

# Young Onset Dementia Diagnosis?

This information is for you



**Call us for support.  
Because you have more living to do.**

**Alzheimer***Society*

BRANT, HALDIMAND NORFOLK,  
HAMILTON HALTON

If you have this booklet, it is because you or someone in your life has been diagnosed with a form of dementia before the age of 65. Please read this when you are ready. Take your time. The Alzheimer Society is here to provide support and education at no cost.

*This resource was developed by persons living with young onset dementia and care partners and is based on what they wished they knew at the time of their diagnosis experiences. The Alzheimer Society of Brant, Haldimand Norfolk, Hamilton Halton acknowledges the wonderful contributions that our Young Onset Dementia Advisory Group provided. They worked together to provide this to empower others. We value the importance of having lived experience to inform our work.*

To have a diagnosis of young onset dementia means that you have been diagnosed with a form of dementia before reaching the age of 65. People living with young onset dementia face different challenges than those who are older. The most common misconception surrounding young onset dementia is that you are too young to have this condition.

Education about the realities of young onset dementia and the changes that come along with it can allow you to decide on the best plan of action for you and for your family. Although this guide was developed for those with young onset dementia, the content is valuable for anyone with a dementia diagnosis.

## Dealing with your Emotions

Being diagnosed with dementia at a young age can cause many emotions to arise. You may be fearful of what is to come as your condition progresses. You may be frustrated in learning to deal with changes in your capabilities or adjusting to new medications. Maybe you are overwhelmed with all of the new information you are receiving. These emotions are all normal as you adjust to the diagnosis you've just been given.

## Tips & Tricks

- > Be aware of your personal triggers
- > Do your best to avoid overwhelming situations
- > Alter or adjust to the environment – for example, remove yourself temporarily from difficult situations
- > Allow your care partner to provide assistance

## Facing Stigma

You may often feel excluded or treated differently because of your condition. For younger people with dementia in particular, there's a tendency for others to dismiss the condition as a mental illness, or to simply not believe it. The common perception is that dementia is a disease of the "old".

- > Be proactive. Educate yourself on what support is available. You may need more as your condition changes – for example, help in living situations, cooking, etc.
- > Help decrease the stigma attached to young onset dementia by sharing your experience. When you share, you encourage others to learn more about young onset dementia.



**“Stay strong.  
Who you are the  
day before your  
diagnosis hasn’t  
changed the day  
you got the  
diagnosis.”**

*Phyllis, diagnosed at age 52*

## Planning For the Future

Think about talking to a financial advisor and a lawyer. Be part of the decision-making about your financial and legal affairs while you are able to make decisions and sign legal papers. Make sure someone you trust is in control of your money. A Power of Attorney will authorize someone to legally make decisions on your behalf once you are no longer able to.

# Making a Care Plan

- 1** Think about what's important to you.
  - Are you wanting to travel?
  - Are there things on your “bucket list” that should be completed sooner?
- 2** Learn about different medical procedures and what they can or can't do.
  - Ask your doctor what may help your condition
  - Weigh the pros and cons of any available procedures
- 3** Decide on a substitute decision-maker (Power of Attorney) – someone who is willing and able to speak for you if you are unable to speak for yourself.
- 4** Talk about your wishes with those closest to you.
- 5** Record your wishes. The Alzheimer Society can help you find out if your province/territory has legal documents regarding planning for future health care.



**“Surround yourself with those that will lift you up, encourage your independence, honour your wishes..”**

*Debbie, diagnosed at age 59*

## Finances

When diagnosed with young onset dementia it is important to consider how your financial situation may change. You may not wish to feel as though you are depending on your family or friends so find solutions that work for you and allow you to keep a comfortable lifestyle as you age.

### Local government resources can provide assistance:

**Contact Service Canada to find out (1-800-622-6232):**

- > Disability Benefits under the Canada Pension Plan
- > Canada Pension Plan options

**Contact Service Ontario to discuss (1-800-267-8097):**

- > Ontario Disability Support Program (ODSP)

### If you are still working:

- > Discuss adapted work options with your employer – are reduced hours an option?
- > Begin planning for your retirement from work – if you own your own business, what will future plans be?

### Paying bills:

- > Set up a reminder system (ie: calendars, siri/google, friend/family).
- > Arrange automatic bill payments.
- > If using online banking or writing cheques, have someone you trust check that your transactions are correct.
- > Put a maximum limit on your credit card.
- > Put a maximum daily or weekly limit on your debit card.
- > Find a financial advisor you trust, and who will speak with you about your personal situation separately from family members.

## Self Care

You know yourself best. Learn skills that will benefit you as the condition progresses. You have ownership over your body and the care that you receive. Also, keep in mind, it is important to take care of your mental health when diagnosed. Caring for yourself is vital for your well-being.

## Strategies

- > Use technology to your advantage. This can be helpful in keeping your mind engaged to learn new things
- > Continue to educate yourself (read, have discussions with others, join in community or group activities)
- > Take advantage of your physical health; go for walks, participate in sports, or other hobbies that you enjoy
- > Reach out to friends and family members and talk about your diagnosis; talk about how everyone involved feels



**“Every diagnosis is different and through the many resources available you learn how to live and possibly thrive in this new reality.”**

*Louise, care partner for spouse diagnosed at age 59*

## Resources for Information and Support

Contact the Alzheimer Society of Brant, Haldimand Norfolk, Hamilton Halton for more information on services, support and education

[www.alzhn.ca](http://www.alzhn.ca) or call **1-888-343-1017**

The Young Caregivers Association offers support for your children who are under the age of 25 – [www.youngcaregivers.ca](http://www.youngcaregivers.ca)

Young onset dementia – [information and more resources](#)

Statistics about dementia – [the impact on Canadians](#)

An Inspirational Guide for people living with Young Onset Dementia:

[By Us For Us Guide](#) (the Murray Alzheimer Research and Education Program)

Contact us for information on Legal and Financial Planning tips:

[Tax Credit Guide for Ontarians Living with Dementia and their Care Partners](#)

[Advance care planning information](#)

[Speak Up Canada](#) – tools and resources for advanced care planning

[Approaching an Unthinkable Future](#) - understanding the support needs of people living with young onset dementia (this document is from England)

## Suggested Books

The Estate Plan Workbook *by Paul Lambe*  
(ensure you purchase a Canadian workbook)

What the Hell Happened to My Brain *by Kate Swaffer*

Alzheimer's from the Inside Out *by Richard Taylor*

Speaking Our Minds *by Lisa Snyder*

The Banana Lady and Other Stories of Curious Behaviour and Speech  
*by Andrew Kertesz*

For the following Programs and Services offered at the Alzheimer Society go to [www.alzhn.ca](http://www.alzhn.ca) or call **1-888-343-1017**.

### Young Onset Peer Support Group

This peer lead support group is where you can connect and share experiences.

### First Steps

Meet others newly diagnosed with a dementia to understand your illness and the changes you are experiencing. This is a 4 week program (6 weeks if on-line)

### Taking Control of our Lives

A 6 week series where coping strategies for living with a changing brain are shared.

### Health and Wellness Programs

From social groups, to exercise sessions to creative outlets, check out our calendar for options.



## Information about online support:

[Dementia Alliance International](#) is a registered non-profit organization whose membership is exclusively for people with a medically confirmed diagnosis of any type of a dementia from all around the world. They host on-line support groups lead by people living with dementia.

[Young Onset Dementia Resources](#) Go to page 19-22 of this document to see a full list of clickable resources.

## Information about advocacy:

[Dementia Advocacy Canada](#) is a grassroots group of people living with dementia and care partners. They want to influence policy, inform program development and improve access to support and services across Canada.

Most importantly, we want you to know that you are not alone. By sharing with you what we wish we knew when we were diagnosed, we hope that you find the supports you need quickly and easily. We are thankful to the Alzheimer Society for being there to help us find our way when we didn't know what to do. The Alzheimer Society is the first place to turn to, because you have so much more living to do!