

Young Onset Dementia



You have more living to do.
Call us for support.

Société Alzheimer Society

BRANT, HALDIMAND NORFOLK,
HAMILTON HALTON

☎ **1-800-565-4614**

💻 **www.alzda.ca**

✉ **help@alzda.ca**

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. 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.



M Lewis

Michelle Lewis, CEO



FROM THE YOUNG ONSET ADVISORY GROUP

Please read this when you are ready.

Take your time. The Alzheimer Society of Brant, Haldimand Norfolk, Hamilton Halton is here to provide support and education at no cost.

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!

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 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.

SOME SUGGESTIONS

- > 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, family and friends, to provide assistance

FACING STIGMA

You may 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 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.

GOVERNMENT RESOURCES CAN PROVIDE ASSISTANCE:

Contact Service Canada to learn about federal support programs (1-800-622-6232):

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

Contact Service Ontario to learn about provincial support programs(1-800-267-8097):

- > Ontario Disability Support Program (ODSP)

IF YOU ARE STILL WORKING:

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



PAYING BILLS:

- > Set up a reminder system (For example, 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.

SOME SUGGESTIONS

- > Use technology to your advantage. Technology can help you in keeping your mind engaged in learning new things.
- > Continue to educate yourself (read, discuss 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 her spouse diagnosed at age 59

BOOKS WE SUGGEST

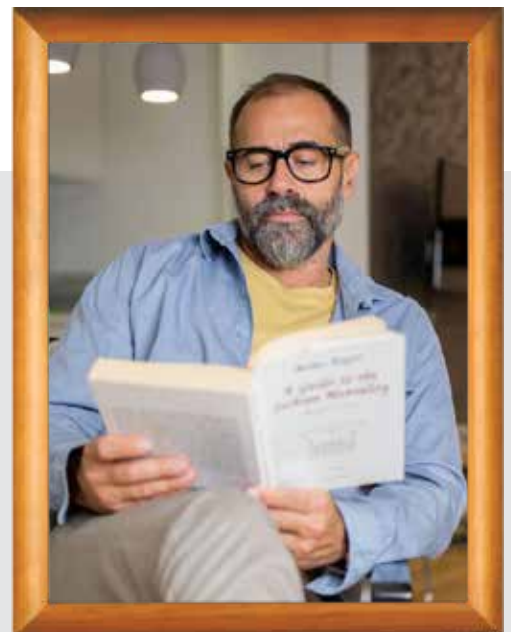
The Estate Plan Workbook *by Paul Lambe*
(ensure you purchase a Canadian workbook)

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



OUR PROGRAMS

Education

The Alzheimer Society offers practical information, education and programs at every stage of the disease to help those affected and their families live well with dementia.

Counselling

The Alzheimer Society offers a robust counselling program providing people living with dementia and care partners a reliable trust-worthy advocate to support them through their dementia experience.

Support Groups

Alzheimer Society support groups offer participants a safe place to ask questions and discuss the realities of day-to-day life.

Health & Wellness

The Alzheimer Society offers a variety of programs, that encourage a healthy lifestyle and provide an opportunity for participants to connect with others in a dementia friendly environment.

There may be more programs in your community offered by other organizations:

Young Caregivers Association

provides opportunities for children and youth to connect with others who have a loved one living with dementia in their life. Learn more at www.youngcaregivers.ca, or call 905-768-4488.



OUR LOCATIONS:

1-515 Park Road N.
Brantford, ON
N3R 7K8

205-550 Fennell Ave E.
Hamilton, ON
L8V 4S9

101-3430 South Service Road
Burlington, ON
L7N 3T9

645 Norfolk Street N.
Simcoe, ON
N3Y 5C1

42 Main Street S.
Hagersville, ON
N0A 1H0

Need help?
Phone: 1-800-565-4614
Email: help@alzda.ca