.pdf

Dementia and staff grief: Resource for Professionals:

http://alzheimer.ca/sites/default/files/files/national/for-hcp/staff_grief_e.pdf

Dementia Supports Resource list

<http://alzheimer.ca/en/on>

- Alzheimer Society of Ontario. Find supports and connect to your local Alzheimer Society.

<http://findingyourwayontario.ca/>

- Resource to lower missing incidents. Contains a free 4-part online training program for professionals. Content is multi-lingual.

<http://findingyourwayontario.ca/wp-content/uploads/2016/03/FYW-Shifting-Focus-English-Jul2016.pdf>

- Shifting Focus – A guide to understanding dementia behaviours. Contains tips on managing responsive behaviours

https://www.mcass.gov.on.ca/en/mcass/publications/developmentalServices/ltc_home_guidelines.aspx#part4a

- Guidelines For Supporting Adults With A Developmental Disability When Applying To, Moving Into And Residing In A Long-Term Care Home

<https://connectability.ca/category/adults/>

- [Engagement and Community Partnerships](#)

<https://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/>

- [Ministry of the Attorney General \(OPGT\)](#)

[https://www.autismontario.com/client/aso/ao.nsf/docs/c3397f85f925779085257855004ee352/\\$file/henson+info.pdf](https://www.autismontario.com/client/aso/ao.nsf/docs/c3397f85f925779085257855004ee352/$file/henson+info.pdf)

- [Henson Trust](#)

<https://www.aadmd.org/ntg/screening>

- The NTG-Early Detection Screen for Dementia, adapted from the DSQIID*, can be used for the early detection screening of those adults with an intellectual disability who are suspected of or may be showing early signs of mild cognitive impairment or dementia.

<https://www.alz.co.uk/research/world-report-2018>

Global voice on Dementia

Type 2 Diabetes and Aging with a Person with a DD

Type 2 diabetes is a disease in which the body cannot make enough insulin, or the body does not properly use the insulin it makes. Insulin is a hormone that helps to control the level of sugar in the blood (Diabetes Canada). As a result, glucose (sugar) builds up in the blood instead of being used for energy. If left unmanaged, the excess sugar can eventually cause problems and lead to serious health complications (e.g., stroke and cardiovascular symptoms). Many people don't present with any symptoms, which means some people can live with Type 2 diabetes for many years without knowing it.

General aging predisposes persons in developing Type 2 diabetes as the body becomes less efficient in breaking down sugar. Having any of the following conditions also increases your chances of developing Type 2 diabetes:

- high blood pressure,
- smoking,
- high levels of cholesterol or other fats in the blood,
- a high body mass index (**BMI**) or are overweight (especially if that weight is mostly carried around the tummy),
- prediabetes (impaired glucose tolerance or impaired fasting glucose),
- Polycystic Ovary Syndrome (PCOS),
- psychiatric disorders (schizophrenia, depression, bipolar disorder),
- obstructive sleep apnea,
- darkened patches of skin called acanthosis nigricans, and
- prescribed a glucocorticoid medication by a physician/ specialist/ healthcare provider.

*Did you know?
1.5 million
Canadians do
not know they
have diabetes &
90 per cent of
Canadians with
diabetes are
living with
Type 2 diabetes
(Diabetes Canada,*

Note: There is a greater risk of developing Type 2 diabetes if you are over the age of 40 or if you have a parent, brother, or sister with diabetes. Your ethnic background is also a factor: being of African, Arab, Asian, Hispanic, Indigenous, or South Asian descent can increase your risk of living with Type 2 diabetes and with Prader-Willis and Down Syndromes.

Prader-Willi & Down Syndromes

Prader-Willi Syndrome (PWS) is a rare genetic disorder that occurs in approximately one out of every 15,000 births. PWS affects males and females with equal frequency and affects all races and ethnicities. PWS results from an abnormality of chromosome 15 (2016 Foundation for Prader-Willi Research). Unregulated appetite (hyperphagia) and easy weight gain are common challenges associated with PWS as well as the metabolic rate is lower than normal making it difficult to burn off calories from consumed fats and sugars. Maintaining a healthy weight can be challenging. According to research conducted by zipfw@pediatrics.ohio-state.edu, diabetes is becoming a more frequently recognized complication of Prader-Willi Syndrome. It has been reported that as many as 70% of persons with Prader-Willi Syndrome may develop this complication. Diabetes adds to the complexity of an already complex treatment program, causes many serious complications that greatly affect the quality of life of the person with a DD and can lead to serious morbidity and mortality from complications associated with diabetes (e.g., cardiovascular disease such as stroke).

Additional information about Prader-Willis Syndrome is in the links below:

Foundation for Prader-Willi Syndrome:

https://www.fpwr.org/about-prader-willi-syndrome?gclid=CjwKCAjw-7LrBRB6EiwAhh1yX5V5M4ejR03Ou7ZISOIjdFoCmUE2YOeLQk2QRAXChoPy1Y8xIyZ9ohoC0WQQA_vD_BwE#a_cure

Down Syndrome is a genetic disorder in which a person has extra chromosome 21 material resulting in delays and limitations in physical and intellectual development. As the life expectancy of persons with Down Syndrome has significantly increased so has the risk of developing Type 2 diabetes and the associated complications. See the attached links for additional information:

<https://www.ds-int.org/Pages/Category/what-is-down-syndrome>

<https://www.ds-int.org/in-their-own-words> - Down Syndrome International
A short video performed by persons with a DD.

Warning Signs of Type 2 Diabetes

According to Catherine Robarts (2018), there are 15 common warning signs of Type 2 diabetes and associated rationale illustrated in the Table below.

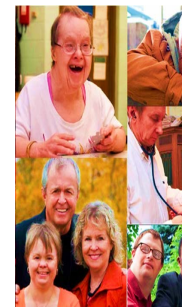


TABLE: 15 COMMON WARNING SIGNS OF TYPE 2 DIABETES

SIGNS/SYMPTOMS	RATIONALLE
1. Numbness	Numbness that starts as a tingling in the hands, fingers, legs, and feet is often an early warning sign of diabetes. This occurs due to an increase in blood sugar levels, causing decreased blood flow to the extremities; and eventually damage to nerve fibers. For many, this numbness is often the first sign of any health issues.
2. Increased Urination (Polyuria)	Diabetes sufferers claim they have an overwhelming urge to urinate, and when they do urinate, the amount is quite significant. When there is excess glucose present in the blood, the kidneys react by flushing it out of the blood and into the urine. This results in more urine production and the need to urinate more frequently, as well as an increased risk of urinary tract infections (UTIs).
3. Weight loss	Rapid and unexplained weight loss is common with diabetes because the body can't absorb glucose (sugar) properly. The body is forced to breakdown fat which accounts for weight loss.
4. Increase in appetite	In a diabetic state, the cells are being robbed of essential energy, which explains the increased hunger that often isn't satiated for long after eating a meal.
5. Blurry vision	This occurs as glucose (sugar) levels rise, damaging blood vessels and restricting the flow of fluid to the eyes. Statistics from the <u>American Diabetes Association</u> claim that the longer a person has diabetes, the higher the risk of glaucoma. Likewise, the risk of cataracts (clouding over of the eye's lens) is 60-percent higher in persons with diabetes.

<p>6. Itchy, dry skin</p>	<p>Diabetes affects blood circulation therefore sweat glands will often become dysfunctional, resulting in dehydrated, flaky, itchy, and irritated skin. This is why skin issues are often the first sign of a problem and the first indication of diabetes.</p> <p>Undiagnosed diabetes persons are more prone to several skin ailments, including diabetic dermopathy, fungal infections, diabetic blisters, bacterial infections, dry and itchy skin due to poor circulation in the lower parts of the legs, boils, carbuncles, fingernail, and toenail infections.</p>
<p>7. Fatigue</p>	<p>When blood glucose is high, as it is with type 2 diabetes, blood can become thick and “sludgy,” resulting in decreased circulation that prevents the transport of vital nutrients and oxygen to cells. This can also occur when blood sugars are low and fuel is not adequate to energize the body. Many persons with Type 2 diabetes also suffer from extreme exhaustion due to inflammation of the blood vessels.</p>
<p>8. Unquenchable thirst</p>	<p>Due to dehydration from frequent urination (polyuria) and diabetics can also become extremely thirsty for other reasons. For instance, high blood sugar levels can cause dry mouth, dehydration, and increased thirst in those with undiagnosed diabetes</p>
<p>9. Slow healing of cuts/bruises</p>	<p>Slow healing is due to high blood glucose(sugar) levels weakening the immune system and slowing the rate of healing.</p> <p>This is also due to high blood glucose levels gradually damaging the nerves. Neuropathy (“disease of nerves”) can lead to poor blood circulation over time, impeding the transport of fresh blood for</p>

10. Irritated gums	Research from the American Academy of Periodontology (AAP) shows that unmanaged diabetes is particularly at risk for periodontal disease. The reasoning is that both gum disease and diabetes encourage inflammation throughout the entire body, and consider inflammation of essential body parts, such as blood vessels, inflammation can result in all sorts of issues, including stroke, kidney disease, heart disease, and more.
11. Dry mouth	It is believed that high blood sugar levels could be one of the culprits, as well as dehydration and some medication.
12. Frequent yeast infections	Yeast gets energy from sugar, so in an environment that is moist with sugar, yeast may overgrow, leading to infection.
13. Dark patches of skin	This condition is known as acanthosis nigricans and is most often a result of too much of the hormone that regulates glucose in the blood. High levels tend to occur because they've developed resistance, where the body can't use the glucose the body is creating. This leads to a buildup that "causes normal skin cells to reproduce at a rapid rate," resulting in the appearance of dark patches of skin.
14. Erectile dysfunction	Lack of blood circulation impact's ability to achieve an erection
15. Frequent or re-occurring infection	Bladder and foot infections are common due to the high levels of blood glucose in the bloodstream interfering with the healing process.

Strategies/Recommendations for a Person Aging with a DD

A. Screening

1. Endocrine disorders can be challenging to diagnose in persons with a DD, as there is a higher incidence of thyroid dysfunction compared with those in the general population. It is recommended that thyroid functioning be tested annually with persons with Down Syndrome (<https://ddprimarycare.surreyplace.ca>).
2. Screen for Type 2 diabetes at an earlier age than is recommended for the general population. The prevalence of diabetes is higher among persons with a DD compared with those in the general population and slightly higher among women than men (<https://ddprimarycare.surreyplace.ca>).
3. Anyone over the age of 40 should be tested every three years or every year or more if there is an identified risk factor (Diabetes Canada).
4. Monitor HbgA1C every six months with a diagnosis of Type 2 diabetes
5. Monitor blood pressure, cholesterol, and triglycerides annually. Monitor weight regularly and assess risk status for obesity, endocrine disorders etc. using body mass index (BMI), waist circumference, or waist-hip ratio measurement standards. Physical inactivity and obesity are prevalent among persons with a DD and are associated with cardiovascular disease, diabetes, constipation, osteoporosis, early mortality, and other health risks. Being underweight, with its associated health risks, is also common. In addition, research suggests that environmental and social factors often contribute to obesity and low physical activity rates as well (<https://ddprimarycare.surreyplace.ca>).
6. Monitor blood glucose by home glucose testing monitors and report results to physician/specialist and other healthcare/social service providers in order to develop care and treatment plans. Glucose monitors are free however the lancet and test strips are not.

Note: Funding support for diabetes management and testing products can be obtained from the following sources:

Ministry of Health - Assistive Devices Program (ADP)

1. If you are a senior (65+ years) who needs insulin every day and lives at home, you can apply for \$170 annually to help pay for syringes and needles
2. The Monitoring for Health Program helps Ontarians with diabetes who use insulin or have gestational diabetes pay for the cost of their blood glucose testing supplies. The program is funded by the Ministry of Health and administered by Diabetes Canada (1-800-361-0796 mfhp@diabetes.ca)
3. Ontario Disability Support Program (ODSP)
Diabetic supplies, such as syringes, alcohol swabs and blood glucose monitors may be covered. The program is funded by the Ministry of Children, Community and Social Services (MCCSS). Assistance with these costs is provided under the Ontario

Disability Support Program's Mandatory Special Necessities benefit.
(https://www.mcass.gov.on.ca/en/mcass/programs/social/odsp/income_support/odsp_medical_supplies.aspx).

Note: Additional information and screening tools are available below:

<https://ddprimarycare.surreyplace.ca/>

HEALTH WATCH TABLE: DOWN SYNDROME

The Health Watch Table: Down Syndrome, developed by the Developmental Disabilities Primary Care Initiative at Surrey Place (Toronto, 2011), complements the primary care guidelines and Preventive Care Checklist and flags issues relevant to the genetic condition Down syndrome.

HEALTH WATCH TABLE: PRADER-WILLI SYNDROME

The Health Watch Table: Prader-Willi syndrome, developed by the Developmental Disabilities Primary Care Initiative at Surrey Place (Toronto, 2011), complements the primary care guidelines and Preventive Care Checklist and flags issues relevant to the genetic condition Prader-Willi syndrome.

HEALTH WATCH TABLE: 22Q11.2 DELETION SYNDROME

The Health Watch Table: 22q11.2 deletion syndrome, developed by the Developmental Disabilities Primary Care Initiative at Surrey Place (Toronto, 2011), complements the primary care guidelines and Preventive Care Checklist and addresses issues relevant to the genetic condition 22q11.2 deletion syndrome.

B. Comfort & Other Interventions

1. Make healthy food choices and monitor weight gain/loss (Recommend linking to Diabetes Educator/ Nutritionist support)
2. Exercise regularly. For exercise information and examples, visit the National Institute of Aging's *Go4Life*® website or call 1-800-222-2225 (toll-free).
3. Manage medication. Type 2 diabetics (even if not on diabetic medication) are eligible for an annual medication assessment by a pharmacist through the MedsCheck for Ontarians Living with Diabetes Program. The assessment may include, training on the use of diabetic supplies, education on medication and advice on lifestyle changes. Contact information for questions: 1-866-255-6701 or ontario.ca/MedsCheck.
4. Stop smoking. Smoking raises the risk for many health problems, including heart attack and stroke.
5. Regular foot care and monitoring of sores, blisters, infection, etc.
6. Annual ophthalmology and hearing tests.
7. Regular dental assessments for monitoring of gums, tongue, and teeth.

SUMMARY

General aging consists of many changes both physically and mentally requiring early planning (e.g., home modifications for safety), pursuing health promotion, and healthy living activities (e.g., exercise programs, healthy diets), and maintaining regular assessments and good communication with the physician and health and social service providers in the community.

Persons aging with a DD have similar changes and needs with additional challenges. Age-related decline in physical and mental health, in addition to the existing DD, will most certainly result in the need for increasing levels of health care and social services. In the Table below is a summary of general comparisons of aging with and without a DD.

TABLE: COMPARISON OF GENERAL AGING AND AGING WITH A DEVELOPMENTAL DISABILITY

Change	General Aging vs. Aging with a DD		Comments
	Similar- Yes/No		
1. Loss	Yes		Both experience emotional & physical loss e.g., changes in abilities, loss of caregivers & family members
2. Physical	Yes, note a person with a DD will experience changes earlier		Both experience changes in muscle strength, vision, hearing etc.
3. Age related changes	No		Aging with a DD begins earlier e.g., Down Syndrome Frailty is 3 times greater in a person with a DD
4. Fear	Yes		Experience concerns re: loss of independence, choice of living accommodations
5. Life events	Yes		Adapting to lifestyle changes due to chronic conditions e.g., diabetes & loss of significant family & friends
6. Dependency on others	No		New to general aging and life-long experience for a person with a DD
7. Roles	No		General aging roles change where there is no significant change with a person with a DD
8. Advocacy	No		General aging main advocates children/spouse. Aging with a DD's main advocates parents/sibling(s)/volunteers/caregivers
9. Retirement Goals	No		Persons aging with a DD may wish to continue to participate in the same activities as long as possible e.g. attending an adult day program
10. Level of Care Needs	No		Care needs may increase at a greater rate with persons aging with a DD as frailty has been noted as being 3 times greater.

Significant challenges have been reported by persons aging in the community with a DD, their caregivers and families such as proper nutrition, sufficient exercise, social programs, and accessing services for their changing needs. In subsequent sections, resources, links, and other information related to accessing health and social service programs and services will be provided. For now ...

“MONITOR AND OBSERVE FOR SIGNS AND SYMPTOMS OF AGING...ASK QUESTIONS...PLAN EARLY...”

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