ntg
National Task Group
on Intellectual Disabilities
and Dementia Practices

Reena

UNDERSTANDING STAGES OF DEMENTIA

For Adults with Intellectual Disabilities

A booklet to go with the *2024 Canadian Guide for Community Care and Supports for Adults with Intellectual Disabilities Affected by Dementia*

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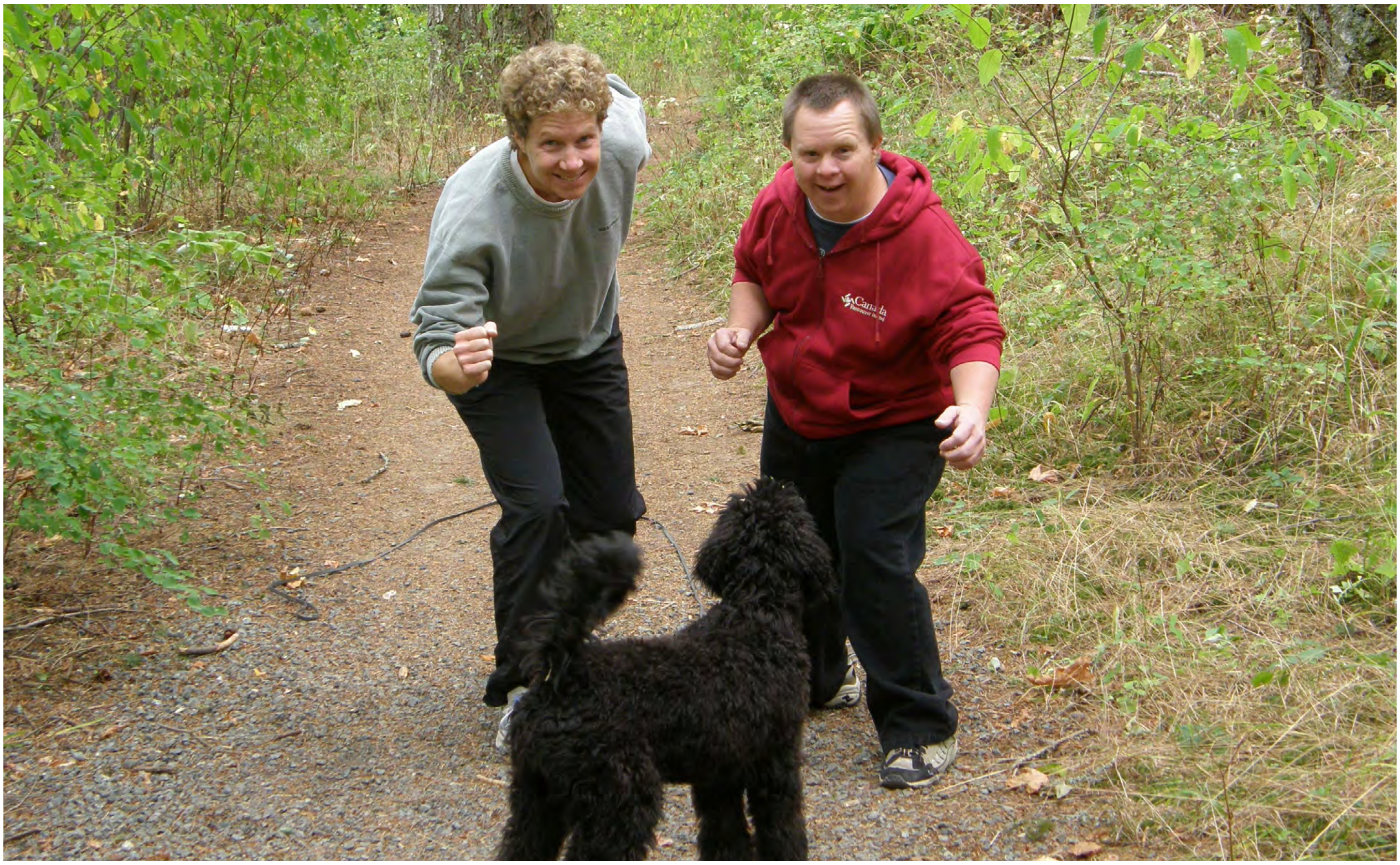

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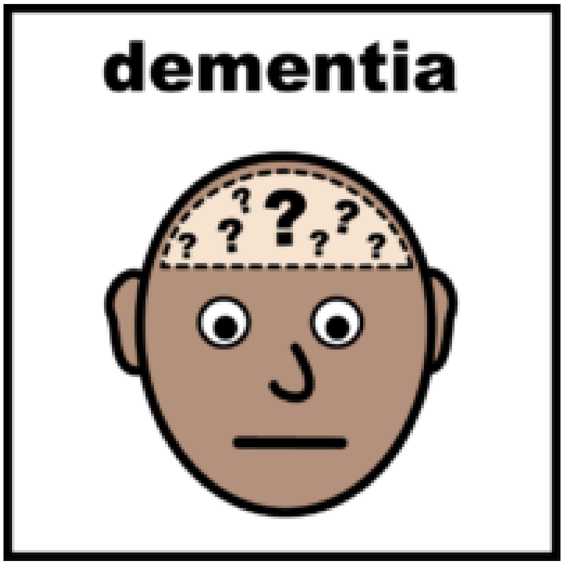


- This guide can help you and people who matter to you.
- It can help plan and be ready for the different stages of dementia.
- This version is simplified to help anyone who may understand information in a different way.
- You can read it by yourself or with someone else.
- Don’t be afraid to ask questions or tell your story.

Understanding your current abilities, What’s changing, and Who to ask for help.

NTG-EDSD

Ask a person you trust to help you find and use a form to record how you are today.

The form is called the NTG-EDSD.

Next, ask the person to help you make a short video using a phone.

The video can show you doing 4 things:

- Sit in a chair, stand, walk and then go back to the chair to sit.
- Pick up small coins off the table and put them in a jar.
- Doing something you always do. Such as put on your jacket or set the table or make your bed.
- Talk in person with someone you know.

Keep both the NTG-EDSD and video in a safe place.

Redo both every year.

These are a record of your abilities and health. They help to see if any changes are happening as you get older.

If you notice changes, update the form so you can see what changes are happening.

Decide with a person you trust if you should see the doctor about these changes.

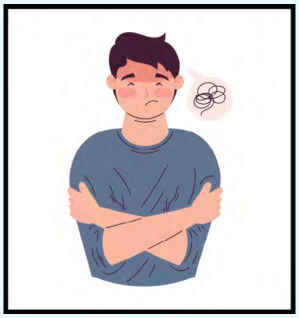
Do you have Dementia?

Dementia means that things are changing in your brain.

It can affect how you think and act.

A doctor decides if the changes that are happening are dementia or a different health issue.

Each person is different. Not everyone experiences changes in the same way.



Here are some examples of early changes you might notice:

- Having trouble doing things that you know how to do.
- Getting angry or unhappy more than usual.
- Taking longer to do things you.
- Getting lost or confused in places you know well

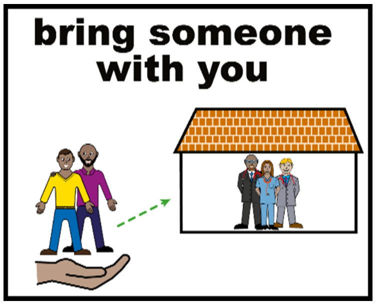
These changes don't always happen.
They don't always mean that you have dementia.

But it is very good to learn more about changes you might have.
Pay attention to them.
This guide will help you to learn more.

If you feel afraid or confused about changes that are happening to you, it is important to tell someone you trust.

Don't wait too long to tell them.

Things you can do when you think things are changing in your brain:



- Talk to someone you trust and who knows you well.
- Together, write down the changes and when you notice them.
- Redo the NTG-EDSD form and video.
- Think about your life. Is there something that might be a reason for the changes and the way you are feeling?
- If you are worried about the changes, make a doctor's appointment.
- Ask someone you trust to come to the doctor to help you at the appointment.
- Talk with your family, staff and friends about how they can support you until you see the doctor.

Confirming that changes are happening in your brain

Tell the doctor about the changes you have and show them the NTG-EDSD form and video.

The doctor may ask you more questions about:

- The changes you see.
- The medications you take.
- Your living situation.
- Other health problems you might have.

The people who help you, care for you and love you might also need to tell the doctor what changes they see you going through.

The doctor might want to do some tests to see what might be causing the changes.
The doctor may also set up a time for you to have a physical checkup.

Sometimes, a doctor will want you to see other medical professionals.
They may help you to understand why the changes are happening.

The questions they ask and your physical check-up with your doctor will help to decide if you are going through the first stages of dementia or not.

You may not have dementia.
There may be other reasons why you are having these changes.
The doctor will talk to you about what is going on.

Knowing if you have or don't have dementia will help you and other people make sure you are getting the right kind of care.

Dementia and You – Early Stage

You have just been told by the doctor that you are in the early stage of dementia.

Is it hard to understand what your body and brain are going through?

When a person has dementia, they will keep having more changes.

It is important to keep other people up to date about how you feel. Give them a chance to ask questions.

It will be good to continue learning about dementia and the things you can do that will help.

It could be that you more often

- Forget things.
- Feel afraid, confused and angry.
- Have trouble understanding people or saying things
- Less interested in things you used to enjoy doing.
- Slower to complete activities and they are harder to do.

Some days you may feel like your old self and other days you may feel confused or unsettled.

Here are actions you can do to make life easier:

- Learn what you need to be safe in your home, neighborhood, and community.
- Ask your friends, family, and or staff to help you decide who needs to know about your dementia.
- Make a list of people who help you with your healthcare needs.
- People you trust can also help take other actions that are needed.

For example:

- Put up a large print schedule of what you do each day. Include pictures of your daily routine. Practice looking at it every day.
- Always carry your identification, emergency contact card and a list of your medications.
- Tell your neighbours that you may get lost and, if they see you, they can help you get home.

If you have roommates, take time to talk about what you are going through. This will help them be prepared for your changes. Show them the video: 4 ways to connect with Kindness.

https://www.youtube.com/watch?v=Xofm1B9DX2A&t=1s

Share and watch the other videos with family and staff:

https://www.youtube.com/watch?v=czWngSTCyms&t=2s

https://www.youtube.com/watch?v=Hgh8aGlsfSM&t=1s

There are two important actions you can take to make your life easier:

1. Put together information about your life story
2. Make a plan for your future care with people you trust.

1 Work on Your Life Story

It's important for you to make sure the people around you understand your life history.

When you are no longer able to share your memories , your life story will help everyone give you the care you need and offer you activities you enjoy.

A Life Story can be a book, video or even a memory box.

Family and friends might like to help you with this.

It should include things like:

- Your important memories and history.
- Friends and family who are important to you.
- Your current and past hobbies.
- Routines that are important to you.

Life Story resources include:

Planning Resources and Templates
www.helensandersonassociates.com/person-centered-thinking-tools/

My Plan a Self Advocate Workbook
www.communitylivingbc.ca/wp-content/uploads/2018/04/Plain-Language-Planning-Workbook.pdf

My Book
https://mybookletbc.com/

2 Make a plan for your future care

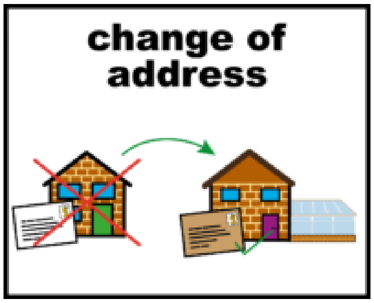
With help from someone you trust, begin to think about what should go in your plan:

- How can you continue doing things you enjoy but in a different way?
- All people should also have a plan for their future healthcare needs.
  - If you don't have one, ask someone you trust to help you find Advance Care Planning booklets.

Thinking about where you will live as your dementia gets worse.

Before you reach the next stage of your dementia it is a good time to consider a change to where you live so you can be better supported.

Some reasons why you might need to move to a new home include:



- It may be dangerous to live in a home with lots of stairs.
- You may find that the other people in the home are more annoying to you.
- The people who care for you cannot help you as well as they did before

If you decide to move, it will be much easier to settle into your next home if you move early.

Together with your family, friends and staff, you can plan where you will live next.

There are several resources and books that can help you plan. Here are some links to check out:

My Voice in Action Workbook

https://patienteduc.fraserhealth.ca/file/my-voice-in-action-a-work-book-for-advance-care-pla-583174.pdf

Speak Up - Advance Care Planning Workbook

www.advancecareplanning.ca/wp-content/uploads/2024/10/ACP-Activity-Bundle-EN-ver-reduced-size-FINAL.pdf

Accessible End of Life Planning Tool

www.tcd.ie/tcaid/accessibleinformation/

Your plans for future care and health care need to be in writing and put in a safe place.

Your key people need to know where they are kept.

Remember that the things that matter to you will always be important.

Your choices and values will also be important.

Be sure to have it written in your plan and let people know.

Making changes to where you live and go in community

You may notice that you need help to move safely and confidently around your home and in your community.

This is a good time to ask the people who help you and care for you to make some changes that will keep you safe.

Here are some examples to make it easier for you:

- Move furniture so it is easy to get around.
- Remove rugs that you could trip on.
- Put pictures up around your home to show you where to go or to find things.
- Increase lighting so you can see things more clearly.
- Put grabs bar in the shower, bathtub and beside the toilet.

Later, there may be other ways to keep you safe, comfortable and allow you to stay in your home or at your program for as long as possible.

Here are some things you can do to help keep your mind and body active:

- Eat well.
- Exercise such as walking or dancing.
- Play games on your tablet, put a puzzle together, or paint and colour pictures.
- Visit with friends and family
- Get a good night's sleep.
- Pat a dog, cat or other pet.

Dementia and You – Middle Stage

Your dementia is getting worse, which means things are getting harder for you to do.

At Middle stage dementia, the changes you saw earlier on show up more often. There are new changes too.

You may:

- Have some difficulty remembering family, friends, and staff
- Lose interest in activities you once enjoyed.
- Think that past memories are happening now. Like you still live in a home that you grew up in a long time ago.
- Say the same thing over and over again.
- Be upset and anxious.
- Have trouble talking with people – understanding what they say or being understood by them.

Accepting the changes, you are going through will be difficult and sad for you. your family and others who care for you will try to help.

Steps to make life easier

You can still:

- Do the activities you like to do.
- Enjoy spending time with family and friends.

You will need more help with your routines like:

- Showering or having a bath.
- Taking medications.
- Getting dressed and undressed.

You will need to keep going to all your doctor's and other medical appointments with people who know you well and can help you.

Dementia and You - Late Stage

At this late and end-stage of dementia, your skills and abilities will change a lot.

People will notice that you:

- Can't dress and bath yourself any longer
- Eat less and need help to feed yourself
- Get sick more often
- Fall more often or cannot walk by yourself anymore
- Talk less and are quieter

You will require more help to stay safe.

Your family and staff will arrange for you to have:

- Softer foods to help you swallow.
- Forks, knives, and spoons that fit your hands better.
- Canes, walkers, and or wheelchairs.
- Lifts to move you in and out of bed.

Your family, friends and staff want you to still enjoy life and have visits.

They will arrange ways to maintain contact with people important to you, such as:

- Phone calls, video calls or in-person visits
- Celebrating special occasions together
- Doing simple exercises with you
- Playing your favorite music
- Looking through photo albums
- Helping you to look your best.

Comfort Care

At this late stage of dementia, the people who care about you will give you comfort care.

There are many ways to provide comfort to you. Such as:

- Having a cozy armchair with a warm blanket
- Changing your position to avoid discomfort
- Light massage, gentle touching and pleasant smells

They will need to arrange for how your final days of life will be for you and make plans to celebrate your life after you have gone.

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