

# Actions and Ideas to Help with Dementia

For 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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If someone you know has dementia, you can learn about what's happening and how you can help.

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# Getting Started

# This booklet is to help adults with intellectual disabilities understand and support a person who has dementia.

Sometimes, when people get older, they might change in the way they think and act or remember things. These changes can happen for different reasons. Sometimes it is caused by dementia.

Not everyone will get dementia. By understanding dementia, you can help someone who has it.

This booklet helps to learn about dementia and how to support a person with dementia. It talks about 4 stages of dementia. Each stage has:

**Personal stories** from adults with intellectual disabilities who help a person with dementia.

**Changes** that a person with dementia might have. These changes can be different for some people.

**Actions and ideas** that you can do with the person who has dementia. This can help you know what to do and how to support the person.

Ask someone you trust to help you get more information about dementia.

Look at the *Canadian Guide for Community Care and Supports for Adults with Intellectual Disabilities Affected by Dementia*. This information about dementia is on the internet.

See [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

## Before a person is diagnosed with dementia

Changes you might see in the person before dementia is diagnosed:

- Forgets things.
- Gets lost or confused about things they used to know about.
- Gets more frustrated or impatient.
- Takes a longer time to do things they used to do.
- Acts differently.

You might wonder what is happening to them.

### PERSONAL STORIES



I lived with my mom. She started saying people were breaking into our apartment and that someone was after her. I didn't know what was going on and didn't notice the signs of dementia.

We finally went to a place where they did tests and asked a lot of questions. They said she had dementia. There are medications that can sometimes help.

– Adult with an intellectual disability

My friend loves his hockey team. He used to come to work and tell me all about the games, like who scored the goals, who got in trouble for fighting, and stuff like that.

I started to notice that he didn't talk so much to me about the games. Sometimes he seemed to forget who scored the goals.

– Adult with an intellectual disability

## HELPFUL IDEAS AND ACTIONS YOU CAN DO

### What can I do?

- Learn more about dementia.
- Ask for help to find some information.



- Spend time with the person.
- Be friendly and patient.
- Smile and try not to argue.
- Ask trusted people for their ideas on what to do.

- Ask for help if you are upset about your friend and how they are changing.
- Take care of yourself.

### Who or what might help?

- Family, staff, or a doctor.
  - 2 booklets on the internet called:
    - *Jenny's Diary* from the Square Peg Training website ([learningdisabilityanddementia.org](http://learningdisabilityanddementia.org))
    - *Let's Talk About Dementia* from Down's Syndrome Scotland ([dsscotland.org.uk](http://dsscotland.org.uk)).
  - Watch a video called *4 Ways to Connect with Kindness* found on the Reena website and NTG Canadian Consortium websites ([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)).
  - Local Alzheimer Society
- 
- Look at pictures, listen to music, or take walks together.
  - Watch your favorite TV show.
  - Talk to family, staff and other trusted people
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- Ask family, friends, or staff for help.
  - Talk to your doctor, nurse or social worker.
  - Eat healthy food, relax and get enough sleep.



# Early Stage Dementia



In early stage dementia, sometimes, the person may seem the same as before. At other times, they act and say things very differently. You might see changes happening more often.

The changes might be:

- Being more forgetful.
- Finding it harder to do everyday activities.
- Feeling more confused and worried.
- Having trouble talking or understanding what people say.
- Not wanting to do things they used to really like doing
- Being slow to walk, dress or do other things.

## PERSONAL STORIES

My wife started throwing her pills in the garbage. She'd get mad at me if I took them back out of the garbage.

We'd end up getting in a fight.

– Adult with an intellectual disability

She used to love going out and doing things with me. But she started saying she didn't want to go out.

We had to just sit in the apartment. That was very boring. I missed our friends and the things we used to do.

She couldn't tell me why she didn't want to go out anymore.

– Adult with an intellectual disability



## HELPFUL IDEAS AND ACTIONS YOU CAN DO

### What can I do?

- Ask someone you trust if you have questions.
- Be patient and kind.
- Don't argue or say no.
- Spend time with the person doing things they like to do.
- Plan time to do things together.
- If they have trouble doing something, ask if you can help them.
- Talk to the person about the changes and how they feel.

### Who or what might help?

- Talk to family, friends and staff.
- Ask the person with dementia.
- Photograph albums or favorite things they have.
- Make a calendar of activities with the person with dementia of the things you can do together.
- Talking about feelings can help people feel better.



# Middle Stage Dementia

In middle stage dementia, the person may have a hard time doing everyday tasks. They might get really frustrated and angry. New signs of dementia can be hard to understand.

The changes might be:

- Forgetting activities that just happened.
- Not knowing people like friends and family.
- Thinking past memories are what's happening right now.
- Not wanting to do things they used to enjoy.
- Being angry and upset more often.
- Getting restless, walking around a lot.
- Wandering off or following you around.
- Having a hard time talking and understanding what people are saying.
- Asking the same questions over and over again.

## PERSONAL STORIES

My husband got to the point where he started falling out of bed. I couldn't help him get up from the floor. I was so scared that he was hurt, and I didn't know how to get help.

I went and got a neighbour. They helped me get him up.

– Adult with an intellectual disability

I needed to help him get dressed and have a shower. He didn't want to stand up and walk with me.

I really needed someone to teach me how to motivate him because I knew I needed to keep him up and walking.

– Adult with an intellectual disability

## HELPFUL IDEAS AND ACTIONS YOU CAN DO

What can I do?	Who or what might help?
<ul style="list-style-type: none"><li>• Talk to someone about changes you see in the person with dementia.</li><li>• Get information about how to deal with the person's new behaviours.</li><li>• If you are going to help the person with some tasks, learn how to do that.</li></ul>	<ul style="list-style-type: none"><li>• Family, staff, doctor, and friends.</li><li>• Watch a video called <i>4 Ways to Connect with Kindness</i> found on the Reena website and NTG Canadian Consortium websites (<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>• Local Alzheimer Society.</li></ul>
<ul style="list-style-type: none"><li>• If you feel scared, sad, or frustrated, talk to someone you trust about your feelings.</li><li>• Find ways to help you stay calm and be safe when the person is upset.</li></ul>	<ul style="list-style-type: none"><li>• A support group you can join about helping people with dementia.</li><li>• Do activities that relax you and take care of yourself to stay healthy.</li></ul>





# Late and End Stage Dementia



The person you know will have big changes in their health and what they can do. They will need a lot of help.

Changes might include:

- Not being able to talk.
- Trouble understanding what people are saying.
- Needing help with everything they do.
- Getting sick a lot.
- Seizures that get worse.
- Not being able to walk or move on their own.
- Falling down.
- Choking when they eat and drink.
- Difficulty breathing.

## PERSONAL STORIES

I didn't know what to do for her. I would rub her back and talk to her.

– Adult with an intellectual disability

I just couldn't help my mom anymore. So, they sent her to a nursing home. All she wanted to do was sleep. She couldn't stand up on her own or do anything for herself. Most the time she was in a doper state. I was heartbroken.

– Adult with an intellectual disability

I finally asked staff to phone the doctor to find out what was wrong with my husband. They took him to the hospital and he had to stay for a month. They ended up moving him to a group home. I go there a couple of times a week to visit.

– Adult with an intellectual disability



## HELPFUL IDEAS AND ACTIONS YOU CAN DO

What can I do?	Who or what might help?
<ul style="list-style-type: none"><li>• Ask questions about end of life and dying.</li><li>• Understand what you will see and hear when someone dies.</li></ul>	<ul style="list-style-type: none"><li>• Family, staff and healthcare workers.</li><li>• Hospice or palliative care staff who are people who help at end stage dementia.</li><li>• Knowing what to expect.</li></ul>
<ul style="list-style-type: none"><li>• Learn about what it means to give <i>comfort care</i>.</li></ul>	<ul style="list-style-type: none"><li>• Ask the staff or healthcare workers to explain this and how to offer comfort care.</li></ul>
<ul style="list-style-type: none"><li>• Learn how to spend time with someone when they are near the end of their life.</li></ul>	<ul style="list-style-type: none"><li>• Ask family, friends or staff.</li><li>• Hold the person's hand, share stories, brush their hair, listen to their favourite music, or get them a warm blanket.</li><li>• Remember, even if the person cannot talk or does not seem to know you, they still somehow know you are there.</li></ul>
<ul style="list-style-type: none"><li>• Talk about your feelings.</li><li>• Join a support group.</li></ul>	<ul style="list-style-type: none"><li>• Family, friends, staff.</li><li>• Family, friends or staff can help you go through a booklet called <i>Supporting People with Disabilities Coping with Grief and Loss</i> from the Down Syndrome Association of Greater St. Louis (<a href="http://dsagsl.org">dsagsl.org</a>).</li><li>• Support group about grief and loss.</li></ul>





For more help understanding dementia and supporting adults living with dementia, ask family or staff to help you go through the *Canadian Guide to Community Care and Supports for Adults with Intellectual Disabilities Affected by Dementia*.

You can find this guide and more information online from the Reena or National Task Group (NTG) websites:

**Reena**

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

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

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



