LET'S TALK ABOUT DEMENTIA



Host: Diana Vincze, Pallium Canada

Presenter: Claire Webster, PAC, CPCA

Date: January 23rd, 2025

Territorial Honouring



The Palliative Care ECHO Project

The Palliative Care ECHO Project is a 5-year national initiative to cultivate communities of practice and establish continuous professional development among health care providers across Canada who care for patients with life-limiting illness.

Stay connected: <u>www.echopalliative.com</u>

The Palliative Care ECHO Project is supported by a financial contribution from Health Canada. The views expressed herein do not necessarily represent the views of Health Canada.



Health Canada Santé Canada



LEAP Core

- Interprofessional course that focuses on the essential competencies to provide a palliative care approach.
- Taught by local experts who are experienced palliative care clinicians and educators.
- Delivered online or in-person.
- Ideal for any health care professional (e.g., physician, nurse, pharmacist, social worker, etc.) who provides care for patients with life-threatening and progressive life-limiting illnesses.
- Accredited by CFPC and Royal College.



Learn more about the course and topics covered by visiting

www.pallium.ca/course/leap-core

Introductions

Host

Diana Vincze

Palliative Care ECHO Project Manager Pallium Canada

Presenter

Claire Webster, PAC, CPCA

Certified Dementia Care Consultant (PAC)

Certified Professional Consultant on Aging (CPCA)

Founder, Ambassador and Lecturer, Dementia Education Program, McGill University Founder and President, Caregiver Crosswalk Inc.



Welcome and Reminders

- For comments and introductions, please use the chat function!
- For questions, please use the Q&A function, these questions will be addressed at the end of the session.
- This session is being recorded—this recording and slide deck will be emailed to registrants within the next week.
- Remember not to disclose any Personal Health Information (PHI) during the session.

Conflict of Interest

Pallium Canada

- Non-profit
- Partially funded through a contribution by Health Canada
- Generates funds to support operations and R&D from course registration fees and sales of the Pallium Pocketbook

Host/Presenter

- Diana Vincze: Nothing to disclose
- Claire Webster: Consulting on patient/caregiver experience:
 - Hoffmann La Roche Canada Ltd.
 - Eisai Canada Inc.,
 - Eli Lilly Canada Inc.







Presented by CLAIRE WEBSTER, PAC, CPCA January 23, 2025





Dementia Education Program



Disclosures

Claire Webster

Certified Dementia Care Consultant (PAC)
Certified Professional Consultant on Aging (CPCA)

Founder and Ambassador Dementia Education Program, McGill University

Founder and President Caregiver Crosswalk Inc.

Member

Government of Canada's Advisory Board on Dementia

Consulting on patient/caregiver experience:

Hoffmann La Roche Canada Ltd.

Eisai Canada Inc.,

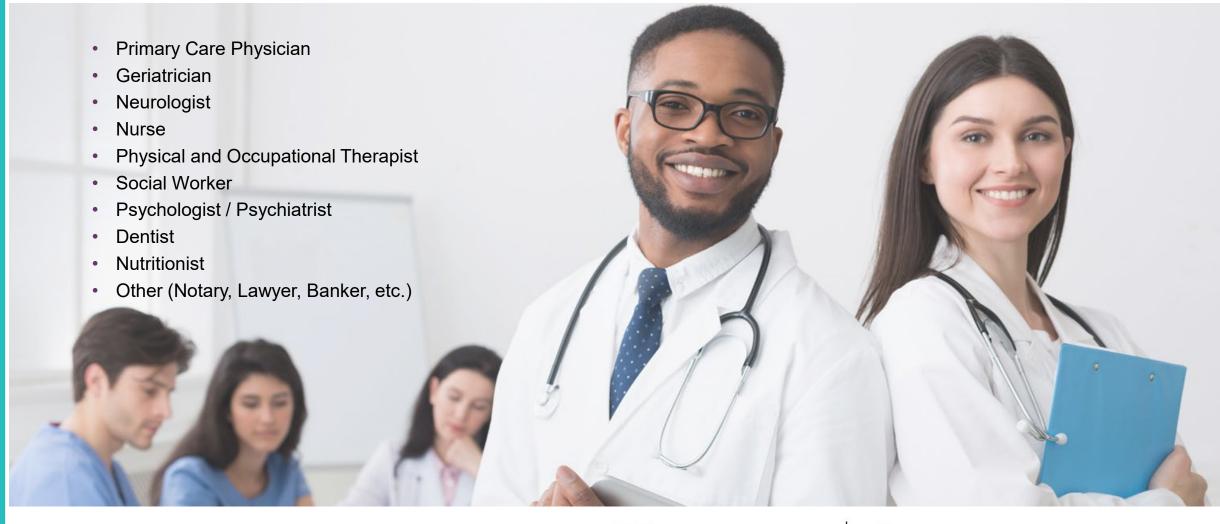
Eli Lilly Canada Inc.



Learning Objectives

- Provide an overview of the signs and symptoms of dementia; how the disease impacts memory, behavior, personality as well as activities of daily living throughout the early, middle and late stages.
- Explain the emotional and physical impact that caring for a person living with dementia has on family members, how to identify caregiver burnout and provide strategies to minimize stress.
- Recognize caregiver limitations when it is no longer possible to keep a person living with dementia at home and understand how to advocate for care.
- Provide an overview of the comprehensive free resources offered by McGill University's Dementia Education Program.

Multidisciplinary Team Throughout the Journey of Dementia



My Caregiver Journey

As a result of my personal experience caring for my late mother, Vieno, who was diagnosed with Alzheimer's disease in 2006, I understood first-hand the importance of educating and supporting informal caregivers to help them understand the challenges of caring for a person with dementia.

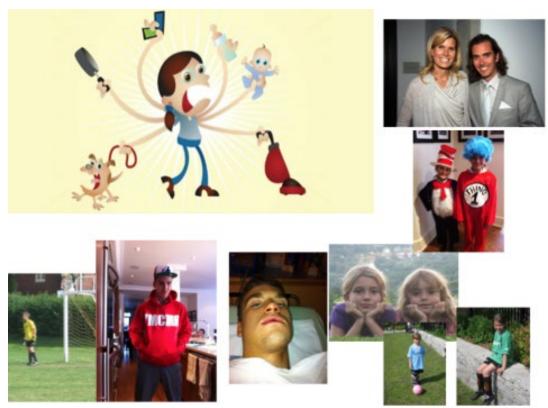


"GOOD LUCK MRS. WEBSTER"

The **PRESCRIPTION OF CARE** that we received in September 2006 after announcing that she had Alzheimer's disease.









The Ripple Effect of Dementia



- Person living with dementia
- Caregiver
- Caregiver's family
- Employment
- Social life
- Finances
- Health care system

Advocate

As the disease evolves and the person living with dementia loses their ability to communicate and represent themselves, the caregiver becomes their voice to ensure that they receive the best care possible.



Providing Care

Providing care for someone with dementia requires:

- Patience
- Creativity
- Empathy



The ability to step outside your personal needs and logic to understand why a certain behaviour is happening. Be prepared that things may not work out as you had hoped.



Knowledge is the Most Powerful Resource



People living with dementia and their care partners need to be educated on the disease and its progression. This includes understanding how to deal with responsive behaviours and learning about resources available in the community that can provide support.



Seeking Support from McGill University

I became a **passionate advocate** for dementia care and pursued training and volunteer opportunities, sharing my story and connecting with other caregivers.

In 2017, I met with **Dr. David Eidelman**, former Dean of McGill's Faculty of Medicine and Health Sciences and asked him to help me **change the healthcare system**.



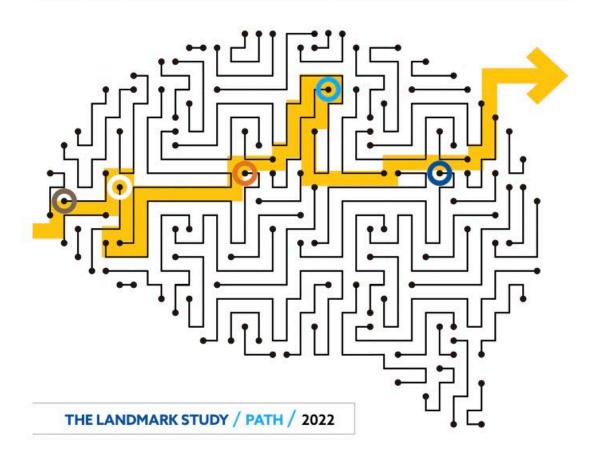






AlzheimerSociety

FORWARD FOR DEMENTIA IN CANADA

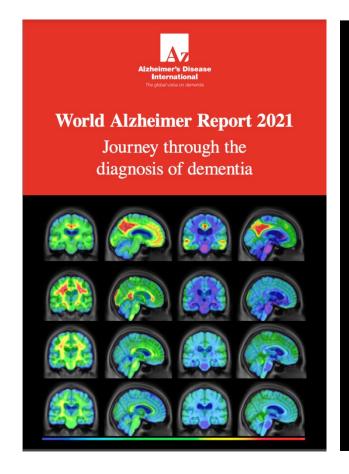


THE CURRENT DIRECTION OF DEMENTIA IN CANADA

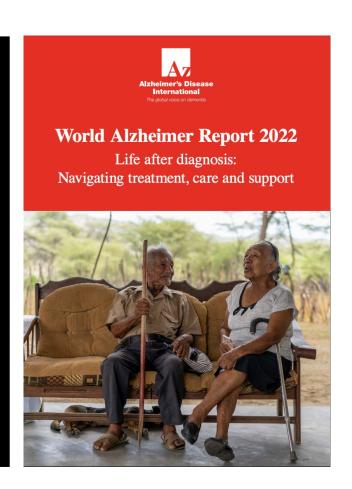
By 2050, 1.7 million Canadians will be living with dementia, almost triple the number in 2020

Figure 2. Number of people in Canada with dementia by age group, 2020 and 2050 2020 2050 dementia 600,000 Number of people in Canada with 450,000 300,000 150,000 65-69 70-74 75-79 80-84 85-89 90+ **AGE GROUPS** 2050 2020 597,300 1,712,400 Total number of people living with dementia

World Alzheimer Reports



McGill University was commissioned by Alzheimer's Disease International to deliver the World Alzheimer Reports on the crucial and inter-related topics of diagnosis (2021) and post-diagnostic support (2022).

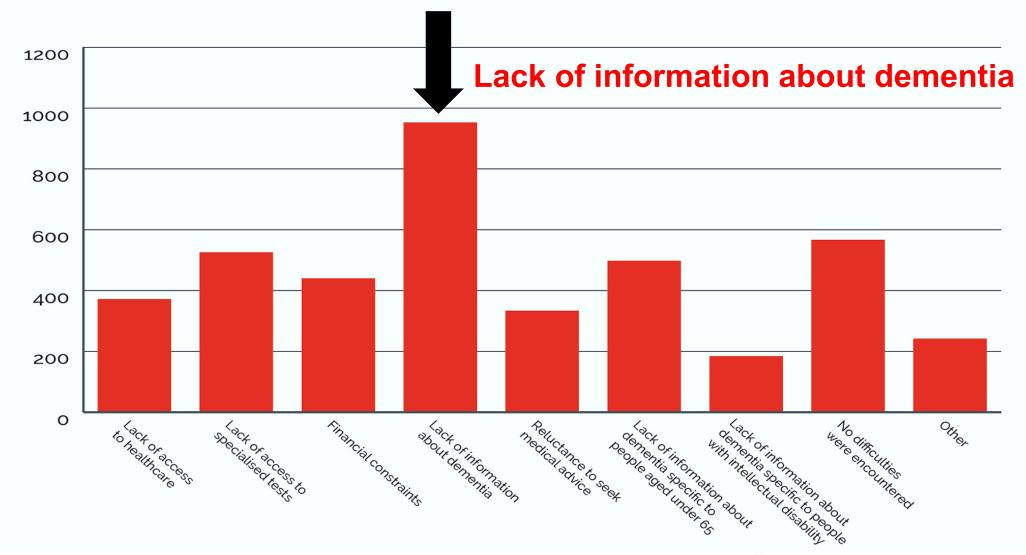


Free to access and download at www.alzint.org





What difficulties were encountered as part of receiving the diagnosis of dementia?



Based on 2021-2022 survey results from carers.





Based on information from 2021-2022 World Alzheimer Reports

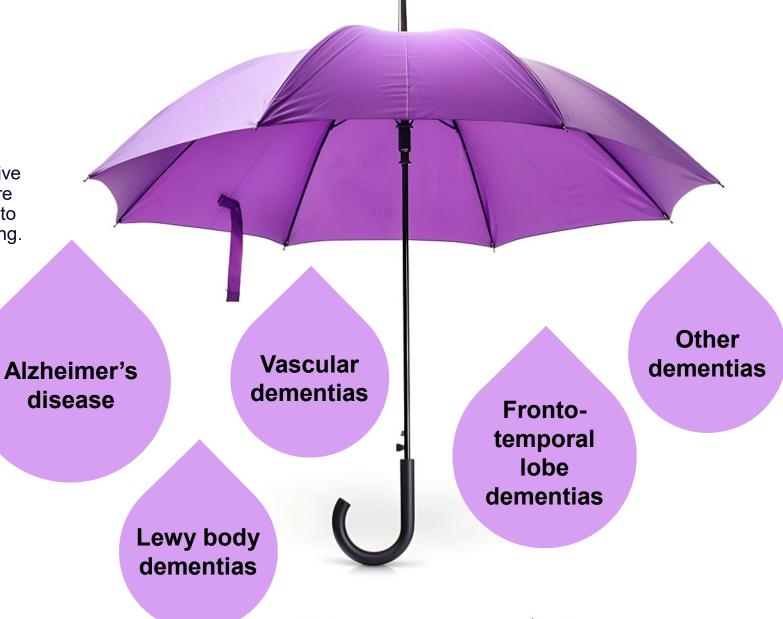
Gaps in Education for Persons Living with Dementia and their Carers:

- Signs and symptoms of dementia
- Importance of seeking a diagnosis to ensure best quality of life and care as well as requiring a diagnosis to implement future financial, legal and advance care planning wishes
- The pathway to receiving a diagnosis
- Managing challenging/responsive behaviours using non-pharmacological approaches
- Safety concerns
- Leisure activities and cognitive stimulation therapies to enhance health and wellbeing
- Knowledge about and accessing support services from community organizations and government agencies
- Carers recognition of their own limits and ability to cope with overwhelming feelings of guilt, anger, and anticipatory grief



Dementia

is an umbrella term for several diseases affecting memory, cognitive abilities and behaviour that interfere significantly with a person's ability to maintain their activities of daily living.

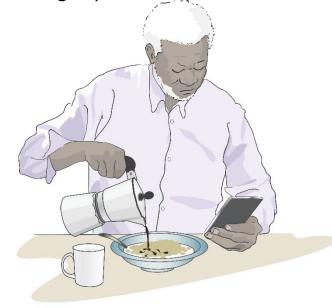






A Few Warning Signs of Dementia, as Per My Personal Experience with My Mother

- Personality / behavior changes (lack of filter, emotional roller coaster, lack of social skills, insensitivity, etc.)
- Believing or seeing things that are not true (conspiracy theories & hallucinations)
- Struggling with vocabulary and forming sentences (reverting to mother tongue)
- Excessive hoarding
- Vision and mobility changes
- Easily distracted and difficulty following conversations
- Forgetfulness and confusion items and people
- Loss of logical thinking = Unable to manage finances
- Significant changes in handwriting
- Difficulty with activities of daily living (preparing recipes)
- Repetitive speech or actions





















Clinical Work Up - Arrive Prepared for Your First Doctor's Appointment

- Medical history
- List of medications
- List of symptoms and concerns this list should ideally be sent ahead of the appointment.
- List of all audio, visual and physical aids
- Ask for clear next steps
- Ask about risk of driving and managing fiances.
- Ask for information about the disease and resources



Supporting Patients and Caregivers After A Diagnosis of Dementia

SUPPORT

- Understanding the Disease
- Physician Guidance
- Patient-Centered Care
- Communication Strategies
- Legal and Financial Plan
- Caregiver Support
- Treatment Options
- Clinical Trials and Research
 Opportunities
- End-of-Life Care



Journey of Caregiving After the Diagnosis of Dementia

CHALLENGES

- Anosognosia
- Lack of Education about Dementia
- Communication Challenges
- Behavioural Changes
- Emotional Impact
- Financial Stress
- Isolation



Anosognosia

A lack of awareness about their condition; they may appear indifferent or unconcerned.











Agitation Associated with Dementia Due to Alzheimer's Disease Includes Behaviours Across Three Domains:

Verbally Agitated Behaviors

- Complaining
- Constant unwarranted request for attention or help
- Repetitive sentences or questions
- Negativism

Physically Nonagressive Behaviors

- Pacing, aimless wandering
- General restlessness
- Inappropriate dress or disrobing
- Trying to get to a different place
- Handling things inappropriately
- Performing repetitive mannerisms

Agressive Behaviors

- Screaming
- Biting
- Hitting
- Kicking
- Hurting self or others
- Cursing or verbal agression
- Pushing
- Scratching
- Throwing things
- Spitting
- Tearing things/destroying property
- Grabbing onto people

Source: International Psychogeriatric Association https://www.ipa-online.org/





Understanding and Responding to Challenging and Unexpected Behavior

- Do you know the person's life story? Their likes and dislikes?
- What, why and when is it happening? (health/wellness, the person, environment, time, people/relationships, brain changes).
- Pick your battles and "join their journey"; if what they are doing or saying is not harmful, let them be.
- Let go of what was and evolve/adapt to what is.
- Embrace and encourage them to continue doing everything they still can.
- Be a detective and not a judge. Are there any unmet physical or emotional needs?
- Use the compassionate lie to avoid catastrophic responses.
- Care partners, how is your mood and energy?



Activities of Daily Living Provided by Family Care Partners without any Formal Training

- Eating
- Bathing
- Dressing
- Transferring
- Toileting
- Walking or moving around





Plus management of medication as well as other medical needs.























The Impact of Dementia on Eating

Physical Challenges

- Difficulty Chewing and Swallowing (Dysphagia):
 As dementia progresses, some individuals may have difficulty chewing or swallowing, which can lead to choking or aspiration (food entering the airway).
- Decreased Motor Skills: Fine motor skills decline, making it difficult to use utensils or bring food to the mouth.



Sensory Impairments

- Changes in Taste and Smell: The ability to taste and smell can diminish, making food less appealing.
- Visual Impairments: Difficulty seeing can make it hard to identify food on the plate or navigate eating utensils.

Nutritional Issues

- Weight Loss and Malnutrition: These are common due to reduced food intake, difficulty eating, and increased energy needs from physical agitation or wandering.
- **Dehydration:** Forgetting to drink or not feeling thirsty can lead to dehydration, exacerbating cognitive and physical symptoms.















Hitting the brakes on driving

Reading signs, anticipating traffic lights, keeping a steady foot on the accelerator or brake pedal and being aware of other cars, pedestrians and cyclists - so many details about driving requires one's full attention as well as good reflexes. Dementia affects these skills as memory, depth perception, psychological and physical response rates may be altered or slowed.





Wandering

A person can wander in, around, about...or off. Wandering off is a dangerous reality that can adversely affect a person with dementia. Though most often seen in the later stages, it can happen at any time. It is usually an indicator of your declining ability to recognize time, familiar faces or places.



GPS locators

Should you lose your way, these devices alert your family and let them know where you are. If you and your care partners agree to use this type of device, it could go a long way to bolstering your independence and reducing their stress and anxiety when you are out and about.



It is highly recommended that you register in the MedicAlert® Safely Home® program. This partnership between the MedicAlert Foundation Canada and the Alzheimer Society of Canada has produced a unique MedicAlert bracelet that displays your medical condition and a 24-hour emergency hotline. When calling the emergency number, first responders or police can access your complete medical history and your emergency contact information.







The Impact on Families When There Is a Dementia Diagnosis

- **1. Emotional Strain**: Family members often experience grief, sadness, anger, guilt, and confusion as they adjust to the diagnosis.
- **2. Role Reversal**: Adult children may assume parental responsibilities, which can feel unnatural and stressful.
- **3. Financial Stress**: The costs of care, medications, and potential loss of income can burden the family.
- **4. Changes in Family Dynamics**: Decision-making roles may shift, potentially causing tension or disagreements.
- **5. Increased Stress**: The constant care needs can exhaust family members physically and emotionally.



Why Am I So Angry?

- How could this have happened to my...?
- How could this have happened to ME?
- Our plans for our/my future are interrupted/over.
- How will I cope/care I don't have the patience or energy for this!
- WHY ARE THEY ACTING THIS WAY?!
- How will we afford care?
- What about MY life?
- I can't stand my... and now have to care for ...!



Common Caregiver Emotions & Coping Mechanisms

- Denial
- Guilt
- Anticipatory Grief
- Isolation and Stigma
- Anger
- Shame

YOU ARE NOT ALONE!



Find acceptance and avoid denial...

Let go of who the person used to be and embrace everything that they still can do.

"Many thanks but we are just not there yet."



Identify and accept as much support as possible in order to avoid caregiver burnout...



'The Anchoring Effect'



Navigate

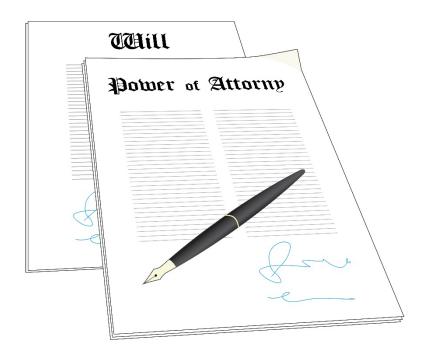
- Understand the role of the public healthcare system as it relates to home care, support services, palliative care and transition to long term care.
- Proper research is recommended if considering transition to a private residence or hiring a private homecare agency in order to ensure that staff are trained in dementia care.

IT IS IMPERATIVE TO BEGIN RESEARCHING INFORMATION AS SOON AS POSSIBLE – BE ONE STEP AHEAD OF THE DISEASE!



Plan for the Future

- Health and personal care
- Living arrangements
 - do your research and start early!
- Finances
- Legal and estate planning
- Advanced care planning
- The importance of a mandate!



Considerations for Planning a Transition to Receiving Home Care Support or Move to an Elder Care Home

- Carer's ability to provide appropriate care
- Managing basic activities of daily living: transferring, bathing, lifting, dressing and undressing, toileting, feeding and navigating stairs
- Managing behaviors: sundowning, confusion, wandering, physical and verbal aggression, hallucinations, paranoia, etc.
- Care partner's physical and mental health



The Importance of Self-Care

- Surround yourself with people and commitments that add positive energy and value to your life.
- As much as possible, set boundaries with people and projects that bring negative emotions... if it does not feel good, don't do it.
- Don't be afraid to say no, stop feeling guilty and please stop apologizing!

www.mcgill.ca/dementia



Dementia, Your Companion Guide

Download our free educational guide, now available in 14 languages!

English, French, Spanish, Italian, Greek, Portuguese, Russian, Ukrainian, Polish, Tagalog, Punjabi, Arabic, Mandarin and Cantonese.



McGill Cares

Watch our free webcast series featuring interviews with leading experts who explore topics related to caring for a person living with dementia.

Over 110 episodes posted on YouTube. Also available as audio podcasts.



World Alzheimer Reports

Read the 2021 and 2022 reports on the diagnosis and post-diagnosis treatment, care and support for people around the world who are living with Alzheimer's disease. This report was delivered by leading experts from our program.



Virtual Support Groups & Forums

The Sharing Room Caring Conversations Young Caregiver Community

Join our safe online spaces where care partners can learn from experts, share concerns and ask questions.



Public Lectures

Book a lecture!

We partner with community organizations and private companies to offer lectures that raise awareness and provide basic information on Alzheimer's disease and other forms of dementia.



Trusted Resources

Visit our website to access all of our free resources!

You will also find trusted links to external resources, services and organizations that support people with dementia and their care partners.



Dementia Activity Booklet & Video Capsules

Download our free virtual toolkit and watch our video capsules!

Access over 40 recreational activities designed to engage a person with dementia, and learn how to adapt the activities to the person's needs.



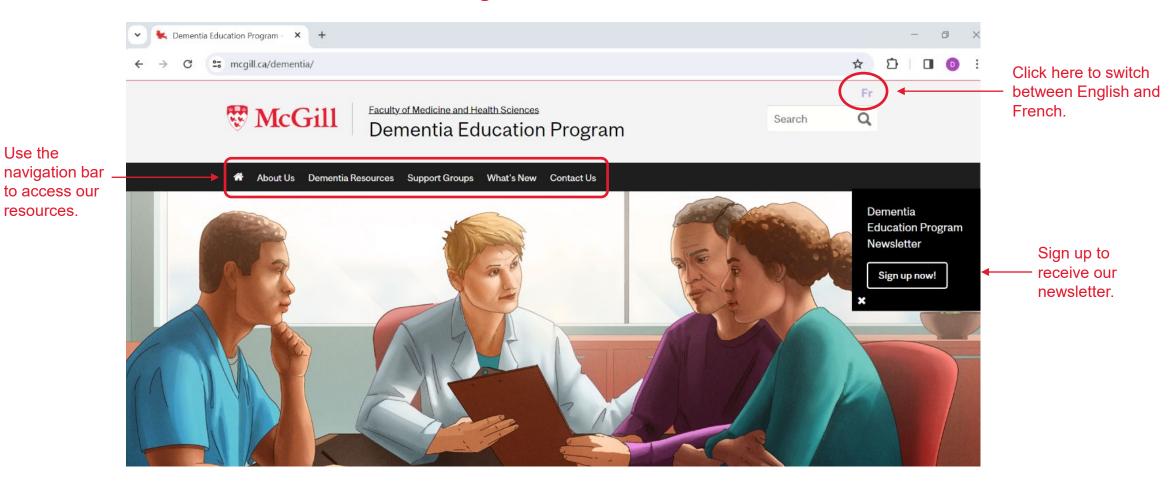
Dementia Education for Care Partners - New Online Program

Register for this free self-guided online course!

It features 10 modules created by experts to educate and support you throughout your journey as a care partner to a person living with dementia.

All our free resources can be found on our bilingual website

www.mcgill.ca/dementia

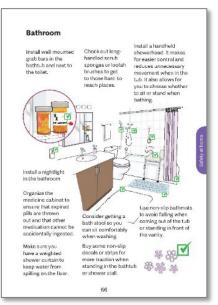


Dementia, Your Companion Guide

- Currently available in English, French, Spanish, Portuguese, Italian, Greek, Punjabi, Mandarin,
 Cantonese, Ukrainian, Russian, Polish, Tagalog, and Arabic... with other languages currently under translation.
- Available to download for free at www.mcgill.ca/dementia or purchase a printed copy for \$20
 CDN with all proceeds going to support the Dementia Education Program.











New Online Program to Support Care Partners



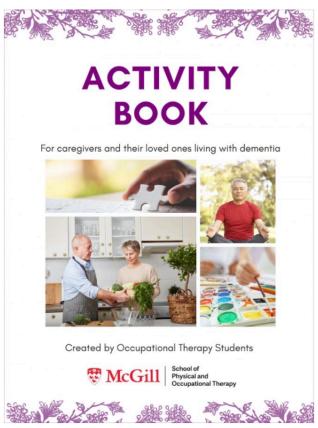
- This online program was designed to educate and support individuals through their journey as care partners for a person living with dementia.
- The program consists of **ten online modules** that the participant can go through at their own pace.
- The content includes expert advice, shared experiences from participants, and solutions to the challenges of being a care partner in the context of dementia.
- This program is free and open to all.
- · Available in English and French!
- While the information provided in this course addresses universal concerns that are applicable to most care partners, note that information regarding the legal framework, tax credits, and health & social services resources are specific to Quebec, Canada.

The online platform was developed in collaboration with the McGill Office of Ed-TECH with funding from the Public Health Agency of Canada to raise awareness of dementia and promote dementia-inclusive communities.



The Importance of Leisure and Recreational Activities to Stimulate Persons Living with Dementia







Activity Booklet and Video Capsules

The **Dementia Activity Booklet** is a very engaging virtual toolkit that offers over **40 recreational activities in 6 different categories**, with instructions on how to adapt the activities to the needs of the individual. It is available to download for free in both English and French.













McGill Cares

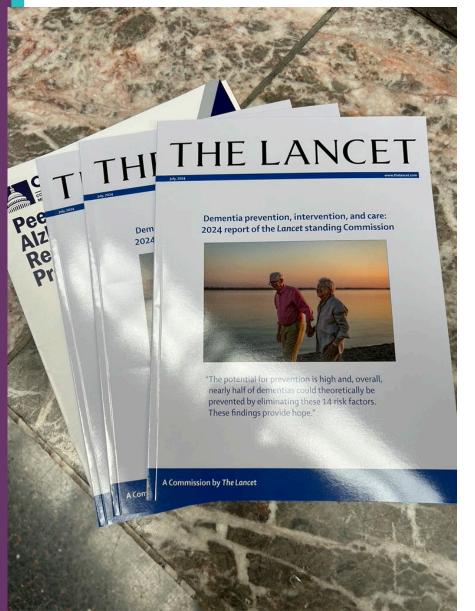


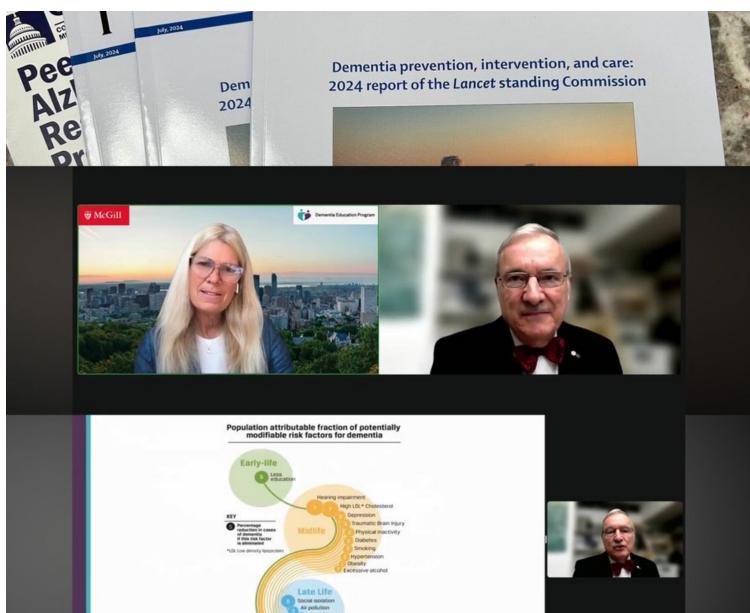
- During candid, 30-minute interviews with leading experts, Claire Webster explores topics related to caring for a loved one with dementia.
- We have over 110 webcasts available on our website to view at your convenience.

These webcasts are also available as audio podcasts on Spotify, Google Podcasts, and PocketCasts, among others.

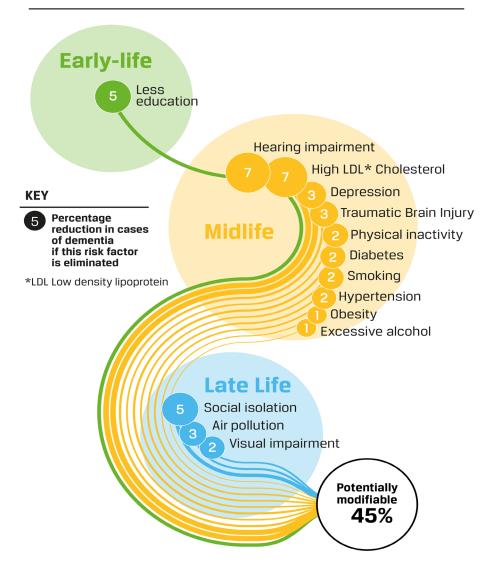


McGill Cares – Dr. Serge Gauthier – September 18, 2024 www.mcgill.ca/dementia





Population attributable fraction of potentially modifiable risk factors for dementia



Livingston, G., Huntley, J., Liu, K. Y., et coll. « Dementia prevention, intervention, and care: 2024 report of the Lancet standing Commission. » The Lancet 2024, publié en ligne le 31 juillet. https://doi.org/10,1016/S0140-6736(24)01296-0.

Fraction attribuable à la population des facteurs de risque potentiellement modifiables de troubles neurocognitifs

Petite enfance

5 Faible niveau d'éducation

CLÉ

5 Pourcentage de réduction des cas de troubles neurocognitifs si le facteur de risque est éliminé

*LDL : lipoprotéine de faible densité

Milieu de la vie

- Déficience auditive
- Taux élevé de cholestérol LDL*
- 3 Dépression
- 3 Lésion cérébrale traumatique
- 2 Inactivité physique
- 2 Diabète
- 2 Tabagisme
- 2 Hypertension
- Obésité
- Consommation excessive d'alcool

Vieillesse

- 5 Isolement social
- 3 Pollution atmosphérique
- 2 Déficience visuelle

Potentiellement modifiable 45 %

Virtual Support Groups

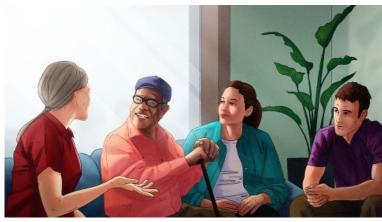


Caring Conversations

An online forum for care partners to learn from experts, share concerns and ask questions.



Moderated by social worker **Lucy Barylak** and professional coach/educator **Joanne Besner**.



The Sharing Room

A safe online space for care partners to connect and share their experiences



Young Caregiver Community

A supportive space for care partners who are looking after a person with young-onset dementia.





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www.instagram.com/mcgilldep/

Contact us dementia@mcgill.ca





Q & A ?

Session Wrap Up

- Thank you for joining us!
- Please fill out the feedback survey following the session—a link has been added into the chat

Thank You





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