

# Canadian Guide for Community Care and Supports for Adults with Intellectual Disabilities Affected by Dementia



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We sincerely appreciate the families and adults with intellectual disabilities who willingly contributed photographs to be used in this publication.

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This guide is an updated and Canadian version of the original U.S.A. National Task Group (NTG) on Intellectual Disabilities and Dementia Practices "Guidelines for Structuring Community Care and Supports for People with Intellectual Disabilities Affected by Dementia" first published in the Journal of Policy and Practice in Intellectual Disabilities (March 2013, 10(1), pp. 1-24) with a stand alone version on the NTG website. ( <https://www.the-ntg.org/> )

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# EXECUTIVE SUMMARY

The inclusion of adults with an intellectual disability and their caregivers in the National Dementia Strategy, *A Dementia Strategy for Canada: Together We Aspire* (Public Health Agency of Canada, 2019) was a major milestone achieved through significant advocacy. It generated considerable optimism and opened the door to important opportunities. The first was the successful bid for funding by Reena and the NTG Canadian Consortium through the PHAC-Dementia Strategy Fund to develop an updated Canadian Guide to raise awareness of issues and inform future direction.

This Guide is intended to support planning and preparation for the creation of community-based dementia-capable supports and services for adults with intellectual disabilities across Canada. It is based on knowledge and feedback gathered from the Advisory Committee, focus groups, interviews, and a survey completed by disability, seniors and health organizations, as well as a scan of research and gray literature. The Guide reflects relationship-centered and person-centred care approaches, emphasizing the importance of relationships and the inclusion of adults with intellectual disabilities and dementia as active participants in planning for their future. The hope is that it will also guide the future efforts of various levels of government and national organizations to create an environment promoting collaboration and innovation.

The Guide is written for adults with an intellectual disability, their families, staff and disability, health and seniors organizations involved in the provision of supports and services. It is written using a stage-based approach, highlighting possible symptoms, actions steps and support options for each stage and includes information and resources related to program supports and emerging issues.

# 1.

## INTRODUCTION

In 2017, the Canadian federal government enacted the National Strategy for Alzheimer’s Disease and Other Dementias Act (S.C. 2017, c. 19) which laid the foundation for the Federal Minister of Health to establish and implement a national dementia strategy (Public Health Agency of Canada, 2019). Working with provincial and territorial governments responsible for health and social services, with input from various organizations, groups, and people across the country, *A National Strategy for Canada, Together We Aspire* was released in June 2019. The National Strategy has three objectives to (1) prevent dementia, (2) move forward on therapies and identify a cure, and (3) enhance quality of life for those affected by dementia. It is based on five underlying principles focused on quality of life, diversity, human rights, evidence-informed, and results. Importantly,

advocacy efforts during the development phase of the Strategy led to Canada’s National Dementia Strategy recognizing adults with intellectual disabilities<sup>1</sup> as a population at higher risk for dementia who face many barriers to equitable care. Over the ensuing years, financial resources became available through the Public Health Agency of Canada – Dementia Strategy Fund (PHAC-DSF<sup>2</sup>) and awarded to various organizations and groups in pursuit of achieving the aims of the strategy.

Canada is the second largest country in the world with the longest coastline. People live and work across eight climate zones and six time zones. It is a society with a population of approximately 40 million people enriched with ethnic and cultural diversity (Statistics Canada, 2023). Canada

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<sup>1</sup>As with the original NTG 2013 guidelines, this Canadian guide adopted a practical definition that characterizes adults with an intellectual disability affected by dementia as adults who: (a) have intellectual limitations that limit ability to participate in day-to-day activities such as self-care, communication, or work, (b) developed the intellectual limitation during the ‘developmental period’ (prior to age 22), (c) have a limitation anticipated to result in long-term adaptive or functional support needs, (d) are eligible for public support programs because they are recognized as having an intellectual disability, and (e) are affected by dementia that is either suspected, undergoing assessment for dementia or formally diagnosed by a healthcare professional with possible, probable, or definitive dementia (adapted from National Task Group and Dementia Practices, 2012). This Guide recognizes a distinction between intellectual and developmental disabilities, yet also acknowledges that some adults with a developmental disability also have an intellectual disability and that, in some jurisdictions, these terms are used synonymously. For this Guide intellectual disability, as defined above, is the focus, unless otherwise specified.

<sup>2</sup>This Canadian Guide uses the definition of dementia provided by the Public Health Agency of Canada (2019): Dementia is an umbrella term used to describe a set of symptoms affecting brain function that are caused by neurodegenerative and vascular diseases or injuries. It is characterized by a decline in cognitive abilities such as memory; awareness of person, place, and time; language, basic math skills; judgement; and planning. Dementia can also affect mood and behaviour. As a chronic and progressive condition, dementia can significantly interfere with the ability to maintain activities of daily living...

consists of 10 provinces and three territories with two official languages (English and French). Most of the population lives along Canada's southern border while other citizens live in rural, remote and northern areas of Canada. The Alzheimer Society of Canada (2024) estimates over 700,000 Canadians are currently living with dementia and an additional 350 people are diagnosed with dementia each day.

While Canadian federal, provincial and territorial policies and laws are in place to protect citizen rights, each province and territory is responsible for its respective health and social services and data collection strategies. Federal, provincial and territorial governments also play a supporting role in health and social services for Indigenous peoples including First Nations, Inuit and Métis. The complexity of these systems often hampers the collection of national data on health and social services specific to people with intellectual disabilities. If this data were available, it would hold a wealth of information and research potential that could be shared nationally and internationally to the benefit of this often-marginalized group affected by dementia.

Few Canadian research reports have examined dementia as it affects adults with intellectual disabilities and their caregivers. Sullivan et al. (2018) make brief mention of guidance for Canadian physicians in reference to dementia and people with intellectual disabilities (recommendation 32), yet there is no Canadian Guide to support adults with intellectual disabilities living with dementia in the community. In the absence of Canadian research and guidance to support community

living for adults with intellectual disabilities affected by dementia and their caregivers, many rely on international information despite differences in social and healthcare systems (Jokinen, 2019).

Adults with intellectual disabilities without Down syndrome may be at higher risk of developing mild cognitive impairment (MCI) and dementia at younger ages compared to the general population. There is also clear evidence that adults with Down syndrome are at a particularly high risk for young onset dementia and may experience a precipitous decline (Allen et al., 2023; Janicki et al., 2022), and there is preliminary evidence related to people with other intellectual disabilities. For example, information is now being gathered on the health risk of dementia and diagnostic process for adults aging with various neurodivergent conditions (Janicki et al., 2022), and we are starting to hear about new therapeutic treatments for Alzheimer's disease and the potential applicability to adults with intellectual disabilities (Hillerstrom et al., 2023). Brain health and the identification of potential modifiable risk factors related to dementia is another area of keen emerging interest (see, as example, Allen et al., 2023). At the 2nd International Summit on Intellectual Disabilities and Dementia, hosted by Reena in October 2023, discussions were held on human rights and equity, brain health and risk reduction, and neurodivergent populations as they relate to adults with intellectual disabilities affected by dementia. The International Intellectual Disabilities & Dementia Summit Secretariat, officially formed at the event, (see <https://www.the-ntg.org/summit-secretariat>) is producing a report based on these discussions.



Reena and the NTG-Canadian Consortium identified the need for a guide to support adults with intellectual disabilities affected by dementia living in Canadian communities with support from family, friends and service providers. The field of intellectual disability and dementia has evolved on a national and international basis since the inception of the 2013 guidelines developed under the auspices of the National Task Group on Intellectual Disabilities and Dementia Practice (NTG) (Jokinen et al., 2013). For example, we now know adults with an intellectual disability are becoming involved as caregivers of family members and spouses/partners who have developed dementia.

To that end, Reena and the NTG-Canadian Consortium partnered on a 16-month project with funding approved by the Public Health Agency of Canada – Dementia Strategy Fund to create *The Canadian Guide for Community Care and Supports for Adults with Intellectual Disabilities Affected by Dementia*. The Guide developed using the “Edinburgh Principles” (Wilkinson & Janicki, 2002) as the conceptual framework, aligns with the National Dementia Strategy principles, and reflects new developments in thinking, practice, and guidance in Canada. It is supported by numerous individuals, communities and organizations across the country.

### Edinburgh Principles emphasizes activities should

- Promote quality of life.
- Use person-centered approaches.
- Affirm individual strengths, capabilities, skills, and wishes.
- Involve the individual, family and other close supportive persons.
- Advocate for and provide access to appropriate diagnostic, assessment and service resources.
- Plan and provide service support for the individual to remain in their home and community.
- Provide access to services and supports that are available to other persons in the general population affected by dementia.
- Commence proactive strategic planning across policy, provider and advocacy groups



The Guide recognizes that relationships are fundamental in the provision of supports and services and is, therefore, also written based on principles of Relationship-Centered Care (Beach et al., 2006), taking into account:

- each person's unique attributes and role in developing and maintaining authentic relationships,
- the importance of affect and emotion in relations,
- the reciprocal nature of relationships, and
- the moral value in forming and maintaining relationships.

These principles are complementary to and enhance person-centred care.

Similar to people in the general population, adults with intellectual disabilities affected by dementia experience various transitions as skills and abilities decline. These transitions present challenges, as well as opportunities to be creative in providing quality supports and resources.

**Efforts to support adults with intellectual disabilities who wish to remain in their own homes and communities will require the following system-wide considerations:**

- families and services are prepared for dementia care;
- services shift from the acquisition of new skills to maintaining abilities for as long as possible;
- availability of a specialized dementia-capable workforce and stage-based support strategies;
- support and technical assistance from dementia care programs, Alzheimer's support programs, hospitals and hospice/palliative care programs including staff trained in aging and dementia care for adults with intellectual disabilities; and
- funding and public social policies that support home and community care for people with intellectual disabilities affected by dementia.

This Guide highlights actions and best practices that can be applied to address the many challenges faced by adults with intellectual disabilities, compounded by the onset and progression of dementia. It is based on the knowledge and insights of adults with intellectual disabilities, organizations, staff and families, as well as information gleaned from research and a gray literature scan and clinical and practical experiences, presented in three sections:

1. **Community Care Guidelines** – Outlined in a stage-based approach (pre-diagnostic, early, middle, late and end stages), recognizing that symptoms vary from person to person and are based on the type of dementia.
2. **Program/Support Options** – Information is presented based on where individuals live and how they engage with others with the aim of informing community support practices.
3. **Emerging Issues** – In this section, the Guide explores topics relevant to people with intellectual disabilities and their caregivers, such as brain health, cross-sector collaboration, grief and loss and indigenous populations.

Each section includes recommended actions and activities that may be undertaken by caregivers, organizations and government departments.

# 2.

## COMMUNITY CARE GUIDELINES

### 2.1 DISEASE/CONDITION PROGRESSION

Generally speaking, with some variations, dementia affects adults with intellectual disabilities in a similar way as other adults in the general population (Janicki et al., 2022). Various dementias, with no known cure, differ in presentation and progression. For instance, Alzheimer's is commonly considered to progress with a slow steady decline in abilities while vascular dementia may progress in a step-like fashion, plateauing between vascular events. Eventually, with progressive loss, the person will rely on others for complete daily support.

Most research on dementia as it affects adults with intellectual disabilities focuses on those with

Down syndrome and Alzheimer's disease. There is a general consensus this group is at a higher risk of dementia, the onset of symptoms occurs at an earlier age, and a rapid progressive loss in abilities can occur (Frizell 2017; Janicki et al., 2022; Sinai et al., 2017). Adults with intellectual disabilities without Down syndrome often mirror the risk of dementia seen in the general population. However, some individuals may have syndromes and/or be living with medical conditions that increase their risk of dementia as they age compared to the general population.

Recent preliminary work on the impact of dementia on adults aging with intellectual disabilities and other concurrent conditions (e.g., intellectual disability and autism or cerebral palsy) is garnering attention (Janicki et al., 2022). International research on biomarkers, another emergent area of study, will also likely lead to important information on the preclinical course of dementia and potential interventions to prevent progression, particularly in relation to adults with Down syndrome (Fortea et al., 2020; Montoliu-Gaya et al., 2021; Rafii, et al., 2021). There are also several new disease-modifying drug treatments

**Some symptoms of dementia may be caused by medical issues or conditions that are responsive to treatment (e.g., sensory impairment, adverse drug reactions), so it is important to investigate noticeable change in an individual's ability to function on a day-to-day basis.**

being tested and approved for use in the general population that may slow the progression of dementia. To date, none of the clinical trials have included adults with intellectual disabilities (Hillerstrom et al., 2024).

While there may be some commonalities in how people experience dementia, it is important to remember each person's experience is unique. Additionally, adults with intellectual disabilities affected by dementia face ongoing health inequities and challenges in accessing appropriate dementia-related support services (Public Health Agency of Canada, 2019). Given the nature of dementia, its progression and complexities, and the impact of variables, such as the circumstances and environments where people reside and the availability of services and supports, there is growing awareness and recognition of the challenges faced by caregivers and provider organizations in accommodating the needs of adults with intellectual disabilities affected by dementia.

**The person is much bigger than the disease. Never forget the beauty of the individual.**

Many organizations will also likely need to fundamentally change their approach to provide services for adults with intellectual disabilities affected by the onset and development of dementia symptoms. This will require strategic planning, preparation, redesign, training and integration of new services. It should also include supports provided to families and other direct caregivers and collaboration with other

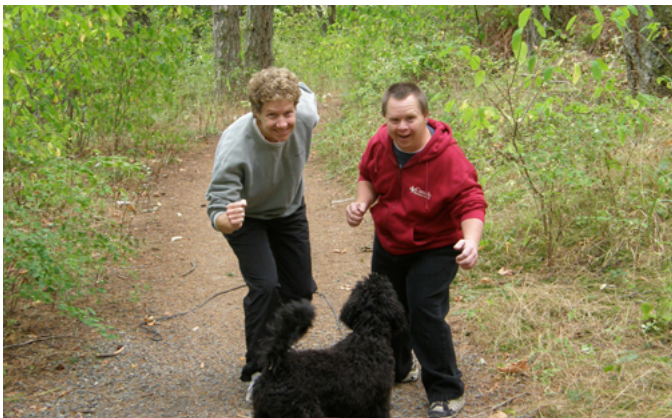
community organizations, policy makers, and funders.

To enable the development of the most appropriate and useful services and support for adults with intellectual disabilities and caregivers affected by dementia, we have used a staging model of dementia in this Guide — a generally accepted practice among generic dementia services. The staging model follows the progression of dementia through four stages from a pre-diagnosis stage, with early recognition of symptoms associated with cognitive decline, through the early, middle, late and end stages of dementia. Activities and actions to assist individuals in maintaining engagement with others and enjoyment of daily life, while supporting them through the loss of their abilities are shown in Tables 1a-1d.

## 2.2 PRE-DIAGNOSIS STAGE

### RECOMMENDED ACTIONS

1. Provide information to support individuals experiencing changes, family members and friends, and deliver staff training to deepen understanding of the diagnostic process and progressive nature of dementia.
2. Establish a baseline of the person's skills and abilities using one of the many screening tools that are available and keep this record for future comparison purposes. The screening tool offered by the National Task Group on Intellectual Disabilities and Dementia Practices, Early Detection and Screen for Dementia (NTG-EDSD) is recommended.
3. Conduct screenings on an annual basis to capture early warning signs that may or may not indicate dementia. Note: healthcare professionals may recommend assessments be done more frequently.
4. Arrange for a medication review by a pharmacist to identify adverse drug reactions that may cause dementia-like symptoms or seem to make other conditions worse.
5. If the screening tool indicates a change that is concerning, arrange an appointment with a healthcare professional. Follow-up may be needed (e.g., continued monitoring for further change, routine laboratory testing, or a referral to a specialist).
6. Have someone familiar with the adult with an intellectual disability, their history and communication style accompany them to healthcare and assessment appointments.
7. Advocate for trained professionals, familiar with assessment and diagnosis of adults with intellectual disabilities and cognitive / functional decline, to be available and involved when needed.
8. Hold virtual or in-person meetings with the individual, family members and others important to them after healthcare appointments. If a diagnosis of dementia is obtained, ongoing meetings will be needed to explain the diagnosis, prognosis, and to map out priorities for future support.



In the pre-diagnosis stage, family or staff members familiar with the individual may notice subtle changes that may or may not be early signs of dementia. The individuals themselves may also raise questions about changes they are experiencing.

Such early warning signs may initially fluctuate – observed one day and not the next - and may go unrecognized, overlooked, or possibly dismissed (Deb et al., 2022). Early changes may include:

- sporadic memory lapses
- occasionally getting lost or misdirected
- problems with gait or walking
- unusual confusion with familiar tasks and situations
- increased frustration and lack of patience
- changes in personality and behaviour
- slowness in activities

Symptoms will likely vary from person to person depending on the nature and severity of the individual's intellectual disability and their overall physical and mental health (Deb et al., 2022).

**The hardest part with him was knowing or recognizing that he was actually developing dementia**

Memory impairments, for instance, may be early signs among some adults with mild or moderate intellectual disability, whereas early personality changes may be more pronounced in adults with Down syndrome (Ball et al., 2006; Tor et al., 2010). Family caregivers have also noted behaviour changes generally indicative of middle stage dementia, such as wandering, becoming unusually argumentative or aggressive, changes in sleeping patterns, incontinence, and rummaging (Jamieson-Craig et al., 2010). Wissing et al., (2022) note far less is known about dementia concerning adults with severe/profound intellectual disabilities and suggest early signs include changes in speech, social and everyday skills.

Despite noticing changes in an adult with an intellectual disability, family members or staff sometimes wait to seek help until everyday life is disrupted and care demands have increased based on changed behaviours (Adams et al., 2008; Dekker et al., 2021). Often families who are unknown to intellectual disability services reach out for much needed support when their relative with an intellectual disability is experiencing ongoing perplexing changes. Unfortunately, appropriate and timely help is not always available, particularly if they have been unknown to social support services (Frizell, 2017). It is important that the adult with intellectual disabilities experiencing changes and caregivers understand the diagnostic process and possible outcomes (e.g., a diagnosis of dementia or a diagnosis of a different condition/illness causing the changes) and begin engaging with support and service providers as early as possible.

**Table 1a**  
Pre-Diagnosis Support Model

| Functional changes  | Change indicators   | Actions   |
|---|---|---|
| Sporadic memory, personality changes and or performance changes including slowness, confusion, other generic warning signs. | Individual shows distress or complains of losses<br><br>Initial symptoms becoming evident | Establish a baseline if one has yet to be done.<br><br>Use a screening tool, like the NTG-EDSD<br><br>Monitor behaviour.  |
|   | Screening indicates unexplained change(s) in behaviours or abilities.                     | Ask a pharmacist for a medication review for possible adverse drug reactions.<br><br>Discuss changes with the individual and caregivers (family and support staff). Plan for the medical appointment.<br><br>Make an appointment with a healthcare professional to discuss changes and a possible course of action (e.g., continue monitoring changes and or get referral for tests/assessments).   |
|   | Assessment indicates symptoms are <b>not related to dementia.</b>                         | Follow recommended treatment (medication, nutrition, etc.) to treat non-dementia conditions and symptoms.   |
|   | Assessment indicates changes may be symptoms <b>related to dementia.</b>                  | Provide education/information to help the person, family, friends and housemates to understand and cope with changes.<br><br>Listen and talk with the person about the changes they are experiencing using familiar terms that are consistently used by others in contact with the person.<br><br>Focus, in a planned manner, on encouraging continued engagement to keep the person as independent as possible.<br><br>Initiate support planning to meet changing needs.<br><br>Continue to monitor for ongoing changes. |



## Establishing a baseline and an annual screen of abilities

There are several dementia screening tools available; however, the NTG-Early Detection Screen for Dementia (NTG-EDSD) (National Task Group on Intellectual Disability and Dementia Practice, 2013) is recommended for use in establishing a baseline and completing annual reviews of abilities and health; it is an effective tool designed specifically for family and support staff to complete with minimal direction or training (Esralew et al., 2013; Walaszek et al., 2022). The NTG-EDSD is not a diagnostic or assessment tool. It is a screening tool used on a regular basis that helps identify cognitive, functional or health changes over time. These changes may be related to a dementia, such as Alzheimer's, or to other causes (e.g., thyroid disorder, adverse drug reactions, depression, etc.). The tool is available free in multiple languages (including French and English) (<https://www.the-ntg.org/ntg-edsd>) with a manual (Esralew et al., 2013) which provides succinct instructions.

**Changes in behaviour that are often attributed to dementia may be possibly related to other causes, such as physical loss or debility (e.g., gait changes, falling, and sensory impairment), medical issues, adverse drug reactions, or pain. It is critical that other causes be eliminated prior to attributing the behaviour manifested to dementia**

To establish a baseline, it is suggested to use both the NTG-EDSD and a short video, taken with the person's permission. Although a baseline using psychometric measures could be established by a healthcare specialist (e.g., psychologist, neurologist) who is familiar with adults aging with intellectual disabilities, access is limited in many locations across Canada and some provincial health programs do not cover the costs for this service. A baseline is essentially evidence of a person's abilities recorded when an adult is in their prime, or, if not in their prime, completed as soon as possible. A baseline and screening for people with Down syndrome is recommended to be established as early as age 30 (McKenzie et al., 2020). Others suggest ages 35 (Esralew, 2020) or 40 (Tsou et al., 2020). Deb et al. (2022) recommends screening between ages 30 and 35. For adults with intellectual disabilities without Down syndrome, recommendations suggest screening start at age 50. Once established, this baseline can be used to compare past to current abilities and discuss changes with a healthcare professional as soon as change(s) are observed to determine what might be the cause. The importance of early detection is acknowledged in the Canadian national dementia strategy. Early recognition of changes in adults with intellectual disabilities provides opportunities for families and staff to allocate resources, access available treatment, and plan for needs, services and supports.

It is important to share the recommendation to include smart phone video with the NTG-EDSD baseline, and in subsequent screenings, draws upon information from an earlier video protocol

(Janicki & Dalton, 2024). The video is a visual record of the person demonstrating a limited number of tasks.

**The original protocol identified four tasks:**

- standing up, walking several steps, turning and returning to sit in the chair,
- picking up coins on a table and putting them in a jar,
- following a demonstration of the task, opening a padlock, and
- engaging in a brief conversation.

Each of these tasks were methodically chosen to demonstrate specific skills and abilities. If task substitutions are used, they should reflect the demonstration of similar skills and abilities. Tasks should be consistently used in successive annual reviews alongside the NTG-EDSD.

## Formal assessment and diagnosis

Well-trained professionals and reliable diagnostic services are essential for adults with intellectual disabilities to receive an accurate diagnosis and access to appropriate treatment when they experience unexplained changes in mid-to-late life. The process of formal dementia diagnostics is a complex endeavor (Deb et al., 2022; Janicki et al., 2022) that should involve specialists such as geriatricians, psychologists, neurologists, psychiatrists, or others who have experience and expertise in evaluating adults with an intellectual disability. Such diagnostics should also be carried out according to generally accepted practices by the professional conducting the assessment (e.g., American Psychological Association, 2021; Canadian Psychological Association, 2021). That said, it is important for caregivers to understand the basics of the diagnostic process to support adults with intellectual disabilities going through

**Knowing more about being able to identify which type of dementia the individual has developed will also probably help with knowing how to care for them better**

it and advocate on their behalf. Moran et al., (2013) offer a framework for evaluating and managing dementia affecting adults with intellectual disabilities that includes a physical examination, cognitive assessment, diagnosis, treatment and follow up. The framework considers nine aspects identified in Table 2.

**Table 2**  
Aspects of a Diagnostic Framework

**Framework includes:**

1. Medical & psychiatric history
2. Baseline functioning
3. Current functioning/compare with baseline
4. Focused review of systems
5. Medication review
6. Family history
7. Other psychosocial issues/changes
8. Social history, living environment, level of support
9. Synthesis of information

*Source: Moran et al., 2013*

The diagnostic process rules out life events or other health issues that may cause dementia-like symptoms (e.g., residential move, sensory impairments, nutritional deficits, delirium, or depression) that may respond to support or treatment — sometimes referred to as conducting differential diagnoses. Diagnostic overshadowing, assuming the change is part of the existing disability, may also hinder an accurate diagnosis (Hallyburton, 2022). Distinguishing normal age-related decline from dementia symptoms can also complicate dementia diagnosis (Deb et al., 2022; Janicki et al., 2022). Each of these processes have distinct purposes. Some serve as preliminary screenings for symptoms that may indicate mild cognitive impairment or mild dementia. Others are more formative and aid in assessing symptoms to establish the probable presence of dementia and potentially identify the type and stage.

It is important to note that some clinical assessment tools used for the diagnosis of

dementia in the general population are also appropriate for adults with a mild intellectual disability or those bordering on being neurotypical. Tools such as the MMSE and MoCA generally evaluate normal cognitive abilities for the general population and are of limited value for assessing many adults with intellectual disabilities due to the variation of cognitive capabilities characteristic in lifelong disability (see Janicki et al., 2022). There are, however, instruments designed specifically for adults with intellectual disabilities, particularly for adults with Down syndrome, that clinicians use to validate suspicions of dementia that can help clinically track decline or changes. Table 3 identifies examples of those used for both screening and early detection as well as tools used for diagnosis. This is not an exhaustive listing and clinicians vary in their choices to use depending on circumstances.

**Table 3**  
**Informant-Report and Objective Measures for Clinical Assessment**

| Name of Measure  | Instrument Characteristics  |
|--|---|
| <b>Measures Appropriate for Screening and Early Detection</b>  |   |
| Cambridge Cognitive Examination Adapted for Individuals with Down Syndrome (CAMCOG-DS).<br>(Ball et al., 2004).  | A clinical screening tool that is part of the CAMDEX-DS. Used to determine if further assessment is required.   |
| Dementia Questionnaire for People with Learning Disabilities (DLD).<br>(Evenhuis, 2018).   | Made up of eight sub-scales: short-term memory, long-term memory, orientation (making up Sum of Cognitive Scores), speech, practical skills, mood, activity and interest and behavioural disturbance (making up a Sum of Social Scores).                |
| National Task Group-Early Detection and Screening for Dementia (NTG-EDSD).<br>(National Task Group on Intellectual Disability and Dementia Practices, 2013). | An informant-based rating tool for use with adults with intellectual disability who are suspected of having changes in thinking, behaviour, and adaptive skills suggestive of mild cognitive impairment or dementia. Derived, in part, from the DSQIID. |
| <b>Measures Appropriate for Substantiating Diagnoses</b>   |   |
| Cambridge Examination for Mental Disorders of the Elderly – Down Syndrome (CAMDEX-DS).<br>(Ball et al., 2004).   | Designed to assess the cognitive deficits identified in criteria for dementia for people with Down syndrome and other intellectual disabilities.  |
| Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID).<br>(Deb et al., 2007)  | Comprised of 43 questions in three sections. Measures memories, confusion, feelings of insecurity, sleep problems, and behaviour problems. Includes information about medical conditions, psychiatric conditions, and medication.                       |
| Severe Impairment Battery (SIB)<br>Panisset, M., et al., (1994)  | Developed for people with a range of cognitive abilities, it has been used with some frequency with people with intellectual disabilities.  |

Accuracy is becoming even more critical when diagnosing the presence and impact of Alzheimer's disease specifically, given the requirement for documentation to establish eligibility for obtaining anti-amyloid medication for adults with mild cognitive impairment or early-stage Alzheimer's disease. While these medications are not yet approved for use in Canada, they are approved in the USA and Japan (Watt et al., 2023). Hillerstrom et al. (2023) identify and offer recommendations to overcome several challenges that impede prescription of these drugs in the USA once they are found safe for adults with intellectual disabilities who are in early stages Alzheimer's disease. They are worth noting and considering as similar challenges may exist in Canada and other countries when the drugs are approved.

In Canada, a referral for formal assessment by a qualified specialist who is knowledgeable about adults with intellectual disabilities and dementia is usually made by a healthcare professional (e.g., family physician, nurse practitioners) or the provincial funder. In some communities, including small, rural, or remote locations, these

resources may be very limited or unavailable. As such, telephone or video consultations need to be arranged. A framework for telemedicine use based on the literature and work with people in the general population may be used (Geddes et al., 2020). Elbaz et al. (2021) suggest the use of technology to provide services to adults with intellectual disabilities affected by dementia may be both practicable and necessary in the future. Yet, the benefit of this approach needs to be thoroughly explored. Development of regional teams may also improve access and assessment services for adults with intellectual disabilities affected by dementia and their caregivers.

## **Supporting individuals with intellectual disabilities**

It is important to support adults experiencing changes in understanding the diagnostic process and outcome(s). *Jenny's Diary* (Watchman et al., 2015) offers a four-step framework, including suggestions for engaging in these conversations, outlined in Table 4.

**Table 4***Jenny's Diary* – Steps for Talking about a Dementia Diagnosis

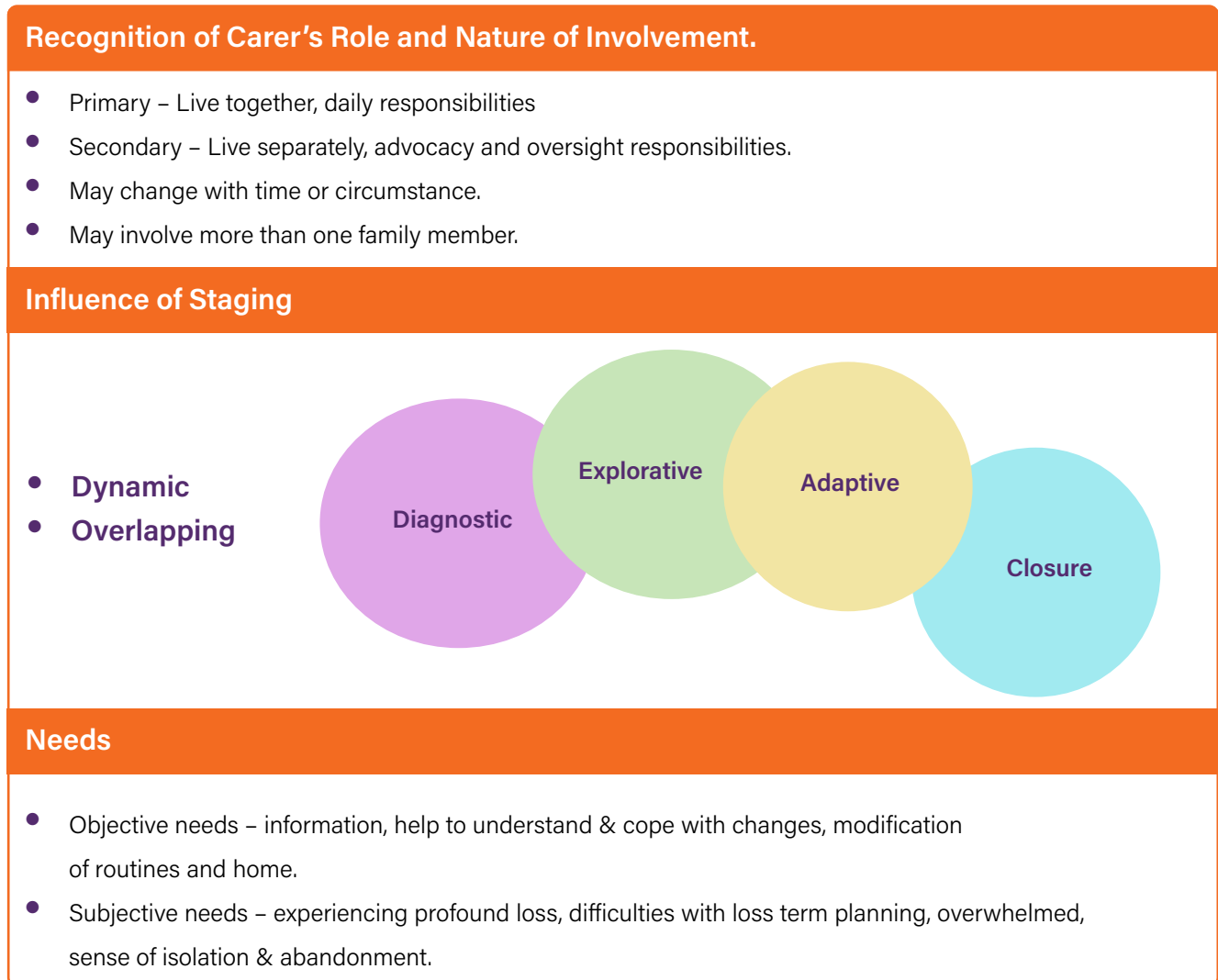
| Step          | Focus                                       | Aspects  | Considerations  |
|---------------|---|--|---|
| <b>Step 1</b> | Know the person's current knowledge         | Consider their background<br>Discuss what's happening now.<br><br>What about the future?   | Person's experience, understanding.<br>(e.g., family history, day to day living)  |
| <b>Step 2</b> | Simplify information into manageable pieces | Focus on what's important to know right now.<br><br>Gauge understanding about the future.  | Coping skills<br><br>Insight into what is changing<br><br>The impact of changes   |
| <b>Step 3</b> | Provide new information one bit at a time.  | Frame the information to make sense based on their knowledge and understanding.  | Use words that are familiar to the person<br><br>Knowledge of the immediate situation versus future implications<br><br>How the individual processes and utilizes information |
| <b>Step 4</b> | Provide new information one bit at a time.  | Recognize that understanding will change with time.<br><br>Individuals may not understand information until they experience changes. | Evaluating progression of the disease and the need for new, updated information<br><br>Current level of understanding   |

Each step is focused on supporting the adult and including them in decisions that need to be made at each stage. By starting these discussions early on, caregivers and professionals can gain a deeper knowledge and appreciation of the person's history and current situation, and, ideally, build a stronger relationship with them. Understanding their life story can provide valuable insights about preferences that can be incorporated into daily life. *Jenny's Diary* is available in several languages; see reference list for free download link.

## Supporting family caregivers

Many family caregivers have been an important source of support throughout the lives of their relatives with intellectual disabilities who are now affected by dementia. These caregivers now face new care challenges as dementia changes become evident and progressively take over day-to-day living. The caregiver support framework for decision-making (Jokinen et al., 2018; Jokinen, 2023) is a stage-based approach that came out of the 2016 Glasgow Scotland International Summit on Intellectual Disabilities and Dementia. The framework is a dynamic process that offers a means of assessing the particular phase the family caregiver may be at to help target the most beneficial services. Figure 1 provides an overview of this framework.

**Figure 1**  
Three Aspects of the Caregiver Support Staging Model



Source: Jokinen, 2023



## 2.3 POST-DIAGNOSIS STAGES

This section of the Guide outlines actions, symptoms, care focus, environmental modifications, training, and outcomes for each of the post-diagnosis stages. The transition from one stage of dementia to another is usually subtle, signalled by noticeable change in symptoms and or abilities unless there is a pronounced change either behaviourally or neurologically (e.g., seizures). The progression of a dementia from diagnosis to end stage usually takes years, however, some adults with Down syndrome may experience a rapid decline (Janicki et al., 2022; Frizell, 2017).

**Everything happened so quickly... Before we could understand what to do, let alone find out where or how to go about helping him, he entered the next phase of this fast-paced disease, bringing with it a new set of challenges and uncertainty (Frizell, 2017).**

A person's experience with dementia is personal. Symptoms that are associated with each stage will vary and not all people will experience every symptom. Careful observation of changes and indicators of worsening symptoms is necessary to determine appropriate accommodations, support and supervision (Moran et al., 2013).

### 2.3.1 EARLY STAGE

#### RECOMMENDED ACTIONS

1. Engage in conversations with the individual, their family, and/or other caregivers or guardians about future care needs and prepare advance directives consistent with provincial or other requirements.
2. Establish a daily routine with the adult with an intellectual disability and their caregiver(s) that provides opportunities for meaningful and purposeful activities based on needs and preferences. The routine should provide a sense of safety and security.
3. Identify and plan to alter aspects of environments to help maintain home and community living.
4. Redesign daily activities and programs so that participation in valued activities and opportunities for interaction with others continues.
5. Provide respite opportunities for family members living with relatives with intellectual disabilities affected by dementia. Other caregivers may also require short respite breaks.
6. Access ongoing clinical supports to address responsive behaviours (e.g., behavioural and psychological symptoms) and assist the individual with anticipatory grief.



During early stage dementia, ongoing information and education can help build understanding and confidence in coping with changes and proactively planning for the future. Adapting

both the physical and social environments to accommodate changing abilities will enable the individual to maintain their home and community living situation and routines.

**Symptoms.** Abilities continue to fluctuate initially in early-stage dementia. Symptoms will, however, become more pronounced and constant, including:

- memory losses further impact daily activities and social interactions
- confusion and anxiety increase
- communication becomes more difficult
- enthusiasm for life diminishes
- movement and completion of activities slows

**Care focus.** For some people, the early stage of dementia may last for several years. Adults with intellectual disabilities often live independently or with family, spend periods of time alone and/or travel independently using public transportation. However, this independence may become a concern and safeguards, increased support and supervision will be required. Family members, friends, volunteers, and members of various community support networks may need to become involved to provide additional companionship and/or respite services. Daily routines that provide purposeful engagement based on individual needs and preferences is generally helpful. These routines can help reduce the individual's anxiety and confusion and possibly prevent agitation or aggressive behaviours. Support is also needed to facilitate community engagement and communication with peers/staff/family. As much as possible, routine activities that are valued by the person and known to be comforting, including

religious practices, sports, and/or the arts should be continued (Timmins et al., 2023).

**Engage the individual, their family, and/or other caregivers or guardians in conversations about future care needs and prepare advance care directives consistent with provincial or other requirements. Early planning provides the individual affected by dementia with opportunities to discuss what is important to them.**

Care and support of adults with an intellectual disability affected by dementia should take place as much as is possible in community settings. In most instances, continued community engagement is recommended, based on human rights (Alzheimer Society of Canada, 2018)

and best practices. With appropriate supports and supervision, most, if not all, adults with an intellectual disability can continue to reside in a community living setting and enjoy an enhanced quality of life. However, if challenges in their living situation arise, they need to be identified and, if possible, a plan to remedy the situation should be

initiated. Medical treatment and surveillance and management of co-morbid conditions should also be planned for and occur in tandem with gradual increases in support as dementia progresses.

**Given these considerations, care plans should emphasize:**

- maintaining skills and abilities rather than acquisition of new skills;
- continuation of community participation, including day services and spiritual supports;
- modifying routines as needed to enable the person to manage their own day and living situation to the greatest extent possible and to lessen resistance to care in later stages;
- modifying home and day program environments so that the individual's participation and quality of life is maintained;
- discussing and planning for future needs and preparing advance care directives,
- continuing use of the screening tool (e.g., NTG-EDSD) to track changes;
- proactively addressing any related physical or mental health issues, including pain management or depression, which may impact or be worsened by dementia symptoms; and
- identifying resources and providing support for staff, family caregivers and friends who may experience compassion fatigue, stress and caregiver burden and grief.

## ***Future Planning***

The individual's values and preferences should be considered in advance care and end-of-life planning (McCallion et al., 2017). It's important to recognize that values and preferences will evolve based on dementia-related changes (McCallion et al., 2017). Wherever possible, choices should influence all care planning, including end- of-life care and be formalized in writing. (McCallion et al., 2017; Loughheed, 2019; McCarron et al., 2018).

There are several planning resources available including a general advanced care planning resource developed by the Fraser Health Authority (2024) and a resource developed specifically for adults with intellectual disabilities (Burke, et al., 2017).

**Table 1b**  
Early Stage Support Model

| Functional changes  | Change indicators   | Actions  |
|---|---|--|
| <p>More pronounced changes in function, personality, and or attention to daily activities</p> | <p>Progression of early stage symptoms that become more obvious and constant</p>                      | <p>Monitor and document additional changes and or symptoms.</p> <p>Monitor health for secondary conditions.</p> <p>The individual, family and other caregivers should plan and schedule daily routines and activities.</p> <p>Introduce additional assistance with daily tasks, personal care and memory aids as needed.</p> <p>Develop appropriate emotional, spiritual, and cultural support strategies.</p> <p>Have medication review done by a pharmacist if possible adverse drug reactions are suspected.</p> <p>Have an emergency plan in place for family caregivers who live with and are suddenly unable to care for their relative with dementia.</p> |
|   | <p>Communication problems</p>   | <p>Adjust communication and be prepared to use non-verbal communication methods (e.g., use of pictures, facial expressions and gestures, use of shorter sentences).</p> <p>Take time to communicate clearly, listen and allow time for the person to respond.</p> <p>Ensure life story work begins.</p>  |
|   | <p>Assessment indicates symptoms most likely represent progression towards middle stage dementia.</p> | <p>Identify and plan for future care needs and preferences, including possibly changing living arrangements. Prepare advance care directives.</p> <p>Adjust daily routines as needed. Modify physical and social environments.</p> <p>Establish plans to address safety (e.g., wandering, ingesting harmful products, falling).</p> <p>Explore resources for additional "in home" supports and specialized therapeutics (e.g., massage).</p>   |

**Environmental Modifications.** Staff and family members should anticipate and plan for environmental modifications to support continued independence and reduce stress and demands on the individual and caregivers. For instance, in early stage, some initial physical environment modifications can be relatively low-cost and helpful in creating a calm, relaxing environment (e.g., declutter the environment, reposition furniture for ease-of-use and movement, paint, display familiar objects and possessions, supply adequate lighting). Homes with stairs will become increasingly problematic with the progression of dementia, so mobility aids (such as a second stair rail, or stair glide) may be considered. In some homes where stairs, small bathrooms, thresholds, and other barriers interfere with walkers or wheelchairs, solutions should be considered before exploring alternative living arrangements. Long-range planning should also consider the need for specialized equipment in late and end stage dementia. Table 6, in the middle stage

dementia section, identifies several evidence-based recommendations to consider.

Non-pharmacological approaches are often preferred as a first step toward supporting the individual and managing responsive behaviours and symptoms of dementia (Jokinen, 2014; Jokinen et al., 2013; Dodd et al., 2018; Dyer et al., 2018). Renovating the individual's home is one example of a non-pharmacological intervention.

**Anticipate and plan for environmental modifications that support continued independence and reduce stress and demands on the individual and caregivers.**

The Canadian National Dementia Strategy also identifies non-pharmacological interventions as a priority for a skilled workforce (Public Health Agency of Canada, 2019). Table 5 offers examples of approaches that may be used.

**Table 5**  
Non-pharmacological Interventions

| Intervention Type                            | Examples  |
|--|---|
| Counselling and group support                | Individual, family and significant others                               |
| Culture, arts-based and other therapies      | Dance/movement, music, art, pet, massage, Aboriginal cultural practices |
| Environmental design and home modifications  | Safe walking paths, use of colour, furniture style and placement        |
| Education and skills training for caregivers | Dementia information, communication strategies                          |
| Health-related activities                    | Physical exercise, dining and sleep routines                            |
| Multi-sensory approaches                     | Snoezelen, Montessori   |
| Programmatic adaptations                     | Change in content, implementation, duration                             |
| Technology-based strategies                  | Assistive devices, tablets, smart phones                                |

*Adapted from: Jokinen, 2014 cited in Deb et al., 2022.*

**Communication.** Early stage dementia is often marked by forgetfulness and increasing difficulty managing routine tasks and conversations. Family, friends and staff who come in contact with and support the person with dementia will need to take on a greater, yet respectful, role in conversations, and, as dementia progresses, they will need to learn to reframe their communication approaches to reflect stage-based best practices (McCallion, 1999). Starting a conversation on a positive note (e.g., reduce distractions, face the person), listening closely (e.g., pay attention) and speaking gently (e.g., clearly, simply, yet not childishly) are helpful strategies (Public Health Agency of Canada, 2022).

If assistive devices (e.g., glasses, hearing aids) and technology (e.g., communication devices, smart phones, tablets) have been part of the individual's life, ensure that the equipment is in proper working order and is still appropriate. Continue use for as long as possible, and, if necessary, consider other memory aids (such as scrap or memory books, videos or posters for an individual's room) as sources of engagement and conversation.

**Health.** Throughout all stages of dementia care, providers should document changes in symptoms and abilities, as well as the status of chronic conditions or emerging co-morbid health problems. Keen observation skills are important attributes of an informed, proactive care provider. Specific instruction should be provided regarding how and what to observe and document. Reporting these to the individual's health care practitioner will influence treatment options if any are needed.

The individual and their caregivers should provide feedback to healthcare practitioners on the effectiveness of pharmacological and non-pharmacological therapies. Care providers should know which treatments are being administered, the expected outcomes, and possible side effects.

**Training.** There are several existing training programs and educational sessions offered by various organizations and services on dementia in general and as it impacts adults with intellectual disabilities and their caregivers. As an example, local and provincial Alzheimer Societies in Canada offer training workshops, webinars, e-learning modules and other educational materials to inform adults in the general population affected by dementia and their families. The NTG-Canadian Consortium on Dementia has offered in-person small group workshops for several years for caregivers of adults with intellectual disabilities affected by dementia. These Canadian workshops use a curriculum originally based on the *Dementia Capable Care of Adults with Intellectual Disabilities and Dementia*, developed by the National Task Group on Intellectual Disabilities and Dementia Practices in the United States and adapted for the Canadian context. The NTG-Canadian Consortium support over 100 NTG-Canada Affiliated Provincial Trainers who also offer basic, topic-specific training in their local communities.

In early stage dementia, training should be targeted to adults with intellectual disabilities, family members, health, and social support staff. It should build understanding and knowledge of the nature of Alzheimer's disease and other dementias

with a focus on developing quality supports for adults with intellectual disabilities. Caregivers and friends should be provided with information and guidance on changes to be expected and helpful tips for managing care (Samus et al., 2014), along with care strategies to help reduce stress and anxiety for all those involved as dementia progresses. Caregivers should also be aware of supports that are available to assist them (e.g., spiritual support, day services, respite).

Seeking information and support is important

for sustaining the wellbeing of the caregiver and supporting a person throughout the course of dementia. Community health or social service organizations have staff, such as care managers, care coordinators or system navigators who are adept at assessing situations and knowledgeable about local programs and supports and the eligibility criteria for accessing them (e.g., respite, home care, day services). They may also assist with planning to meet future care needs. Local intellectual disability associations and senior services may also be helpful resources.

## 2.3.2 MIDDLE STAGE

### RECOMMENDED ACTIONS

1. Provide the person with increased assistance for personal care and other routines when needed.
2. Continue to observe, document and report further changes and loss of abilities, as well as the possible development of additional health conditions.
3. Monitor medication use for early detection of adverse drug reactions.
4. Enhance training/education and consultations for staff, family, friends and housemates to help them cope and adapt routines as needed.
5. Ensure protections are in place to prevent harm or abuse in both formal and informal settings, and establish policies and procedures related to reporting incidents.
6. Ensure housing is still appropriate and secure residential supports to meet changing needs.
7. Contact community services (e.g., disability, health, home and community care and seniors) to plan for long-term services and support, including alternative living arrangements if needed to accommodate complex needs.

During middle stage dementia, a person may change significantly. This stage varies in duration, although this is often shorter for adults with Down syndrome (Sinai et al., 2018). Additional pressures will be placed on caregivers as the person experiences further losses in abilities and expresses responsive behaviours/behavioural symptoms that present daily challenges. It is common for family and caregivers to struggle with changes and question their ability to continue providing care (Heller et al., 2018). It is important

caregivers initiate a self-care regime, live in the moment, rejoice when things are going well, and reach out for support when things are difficult.

Environment also plays an important role. For example, environments should be calm and not over or under stimulating, loud or chaotic. More dementia-focused environmental suggestions are offered in Table 6.

**Symptoms.** Throughout the middle stage, there will be increased loss of abilities, and greater likelihood of responsive behaviours and other symptoms that may be difficult to ease, including:

- continuing short-term memory loss with possible difficulties recognizing family, friends and staff;
- memories of people and events from the past surface and the person believes these are their current reality;
- withdrawal from familiar activities;
- restlessness, pacing and agitation;
- hoarding, wandering, and shadowing;
- communication challenges, including difficulty understanding what is being said and being understood; and
- repetitive talk or questioning.

Other responsive behaviours or symptoms may occur including verbally or physically abusive outbursts, “sundowning,” and hallucinations/delusions. Late day confusion (sundowning) may occur consistently when there is an increase or worsening of responsive behaviours or symptoms (Alzheimer Society of Canada, 2024). Changes in sleep patterns, resistance to bathing or changing clothes, and expressions of heightened anxiety

also often present challenges. An individual with dementia may try to leave without notice and wander the neighbourhood or beyond. Other behaviours (e.g., wailing or crying, calling out, repetitive questioning) may create tension and be taxing for caregivers. Hoarding, shadowing, and rummaging may be somewhat less problematic and should be addressed in a non-punitive manner.

**Care focus.** Supervision needs to be increased as a person moves through the middle stage of dementia. The person will also need more assistance with previously familiar tasks. Adaptations to the environment and caregiver communication strategies may help alleviate anxiety and confusion. Preparing caregivers (family and staff) on how to provide increased levels of care and cope with responsive behaviours and symptoms associated with dementia will help them continue to meet the individual's needs. Active monitoring and treatment of new health conditions, such as depression is also critical. In some situations, alternate living arrangements may be necessary and, if possible, should be anticipated prior to the need arising.

**Table 1c**  
Middle Stage Support Model

| Functional changes   | Change indicators  | Actions   |
|--|--|---|
| Significant changes in skills and abilities, personality and orientation | Assessment indicates symptoms related to significant further loss of skills and abilities  | <p>Shift the type and degree of supervision needed.</p> <p>Increase assistance, as needed, with personal care, nutrition, safety and activities.</p> <p>Focus on daily rituals and activities preferred by the individual.</p>  |
|  | <p>Progression of middle stage symptoms</p> <p>Occurrences of responsive behaviours and other symptoms of dementia</p> <p>Gait/walking problems</p> <p>Change in eating / food preferences, possible swallowing difficulties emerging</p> <p>Communication (e.g., loss of words, understanding).</p> <p>Incontinence</p> | <p>Ensure caregivers are supported.</p> <p>Continue ongoing access to clinical support to manage and cope with responsive behaviours and other symptoms.</p> <p>Adjust home and other settings to reduce safety hazards and enhance wayfinding and independence.</p> <p>Continue use of non-pharmacological interventions</p> <p>Investigate use of mobility aids and other adaptive devices.</p> <p>Access support from professionals, as needed (e.g., speech and language, occupational therapist, home health care).</p> <p>Request an initial swallowing assessment.</p> <p>Introduce foods/drinks that are easier to swallow, finger foods, and provide smaller, more frequent meals.</p> <p>Organizations should establish connections with resources including health programs and palliative/hospice care that may be needed in the future or to address an urgent need.</p> |



**Supporting caregivers.** Providing care and support to a person experiencing dementia can be both rewarding and demanding and can take an emotional and financial toll. At times, caregivers may speak of 'losing' the person they once knew.

**"Ken was becoming someone we no longer knew or had any idea how to help."  
(Frizell, 2017 , p. 55)**

Supporting caregivers who feel grief and loss and encouraging them to establish and maintain self-care routines will help alleviate stress and sustain their involvement. In addition, information about the changes they are seeing and teaching creative ways to respond or intervene will help them manage on a day-to-day basis. They may also require help handling distressing situations on an ongoing basis. Respite and day services should be available to meet family needs and provide relief. Caregivers, as a group, should also have options to support one another. Many caregiver support groups are organized by the Alzheimer's Societies or other dementia-focused organizations targeted to spouses and adult child caregivers in the general population. However, older-aged parents and siblings who provide care and support for their relative with an intellectual disability affected by dementia often have differing perceptions and experiences based on years of caregiving; stigma, discrimination,

and marginalization of their relative; and possibly decades long engagement with changing health and social services (Jokinen, 2019). There are few support groups for these caregivers in Canada. In the USA, the National Task Group on Intellectual Disabilities and Dementia Practice (NTG) and other organizations offer online support groups for families of adults with intellectual disabilities affected by dementia. See further information on this group at <https://www.the-ntg.org/family-caregivers>.

Options for respite support for families caring for their relative at home could be offered in or out-of-home at times that work best for the family. Adult day services associated with the seniors' network and intellectual disabilities services, home and community care services, faith communities and recreational associations may also provide valuable support to primary caregivers and the individual affected by dementia.



## Managing responsive behaviours and symptoms.

It's important to remember that not all people experience all responsive behaviours or symptoms associated with dementia and abilities will vary from person to person. Some behaviours or symptoms will eventually fade and cease occurring. This can be distressing to caregivers and very stressful and confusing for the individual experiencing them. What helps caregivers in managing various types of responsive/behavioural symptoms one day may not work on another day. Non-pharmacological approaches are the preferred first step for coping with changes in middle stage (Deb et al., 2022). Simplifying approaches, being aware of different strategies, and knowledge of the person and their routines are key. Proactive management of these responsive behaviours and symptoms can help the individual maintain their current living situation for a longer time and enhance their sense of security and quality of life. Staff, family, friends and housemates will benefit from ongoing information, education, training and support from specialized and general services to manage caregiving situations (Deb et al., 2022).

**As a family member, I had to get very quickly in tune with charting when my sister would stay with me. This helps people to understand what is going on but is also helpful to see swings, triggers**

In managing responsive behaviour and symptoms, strategies shift from focusing on consequences to prevention by observing antecedents. Antecedents occur just prior to the behaviour or an environmental condition leading to that behaviour. Keen observation skills, altering communication, changing approaches, and avoiding confrontations and difficulties are likely to be more effective than trying to control behaviour (McCallion & McCarron, 2004). After checking for pain, which is often not recognized (Dillane & Dooly, 2019), continuing use of non-pharmacological interventions is preferable prior to the use of medications to address responsive behaviours and symptoms that emerge during middle stage dementia (De Vreese et al., 2012; Jokinen, 2014). Interventions can include known and preferred activities (e.g., music, spiritual practices and religious rituals, massage therapy, etc). Assistive devices and technology should be reassessed (e.g., glasses, hearing aids, communication devices, motorized wheelchairs), as should adaptive utensils, plate guards, and simplification of meals to help sustain independence. Continued use of memory aids is also highly recommended (McCallion, 1999).

It may be necessary to alter the physical environment to be familiar, safe, and supportive to avoid confusion. Remove agitation, and anxiety. Facilitate wayfinding and orientation by providing access to safe areas that encourage self-direction. Access to these areas should change when abilities and understanding have diminished to the point that supervision is necessary (e.g., stairs). Table 6 provides examples of dementia-focused environmental modifications. "The Dementia-

Friendly Home app" (Dementia Australia, updated June 2019) offers suggestions for modifying the home to be more accessible for people with dementia. It is a free download for tablets and mobile phones, see the reference for download link. Local Alzheimer Society branches also often offer advice on 'dementia-proofing' a home and introducing safety-first adaptations.

**Adapting activity levels in general and at day programs or services should include:**

- avoiding new learning and redesign personally preferred activities so they are "failure free";
- focusing on enjoyment of activities rather than completion;
- using variety of activities and change sequencing to maintain attention and a variety interest;
- using highly valued items in activities (e.g., photos, scrapbooks);
- engaging the individual with music, reading aloud, tactile activities, (e.g., gardening, painting and puzzles) and use of apps on tablets/computers that encourage self-directed activities;
- providing food that is easily eaten without choking (e.g., a soft food diet) and requires less assistance (e.g., finger foods).

**Table 6**  
Dementia-Focused Environmental Modifications

| Home area        | Action  |
|------------------|---|
| <b>Bathrooms</b> | <ul style="list-style-type: none"> <li>• Install assistive devices (e.g., grab bars, raised toilet seats, bath/shower chairs).</li> <li>• Use hand-held showers.</li> <li>• Consider removing or camouflaging mirrors as they may cause distress.</li> <li>• Regulate water temperature on taps.</li> <li>• Replace standard showers/tubs with accessible options for bathing or showering based on what works best and meets the individual's preferences.</li> <li>• Consider installing a towel warmer or individual heat control systems to avoid the person becoming chilled</li> <li>• Widen doorways if necessary to accommodate walkers, wheelchairs, and lifts.</li> </ul>   |
| <b>Colour</b>    | <ul style="list-style-type: none"> <li>• Use contrasting colour to create visual cues (e.g., white light switch with a dark-coloured switch plate; coloured toilet seat on a white toilet; dark handrail against a light-coloured wall; coloured placemat under a light-coloured dinner plate).</li> <li>• Use tableware in contrasting colours to the foods being served but avoid distracting patterns (e.g., milk served in a white cup will appear to be empty to the person with dementia).</li> <li>• Use colour to reduce visibility of exits, cupboards and other areas (e.g., exits and cupboards painted the same colour as surrounding walls makes them less visible).</li> <li>• Keep in mind that colours in the red to yellow range are easier to see than blues and greens.</li> <li>• Use solid colours or simple patterns instead of complicated or highly unusual designs.</li> </ul> |

| Home area        | Action  |
|------------------|---|
| <b>Flooring</b>  | <ul style="list-style-type: none"> <li>• Use non-patterned flooring that has a matte versus high gloss finish.</li> <li>• Provide floor markers to aid with wayfinding — people with dementia may develop the habit of looking down when walking.</li> <li>• Remove scatter rugs and other loose floor rugs to reduce the risk of falling.</li> <li>• Remove or reduce level changes in flooring to prevent falls and ease movement with mobility aids.</li> <li>• Keep flooring consistent in common areas.</li> </ul>   |
| <b>Furniture</b> | <ul style="list-style-type: none"> <li>• Use sturdy, simple and versatile furniture with rounded versus sharp edges.</li> <li>• Contrast furniture colour with floors and walls.</li> <li>• Arrange furniture to create clear pathways for movement.</li> <li>• Secure lightweight items such as lamps.</li> <li>• Ensure tabletops and tablecloths that are smooth and pattern-free.</li> <li>• Consider the placement of objects and signage based on if the person is sitting or standing.</li> <li>• Ensure chair(s) are low enough that people's feet touch the floor to make it easier to stand up from a seated position.</li> </ul> |
| <b>Lighting</b>  | <ul style="list-style-type: none"> <li>• Use adequate lighting to avoid shadows — a common source of visual illusions for persons with dementia.</li> <li>• Reduce direct sunlight with curtains or tinted glass.</li> <li>• Use indirect lighting to avoid glare and sudden changes in lighting levels (e.g., use dimmer switches and night lights).</li> <li>• Reduce reflective surfaces (e.g., floor surfaces should not be buffed or waxed to produce shine).</li> </ul>   |
| <b>Kitchens</b>  | <ul style="list-style-type: none"> <li>• Label cupboards pictorially for visual cues.</li> <li>• Provide safe storage for hazardous kitchen tools, liquids and powders in discreetly locked cabinets.</li> <li>• Install shut-off switches on appliances.</li> <li>• Regulate water temperature on taps.</li> </ul>   |
| <b>Noise</b>     | <ul style="list-style-type: none"> <li>• Improve acoustics through use of acoustic tiles, curtains, fabric wall hangings and other sound-absorbing materials.</li> <li>• Reduce ambient sound levels associated with TVs, dishwashers and radios.</li> <li>• Design and encourage use of quiet spaces.</li> </ul>   |
| <b>Outdoors</b>  | <ul style="list-style-type: none"> <li>• Provide access to safe outdoor spaces for walking and wandering (e.g., fenced yard with seating area, raised garden beds, and walking path that leads back to the house door).</li> <li>• Provide shelter from heat and rain.</li> <li>• Install ramps and remove transition barriers at entrances/exits for people who have gait difficulties or use walking aids.</li> <li>• Install systems to alert caregivers when someone has left the home.</li> </ul>  |
| <b>Bedrooms</b>  | <ul style="list-style-type: none"> <li>• Install blackout curtains to avoid nighttime shadows.</li> <li>• Use mirrors cautiously to avoid distress and creating the illusion of additional space.</li> <li>• Avoid the use of patterned comforters and sheets that may trigger hallucinations.</li> <li>• Ensure the room has adequate space for the safe use of mobility aids (e.g., lifts, wheelchairs).</li> <li>• Keep personal items of importance on display.</li> </ul>  |

Source: Adapted from McCallion & McCarron (2005) and Watchman (2007).

**Communication.** Middle stage dementia is often marked by forgetfulness and increasing difficulty with finding words and forming

sentences. The individual may also talk of past persons or events as if they are current and become confused or agitated if contradicted.

**Staff and family caregivers should take on a greater, yet respectful, role in conversations.**

- Use simple and direct language.
- Observe and listen for changes.
- Offer additional information to help with understanding.
- Embrace your own continuous improvement when it comes to being understood and avoiding disempowering behaviours (such as talking for the person or filling in his or her words).

Caregivers and others encountering the person with an intellectual disability affected by dementia should also consider how their own behaviours (e.g., stance, facial expressions, tone of voice, use of gestures) might influence communication.

Taking a flexible communication approach that can be modified as needed (Van Manen et al., 2021) and re-framing communication to reflect stage-based best practices is recommended (McCallion, 1999).

**Additional communication tips include:**

- speaking at eye level, face-to-face, and touching the person's hand or saying their name before beginning to converse with them;
- identifying yourself by name and using the person's name (avoiding questions like "do you know who I am?");
- when communicating, try to understand the person's perception of what is being said, and do not assume that your reality is the same as theirs;
- meeting or visiting in a calm environment with few distractions (minimize excessive noise or things that block or affect their vision);
- using simple language, short sentences, and speaking clearly and slowly;
- talking to the person as an adult and giving them time to respond;
- overemphasizing gestures, facial expressions, and pointing to familiar objects to support communication;
- using a pictogram that the person can use to show what they want or need;
- avoiding correcting the person who has made a mistake or insisting that they respond to you;
- avoiding confrontation and conflict. (McCallion, 1999; Banovic, et al., 2018).

The onus is on caregivers to ensure they have been understood and, above all, to be patient and provide ample time for the individual to process what has been said and respond.

**Relocation, change of housing.** A change in housing may be considered if:

- the physical environment in the current home is unsuitable;
- family are not available to provide care or staffs unable meet needs
- other people living in the home are adversely affected or are adversely affecting the person with dementia; and/or
- the caregiver feels pressure to provide support beyond his/her capacities.

Prior to deciding a move is necessary, consider other actions that might help, such as modifications to the environment (see Table 6); additional resources needed (and for how long); changes that may improve the lives of others living in the home; and coping strategies or new supports to enhance caregivers' ability to manage.

If relocation is unavoidable, planning should be proactive and include consultation with experts, listening to caregivers' perspectives, finding support for others in the home, and collaboration with other agencies to help reduce potential trauma.

**Movement to another home should be:**

- a last resort,
- proactively planned and not abrupt,
- undertaken using person and relationship-centred practices,
- permanent, if possible, and
- undertaken in a manner that maintains familiar routines, places, people, and things.

Formal and informal training and information about providing care must take cultural differences into account and acknowledge that caregivers may perceive 'dementia' differently. For example, in some cultures, dementia is not a distinct concept related to a neuropathology; it is simply an extension of the personhood of the adult.

**Outcomes.** Middle stage dementia is often the most challenging for caregivers and people with dementia. Despite intentions to support the person over the full course of dementia, this stage often triggers consideration of an alternative residence (particularly if behaviour has become increasingly problematic). The consistency with

which responsive behaviours or symptoms of this stage occur (e.g., wandering, hoarding, shadowing, verbal and physical aggressiveness, and paranoia) can lead to caregiver burnout. At this stage, personal care needs (particularly around incontinence) and behaviour management place the greatest demands on caregivers. The dilemma

is whether to continue supporting a caregiver who is experiencing increased stress and exhaustion, or to recommend a move out-of-home. A move may increase difficulties and negatively impact the person with dementia, triggering further disorientation, anxiety and additional difficult behaviours.

## 2.3.3 LATE AND END STAGE

### RECOMMENDED ACTIONS

1. Shift the focus of support and service towards providing non-ambulatory comfort care.
2. Reassign staff to activities that are more structured around providing comfort, health and personal care.
3. Provide support to family caregivers who wish to have their relative remain at home.
4. Support family members who do not live in the same home who wish to visit and offer suggestions on what to do while visiting.
5. Access ongoing support from palliative/hospice care or hospice specialists, including gathering information and seeking education about end-of life details.
6. Establish procedures to address pain and other symptoms and maintain dignity and comfort.
7. Help family and/or significant others organize end-of-life supports and post-death arrangements.

It can be difficult to identify advanced dementia in some adults with intellectual disabilities and to know when to begin end-of-life care (McCarron et al., 2018; Tromans et al., 2019; McCallion et al., 2017). Criteria used to diagnose this stage in the general population are often based on significant losses in activities of daily living (McCarron et al., 2018) that may never have been in the repertoire of adults with an intellectual disability. Staff and family need to be trained in recognizing and documenting changes in late and end stage dementia. (Watchman et al., 2019). This creates challenges in equitable access to palliative/hospice care. In the general population, people with dementia are the least likely to receive palliative care services or to get such supports in a timely manner, likely due to challenges determining when to begin end-of-life care. (Canadian Institute for Health Information, 2023; Health Canada, 2023). McCarron et al., (2018), recommend assessing later and end stage dementia in people with

intellectual disabilities by documenting changes in functioning, using clinical impressions of decline, increasing health issues, and, in individuals with Down syndrome, onset of seizures. This late stage of dementia is characterized by significant cognitive impairment, skill loss, health issues and additional comorbidities. During this stage, adults face dramatic changes in their ability to complete self-care tasks. Eventually they are unable to walk, are no longer able to actively participate in socially oriented recreation/leisure activities and become more dependent on others for most activities of daily living and personal care. Generally, this stage





is shorter in duration and compromises in bodily functions often lead to illnesses and infections that may eventually cause death.

In late stage dementia, as mobility becomes progressively impaired, individuals will have significant difficulty maintaining balance and walking and may experience falls and injuries. Eventually, the ability to move about independently will be lost. Initially, personal mobility aids (e.g., canes, walkers or wheelchairs) may be trialed, although learning to use a new device might be quite challenging for the individual. The person will require assistance to move into and out of a wheelchair and repositioning to avoid pressure sores. Arrangements should be made in advance for other assistive devices (e.g., lift or slings) for staff to support people with mobility losses. It is critical to prevent skin breakdown which is extremely painful and avoidable. Educating both staff and caregivers regarding prevention and early signs of skin breakdown is essential to provide quality care.

The consistency of food will need to change, eventually leading to a pureed diet to overcome eating and swallowing difficulties while maintaining nutrition. Bladder and bowel control will be compromised and require the use of incontinence products.

Communication (expressive language) also becomes increasingly difficult and sporadic. It is important to note that despite all these challenges, the individual may respond in some way (e.g., smile, make eye contact, reach out) to your presence, your voice, other positive non-verbal

communications (e.g., hand holding), music and or fresh air.

With increased medical problems, short-term hospital admissions may also occur. Hospitalization can be highly distressing for adults with dementia (Health Canada, 2018) due to a change of environment and disorientation due to lighting, noise, and unfamiliar sights. Emergency room and acute care stays can be lengthy, emotionally debilitating, and lead to the need for a higher level of care due to an inability to recover upon return to home. At this point, the advance care directives should serve as a guide in making decisions regarding care management.

Staff, family, housemates and friends will need significant emotional and practical support if plans have been made for the person to die at home, including support to deal with the anticipation of death, caregiving in the days and moments leading up to death and post death rituals.

**Although families and organizations have a strong commitment to supporting someone until death, without clear plans, capacity can be exceeded which in turn may lead to crisis placements and greater trauma for all involved.**

If the individual is not planning to die at home, they may have to move from their current residence to a new setting as it becomes more difficult for family, friends and staff to cope with the care at end-of-life. This move should be carefully planned

and resourced as transfer trauma can cause additional stress for the individual with dementia, family, staff and friends. The transition should be as seamless as possible with attention paid to keeping routines intact, incorporating staff known to the person in the new environment to provide consistency, and orientation to new staff (Cleary & Doody, 2017). In agencies with specialized group homes, sometimes one home will be dedicated to adults at the end stage (e.g., the Wichita Project (<https://www.the-ntg.org/wichita-project>). Each community will have its own resources and supports to assist with late and end stage.

To assist with end stage care, palliative/hospice care can be accessed to support family, staff and friends of the person with dementia. However, it can be confusing to understand the differences between the two terms. The *Framework on Palliative Care in Canada* (Health Canada, 2018) defines palliative care as “An approach that aims to reduce suffering and improve the quality of life

for people who are living with life-limiting illness.” Hospice care has similar aims but often refers more specifically to care offered in the community (Canadian Hospice Palliative Care Association, 2024).

The availability of and access to palliative/hospice programs varies across provinces, territories and communities. Once registered with a palliative/hospice care service, some provinces or territories may provide funding to cover needed medications and supplies. According to the Canadian Institute for Health Information (2023) people who live in rural communities are more likely to receive palliative care in hospitals as opposed to their homes. Despite the differences in available resources and potential barriers to end-of-life supports in home settings, it is important to note that death in the end stage of dementia does not have to occur in a health care facility (Watchman et al., 2019).

**Symptoms.** Although psychosocial needs continue to require attention, late stage dementia presents significant medical concerns marked by:

- severe intellectual deterioration and memory loss
- eventual complete loss of self-care skills
- falls
- immobility
- seizures
- difficulty swallowing
- weight loss
- respiratory and breathing problems
- increased time spent sleeping as end-of-life approaches
- medical conditions leading to death (e.g., multiple recurrent infections, aspiration, pneumonia).

**Care focus.** At this stage, some individuals will be living with family at home, in a home share situation or a small group living arrangement. Caregivers will likely feel challenged coping with increasing care demands 24/7 (e.g., multiple medical complications, incontinence). Assessments should be directed toward improving or preventing compounding medical problems due to immobility (e.g., pressure/bed

sores, pneumonia or respiratory distress) and any potential health issues. It may become necessary to change residence to a more intensive care setting or to augment staffing with personnel familiar with nursing, personal and palliative care. That said, every effort should be made to consider and honour, when possible, the previously expressed wishes of the individual.

**Table 1d**  
Late and End Stage Support Model

| Functional changes   | Change indicators  | Actions   |
|--|--|---|
| Notable changes in self-care, daily function, confusion, or lack of awareness and minimal mobility | Assessment indicates loss of mobility and general awareness and need for non-ambulatory care | Introduce more personal care, and, at times, skilled nursing care.<br>Focus on physical stimulation.<br>Prevention of secondary conditions and problems from malnutrition, dehydration and/or aspiration. |
|  | Dependent on others for care.  | Support and prepare family, friends, staff and others for death.<br>Access palliative/hospice care.   |
|  | Swallowing and Difficulties.   | Offer comfort care support. Focus on quality of life by addressing physical and emotional pain and symptom management while minimizing anxiety.   |
|  | Bladder and infections, skin breakdown, leg and lung clots                                   | Support family and friends to continue interacting with the person with dementia. Offer suggestions as needed.  |
|  | Progression to death   | Ensure use of appropriate resources for pain recognition and assessment. Provide pain relief as prescribed.<br>Help family, friends and staff with post-death rituals.                                    |

**Physical health.** Early on in late-stage dementia, care should include a close watch on nutrition and hydration. A speech language pathologist or other qualified professional should be consulted for swallowing assessments and recommendations, and guidance in preparing food to prevent choking (e.g., soft, pureed). Prompts or assistance with eating may be required. Careful documentation of caloric and nutritional intake, body weight, and liquid should be maintained to prevent malnutrition and dehydration. Efforts should be undertaken to provide food that is personally or culturally familiar to the adult, to stimulate eating or encourage acceptance of assistance to eat.

A person in end stage dementia may no longer be able or willing to eat or drink (American Geriatrics Association, 2014). The use of feeding tubes (or alternative approaches) and other life-sustaining treatments may present challenges in the absence of advanced directives and other expressions of the person's wishes (McCarron et al., 2011; McCallion et al., 2012). Adherence to cultural and religious values, as well as the beliefs of the person and their family at the end of life should be respected. Relatives should review advance directives previously made by the individual and be engaged with any end-of-life decisions not lawfully declared by the person prior to mental incapacity. These may involve decisions on the use of feeding tubes, DNRs (do not resuscitate orders) and/or DNTs (do not treat orders) for conditions that arise. It is important to note that the use of feeding tubes is not recommended in the end to late stages of dementia (American Geriatrics Association, 2014) as they do not provide a degree of benefit that outweighs the burden. Feeding tubes lead to agitation, new pressure sores, and often complications related to the tube that can result in more frequent hospital visits (American Geriatrics Association, 2014). Carefully managed hand feeding and food that may stimulate taste buds and memories are recommended alternatives.

**Communication.** In late and end stage dementia, communication abilities also continue to diminish. Caregivers are likely to experience significant challenges in recognizing attempts by the adult to communicate (Ellis & Astell, 2019). There is, however, evidence that many individuals still retain the desire and ability to communicate

(Ellis & Astell, 2019) so efforts at verbal and nonverbal communication by staff and family members are still very important. Key strategies for communication include those previously mentioned for middle stage, addressing the individual in a respectful manner, talking even if a response is not recognized, using touch, responding positively to any sound the person makes (viewing it as an effort to communicate) and always saying hello and goodbye when arriving or leaving.

**Environmental modifications.** Equipment will become necessary to safely transfer the individual (e.g., in and out of bed) and to assist with changing positions as the individual loses mobility and becomes more reliant on others. Lifts such as sling/Hoyer lifts or sit-to-stand lifts should be used for transfers to and from bed, as well as bathing. These devices may cause distress if the person no longer recognizes the device or understands its purpose. As such, the purpose should be explained in a gentle and respectful manner prior to use. Specialized chairs or recliners may provide greater comfort and safety, and specialty mattresses and bed linens should be used (and training provided to caregivers on use) to prevent bedsores. Qualified professionals (e.g., occupational therapists) can offer suggestions on various devices and equipment available for use. Policies regarding underwriting costs for equipment vary in provinces and territories. Home care programs and possibly government departments that provide support funding for adults with an intellectual disability can be helpful resources. Organizations providing supports for adults with intellectual disabilities affected by

dementia should proactively seek funding from provincial, territorial or federal health or social services ministries or community foundations prior to needing equipment and other resources. This will help prevent a delay between the need being identified and equipment being available for use in the home. In some situations, families have been frustrated with funding procedures (e.g., requiring evidence of need prior to submitting request for funding, lengthy processes for approval) and have been able and willing to purchase what is needed for immediate use. Families may also consider consulting their insurance providers about possible coverage.

**Training.** Family, staff and others involved should receive training that addresses important issues and concerns and be given the opportunity to explore the values and perspectives they hold related to end stage care (McCallion et al., 2017). It is also important to consider their personal experiences with dying (e.g., an individual may have been traumatised by the death of a close family member). If a staff person experiences discomfort with death and dying, it might affect the quality of care they are able to provide. Supervisory staff should be prepared for this scenario and plan accordingly.

Practice guidelines and standards of care offer information and guidance for staff (McCarron et al., 2018, Janicki & Keller, 2015). Staff training should focus on providing comfort, respecting the dignity of the person, relieving pain and uncomfortable symptoms, and understanding the value and consequences of decisions related to

**Training of staff and family caregivers should be oriented more toward comfort, dignity of the person, relief of pain and understanding the value and consequences of decision-making around artificial nutrition and hydration.**

artificial nutrition and hydration (McCarron et al., 2018; McCallion et al., 2017).

They should also be able to identify and respond to common conditions that occur at this stage and receive instruction on the proper use of equipment and adult lifting techniques to prevent injuries. It's also helpful to educate staff, friends and family members about engaging and being present with adults in the late and end stage of dementia, including use of body language, touch, music, aromatherapy, massage and reading favorite stories to the individual.

**Outcomes.** During this latter stage, there is a need for significant collaboration on education and preparation among intellectual disabilities services, local dementia support organizations, families, community supports and hospice/palliative care organizations to provide needed support in the person's last days (Tromans et al., 2019, McCarron et al., 2018).

For the individual, a "good death" means that their pain and other symptoms were managed, plans made for death were honoured and decision-making was clear (Krikorian et al., 2020). However, a "good death" is also influenced by

culture, religion, age, life circumstances, disease and financial issues (Krikorian et al., 2020).

**A “good death,” means a death that minimizes pain, involves preferred supports and caregivers, and honors preferences, values and plans made earlier for last days and post-death ritual and practices**

The staging of dementia provides information in an organized way to think about and plan for peoples' needs as the disease progresses. In each stage, we provided recommended actions, symptoms and support models. The next section considers living circumstances, support options and programs for adults with intellectual disabilities affected by dementia.

# 3.

## PROGRAM/SUPPORT OPTIONS

Several critical aspects should be considered when supporting adults with intellectual disabilities affected by dementia so that they may remain in their homes and communities as long as possible. Not all environments are suitable for individual's living with dementia as it progresses. Some homes are multi-level with stairs, others may have narrow hallways preventing walker or wheelchair use or have small bedrooms and bathrooms that make it difficult to maneuver with adaptive equipment. It is important to consider whether remaining at home, in a familiar setting, or moving to a small community home that can safely support individuals affected by dementia is the best option.

Even with careful planning and exploration of options and resources to enable the person to remain in their home, and access to community and day service, a move may be necessary. If a move occurs, it's essential that friends and other care networks support the person during and after their transition (Sheth et al., 2022). Any change in residence or day services or programs requires concerted care in maintaining these relationships, roles and activities (Sheth et al., 2022). Reports note that often people with intellectual disabilities

and dementia are not involved or consulted when they are moved (Jacobs et al., 2022). This removes choice and can lead to a loss of relationships with family, friends and familiar caregivers (Jacobs et al., 2022). Moving someone quickly without adequate preparation or consideration of a familiar environment can also contribute to 'transfer trauma' (Ryman et al., 2019).

Across Canada, adults aging with intellectual disabilities live in a variety of environments, including living with family or another caregiver, living alone or with housemates, in small group arrangements, or in specialized 'dementia-capable' residences. They, and their caregivers, will require additional support once symptoms of dementia become increasingly more apparent and challenging. Each of these is discussed in the following section with tables reflecting concerns, sources of information / assistance, and examples.

### 3.1 WHEN ADULTS LIVE IN A PRIVATE HOME WITH A FAMILY MEMBER OR FAMILY-LIKE CAREGIVER

Across the globe, many adults aging with intellectual disabilities are apt to live with their families, even though alternative living arrangements are available in some countries (Beadle-Brown, 2022). For many, remaining within the family home may be a cultural preference and the norm, or because there are inadequate local alternatives. In Canada, no country-wide data was found regarding the living arrangements of adults aging with intellectual disabilities although there may be some basic provincial statistics.

Family caregivers of adults with an intellectual disability and dementia (particularly those in a smaller family unit) have unique needs and can find it challenging to provide dementia care at home in most, if not all, countries (Heller et al., 2018; Jokinen et al., 2018). In other situations, a broader intergenerational family unit may be able to offer more support. There may also be multiple family members involved in care or willing to assist even when they live elsewhere. Often, families are unaware of what is available and confused by varied provincial requirements for accessing services.

Families undertaking dementia care should seek support to prevent social isolation and burnout. Local services-based navigators or community health workers can often provide information and connect them with services. Figure 1, mentioned earlier in this document, offers a framework for identifying supports tailored to family carer

needs. Support groups for family members facing similar situations with their relative may provide much needed support and ideas for coping; see as example information about the virtual family support group organized by the National Task Group on Intellectual Disabilities and Dementia Practices. Family caregivers may feel more comfortable reaching out to people in their community who are familiar and part of their lives. Other sources of support might include faith-based organizations, community centers and social/cultural clubs. Regardless of how or where the outreach occurs, establishing support networks will help mitigate crisis situations. Sometimes the aim is 'buying time,' so the family has a chance to plan and think about alternatives.

Respite provides caregivers with time for themselves and relief from the pressures of caregiving. Most families of adults with an intellectual disability have been lifelong caregivers and have adapted to situations and routines that help them maintain caregiving. However, with the introduction of dementia, things change considerably, and they often face new challenges. Flexibility in the purpose and design of respite should be able to meet these new needs (Jokinen et al., 2012). Respite should respond to both psychosocial (e.g., sense of isolation, burnout) and practical needs (e.g., household tasks, time for personal pursuits) of caregivers, and provide an opportunity for the adult with dementia to engage in meaningful activities outside of the family home.



As mentioned previously in this Guide, health and social service organizations operate quite differently from province to province. Optimally, health and social service organizations should work together to form a team with diverse specialties such as occupational and physiotherapists (Kuluski et al., 2017). They could then engage with and build relationships with individual families to understand their strengths and weaknesses in providing dementia care (e.g., abilities, routines, community connections, challenges, and activities) and examine the home environment. Suggestions for adaptations and/

or additional support can then be discussed with the family. Additional support may come from extended family, neighbours, faith and cultural communities, friends, and community organizations (e.g., local or provincial Alzheimer Societies). Table 7 highlights critical concerns to consider, provides suggestions for sources of information and assistance, and examples of what is available.



**Table 7**  
**Living with Family or Another Caregiver**

| Critical concern   | Sources for Information and Assistance  | Examples   |
|--|---|--|
| <p>Family members require information and resources to cope with changes due to dementia</p> | <p>Specialized information available from intellectual disability organizations, such as the:</p> <ul style="list-style-type: none"> <li>▪ Canadian Down Syndrome Society <sup>1</sup></li> <li>▪ National Down Syndrome Society in the United States.<sup>2</sup></li> <li>▪ The National Task Group on Intellectual Disabilities and Dementia Practices (NTG-US)<sup>3</sup></li> </ul> <p>Connecting with intellectual disability -specific and health/seniors care organizations, government departments, to identify potential resources and determine eligibility requirements</p> <p>Connecting families with faith-based organizations, families experiencing similar circumstances (specific to intellectual disability or general Alzheimer Society support groups)</p> | <p><i>Today &amp; Tomorrow: A Guide to Aging with Down Syndrome</i> <sup>1</sup></p> <p><i>Alzheimer Disease and Down syndrome: A Practical Guidebook for Caregivers</i><sup>2</sup></p> <p><i>End-of-Life and Down syndrome</i><sup>2</sup></p> <p><i>FAQ on Dementia and Intellectual Disability - Some Basic Questions about Adults with Intellectual /Developmental Disabilities</i></p> <p><i>Affected by Alzheimer's Disease or Other Dementias</i> <sup>3</sup></p> <p>On-line Family Support Group<sup>3</sup></p> |
| <p>Outreach activities geared to families.</p>   | <p>Local respite services (dementia and or intellectual disability sectors). Home Care programs, day services or programs designed specifically for people with dementia and/or intellectual disabilities</p>   | <p>Local availability varies across the country.</p>   |
| <p>Adaptations to home environment and routines to accommodate stage-based changes</p>       | <p>Guides to adapting home for dementia, such as those offered by the Alzheimer Society of Canada<sup>4</sup></p> <p>Down Syndrome Scotland<sup>5</sup></p> <p>CMHC<sup>6</sup></p> <p>Potential provincial government programs, including departments responsible for adults with intellectual disabilities, for funding accessibility requirements/ home renovations</p> <p>Knowledgeable health care practitioners such as occupational therapists and physiotherapists</p> <p>Health, aging and social systems navigators such as Family Support Workers, Social Workers</p>  | <p><i>Living safely and independently</i><sup>4</sup></p> <p><i>Living with Dementia (adapting the home environment)</i><sup>5</sup></p> <p>Residential Rehabilitation Assistance Program<sup>6</sup></p> <p>Referrals to provincial Home Care programs that provide equipment such as raised toilet seats, grab bars, walkers etc.</p> <p>Ramps, lifts, wheelchairs, shut off switches and emergency response systems</p> <p>Memory aids to assist with way finding, remembering chores, activities and basic skills</p>  |

## 3.2 WHEN ADULTS LIVE ALONE OR WITH A HOUSEMATE

As adults with intellectual disabilities grow older, they may live in a variety of situations with or without support services. Some live alone, with a spouse, or with one or more unrelated people with or without intellectual disabilities. When adults live alone or with housemates and begin to experience changes in behaviour or abilities, it is important that the changes be documented and brought to the attention of the person's health care professional. If the changes are caused by some treatable illness or problem, treatment should start as soon as possible. If the changes suggest early signs of dementia, further assessment should be done. Continued independent living is possible in early stage dementia, as long as the person's safety is not jeopardized, there is no indication of self-neglect, the person can still function with some degree of independence, and they can access reliable support if needed. Formal service support may be limited for some of these living arrangements, resulting in a much greater risk of and need for crisis management (Udell, 2014). Planning for future arrangements is critical at this stage while the person is still able to indicate preferences for care. It may also be helpful to involve family and housemates in planning if alternative living arrangements, providing personal assistance and supervision are required when dementia progresses from early to later stages. Introducing the person to service providers is also important, especially if the provider is new and unknown. In the early stages, outreach support, such as visits from staff,

family and friends should be provided.

**Provide tools to make their life easier, help them remember. Maybe phones that remind them or machines to give out medications**

For more than a decade, new developments in technology and social media have shown promise in helping people with dementia maintain independence and potentially remain in their home environments for much longer (Astell et al., 2019; Shu & Woo, 2021).

A wide range of technologies are available including wearable devices, smart phones, tablets, in-home devices, other 'smart home' technologies, and robotics. Research on the use of a smart phone, for instance, prompted adults with intellectual disabilities to successfully complete an activity without additional supports (Resta et al., 2021). A review of touch screen tablet use in general dementia care suggests it can improve engagement and quality of life and provide reminders about daily activities, such as medications and reduce responsive behaviours (Hung et al., 2021). For adults with or without intellectual disabilities, the use of technology presents many benefits, as well as challenges and issues, including access and affordability of technology, consent for use and guarding against possible human rights violations (Bennett et al.,

2017). See Table 8 for some critical concerns, sources of information and examples pertinent to those living alone or with a housemate.

**Table 8**  
Living Alone or With Housemates

| Critical concern  | Sources for Information and Assistance  | Examples   |
|---|---|--|
| <p>Providing the adult with dementia, their housemates and significant others with information about the disease.</p> | <p>Scottish Down Syndrome Association<sup>1</sup></p> <p>Books Beyond Words<sup>2</sup></p> <p>SquarePeg Training<sup>3</sup></p> <p>Local intellectual disability government funders<sup>4</sup></p>   | <p><i>Let's talk about Dementia</i><sup>1</sup></p> <p><i>Anne Has Dementia</i><sup>2</sup></p> <p><i>Jenny's Diary</i><sup>3</sup></p> <p>Check with local regulations to determine consent requirements for sharing medical information<sup>4</sup></p>  |
| <p>Adaptations to home to accommodate stage-related changes</p>   | <p>Provincial funders for intellectual disability services<sup>5</sup></p> <p>Federal or provincial funding, not specific to people with intellectual disabilities, with program funding for accessibility renovations<sup>6</sup></p> <p>Health care practitioners (e.g., occupational therapists and physiotherapists).<sup>7</sup></p> <p>Local expertise with working knowledge of dementia and adaptations<sup>8</sup>.</p> <p>Alzheimer Society of Canada<sup>9</sup></p> <p>Relevant involved organizations (e.g., intellectual disability services, local and provincial funders, Home Care services)</p> | <p>Potential funding for home renovations or adaptive equipment (e.g., ramps, wheelchairs, lifts, grab bars)<sup>5,6</sup></p> <p>Referrals to provincial Home Care Programs that provide adaptive equipment such as raised toilet seats, grab bars, walkers etc.)<sup>5,6</sup></p> <p>Information, assessments, recommendations and referrals<sup>7</sup></p> <p>Memory aids to assist with wayfinding, remembering chores, activities, and basic skills<sup>8</sup>.</p> <p><i>Living safely and independently</i><sup>9</sup><br/><i>Conversation About Dementia and Living Alone</i><sup>4</sup></p> <p>Holding discussions with adult affected by dementia, family members, and significant others about viable alternative places to live. Assisting people to visit those options.</p> |
| <p>Deciding on alternative living arrangements for the future</p>   | <p>Alzheimer Society of Canada<sup>11</sup></p> <p>Relevant involved organizations (e.g., intellectual disability services, local and provincial funders, Home Care services)</p>   | <p><i>Living safely and independently</i><sup>11</sup><br/><i>Conversation About Dementia and Living Alone</i><sup>11</sup></p> <p>Holding discussions with adult affected by dementia, family members, and significant others about viable alternative places to live. Assisting people to visit those options<sup>11</sup></p>   |

| Sources for Information and Assistance   |   |  |
|--|---|--|
| Critical concern   |   | Examples   |
| Identifying supports that may help maintain the person in their desired living situation | Intellectual disability service providers<br>Local Alzheimer's Societies<br><br>Aging and disability resource centers<br><br>Care coordination, system navigators | Dementia day services and other possible programs.<br><br>Health care services and local organizations offering these services<br><br>Home and Community Care<br><br>Meals on Wheels |
| Periodic checks to assess continued abilities to remain living in place                  | Continued use of baseline tools<br><br>Individual affected by dementia, family, staff, housemates and significant others.   | Screening tool used (e.g., NTG-EDSD)<br><br>Ongoing conversations regarding observations.  |

Information can be a powerful tool that facilitates continued living in place, adapting to changes, and making future plans. Sharing information about signs of change in function is critical in helping housemates recognize diminishing abilities. Adults living on their own, or otherwise independently, will need help coping and adapting to the early signals of change or decline. Spouses and friends will also benefit from assistance and learning more about the nature of dementia and what to expect in the following months and years.

**It was hard connecting to my housemate. She was different when she had dementia, she acted differently**

A team of qualified health and social services, family and friends, similar to the support network for those residing with family, should be created to assist the individual living alone or with a housemate. It is critical to help the person consider the need for future living arrangements and other

advanced planning. Living arrangements also should be assessed for barriers and safety issues that warrant attention. Eventually, with progressive loss of abilities, the person will not be capable of living alone and the demands on housemates or spouses may become too difficult.

Sometimes it is advisable for an adult affected by early stage dementia to move to a supervised setting, such as a group home, a cluster apartment, or similar supported living arrangement (Udell, 2014). Such changes should be based on a person-centred plan and involve the person in planning and organizing. They should not occur abruptly in response to a perceived crisis.

### 3.3 WHEN ADULTS LIVE IN A SMALL GROUP SETTING (HOME OR APARTMENT)

Some adults with intellectual disabilities affected by dementia may be living in small group settings or other supported living arrangements. Community organizations should determine their commitment and ability to provide dementia care through all stages of the disease and identify any resources they will need to provide care.

The options in providing support to adults with intellectual disabilities affected by dementia include an aging-in-place or an in-place-progression approach.

- An aging-in-place approach envisions that an adult affected by dementia remains living in their current situation throughout the course of dementia. Appropriate support is adapted, and resources are provided to meet the changing needs of the person. Home renovations and staff training may be required. Although the intent is to have the person remain living in-place, safety or other health issues may override aging-in-place and necessitate a move.
- An in-place progression approach enables the person to remain with the same organization but they move from one location to another as dementia progresses. The home environment of each location is specifically designed and staff are trained to meet needs at different stages of dementia.

In either approach, the safety and security of the person affected by dementia must be considered to avoid accidents and/or injuries. Ongoing regular support should also be available for staff, family and housemates and provided with their input.

Many group homes provide community care for adults affected by dementia and are being adapted to make them 'dementia capable' (Janicki et al., 2005). However, some organizations may determine that support over the full course of dementia is beyond their capabilities. In this case, the organization should plan for support from outside services, keeping the best interests of the individual in mind (Janicki et al., 2002; Janicki et al., 2005).

Moves are complex for individuals with dementia. Proactive planning can help create a positive experience and mitigate the impact of this transition by considering future needs. Reactive planning occurs when changes require immediate attention and abrupt relocation is necessary. The individual has limited or no choice, which can result in potentially poorer outcomes (Jokinen et al., 2012). Development of organizational policies and procedures can help facilitate proactive planning (e.g., considering changes that might prompt a referral out of the service, meeting current needs on an interim basis, and planning for staff overlap and routines). See Table 9 for critical concerns for living in small group settings, sources of information and assistance, and examples.

**Table 9**  
Living in Small Group Settings

| Critical concern  | Sources for Information and Assistance   | Examples   |
|---|--|--|
| <p>Organization commitment and ability to provide dementia care</p> | <p>Public Health Agency of Canada<sup>1</sup></p> <p>Alzheimer Society of Canada or local chapter<sup>2</sup></p> <p>Canada Mortgage and Housing Corporation<sup>3</sup></p> <p>Leadership discussions with membership, staff and people being supported about perspectives on providing dementia care</p> <p>Provincial Health Ministry responsible for dementia home care.</p> <p>Adaptations to home responsible for people with disabilities</p>                                 | <p>Gather demographics of people supported by the organization</p> <p>Environmental scan of agency locations</p> <p>Gain knowledge of dementia. A <i>Dementia Strategy for Canada: Together We Aspire</i><sup>1,2</sup></p> <p>Housing Options for People Living with Dementia — Volume 2<sup>3</sup></p>  |
| <p>Adaptations to home to accommodate stage-related changes</p>     | <p>Alzheimer Society of Canada or local chapter</p> <p>Dementia Australia<sup>4</sup></p> <p>Canada Mortgage and Housing Corporation<sup>5</sup></p> <p>Provincial Ministry responsible for funding adaptations for adults with intellectual disabilities</p> <p>Federal or provincial funding for renovations for accessibility<sup>5</sup></p> <p>At late end stage of dementia, palliative/hospice care programs that may be able to access necessary equipment for the home.</p> | <p>Way-finding cues, wandering paths, colors, lighting cues for remembering chores, activities, and basic skills</p> <p><i>Adapting your home</i><sup>4</sup></p> <p><i>Helpful home changes for people living with dementia (2021)</i><sup>5</sup></p> <p>Ramps, wheelchairs, lifts, shut off switches and emergency response systems<sup>5</sup></p> <p>Inform funders of changing needs.</p> <p>Identify and access knowledgeable health care practitioners such as occupational therapists and physiotherapists.</p> |

| Critical concern   | Sources for Information and Assistance   | Examples   |
|--|--|--|
| <p>Information and education for staff, housemates, spouses, or others involved with care</p>          | <p>Specialized information available from intellectual disability organizations, such as:</p> <ul style="list-style-type: none"> <li>▪ Canadian Down Syndrome Society <sup>6</sup></li> <li>▪ National Down Syndrome Society in the United States<sup>7</sup></li> <li>▪ The National Task Group on Intellectual Disabilities and Dementia Practices (NTG-US)<sup>8</sup></li> <li>▪ Open Futures Training (fees involved) <sup>9</sup></li> <li>▪ Scottish Down Syndrome Association<sup>10</sup></li> <li>▪ Books Beyond Words<sup>11</sup></li> <li>▪ SquarePeg Training Learning Disability and Dementia<sup>12</sup></li> <li>▪ NTG- Canadian Consortium Dementia Training <sup>13</sup></li> <li>▪ University of Edinburgh<sup>14</sup></li> <li>▪ Local Alzheimer Societies<sup>15</sup></li> </ul> | <p><i>Today &amp; Tomorrow: A Guide to Aging with Down Syndrome</i> <sup>6</sup></p> <p><i>Alzheimer's Disease and Down Syndrome: A Practical Guidebook for Caregivers</i><sup>7</sup></p> <p><i>End-of-Life and Down Syndrome</i><sup>7</sup></p> <p><i>FAQ on Dementia and Intellectual Disabilities</i><sup>8</sup></p> <p><i>Dementia Explained, Dementia Strategies</i><sup>9</sup></p> <p><i>Let's talk about Dementia</i><sup>10</sup></p> <p><i>Anne Has Dementia</i><sup>11</sup></p> <p><i>Jenny's Diary</i><sup>12</sup></p> <p>NTG- Canada curriculum – <i>Dementia Capable Supports of Adults with Intellectual Disabilities</i><sup>13</sup></p> <p><i>Supporting Derek – Intellectual Disability and Dementia e-learning series. (Fees involved)</i><sup>14</sup></p> <p><i>U-First! Training – Alzheimer Society of Ontario</i><sup>15</sup></p> |
| <p>Periodic monitoring of function to track changes that may impact the ability to remain in place</p> | <p>Periodic re-administration of baseline tool for monitoring function.</p> <p>Periodic interviews with housemates and others involved with the adult to identify changing needs</p>   | <p>Screening tools used (e.g., NTG-EDSD)</p>   |
| <p>Supporting caregivers and housemates</p>  | <p>Support groups and/or interviews with housemates</p> <p>Organizational policies and procedures, strategic plans that provide guidance on resolving tensions, and identifying the need for a move.</p>   | <p>Having regular "house" meetings with housemates to discuss issues and concerns</p> <p>Use of resources such as <i>Jenny's Diary</i> to review the impact of dementia</p> <p>Determination that nighttime wandering, verbal or physical outbursts, and other disruptive behaviours are having a negative effect on housemates and affecting their mental health</p>  |



### 3.4 WHEN ADULTS LIVE IN A “DEMENTIA-CAPABLE” GROUP LIVING ARRANGEMENT

A commitment to community living for adults with intellectual disabilities who are affected by dementia is needed alongside interest in creating supportive dementia-capable home options. In Canada and elsewhere, several intellectual disability organizations offer a home or multiple homes which focus on providing dementia care. Janicki (2020) provides an overview and guidance in designing this type of community housing option.

In some cases, aging-in-place might involve one or two adults diagnosed with dementia living with housemates who do not have dementia. In this scenario, it is important to support and consider the needs of the adult(s) without dementia so they can live comfortably within the home. Even if they have been friends for a long time, it can be difficult to live with someone with dementia.

Alternatively, an agency may apply an in-place progression model, where people with various levels of dementia live together in one or more specialty homes. Some agencies operate more than one home and people move from one to the next as dementia progresses. For instance, one home might support people who are experiencing mild decline and symptoms of dementia but are still able to walk, while another may provide more support for individuals with significant decline. A third home may provide even more support for people experiencing profound change who need assistance with most aspects of day-to-day living,

as well as end-of-life planning and palliative care. How and when the person is relocated should be carefully reviewed and considered. Moving a person with dementia can increase stress and anxiety and have unintentional consequences particularly if the new environment differs significantly from the old (Ryman et al., 2019). A change of this magnitude is not advisable and may have serious consequences.

Transitioning from one home to the next may be easier if home designs are largely the same and familiar to the individual. In addition, agencies providing these stage-based homes should:

- determine criteria for admission and movement from one level of care to the next;
- follow generally accepted standards for staff training and adaptations and design of dementia-capable home environments; and
- provide ongoing access to clinical support staff.

Cleary & Doody (2016) suggest having similarities with the interior designs of the homes, and familiar staff facilitating the move (e.g., giving reassurances to the person, orienting new staff to the individual’s communication style, personal history, and preferences), and keeping favorite decorations and personal items in the new environment placed similarly to where they were

in the old location. For more information about the relationship between needs/wants and environmental factors, see the text and various illustrative tables in Fleming et al., (2020)

Table 10 outlines critical concerns, sources of information and assistance, and examples for dementia-capable homes.

**Table 10**  
Living in Dementia-Capable Homes

| Critical concern   | Sources for Information and Assistance  | Examples  |
|--|---|---|
| Environmental designs that make a home dementia capable, safe and secure   | Dementia Australia <sup>1</sup><br>Alzheimer Society of Canada <sup>2</sup><br>Alzheimer’s Disease International <sup>3</sup>   | <i>Dementia-Friendly and Home</i> app for phones and tablets <sup>1</sup> .<br><br><i>How to design dementia-friendly care environments</i> <sup>2</sup><br><i>Making your environment safe</i> <sup>2</sup><br><br><i>World Alzheimer Report 2020: Design, Dignity, Dementia: Dementia-related design and the built environment.</i> <sup>3</sup>  |
| Staff training and expertise   | Agency Human Resources<br>Provincial regulations<br>NTG-Canada <sup>4</sup><br>Local Alzheimer Societies<br>Local palliative/hospice care organizations and health services | Staff training and mentoring <sup>4</sup> including on stages of dementia, communication approaches, day-to-day care, modification of activities, management of co-morbid health conditions, and preparations for end of life<br><br>Job descriptions that reflect the unique aspects of dementia care and support<br><br>End-of-life training provided by local palliative/hospice organizations |
| Assessment at intervals to ascertain that the service can meet the varied needs and abilities of people who live together. | Organization’s leadership team  | Scheduled focused meetings held with family, adults with intellectual disabilities and staff to determine successes and challenges in providing dementia care, as well as recommended changes that might need to be made.   |

## 3.5 WHEN ADULTS ATTEND DAY SERVICES

**Build activities into the day that are both healthy and enjoyable for both people (the person with dementia and staff).**

Data on day services shows that attendance offers adults with intellectual disabilities affected by dementia a chance to get out in the community and engage in social interactions and valued activities. They also provide home-based caregivers with some respite (McCarron et al., 2014). Staff and family caregivers consider day services to be an important resource in supporting adults with intellectual disabilities affected by dementia (Clearly & Doody, 2017; Service & Clifford, 2020). They also offer the adult a place to engage with others; participate in activities; be monitored for health, nutrition and hydration; and observed for any significant changes in status.

Many adult day services are organized and funded for group activities. When dementia becomes more prominent, it is necessary to redesign the environment, adapt activities and adjust hours of involvement for the individual (e.g., avoid overstimulation) to reflect changing goals. (Service & Clifford, 2020; McCarron et al., 2014). To prepare for such a redesign, day services should work closely with aging and Alzheimer/dementia-specific service providers. It is important to focus on maintaining previously learned skills and enjoyable activities rather than expecting the individual to acquire new skills or

engage in new experiences. Eventually, higher staffing ratios and a dementia-capable workforce will be necessary. Staff should be trained on wandering issues, health-related concerns and incontinence to reduce the likelihood that adults with dementia need to be discharged and no longer able to attend the program.

Engaging and collaborating with typical daytime dementia services and seniors' centres in the community will likely increase the value of day services in the overall intellectual disabilities and dementia strategy and create opportunities for cross-programming and shared resources. At some point, day services may not be able to provide the necessary care to address changing needs, so it will be important to have care pathways, discharge criteria and alternative planning supports clearly laid out.

Table 11 provides suggestions on how day services should be modified to support adults with intellectual disabilities affected by dementia.



**Table 11**  
Day Service Modifications

| Critical concern  | Sources for Information and Assistance  | Examples   |
|---|---|--|
| Staffing ratios and training that maximize quality dementia supports  | <p>NTG – Canadian Consortium<sup>1</sup></p> <p>Open Futures Training (fees involved)<sup>2</sup></p> <p>University of Edinburgh<sup>3</sup></p> <p>Local Alzheimer Societies information/training sessions<sup>4</sup></p> <p>Connecting with government funders of disability services<sup>5</sup>.</p> | <p>Curriculum on <i>Dementia Capable Supports of Adults with Intellectual Disabilities</i><sup>1</sup></p> <p><i>Dementia Explained, Dementia Strategies</i><sup>2</sup></p> <p><i>Supporting Derek – Intellectual Disability and Dementia e-learning series.</i> (Fees involved)<sup>3</sup></p> <p>Alzheimer Society of Manitoba Dementia Care Professional Development Series (virtual and open to all)<sup>4</sup></p> <p>Discuss the need for enhanced funding<sup>5</sup></p>  |
| Creating physical environments that meet the social, psychological and physical needs of adults with intellectual disabilities and dementia | <p>Dementia Australia<sup>6</sup></p> <p>Alzheimer’s WA (Western Australia)<sup>7</sup></p> <p>Alzheimer’s Disease International<sup>8</sup></p>  | <p><i>How to design dementia-friendly care environments</i><sup>6</sup></p> <p><i>Dementia Enabling Environments</i><sup>7</sup></p> <p><i>World Alzheimer Report 2020: Design, Dignity, Dementia: Dementia-related design and the built environment. Download Volume 2 for examples of Day Centres and other settings</i><sup>8</sup></p> <p>Small group and one-on-one spaces</p> <p>Dementia appropriate lighting (reducing shadows), noise abatement, flooring (reducing glare and avoiding patterns), wayfinding cues</p> <p>Fully accessible with adaptive toilets and a bathroom area suitable for providing adequate hygiene as a result of incontinence</p> <p>Spaces to wander safely inside and potentially outside with sitting areas</p> <p>Safety considerations within the program and controlled exits</p> |
| Programming geared to meeting the needs of adults with intellectual disabilities and dementia (stage-based and flexible)                    | <p>Alzheimer Society of Canada<sup>9</sup></p> <p>NIKKEI Place<sup>10</sup></p> <p>Minds in Motion programs offered through local Alzheimer Societies</p>   | <p><i>Engaging People Living with Dementia in Meaningful Activities</i><sup>9</sup></p> <p><i>Tips to Creating a Dementia-Friendly Day Program</i><sup>10</sup></p> <p>Multi-sensory in approach; both stimulating and calming</p>   |

| Critical concern | Sources for Information and Assistance | Examples   |
|------------------|--|--|
|                  |  | <p>Maintain existing skills and memories rather than teaching new things</p> <p>Tailor activities based on likes and dislikes and previous experiences</p> <p>Reminisce, going for walks, exercising, massages, gardening, aromatherapy and personal grooming.</p> |

# 4.

## EMERGING ISSUES

### 4.1 BRAIN HEALTH

“Brain health can be defined as the state of brain functioning across cognitive, sensory, social-emotional, behavioural and motor domains, allowing a person to realize their full potential over the life course, irrespective of the presence or absence of disorders” (Geneva World Health Organization, 2022)

Brain health and risk reduction and the relation to dementia for people in the general population has attracted increased attention from researchers, healthcare and various other groups and individuals in Canada and elsewhere. One objective of the Canadian national dementia strategy (Public Health Agency of Canada, 2019) is to prevent dementia – through efforts to identify modifiable and protective factors and build awareness of these factors alongside effective interventions, such as the adoption of healthy lifestyles. Until recently, there has been little reported on brain health and risk reduction regarding people with intellectual disabilities. However, interest in this topic gained momentum at the 2nd International Summit on Intellectual Disabilities and Dementia held in Toronto (McCallion et al., 2023).

The World Health Organization (2022) acknowledges that no single factor determines a person’s brain health. Nevertheless, action can be taken to enhance brain health across several interconnected determinants, such as:

- living in healthy environments,
- maintaining physical health,
- having safety and security,
- having opportunities for learning and socially connecting with others, and
- access to quality services.

Individual life circumstances, health and social supports and needs, and cultural traditions are also important to disease prevention (Carmeli & Imam, 2014; Takenoshita et al., 2023). Addressing these determinants for people at an individual and collective level can help optimize brain function and positively impact perceptions of wellbeing.

Livingston and colleagues (2020), The World Health Organization (2022) and more recently The Alzheimer Society Report (2024) all identify potentially modifiable risk factors for dementia that can lead to valuable outcomes across the lifespan.

### **Suggested action steps include:**

- engaging in activities that exercise the brain such as reading, word puzzles or basic math.
- being physically active and socially involved with others.
- having a healthy lifestyle that includes nutritious food choices, proper amounts of sleep, and learning new things.
- managing health with regular appointments including checks for cholesterol, blood pressure and diabetes and maintaining a healthy weight.
- avoiding tobacco and excessive alcohol use.
- taking care of emotional wellbeing – depression, anxiety, etc.
- protecting the head from trauma, treating hearing problems and trying to reduce the impact of air pollution.

On its own, each risk factor only minimally impacts the overall prevalence of dementia, but, if implemented collectively, these actions could reduce an estimated 40% of cases of dementia (Livingstone et al., 2020)

The Alzheimer Society of Canada Report (2024) draws attention to non-modifiable risks (social, non-medical and economic) that impact individuals' abilities to reduce their risk of dementia. The circumstances surrounding people's living arrangements plays an important role.

### **Some examples of social determinants of health that may increase or positively influence risk factors are:**

- income, social status, and work
- education and literacy
- social support networks
- access to appropriate, timely healthcare
- experiences with discrimination and marginalization, and disability and ableism

Many of these nonmedical, social and economic factors cannot be changed by the individual and require local, provincial/territorial and federal levels of government to improve the contexts in which people live that place them at risk for dementia or other health conditions.

While the evidence on physical activity and risk reduction for dementia is not strong, physical activity is recommended given the improvement to overall health outcomes. Dementia, however, likely results from multiple risk factors and it may be more helpful to address several risks

alongside each other. For instance, increasing physical activities to address a sedentary lifestyle may not, on its own, be enough to prevent dementia. However, becoming physically active while addressing other risk factors (e.g., smoking cessation, enhancing diet, and attending to regular health checks) may be more beneficial. Interventions to address risk of dementia should take into consideration individual needs and preferences (Veronese et al., 2023).

Few reports focus specifically on brain health and or dementia risk reduction for adults with intellectual disabilities. Carmeli and Imam (2014) took a health promotion and disease prevention approach to evaluating optimal interventions. Strategies included adopting a healthy lifestyle and a nutritious diet, health checks and screening and safe and comfortable housing. Preliminary results among this population mirror common risk reduction factors for dementia in the general population. However, for adults with intellectual disabilities, Carmeli and Imam (2014) considered the importance of fostering community support. For older adults with intellectual disabilities, living arrangements, needs, preferences and health status need to be considered in planning. Information related to the benefits of having a healthy brain and discussions about staying healthy are also essential. People with intellectual disabilities must have choice, autonomy and control over healthy lifestyle changes. Strategies should include the individual's perspective, input from caregivers and the integration of activities into everyday life (Kuijken et al., 2020; Roll ,2018)

A combined effort is required, including support from individuals, organizations, and government programs to introduce and maintain health promotion activities. Organizations that lack commitment and the investment of resources such as money and time, may hinder health promotion activities (Kuijken et al., 2020, Caremeli & Imam, 2014).

The information on brain health and reducing risk of dementia reported in the general population provides guidance for supporting adults aging with intellectual disabilities. Risk factors can be mitigated, and healthier lifestyles achieved, if action is taken and communities provide the necessary support.

Understanding factors that are beyond the control of individuals that require joint effort is the first step in working across systems to make improvement. Further research on general population risk factors and interventions, as well as research dedicated to adults with intellectual disabilities, will be needed to fulfill the goals of Canada's National Dementia Strategy (Public Health Agency of Canada, 2019).



## 4.2. CROSS-SECTOR COLLABORATION

Collaboration is one of the five pillars of Canada's national dementia strategy (Public Health Agency of Canada, 2019). The strategy speaks to the benefits of learning, working together and sharing best practices. Dementia care (assessment, management, treatment and support) should be an integrated effort across various provincial health and social care systems guided by the Canadian national dementia strategy (Canadian Academy of Health Sciences, 2019).

A first step towards collaboration is raising awareness and understanding, through education and research, of the importance of the inclusion of adults with intellectual disabilities affected by dementia. Supporting an adult with intellectual disabilities affected by dementia is a complex undertaking (Deb et al., 2022) that can be further complicated by navigating multiple systems, such as health and dementia care, and senior's care.

In most provincial and territorial governments, programs for seniors and or dementia care services are managed under the health portfolio, especially for direct care. Whereas services for adults with intellectual disabilities are often assigned to another area of government such as social or community services. There may also be Federal or municipal programs that are relevant.

These systems often operate separately from one another, are not well coordinated, and have different management structures. Systemic barriers are a long-standing concern because

they prevent the public sectors working together (Thorpe et al., 2020).

Another challenge of cross-sector collaboration is that adults with intellectual disabilities living into older age is a relatively new phenomenon. Many intellectual disability services have yet to shift their primary focus from younger individuals to better meet the needs of older-aged adults. As such, there are gaps in expertise and experience related to geriatric and dementia care. And, health services for seniors, specifically dementia care, often lack the experience and expertise with people aging with intellectual disabilities. This may be due, in part, to the age criteria set for some services that preclude adults with intellectual disabilities from accessing such supports.

The division between sectors may also create practical issues. For instance, when individuals receive support from both the health and social service sectors, lack of communication and coordination of services may result in misunderstandings and gaps in care (Benbow et al., 2014). However, when they work together, they can provide complementary services, deepen geriatric and intellectual disability knowledge and integrate best care practices (Thorpe et al., 2020).

In some communities, resources, such as system navigators or care coordinators (Canadian Academy of Health Sciences, 2019) facilitate collaboration across health and community services. Other advocacy-oriented efforts include

government and community services working together to solve issues, increase access to services, and decrease barriers to partnerships. An example of this is the Ontario Partnership on Aging and Developmental Disabilities that had a leadership committee with representation from government and local or regional groups. However, it takes time to achieve system changes and immediate problems and needs that require a timely and practical solution will not be solved quickly.

Governmental structures may pose barriers but there are creative ways for cross-sector (or inter-sectoral) partnerships to be developed in a local community context. For example, a pilot or special project between two or more organizations may receive funding. This can be helpful to show stakeholders, including governments, how collaboration can be developed and successfully implemented across organizations and sectors. Avoiding assumptions, trying a different model of care, and taking a collaborative approach can reveal many opportunities to work together.

**Martin et al., (2020) and Benbow et al., (2014) identify six elements promoting inter-sectoral collaboration:**

- Identify gaps in care and support and the need to work together.
- Avoid assumptions. Share knowledge about each partners' capacity and resources.
- Secure organizational support to explore possibilities for service delivery.
- Build success through trust, shared accountability and respect for each other's strengths and expertise.
- Implement and monitor a shared plan. Articulate roles and responsibilities clearly in a memorandum of understanding.
- Embed the model into practice to ensure continuation once champions of the project move on.

While there is interest in shared learning and building alliances across the health and social care systems in providing care for adults with intellectual disabilities affected by dementia, the amount of interplay is unclear, and further information is needed about the benefits and pitfalls of delivering cross-sector dementia care. (Watchman et al., 2019).

Formal partnerships across sectors begin with small steps in the local community and can

produce positive impacts. Meeting health and social service providers in your community can help build relationships and understanding. Inviting a potential partner to an event or including them in an activity will begin the relationship in a positive way and open doors for knowledge exchange and discussions about helping one another. This requires time and effort, but the outcomes are worth it and may produce new and innovative ways to support adults with intellectual disabilities impacted by dementia.

## 4.3. GRIEF AND LOSS

Grief can come in many forms. It can be ambiguous (unclear and confusing), disenfranchised (devalued or unrecognized) and anticipatory (expecting the loss to occur).

A diagnosis of dementia, and the losses experienced throughout the disease, impacts the adult with an intellectual disability and their entire support network. There will be unique grief and loss needs, values and cultural beliefs to navigate and address.

Blandin et al., (2017) highlight that the grief and loss related to dementia is unique in that it incorporates ambiguous and anticipatory grief as people mourn the loss of the person they knew while continuing to respond to ongoing needs. The individual with dementia and their loved ones will experience many versions of grief as the disease progresses (Alzheimer Society of Canada, 2023). People who are impacted by dementia are caught between their current situation and anticipating the next set of changes and challenges and may not even have enough time to come to terms with a loss before the next one arises. There is also the issue of compounding losses (Blandin et al., 2017) with a buildup of loss occurring while the person is still alive. This can lead to grief not being recognized, understood or acknowledged, as can occur with both disenfranchised and anticipatory grief (Alzheimer Society of Canada, 2023).

The grief and loss experiences of the adult with an intellectual disability impacted by dementia, may

initially include a phase of trying to understand and cope in the absence of information. Fear, grief and loss can be present in the absence of a diagnosis, which occurs all too often for adults with an intellectual disability. Conversely, a concrete diagnosis can lead to fear of the future and possible institutionalization (Watchman, 2021). The adult with an intellectual disability knows they are losing skills and abilities and may feel confused. As the disease progresses, there are many possible transitions that lead to losses of valued roles, meaningful activities and routines, connection to employment, day services and changing living arrangements, often with the adult with an intellectual disability having no choice or control (Sheth et al., 2020; Jacobs et al., 2022; Watchman et al., 2021).

Disenfranchised grief can be a common experience for adults with an intellectual disability (McRitchie et al., 2014). This lack of information, support and acknowledgment can create an even deeper sense of loss (McRitchie et al., 2014). The impact is felt by both the adult with an intellectual disability who is impacted by dementia, and their housemates, friends and significant others. Friends have reported being fearful of adults with an intellectual disability impacted by dementia just disappearing or seeing much less of them (Sheth et al., 2021).

Family and support network members can feel isolated in their grief and loss (Hogan, 2015). Staff have reported seeing the fear and emotional

distress that families suffer just thinking about the possible diagnosis of dementia (Ryan et al., 2018) and they struggle with denial along the path to acceptance. Grief begins with the diagnosis and can impact how family members are able to process information and cope (Udell, 2014). The families of people with intellectual disabilities are often parents and lifelong caregivers who require different grief supports than spouses and children of people with dementia without intellectual disabilities (Jokinen et al., 2018). Family may be grieving changes in their loved one, while experiencing a possible shift in their role — becoming a more significant caregiver (McLaughlin, K., 2010, Alzheimer Society of Canada, 2023).

Staff also require support throughout the dementia journey. As caregivers, they too have feelings of sadness as they see the person they have known lose their skills, abilities and experience changes in personality and behaviours (Herron et al., 2020; Ryan et al., 2018). These changes lead to feelings of grief and helplessness (Herron et al., 2020). They may also have conflicting feelings about their inability to contribute to decision-making and differing values and cultural beliefs.

## Recommendations for supporting grief and loss

It is important that organizations develop and/or advocate for access to grief and loss supports on behalf of individuals with intellectual disabilities and their caregivers. Formal grief supports in Canada are generally fragmented, underfunded

and have insufficient resources available for the public (Canadian Grief Alliance, 2020), including people with an intellectual disability. Compounding this challenge is an overall lack of skilled professionals with knowledge and experience in providing grief supports tailored to adults with intellectual disabilities and their caregivers.

The acknowledgement of and support for grief is important for people with dementia (Alzheimer Society of Canada, 2023). People with intellectual disabilities need opportunities to communicate their grief and can benefit from counselling and support (McRitchie et al., 2014; Read, 2014). When provided support to understand the situation and opportunities to express themselves, adults with intellectual disabilities are better able to process/cope with grief and may gain a sense of inclusion (McRitchie et al., 2014; Tuffrey-Wijne, 2013).

Grief support can be provided through support groups; use of pictures, art, and memory boxes; life story and reminiscence work and taking part in grief rituals (Read, 2014). Peers can also provide support to one another during times of grief and loss, particularly when they carry each other's history (Sheth et al., 2021). The use of resources, such as *Jenny's Diary* (Watchman et al., 2015), can provide guidance on offering information and support to aid the individual in understanding loss and the source of their grief.

When it comes to family, Jokinen et al., (2018) recommend they receive support and counselling for grief and loss and to help cope with their

changing roles. Supports should be offered in a timely manner, when needed most and consider the values and beliefs of the individual family (Jokinen et al., 2018). It is also beneficial to connect with other family members in similar circumstances, reach out to support networks and meet with professionals (McLaughlin, 2010; Alzheimer Society of Canada, 2023). Depending on the strength of relationships families may feel comfortable seeking emotional support from familiar staff members.

Organizations should provide ongoing support to help staff understand death, dying and individual beliefs, and provide opportunities to talk about concerns and express grief and loss, particularly as they move into the provision of end-of-life care (McCallion et al., 2017). They can gather and share in a safe space, facilitated by someone with a background working with grief and loss (Udell, 2014).

## 4.4 INDIGENOUS POPULATIONS

Indigenous Peoples' worldwide, continue to face health disparities and struggle to access culturally appropriate and culturally safe health services to meet their needs. In May 2023, the World Health Assembly approved a resolution directing the World Health Organization (WHO) to begin developing a global plan of action to address Indigenous health inequities (World Health

Organization, 2023). For more than a decade, Canada has been engaged with the Truth and Reconciliation Commission that listened to the stories and experiences of Indigenous Peoples across Canada and acknowledged the many historical wrongs perpetrated against them. The Truth and Reconciliation Commission's final report (2015) included 94 calls-to-action to continue reconciliation efforts between Indigenous Peoples and Canadians. There is no doubt that colonial beliefs and colonization are root causes of health inequities experienced by Indigenous individuals and their families in Canada. Loppie and Wien (2022) describe a model for the social determinants of health from an Indigenous Peoples' perspective distinguishing root, core and stem determinants. Despite these challenges, cultural resurgence (history, languages and traditions) is now serving Indigenous Peoples in Canada to move forward with strength and resiliency (Halseth, 2018).

The Canadian national dementia strategy (Public Health Agency of Canada, 2019) acknowledges that Indigenous Peoples, as a group, are at higher risk of acquiring dementia, encounter barriers to equitable care, and have unique perspectives and dementia-related needs. One of the priorities in the Strategy is to "Engage with Indigenous governments, organizations and communities to better understand unique dementia challenges and to facilitate the development of distinction-based dementia solutions for First Nations, Métis and Inuit." As implementation of the Strategy

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*1 The term Indigenous Peoples used in this document refers to First Nations, Inuit, and Métis Peoples who have lived upon the lands now called Canada for many generations. It is important to know that, rather than a single Indigenous identity, there are many distinct nations, communities, and individuals across Canada; all with unique histories, languages, and practices.*

moves forward, this collaboration will be vital to the identification of needs, abilities and perceptions about aging and dementia to build both culturally safe and culturally responsive services and supports.

There is limited dementia-related research and data on Indigenous Peoples in Canada. Yet, the limited research available suggests Indigenous Peoples within and across communities may have various understandings of dementia that flow from traditionally based to biomedical understandings (Halseth, 2022; Quigley et al., 2022). The research also suggests that, as a group, Indigenous Peoples have increased rates of chronic conditions such as diabetes, cardiovascular disease, and respiratory disease as well as other dementia risk factors. The rate of dementia for Indigenous Peoples is, therefore, expected to increase more quickly, with an earlier age of onset, compared to the general population (Alzheimer Society of Canada, 2024; Halseth, 2022; Petrusek MacDonald, Ward & Halseth, 2018; Quigley et al., 2022). Accessing culturally appropriate health services and programs is a challenge and individuals face several practical barriers including the availability of local services and transportation to distant services (Quigley, et al., 2022).

Some Indigenous individuals may hesitate or delay seeking out health and dementia related services/programs because most generally operate under a medical model that is contrary to Indigenous perspectives, which are often holistic, and strength-based. Fears associated with past institutional experiences (e.g., the residential and

day school systems) may also impede Indigenous Peoples from reaching out for support. Long-term care residential services may only be considered when other options have failed to meet needs (Jacklin, 2018 as cited by Canadian Academy of Health Sciences, 2019).

At this time, no data was found concerning Indigenous adults with intellectual disabilities (affected or not by dementia) living in Indigenous communities or urban settings. This gap in the research needs to be addressed to better support this unique group within Indigenous communities. What follows are suggestions and examples of resources to consider in supporting an Indigenous person and their family faced with dementia. These are offered as a starting point to learn more and may be of help until we are better informed about providing care to Indigenous adults with intellectual disabilities affected by dementia.

- Clinicians and helpers should be well versed on contemporary and historical issues facing Indigenous Peoples and understand local histories in context, perhaps based on discussions with community leaders or Elders.
- Assessments should be multifaceted investigations based on interviews, observations, and informal evaluations. As part of a holistic approach, family members and community representatives may also be included in the assessment, treatment, and support planning process.
- Case formulation and treatment and support planning may benefit from the use of holistic Indigenous models, such as those guided by the teachings of the Medicine Wheel (Kyoon-Achan et al., 2021). While Medicine Wheel teachings are not shared by all Indigenous nations or communities, the fundamental concepts of holism, balance, and interconnectivity are commonly found in many diverse Indigenous nations. By considering each person as being comprised of inseparable and integrative mental, emotional, physical and spiritual parts within the context of self, family, community, and the land, community care and support can be structured as inclusive of individual needs, rather than fragmented.

Various Indigenous projects help to raise awareness about dementia among Indigenous Peoples and offer tips on caregiving. The three

examples below can be used as a starting point for expanding knowledge about dementia and its impact on Indigenous Peoples.

- In British Columbia, the First Nations Health Authority (2020), together with the Gitksan communities of Kispiox and Sik-e-Dakh,ppie produced a video entitled *The Gitksan Way of Knowing About Dementia*. Members of the community who were willing to share their experiences of caring for a relative living with dementia are featured along with the community health nurse. This 15-minute video can be viewed from FNHA's website.
- Two resources from the Native Women's Association of Canada (NWAC) are available on NWAC's website.
  - NWAC's (2022) *A Sacred Journey: The Long Goodbye*. This is a photo book collection of heartfelt stories by Indigenous family members describing situations of caring for a relative with dementia. The book also includes insights from people living with dementia based on their responses a series of questions.
  - NWAC's *A TOOLKIT: Addressing Dementia Related Stigma with Indigenous Specific Strategies*. The toolkit covers language, culture, knowledge and education and storytelling, each with a brief description and an offering of suggestions. For instance, the storytelling section suggests stories that help dispel misconceptions, reduce stigma, and are healing to both the storyteller and the story listener.
- The Alzheimer Society of Canada's Landmark Study Report #2: *The Many faces of dementia* in Canada.

In supporting Indigenous individuals and families, it is necessary to always keep in mind that while there is commonality amongst Indigenous People's perspectives, there is also variation from nation to nation, community to community, and amongst individuals. Respectful conversations are necessary to better understand what is most valued and wanted by the individual and their family when faced with dementia. Addressing the complex intersection of intellectual disability and dementia within Indigenous populations in Canada requires a comprehensive and culturally responsive approach as well as the wisdom and special qualities that Indigenous Peoples bring to

the conversation. Any program, policy, or practice aimed at enhancing the health and wellbeing of adults living with intellectual disability impacted by dementia, must consider the individual as a whole being, the powerful role of cultural connectivity in facilitating healing and belonging, and the ongoing impact of colonization, systemic racism, and chronic underfunding of healthcare and social services for indigenous peoples overall. Research, evaluation, education, and program development are more vital now than ever, but must be community-led and characterized by fair and ethical partnerships with Indigenous communities.



# 5.

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