

# Actions and Ideas to Help with Dementia

For Staff Members Supporting 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 those in your care.

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# Getting Started

# This resource is a tool for staff supporting adults with an intellectual disability who are suspected of or have been diagnosed with dementia.

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As all people age, they face an increased risk of age-related conditions like dementia. Some adults with an intellectual disability are at higher risk of dementia.

Recognizing and documenting early signs of changes in abilities and behaviour are among the important first steps in finding out what is causing the change(s).

Remember, you are part of a team including other staff, healthcare professionals, family and friends that are supporting the person. Good communication between caregivers is very important.

This resource 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 staff 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 for staff to take in partnership with the adult with an intellectual disability, their family, and other members of the support network. The actions aim to help the staff member and promote the autonomy and quality of life of the adult with an intellectual disability at each stage. Resources are 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

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 activities, changes in personality, as well as behaviour changes.

## CAPTURING THE JOURNEY: PERSONAL STORIES

The individual with an intellectual disability residing in the group living arrangement that I supervise also attends a day service, but the two services didn't perceive the changes he was experiencing in the same way. We noticed significant mood swings and observed that he was unable to provide the same level of detail as before. His day program interpreted these changes as normal aging and were not very concerned. Obtaining a diagnosis was quite a challenge because our requests for referrals were not getting us anywhere. His doctor thought the changes were just part of his disability. Eventually, we utilized the NTG-EDSD Screening Tool, which was very helpful in getting people to pay more attention to the situation.

– Staff member supporting an adult with an intellectual disability



## ACTIONS AND HELPFUL IDEAS

### What can I do?

- Establish a baseline for the adult with an intellectual disability if none exists and keep track of changes by repeating use of the same baseline screening tool.
  - Discuss any noted changes with the person and other caregivers.
  - Support the person to make an appointment with their healthcare provider.
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- Find reliable information and training sources about dementia and the process of receiving a diagnosis for both you as a staff member, as well as for adults with an intellectual disability, and other staff and family members involved in the care process. These resources can help everyone better understand the diagnosis, including how dementia progresses.



### Who or what might help?

- 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.
  - A staff and family member familiar with the person should accompany them to the healthcare appointment to discuss the noted changes.
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- For staff, review 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)).
  - For the adults with intellectual disabilities, *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)) may be helpful to review.
  - Explore resources available from the Canadian Down Syndrome Society ([cdss.ca](http://cdss.ca)) and the National Down Syndrome Society ([ndss.org](http://ndss.org)).
  - Contact the NTG Canadian Consortium ([the-ntg.org](http://the-ntg.org)), a local Alzheimer Society, your provincial funder, or the government agency in your area responsible for services for people with an intellectual disability to find out about available training opportunities and information sessions.

# Early Stage Dementia

At the early stage, dementia symptoms will initially fluctuate but become more noticeable and consistent over time. 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**

One of the women attending our day program received a diagnosis of Alzheimer's disease. Early on, we noticed that she occasionally had difficulty locating the bathroom at work and retrieving her lunch from her locker. We asked for permission to take a look in her locker and actually discovered a few moldy lunches, prompting us to realize we had to provide her with more attention and support. When we talked with her a bit more about what she was experiencing, she told us that she was scared because at times, she could not remember things. We found a resource called Jenny's Diary which helped us to talk to her about dementia.

– Staff member supporting 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>• Help create a daily schedule, with the adult with an intellectual disability and other caregivers, to provide a sense of safety, security, and opportunities for valued activities.</li></ul>	<ul style="list-style-type: none"><li>• Develop a list of the person’s favourite activities and important community connections.</li><li>• Utilize visual aids like a calendar.</li><li>• Connect with your local or national Alzheimer Societies.</li><li>• Refer to the <i>Canadian Guide to Community Care and Supports for Adults with Intellectual Disabilities Affected by 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>• Hold conversations with the adult with an intellectual disability you are supporting, other staff, as well as the adult’s family members to initiate plans for future care needs.</li><li>• As needed, help the person and their family to draft advance directives and family emergency plans.</li></ul>	<ul style="list-style-type: none"><li>• Reference the following helpful planning documents:<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><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>• Review or connect with:<ul style="list-style-type: none"><li>• Provincial regulations and laws pertaining to health care proxies and advance directives.</li><li>• Local disability services or the local Alzheimer Society.</li></ul></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

After COVID-19, we started to welcome people back to our day program and there was a participant who had been diagnosed with dementia. It was hard for him to readjust to the routines at work, and he required more assistance with tasks like using the bathroom and eating lunch. The noise and activity of the program seemed to make him even more confused and frustrated, leading him to yell and strike out at other participants. We did not know how to help him stay calm, and despite our efforts, we were not able to secure additional funding for extra staff to support him. This led us to have to ask him to not return to the program.

– Staff member supporting 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>• Provide increased support to the adult with an intellectual disability as needed (e.g., with personal care and hygiene).</li></ul>	<ul style="list-style-type: none"><li>• Encourage the person to do as much as they can on their own, while providing help when necessary.</li><li>• As needed, adapt your approach, communication style, and the level of support and supervision provided.</li><li>• Adjust routines to fit the person's changing needs.</li><li>• Refer to the <i>Canadian Guide to Community Care and Supports for Adults with Intellectual Disabilities Affected by 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><li>• Connect with your local home/health care and government disability programs to explore additional or enhanced supports and services.</li></ul>
<ul style="list-style-type: none"><li>• Learn how to respond to and cope with the changes the adult with an intellectual disability is experiencing.</li></ul>	<ul style="list-style-type: none"><li>• View <i>Effective Care Strategies for 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><li>• Provide ongoing clinical support with an understanding of dementia symptoms.</li><li>• Monitor and document behavioral changes to identify what might be causing certain behaviours.</li><li>• Adapt the environment and your approaches accordingly.</li><li>• Take care of yourself by exploring stress-relief options and support groups.</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**

Our agency has supported individuals with dementia in the past, which prompted us to increase our involvement with the health care system, including palliative and hospice care. When one of the individuals I supported was diagnosed with Alzheimer's disease, we were prepared with a plan. As her condition progressed to the point where she lost the ability to walk and actively participate in self-care, we were able to get the necessary mobility equipment and ensure staff received training in its proper use. When we noticed she was sleeping a lot more and losing interest in eating and drinking, we requested a referral to palliative/hospice care. They were such an awesome support for the family and the staff team.

– Staff member supporting 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 supports and services to providing non-ambulatory care.</li></ul>	<ul style="list-style-type: none"><li>• Reach out to Home Health and Community Care Programs for assistance.</li><li>• Access Provincial Disability programs for:<ul style="list-style-type: none"><li>• The provision of assistive devices like Hoyer lifts and training on their proper use.</li><li>• Information and training to address or prevent compounding medical issues such as aspiration and skin breakdown.</li></ul></li></ul>
<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></ul>	<ul style="list-style-type: none"><li>• Honor cultural traditions.</li><li>• Leverage spiritual support.</li></ul>
<ul style="list-style-type: none"><li>• Request a referral for palliative or hospice care specialists.</li><li>• Review the person's advance care plan.</li></ul>	<ul style="list-style-type: none"><li>• Coordinate with the person's primary healthcare professional.</li><li>• Refer to resources like <i>End-of-Life and Down Syndrome</i> from the USA National Down Syndrome Society (<a href="http://ndss.org">ndss.org</a>).</li><li>• Access resources for grief and loss support.</li><li>• Rely on the palliative/hospice team for continuous guidance and support regarding end-of-life matters, as well as grief and loss.</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)



