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# Navigating the Journey of Caring for a Loved One with Dementia



McGill



This webinar is dedicated to the memory of my mother, whom I had the honor to accompany on her journey with Alzheimer's disease.

***Vieno Annikki Leskinen***

***June 23, 1932- May 6, 2016***





*“I deeply believe that if I had been properly educated upon my mother’s diagnosis and told that I would need support, I would have been a better caregiver to my mother. I was frustrated and did not understand her behaviour.”*

Claire Webster, Alzheimer’s Care Consultant  
and Facilitator



passageaidant  caregivercrosswalk

N'y allez pas seul. Never roam alone.

FRANÇAIS

ENGLISH



## Caregiver Crusader

Certified Dementia Care Consultant,  
Founder of Caregiver Crosswalk Inc.

[www.carecrosswalk.com](http://www.carecrosswalk.com)



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Faculty of  
Medicine and  
Health Sciences

# Dementia Education Program

[www.mcgill.ca/dementia](http://www.mcgill.ca/dementia)



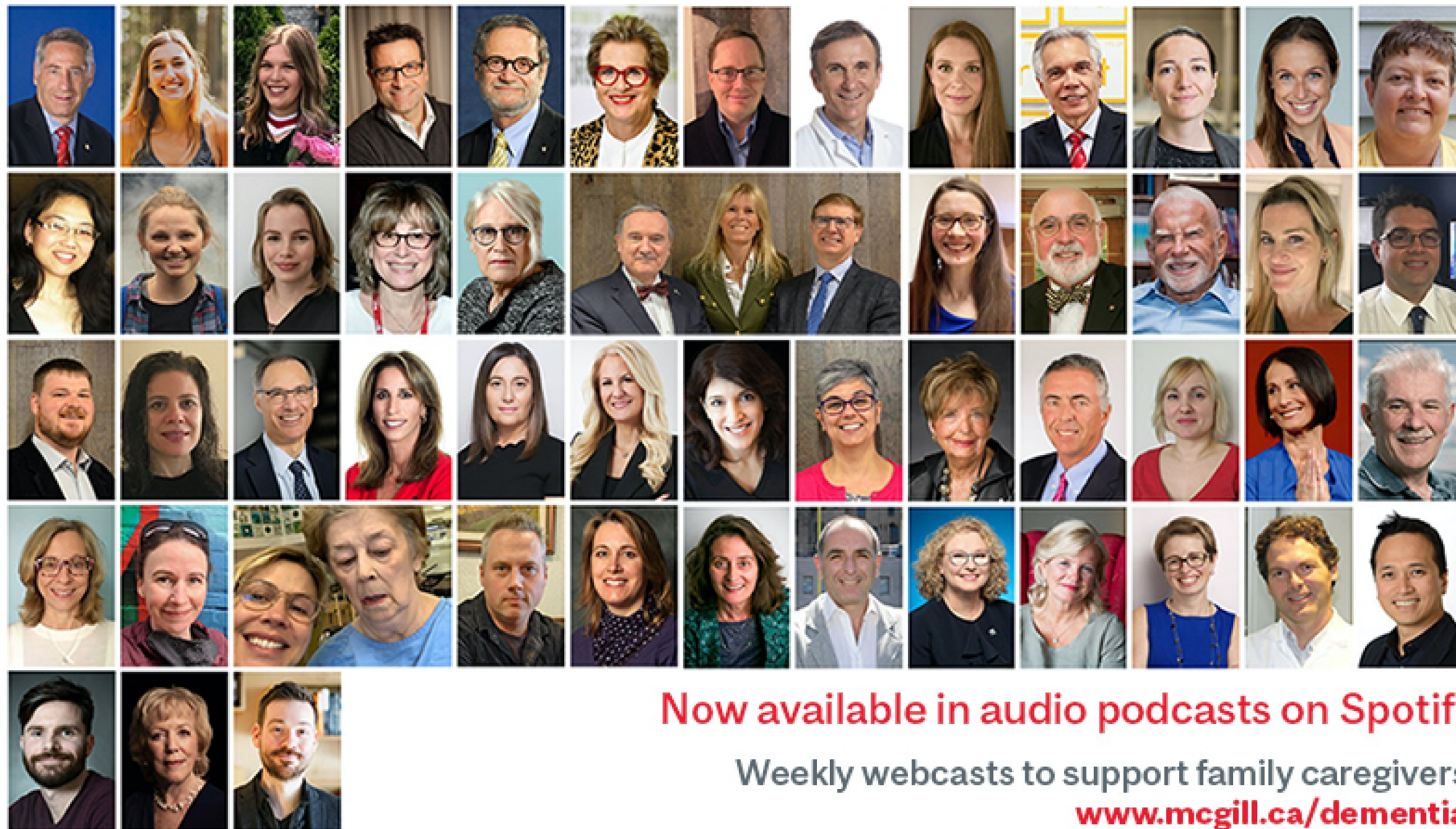
# PROGRAM OBJECTIVES

- *Educate*
- *Anticipate*
- *Navigate*
- *Advocate*
- *Facilitate Connections*  
(New) – “The Sharing Room”



# McGill Cares

Dementia Education Program



Now available in audio podcasts on Spotify

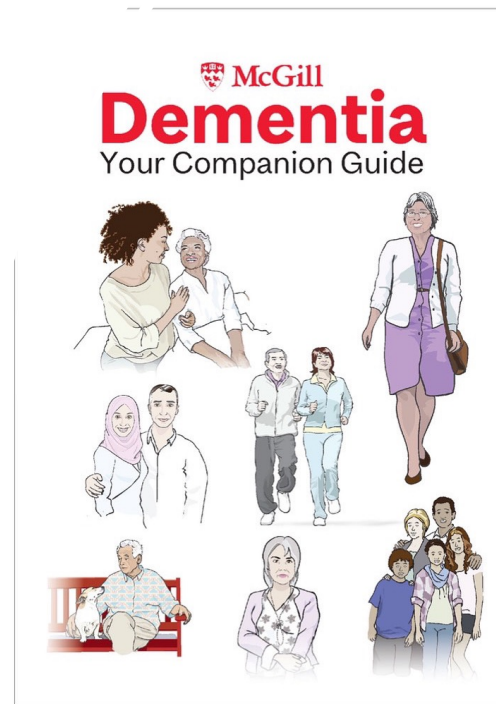
Weekly webcasts to support family caregivers

[www.mcgill.ca/dementia](http://www.mcgill.ca/dementia)

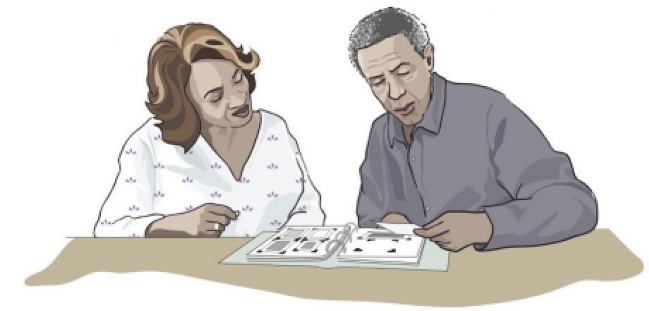
# Dementia Companion Guide Book

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- FREE printed booklet to be distributed throughout MUHC - Memory Clinics, Geriatric Division and hope to expand distribution to CLSC network.
- FREE downloadable PDF and interactive E-book available on DEP website.
- Will be available in more than 8 languages.
- Worldwide audience.



Thank you to the  
Grace Dart Foundation  
for their support.





# Family / Friend Caregivers Program: TOTAL E-Learning

Module 1: Understanding Dementia

Module 2: Assisting with Activities of Daily Living

Module 3: Safety and Fall Prevention

Module 4: Managing and Responding to Challenging Behaviours

Module 5: Planning for the Future: Legal, Financial and Long-Term Care

Module 6: Leisure and Recreational Activities

Module 7: Navigating the Health Care System and Accessing Support

Module 8: Coping with Grief, Loss and End of Life Care

Module 9: Caring for the Caregiver

Module 10: Healthy Aging and Preventing Cognitive Decline

# World Alzheimer Report 2021 committee

The 2021 and 2022 World Alzheimer Report will be overseen by the McGill University Research Centre in Studies in Aging and the McGill Faculty of Medicine and Health Sciences, specifically the Division of Geriatric Medicine and the Dementia Education Program, supported by the Office of Education Technology and Online Learning at the Steinberg Centre for Simulation and Interactive Learning.





## Meet the team

### **Dr. Serge Gauthier, Director of the Alzheimer Disease and Related Disorders Research Unit of the McGill University Research Centre for Studies in Aging; Professor, Departments of Neurology & Neurosurgery, Psychiatry, and Medicine at McGill University**



Serge Gauthier is a Clinical Neurologist specialized in the development of new tools for diagnosis and treatments for people suffering from Alzheimer's disease. He was appointed Director of the McGill University Research Centre for Studies in Aging in 1986. In 1997, he became a Senior Scientist of the CIHR-Rx&D program (Canadian Institutes of Health Research and Canada's Research-Based Pharmaceutical Companies). His accomplishments ultimately led to his appointment as Director of the Alzheimer Disease Research Unit of McGill University in 2000. Furthermore, he is also the author and editor of several books, including Management of Dementia (2nd ed. - 2009), Clinical Diagnosis and Management of Alzheimer's Disease (3rd ed. - 2007), Pharmacotherapy of Alzheimer's Disease (1998), and Alzheimer's Disease in Primary Care (2nd ed. - 1997).

His internationally recognized work led to his introduction into the National Order of Quebec (2017) and the National Order of Canada (2014). He received the Prix d'Excellence (2009), the Irma Parhad Award (2009) and the Prize Gallien (1997) for his continued efforts in improving conditions for those suffering from Alzheimer's disease. His personal interests lie in the management of dementia in different stages, the ethics of research involving individuals with Alzheimer's disease, and primary prevention strategies against cognitive decline and Alzheimer's dementia.

### **Dr. Pedro Rosa-Neto, Director of the McGill University Research Centre for Studies in Aging; Professor, Departments of Neurology & Neurosurgery and Psychiatry, McGill University**



Pedro Rosa-Neto is a Clinical Neurologist with expertise in the quantification of dementia pathophysiology and preclinical diagnosis of Alzheimer's disease using biomarkers.

After years of delivering outstanding work in the field of Alzheimer's disease in both a research and consultancy setting, he was appointed Director of the McGill University Research Centre for Studies in Aging in 2017. This was soon followed by a Full Professor position in Neurology at McGill University in 2019. Furthermore, he was recently given the position of Adjunct Professor at the Department of Biomedical Science and Engineering at the Gwangju Institute of Science and Technology (2020). His outstanding work also came with several recognitions such as Fonds de la recherche en santé du Québec

(FRSQ) Senior Scholar and the leadership role in the Team II Canadian Institutes of Health Research (CIHR-CCNA).

### **Dr. José A. Morais, Professor, Department of Medicine at McGill University; Director, Division of Geriatric Medicine, School of Dietetics and Human Nutrition, Department of Experimental Medicine**



José A. Morais is Full Professor of Medicine at McGill University. He is Senior Scientist at the Research Institute of the McGill University Health Centre (MUHC) in the Metabolic Disorders and Complications axis, in Montreal, Canada. In 2009, he became Director of the Division of Geriatric Medicine, McGill University, as well as of MUHC and Jewish General Hospital. Dr. Morais is also co-Director of the Quebec Network for Research on Aging and is Lead of the Dementia Education Program of the McGill Faculty of Medicine and Health Sciences.

He was the Founder and first Director of the Centre of Excellence on Aging and Chronic Disease of the RUIS McGill from 2012-2015. During this time, he was co-leader of the implementation of the Quebec Provincial Alzheimer's Plan in

Primary Care. He is also Past President of the Canadian Geriatrics Society. His research interest relates to the assessment of protein metabolism and cellular regulation at whole-body and muscle levels and of protein requirements with age, frailty and diabetes using stable isotopes methodology. He is also participating in several studies involving the nutritional assessment of elderly persons with the aim of improving their nutritional status and level of physical function.

He shares an interest in improving services and care to people living with dementia afflicted with chronic diseases. He holds grants from the Canadian Institutes of Health Research and collaborates in several projects supported by provincial and national agencies. He has more than 150 original publications, most of them in high impact journals in the field of aging, nutrition and metabolism.

### **Claire Webster, Founder and Ambassador, Dementia Education Program, McGill University; Founder and President of Caregiver Crosswalk Inc.**



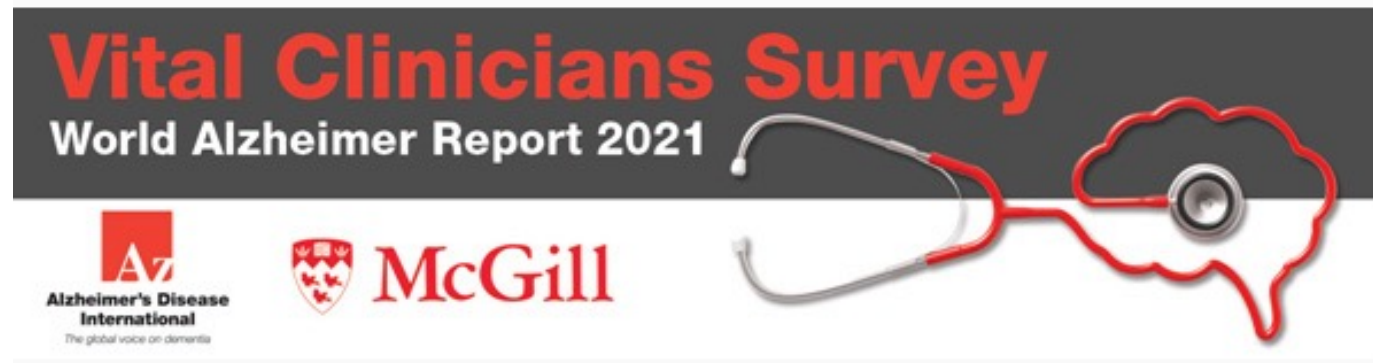
Claire Webster is a Certified Alzheimer Care Consultant (PAC), Certified Professional Consultant on Aging (CPCA), as well as a conference speaker and educator in the field of caring for an individual with dementia. She is Founder and President of Caregiver Crosswalk Inc., a consulting firm that provides education and support services to help individuals navigate the journey of Alzheimer's disease and/or dementia related illnesses.

Claire works in collaboration with McGill University's Faculty of Medicine and Health Sciences and the Division of Geriatric Medicine. She is the Founder and Ambassador of the McGill Dementia Education Program and "McGill Cares", a weekly webcast series designed to support family care partners.

As a former care partner to her late mother, Claire has had first-hand experience in dealing with the overwhelming emotional and physical impact that the disease places on the individual and family members. In this project, she will take on the role of patient partner and will guide the development of the report for family/friend care partners of people living with dementia, to ensure the engagement of people with lived experience.

# World Alzheimer Report

- McGill University has been commissioned by [Alzheimer's Disease International](#) (ADI) to deliver the next two editions of the World Alzheimer Report on the crucial and inter-related topics of **A Journey Through the Diagnosis of Dementia** (2021) and **Post-Diagnostic Management and Support - A Prescription of Care** (2022).
- **Worldwide recognition** of McGill's leadership in dementia care
- Access to **102 membership associations** around the world
- Essays submitted by world leading experts







# Navigating the Journey of Dementia

It takes a Multi-Disciplinary Team of Health Care Professionals:

- Primary Care Physician
- Geriatrician
- Neurologist
- Nurse
- Physical and Occupational Therapist
- Social Worker
- Psychologist / Psychiatrist
- Dentist
- Nutritionist
- Other


## Roadblocks to obtaining a diagnosis of dementia:

- A lack of knowledge and awareness about the disease by the general public. Progressive cognitive decline and/or changes in behavior are often thought to be associated with normal ageing or depression or mistaken for other mental illnesses.
- Confusion about which healthcare professional to consult - Family doctor vs. Psychiatrist/Psychologist?
- Limited access to healthcare due to geographical locations, transportation restrictions and language barriers.
- Shortage of specialized healthcare care experts and accompanying diagnostic tools.
- Absence of health insurance coverage; or a lack of access to free public health care and/or limited finances.
- Stigma



# Telemedicine






**“A lack of EDUCATION about dementia will have a **SIGNIFICANT** impact on the quality of care as well as safety of the individual and their caregiver(s).”**



# The Ripple Effect of Dementia

- 
- Person with dementia
  - Caregiver
  - Caregiver's family and career
  - Career
  - Social life
  - Finances
  - Health Care System











# Anosognosia<sup>a</sup>

lack of awareness about their condition, may appear indifferent or unconcerned.



# 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



**NOW  
WHAT**





***“GOOD LUCK MRS.  
WEBSTER”***

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



**NOW  
WHAT**



**EXPECT THE  
UNEXPECTED**











# Common Caregiver Emotions & Coping Mechanisms

- *DENIAL*
- *GUILT*
- *ANTICIPATORY GRIEF*
- *ISOLATION*
- *ANGER*
- *SHAME*

**YOU ARE  
NOT ALONE!**






# Claire's Prescription of Care... Most Important Lessons Learned

# Caregiver Expectations

- **Happy**
- **Safe**
- **Clean**







**The Shock Factor...**Receiving news about a health condition that will “interrupt” your life.

# Most Frequently Asked Questions that go Unanswered:

- . What is dementia?
- . What are the symptoms and how does it progress?
- . Is there a cure?
- . Is there medication?
- . What type of care is required?
- . Will my loved one have to move? Can they continue to live at home?
- . What type of support is available?
- . How will the disease impact my life?

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COVID-19






# Arrive prepared for your first doctor's appointment (including telemedicine):

- . Medical history
- . List of medications
- . List of symptoms and concerns
- . Ask for clear “next steps”
- . Ask about risk of driving
- . Ask for information about the disease and resources



**Find acceptance and avoid denial... *“Many thanks but I’m just not there yet.”***



**Knowledge is the most powerful resource...Educate yourself about the disease, its progression and all of the resources available in your community that can provide support.**






## Plan for the future:

- . Health and personal care
- . Living arrangements
- . **Finances**
- . Legal and estate planning

***“The importance of a  
Mandate”***



**More than ever, during these unprecedented times, it is as important to have a Plan “A” as well as it is to have a Plan “B” regarding our wishes.**



ANDRÉ PICARD

HEALTH REPORTER AND COLUMNIST  
FOR THE GLOBE AND MAIL

# Neglected No More

The Urgent Need to  
Improve the Lives of Canada's Elders  
in the Wake of a Pandemic







# **Ensure a safe home/work environment inside and out...**

**In order to avoid falls and  
injuries.**

# Activities of Daily Living

Offer assistance as needed...with Care and Patience



# Understanding and Managing Challenging Behaviour

- . **Educate yourself** on the disease – “why” are they doing what they are doing?
- . **Pick your battles** - If what they are doing is not hurting them or others, let them be. What we may find to be “unusual behavior” may actually be very comforting to them.
- . Be a “Detective” and not a Judge
- . The Compassionate Lie
- . Join their journey
- . **Caregivers – how is YOUR approach/mood/energy?**

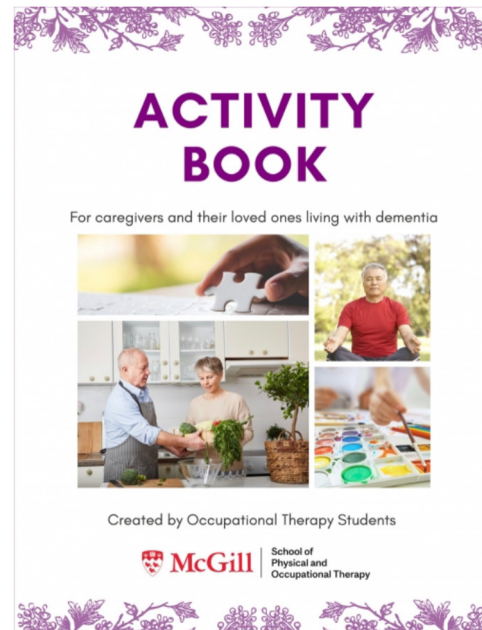
A red vertical bar on the left side of the slide. On the far left, there is a faint, semi-transparent image of a building with a dome and a flag on a pole. The flag has three figures on it.

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

**“The Anchoring Effect”**



**Keep Physically Active and Mentally Stimulated!** Embrace what they can still do and keep evolving your activities to accommodate the stages.



**Dementia Education Program**  
[www.mcgill.ca/dementia](http://www.mcgill.ca/dementia)

# ADVOCATE

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



# ANTICIPATORY GRIEVING



# 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”!





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