

# Actions and Ideas to Help with Dementia

For Family Caregivers of Adults with an Intellectual Disability



A booklet to accompany the *Canadian Guide for Community Care and Supports for Adults with Intellectual Disabilities Affected by Dementia*



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Explore ideas, tools and resources to help support your loved one on your shared journey.



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# Getting Started

# This resource is a tool for family caregivers who are supporting their relative with an intellectual disability who is affected by dementia.

As all adults with an intellectual disability age, they face an increased risk of age-related conditions like dementia. While not all adults with an intellectual disability will develop dementia, some may be at an increased risk.

Recognizing and documenting early signs of changes in behavior and abilities are important first steps in finding out what is causing the change(s). This helps families to ensure timely assessment of the change(s) and to allow possible follow up to occur.

This resource tool can serve as a starting point for providing quality supports, problem solving and taking actions from pre-diagnosis through to the end stage of dementia. Each section of this resource tool offers:

**Personal stories:** Stories shared by family caregivers provide real-life insights into supporting adults with an intellectual disability affected by dementia at different stages.

**Symptom overview:** A general overview of potential symptoms people with dementia may experience. Symptoms do vary and not everyone will have the same symptoms. The aim is to provide a basic understanding of common symptoms.

**Key actions:** These are suggested actions that family caregivers can take with their relative with an intellectual disability, as well as with involved supports. The actions aim to help the family and promote the autonomy and quality of life of the adult with an intellectual disability at each stage. Resources are also provided to assist in taking action.

Additional details and actions for each stage are found in the full *Canadian Guide for Community Care and Supports for Adults with Intellectual Disabilities Affected by Dementia* available from [reena.org/initiatives/dementia-strategy-project](https://reena.org/initiatives/dementia-strategy-project) or [the-ntg.org/canadian-consortium-news](https://the-ntg.org/canadian-consortium-news).

# Pre-Diagnosis Stage of Dementia

In the pre-diagnosis stage of dementia, family caregivers might see changes in their relative's behavior and abilities that might raise concerns about dementia or other health-related conditions.

Some of the early changes that might raise concerns about dementia can include occasionally forgetting things or getting lost, a change in gait or problems walking, confusion with familiar tasks and places, being more frustrated or impatient, a slowness in activity and personality, as well as behaviour changes. Remember to keep track of how often you see these changes.

## CAPTURING THE JOURNEY: PERSONAL STORIES

We were told by professionals that it was hard to do any kind of diagnosis with people with intellectual disabilities.

– Family caregiver of an adult with an intellectual disability

We have a home share for two people, and they've been living with us for 20 years. We started noticing that one of the women sometimes had trouble finding the bathroom, putting the dishes in the wrong cupboard, or finding her purse which she had always kept a close eye on.

– Home share caregiver of adults with an intellectual disability

Initially we thought the little changes we were seeing were just a part of aging and we didn't know what we were looking for. We didn't have any information and we didn't know where to look for information. It was overwhelming trying to do research on our own. It was hard to know what was normal aging versus dementia.

– Family caregiver of an adult with an intellectual disability



## ACTIONS AND HELPFUL IDEAS

### What can I do?

- Find reliable sources of information about dementia for both you and your family member with an intellectual disability.



- Find resources that offer education and training for you and any staff involved in caring for your family member. This can assist everyone in gaining a better understanding of the process of receiving a diagnosis and the progression of dementia.

- Use a tool to establish a baseline for your relative as soon as possible if none exists. Continue to use the tool in the future to monitor and document any changes.
- Discuss any noted changes with your relative and other family caregivers or involved staff members.
- Support the person to make an appointment with their healthcare provider.

### Who or what might help?

- Help your family member to explore helpful resources like *Jenny's Diary* from the Square Peg Training website ([learningdisabilityanddementia.org](http://learningdisabilityanddementia.org)) and *Let's Talk About Dementia* from Down's Syndrome Scotland ([dsscotland.org.uk](http://dsscotland.org.uk)).
- Read the valuable information offered by Canadian Down Syndrome Society ([cdss.ca](http://cdss.ca)) and the USA National Down Syndrome Society ([ndss.org](http://ndss.org)).
- Take a look at the *Canadian Guide to Community Care and Supports for Adults with Intellectual Disabilities Affected by Dementia* from Reena and NTG Canadian Consortium ([reena.org/initiatives/dementia-strategy-project/](http://reena.org/initiatives/dementia-strategy-project/) or [the-ntg.org/canadian-consortium-news](http://the-ntg.org/canadian-consortium-news)).

- Contact your local Alzheimer Society.
- Contact local provincial government ministries responsible for services for people with an intellectual disability, older adults, and healthcare to inquire about available training opportunities.
- Contact NTG-Canadian Consortium ([the-ntg.org/canadian-consortium-news](http://the-ntg.org/canadian-consortium-news)).

- The *NTG-Early Detection Screen for Dementia* (NTG-EDSD) from the NTG ([the-ntg.org](http://the-ntg.org)) and a video are useful in documenting a baseline and any subsequent changes. It is an easy-to-read tool that does not take long to do with your relative. There is a short manual that can help you use the tool.
- You or someone familiar with your relative should accompany them to the healthcare appointment to discuss the noted changes.

# Early Stage Dementia



At the early stage, dementia symptoms will initially fluctuate. Sometimes the person seems like their usual self, but at other times you might notice changes. As times go on, these early stage symptoms become more noticeable and consistent.

These symptoms can include difficulty remembering things which can make everyday activities and social interactions more challenging. Additionally, common symptoms include growing confusion and anxiety, difficulty communicating, decreased enthusiasm for life and increased slowness in activities.

## CAPTURING THE JOURNEY: PERSONAL STORIES

My daughter was living in a group home and we really had to be on the same page to keep track of what was going on and all of the changes. We were doing tracking at the group home and my home.

– Family caregiver of an adult with an intellectual disability

It was so important to work closely and consistently with the staff. I started arguing with my sister when I felt like she was covering up for some of the odd things she was doing. Staff told me it might not be helpful to argue with her.

– Family caregiver of an adult with an intellectual disability

My daughter kept coming to my home for the weekends and it seemed like it would take her a few hours to settle in and get back into her routines and then she really didn't want to go back to the group home on Sunday evening.

– Family caregiver of an adult with an intellectual disability



## ACTIONS AND HELPFUL IDEAS

What can I do?	Who or what might help?
<ul style="list-style-type: none"><li>• Create a daily schedule with your family member and other involved caregivers that incorporates valued activities and meets needs. Make sure the routine fosters a feeling of safety and security.</li><li>• Make a list of favoured activities and important social and community connections.</li><li>• Use visual aids, like a calendar, to help your family member follow their daily routine.</li><li>• Explore helpful technologies like smartphones, watches, and tablet applications that provide visual and verbal prompts to support maintaining a routine.</li></ul>	<ul style="list-style-type: none"><li>• Reach out to family members, agency staff members assisting your relatives, and other involved individuals.</li><li>• Refer to <i>Finding Suitable Activities</i> from the Alzheimer Society of Canada (<a href="http://alzheimer.ca">alzheimer.ca</a>).</li><li>• Connect with your local Alzheimer Society and disability support organizations for assistance and guidance.</li></ul>
<ul style="list-style-type: none"><li>• Have conversations with your relative with an intellectual disability and other family caregivers to explore options and begin planning for their future care needs.</li><li>• Consult with service providers and others involved in your relative's care to discuss potential future care options.</li><li>• Create an emergency plan in case your family member gets lost, or caregivers become unavailable.</li><li>• Help your relative in drafting advance directives in accordance with provincial or other regulatory requirements.</li></ul>	<ul style="list-style-type: none"><li>• Explore the following helpful planning resources:<ul style="list-style-type: none"><li>• <i>A Workbook for Advance Care Planning</i>, from Fraser Health Authority (<a href="http://patienteduc.fraserhealth.ca">patienteduc.fraserhealth.ca</a>).</li><li>• <i>Aging With a Developmental Disability</i> from Community Living British Columbia (<a href="http://communitylivingbc.ca">communitylivingbc.ca</a>).</li></ul></li><li>• Assist your family member in completing:<ul style="list-style-type: none"><li>• <i>Thinking Ahead: My Way, My Choice, My Life at the End</i> from the Minnesota Department of Administration, Governor's Council on Developmental Disabilities (<a href="http://mn.gov">mn.gov</a>).</li></ul></li><li>• Connect with your local Alzheimer Society.</li></ul>

# Middle Stage Dementia

During the middle stage of dementia, a significant decline in abilities occurs. Responsive behaviours (i.e., reactions to internal and external stresses) and other behavioural or psychological symptoms become more frequent.

Additionally, symptoms are difficult to ease, and can include further memory loss and communication difficulties, blending past memories with present reality, withdrawal from familiar activities, restlessness, pacing, agitation, wandering, shadowing, and hoarding.

## CAPTURING THE JOURNEY: PERSONAL STORIES

Changes seemed to happen really quickly for my son and he began to get very angry and stay awake a lot at night.

– Family caregiver of an adult with an intellectual disability

One day my son was yelling at me and even tried to push me over. I knew this was a pretty big, sudden change for him so I took him to the hospital and asked them to check him for a UTI. They told me it was just the dementia and his intellectual disability and to just take him home.

– Family caregiver of an adult with an intellectual disability

There were more and more problems at the day program and they said they didn't have enough staff to supervise my son and to make sure everyone was safe. They kicked him out of the day program so I had to find some respite so I could go out and get groceries and go to my own appointments.

– Family caregiver of an adult with an intellectual disability



## ACTIONS AND HELPFUL IDEAS

What can I do?	Who or what might help?
<ul style="list-style-type: none"><li>• Encourage your family member to do as much as they can on their own.</li><li>• Adjust your approach, communication style, and level of support and supervision as necessary, based on any changes you observe in their skills and abilities (e.g., personal care and hygiene).</li></ul>	<ul style="list-style-type: none"><li>• Connect with your local home care program and government disability services for possible support and respite options.</li><li>• Seek support from other family members or friends.</li><li>• View the video <i>Understanding and Supporting Adults with Intellectual Disabilities and Dementia</i> from Reena and NTG Canadian Consortium (<a href="http://reena.org/initiatives/dementia-strategy-project/">reena.org/initiatives/dementia-strategy-project/</a> or <a href="http://the-ntg.org/canadian-consortium-news">the-ntg.org/canadian-consortium-news</a>).</li></ul>
<ul style="list-style-type: none"><li>• Reach out to relevant professionals who can provide guidance and support around caregiving difficulties.</li><li>• Adapt routines and make changes to the environment as needed to better suit the person's evolving needs.</li><li>• Keep a record of any changes in behaviour and try to identify what happened before and after to better understand potential causes.</li></ul>	<ul style="list-style-type: none"><li>• Connect with:<ul style="list-style-type: none"><li>• A family doctor, occupational therapist, or behavioural specialist.</li><li>• Home health care programs.</li><li>• Local Alzheimer Society.</li><li>• Disability organizations.</li><li>• Provincial Disability Services funder.</li></ul></li></ul>
<ul style="list-style-type: none"><li>• Remember to take care of yourself.</li><li>• Find ways to relieve stress and prevent caregiver burnout.</li><li>• Do activities that interest you and make time to socialize with friends.</li></ul>	<ul style="list-style-type: none"><li>• Consider:<ul style="list-style-type: none"><li>• Healthy eating, getting adequate sleep, and exercise.</li><li>• Socializing with friends (e.g., dining out, walks).</li><li>• Consider engaging with local Seniors centers.</li><li>• Joining local support groups, including grief and loss groups.</li><li>• Participating in group activities.</li></ul></li></ul>

# Late and End Stage Dementia



At the late and end stage of dementia, the adult with an intellectual disability experiencing dementia will likely undergo significant changes in their health and abilities, often requiring substantial support and comfort care.

Common symptoms during this stage can include an inability to perform everyday tasks and self-care, an increased risk of falls and challenges with mobility, difficulties with swallowing, respiratory issues such as breathing challenges, and an increase in both the frequency and severity of seizures and other health issues, some of which can lead to death.

## CAPTURING THE JOURNEY: PERSONAL STORIES



I was really lucky that the health and home care people gave me a lot of help, taught me how to do some things myself and helped me get the equipment I needed. The doctor even came to the house a few times.

– Home share caregiver of adults with an intellectual disability

I took a leave of absence from my work and supported my sister to die at home. It was hard but I had help from palliative care. It was hard but it was also beautiful. After she died I went to a couple of grief groups just to help me try and get over my loss.

– Family caregiver of an adult with an intellectual disability

## ACTIONS AND HELPFUL IDEAS

What can I do?	Who or what might help?
<ul style="list-style-type: none"><li>• Shift the focus of support to comfort care (i.e., keeping the person as comfortable as possible), while ensuring the involvement of significant others.</li><li>• Plan time for you and others (e.g., friends, family members) to spend time with your relative and talk to them, even if they are unable to respond.</li></ul>	<ul style="list-style-type: none"><li>• Consider your cultural values and traditions and seek spiritual support as needed.</li><li>• Consult with nursing and other health care professionals for guidance.</li><li>• Share comforting activities with your relative, like listening to music, reading a book, looking at photos, providing a manicure or applying scented lotions.</li></ul>
<ul style="list-style-type: none"><li>• Learn about equipment and devices that can support adults in late-stage dementia.</li><li>• Prepare in advance to obtain and receive training on any necessary equipment or devices.</li></ul>	<ul style="list-style-type: none"><li>• Connect with local home care programs, pharmacies, or government disability services to acquire assistive equipment (e.g., wheelchairs, Hoyer lifts).</li><li>• Obtain training from the provider on how to properly use this equipment.</li></ul>
<ul style="list-style-type: none"><li>• Obtain a referral for ongoing support from the local palliative or hospice care program.</li><li>• Review the advanced care plan.</li><li>• Consider joining a support group for grief and loss.</li></ul>	<ul style="list-style-type: none"><li>• Consult your relative's primary care professional.</li><li>• Refer to <i>End-of-Life and Down Syndrome</i> from the National Down Syndrome Society (<a href="http://ndss.org">ndss.org</a>).</li><li>• Reach out to the local Alzheimer Society.</li><li>• Consider participating in online support groups.</li></ul>



For further guidance on supporting adults with an intellectual disability at risk of or living with dementia, consult the *Canadian Guide to Community Care and Supports for Adults with Intellectual Disabilities Affected by Dementia*, available from:

**Reena**

[reena.org/initiatives/dementia-strategy-project/](http://reena.org/initiatives/dementia-strategy-project/)

**National Task Group (NTG) Canadian Consortium**

[the-ntg.org/canadian-consortium-news](http://the-ntg.org/canadian-consortium-news)



