



Navigating the Challenges of Caring for a Loved One with Dementia

CLAIRE WEBSTER, PAC, CPCA

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



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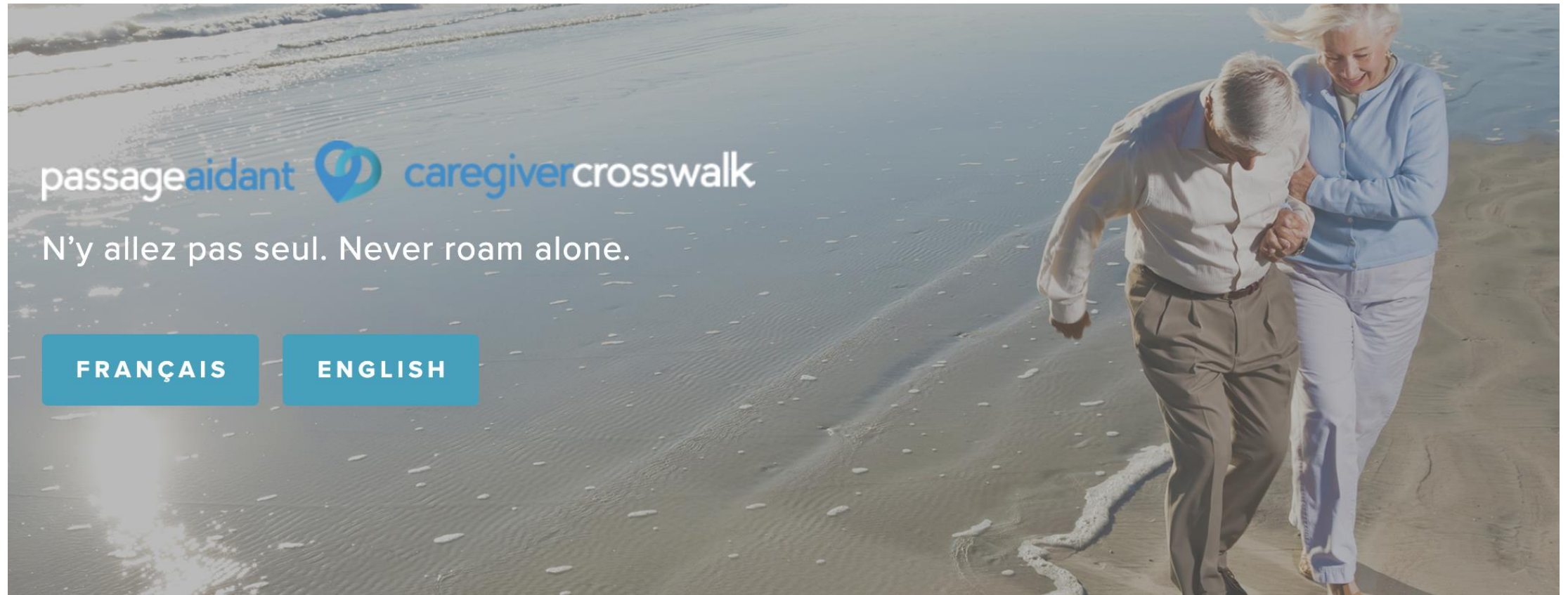


“I deeply believe that if I had been properly educated upon my mother’s diagnosis and told that I would need support, I would have been a better caregiver to my mother. I was frustrated and did not understand her behaviour.”

Claire Webster, Alzheimer’s Care Consultant
and Facilitator

Certified Dementia Care Consultant,
Founder of Caregiver Crosswalk Inc.
www.carecrosswalk.com

Caregiver Crusader





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Faculty of
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sciences de la santé



Dementia Education
Program

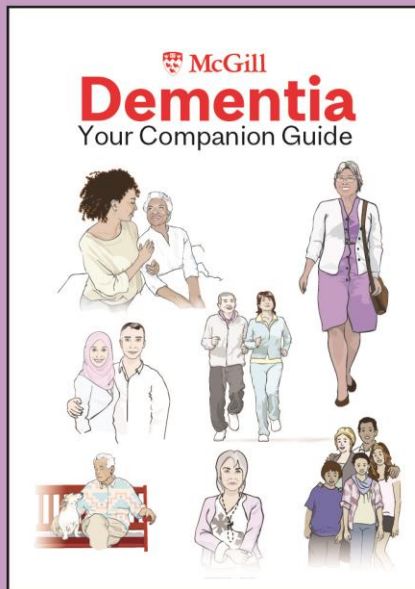
Programme de formation
sur la démence



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Dementia Companion Guide

- Currently available in English, French, Spanish, Portuguese, Italian, Greek and Chinese...with many 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.

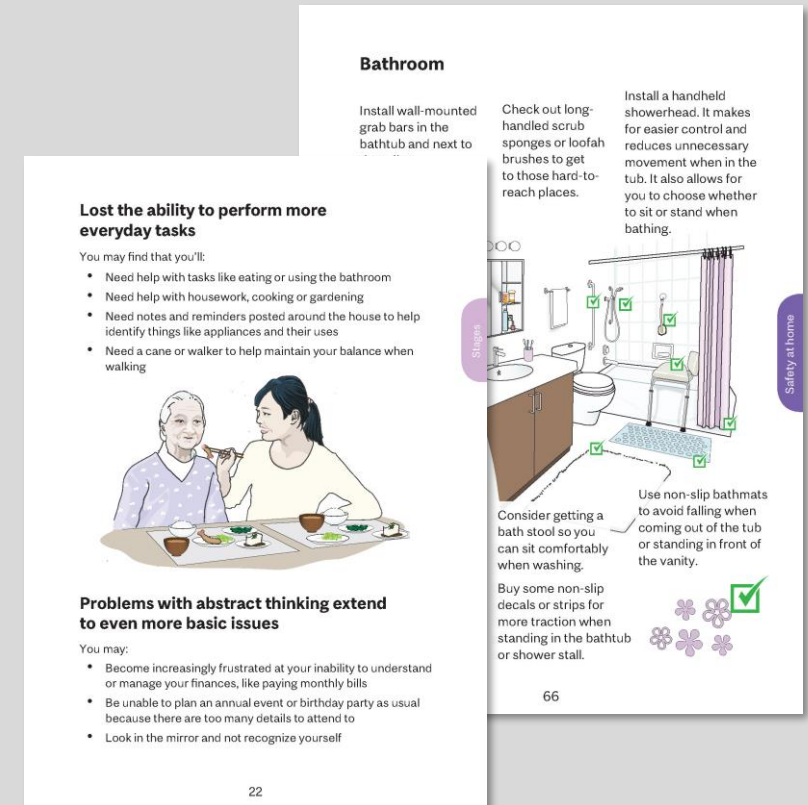


A free new educational guide for people living with dementia and their care partners.



Download the electronic version:
www.mcgill.ca/dementia

Thank you to the Grace Dart Foundation for supporting the creation of this guide.



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Dementia Education Program

Providing Virtual Support to Caregivers

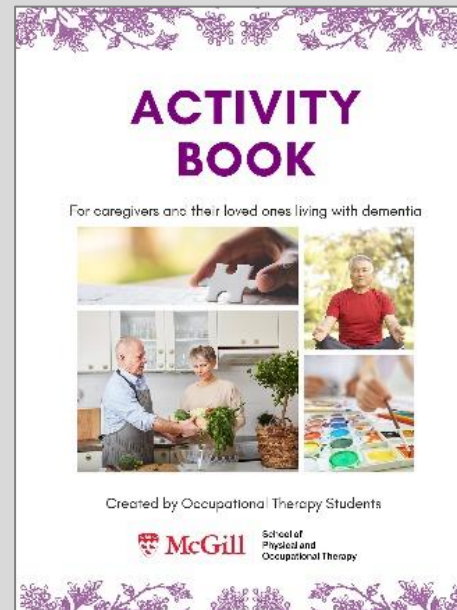
Initiatives launched to support family caregivers during the COVID-19 crisis.



McGill Cares weekly webcasts with leading experts to explore topics related to caring for a loved one with dementia.

**70 episodes posted on YouTube,
30,000+ views**

Also available as audio podcasts on Spotify, Apple, Google, and more.



Dementia Activity Booklet

3,500+ downloads



The Sharing Room virtual support groups for care partners of people living with dementia.



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Dementia Education Program



WORLD ALZHEIMER REPORT 2022
Life after diagnosis: Navigating treatment, care and support

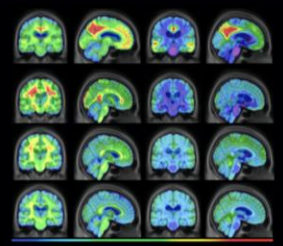
Report launch and panel discussion


World Alzheimer's Day 21 September
1pm London | 8am New York

World Alzheimer Report 2021

Journey through the diagnosis of dementia

Alzheimer's Disease International





World Alzheimer Report 2021
Journey through the
Diagnosis of Dementia

Expert essay

Navigating the journey of dementia after a diagnosis – a prescription of education and support

Claire Webster

Certified Dementia Care Consultant, Founder Caregiver Crosswalk Inc and Founder, McGill University Dementia Education Program, CANADA

Accept, educate, plan ahead navigate, advocate

There are guiding principles that I wish I had known during my mother's Alzheimer's disease diagnosis in September, 2006. She was 74 years old when I took her to the neurologist after consulting with our family physician about her unusual behaviour and significant personality changes following the death of my father in 2005. My mother had been a physically active, independent, and outgoing woman, but over an 18-month period, had become socially withdrawn and impatient, suffering severe mood swings ranging from bouts of anger to depression. She had increasing difficulty managing her finances and preparing meals for herself. She developed a fear of stairs and had zero tolerance for loud noise, often putting her hands over her ears while rocking back and forth in distress. My mother became obsessed with the next-door neighbour, convinced she was operating a cocaine lab (which was definitely not the case). I also noticed that her car had numerous dents and marks that indicated a series of accidents, and that her summer tyres had not been rotated for the winter months.

A few symptoms had begun to appear a year prior to my father's passing. He would often point these out, but I refused to acknowledge them as anything more than her experiencing carer stress. When the symptoms began to worsen after my father's death, I thought my mother was suffering from depression and grief. She'd been his primary carer for over 30 years. My concerns intensified when I realised that she was no longer able to manage her finances and pay for household expenses. She began donating money to the same charity multiple times a year and having unjustified, random expenses. She was often confused, had difficulty finding her words and started to use odd and inappropriate language in the presence of my young children, often screaming at them for no reason. She had also been hoarding hundreds of empty plastic fruit containers that I found in her kitchen cabinets as well as keeping expired food in the refrigerator.



Me and my mother, Vieno Leskinen, Montreal, Quebec, Canada, April 2015.

I decided it was time for her to see a doctor. I didn't know who to consult as her symptoms were more behavioural than physical. Against her will, and in full denial of anything being wrong, I made an appointment with her family doctor, who then referred us to a neurologist. He asked us a series of questions about my mother's cognitive and physical well-being while she sat beside me, in great frustration, refusing to accept or admit to any of the information that was being shared. Her medical history included high cholesterol and a minor stroke at the age of 68. There was a history of cardiac issues in her family and she herself would suffer a heart attack three years post diagnosis a few hours following hip replacement surgery.

The neurologist performed the MoCA (Montreal Cognitive Assessment Test). She scored 17/30. The neurologist then informed us that she had Alzheimer's disease, and upon learning that she was still driving, immediately called the driver's licensing bureau, and without any warning, had her driver's licence cancelled while we were still sitting in his office.

About the authors



Serge Gauthier

Serge Gauthier is a clinical neurologist specialising in the development of new tools for diagnosis and treatments for people living with Alzheimer's disease. He was the Director of the McGill University Research Centre for Studies in Aging from 1986 to 1997, and became a senior scientist of the CIHR-Rx&D program (Canadian Institutes of Health Research and Canada's Research-Based Pharmaceutical Companies) in 1997. Dr. Gauthier is the Academic Co-Lead for the Dementia Education Program and Professor Emeritus, Neurology and Psychiatry at McGill University. His accomplishments led to him being appointed to the Order of Canada in 2014 and the National Order of Quebec in 2017.



Pedro Rosa-Neto

Pedro Rosa-Neto is a clinical neurologist with expertise in the quantification of dementia pathophysiology and preclinical diagnosis of Alzheimer's disease using biomarkers. He is affiliated with the Douglas Research Institute; le Centre intégré universitaire de santé et de services sociaux (CIUSSS) de l'Ouest-de-l'île-de-Montréal; and the Departments of Neurology and Neurosurgery, Psychiatry and Pharmacology and Therapeutics at McGill University. He was appointed Director of the McGill University Research Centre for Studies in Aging in 2017. This was soon followed by a Professor position in Neurology at McGill University in 2019.



José A. Morais

José A. Morais is Professor of Medicine at McGill University. He is a senior scientist at the Research Institute of the McGill University Health Centre (RI-MUHC) in the Metabolic Disorders and Complications axis. In 2009, he became Director of the Division of Geriatric Medicine, McGill University, as well as of the MUHC and Jewish General Hospital. He is also Co-Director of the Quebec Network for Research on Aging and is the Academic 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 RUISSS McGill from 2012–2015.



Claire Webster

Claire Webster is a Certified Dementia 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.

Acknowledgements

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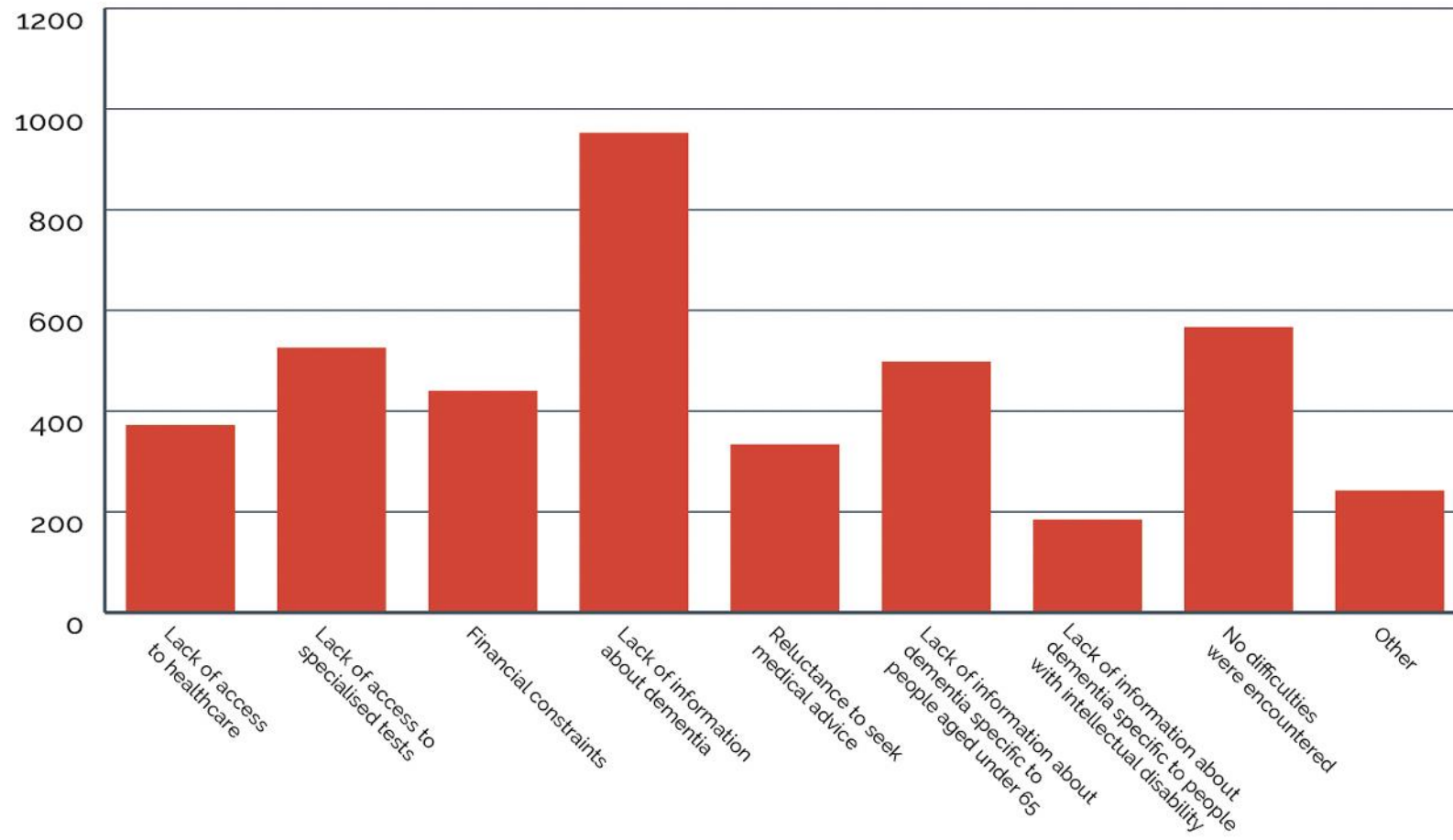
Chapter 16 Initial management following a diagnosis of dementia


Claire Webster

Key points

- Increased education about dementia will have a significant positive impact on the quality of life of people who have been diagnosed with dementia as well as their carers.
- The World Alzheimer Report survey suggests that the greatest difficulties encountered upon receiving the diagnosis of dementia were lack of adequate information (54%), access to specialised tests (28%), financial constraints (25%) and access to healthcare services (21%).
- People with dementia and carers should be provided with information about the type of dementia they face and potential changes in decision-making capacity.

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





“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).”**



October 23, 2004






“GOOD LUCK MRS. WEBSTER”

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




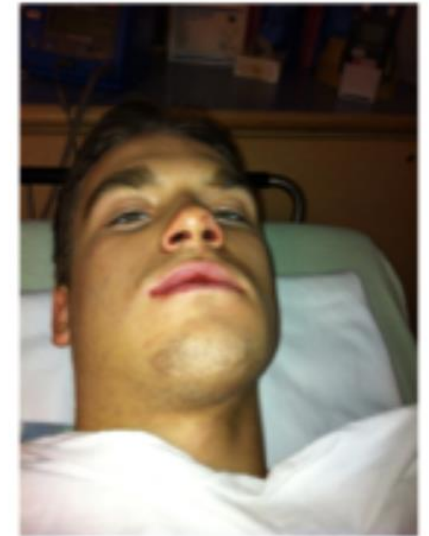
**NOW
WHAT**



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

The Ripple Effect of Dementia

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





November 27th 2008 – April 3, 2009

The collage includes a photo of a caregiver and an elderly woman, a diagram of a hip replacement surgery, a heart with a pulse line, a walker, and a close-up of a hand with a bandage.

Claire Webster, Caregiver Crosswalk Inc.

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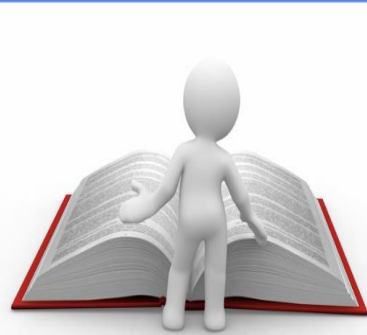
LACK OF COMPASSION FROM HEALTH CARE SYSTEM!

Homologation of a mandate
in anticipation of incapacity

Assisted
Living

VS

Home
Care



Financial Planning

Life Insurance

Funeral Wishes

Navigate & Advocate

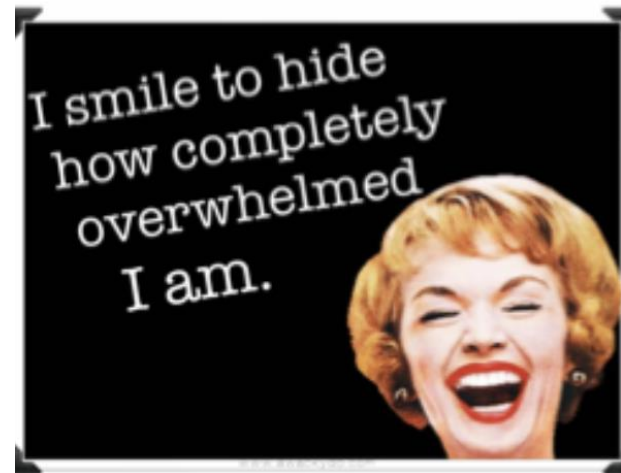


Anticipatory Grieving and Coping with Loss





“Many thanks but I’m just not there yet.”



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 ...!

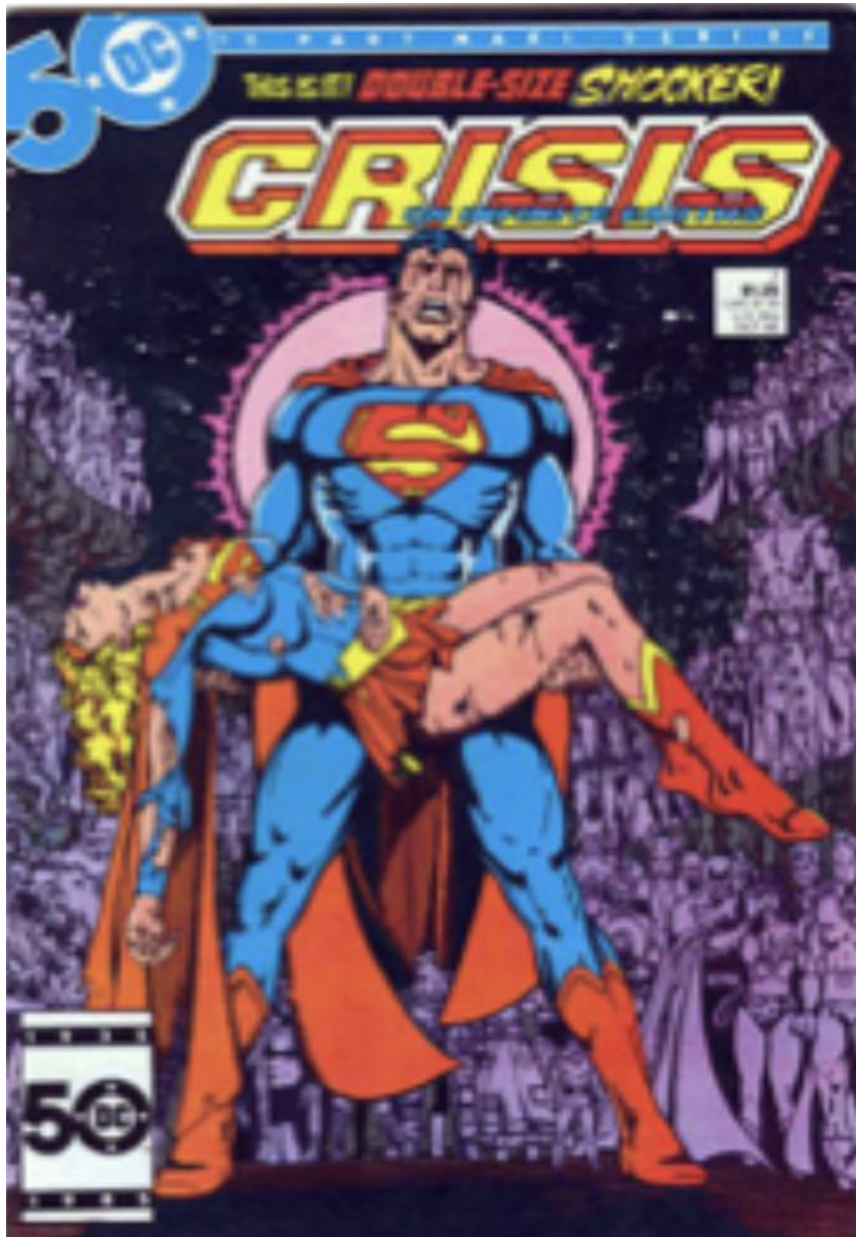


Common Caregiver Emotions & Coping Mechanisms

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

**YOU ARE
NOT ALONE!**





Warning Signs

CONSISTENT and PERMANENT feelings or behavior...

- Angry outbursts, irritability or frustration.
- Feelings of sadness, emptiness or unhappiness.
- Loss of interest or pleasure in social activities (isolation).
- Sleep disturbances.
- Lack of energy.
- Self-medication.
- Unexplained physical problems.
- Appetite and weight changes.
- Suicidal thoughts.



caregivercrosswalk

***Change Happens When You and/or Others
Have Suffered Enough...***





Navigating the Journey of Dementia After a Diagnosis


A Prescription of Education and Support

Accept
Educate
Plan Ahead
Navigate
Advocate


Caregiver Expectations

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





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.



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

A red-tinted image of a building dome and flag is positioned on the left side of the slide. The flag features a crest with three birds. The building has a prominent dome and classical architectural details.

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

“The Anchoring Effect”



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



Plan for the future:

- Health and personal care
- ***Living arrangements – do your research and start early!***
- **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.



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?**



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.

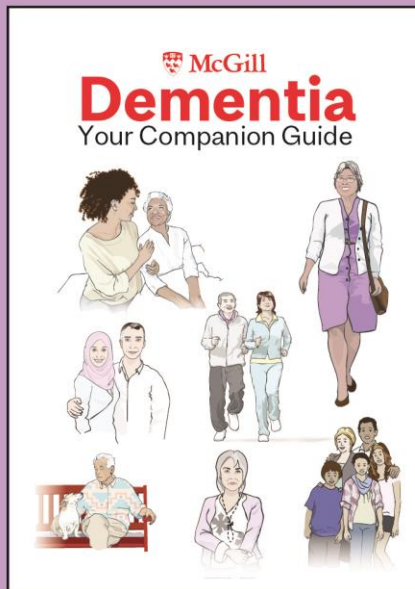
- . Don’t be afraid to “say no”, stop feeling “guilty” and please stop “apologizing”!

Give yourself permission to have a life.



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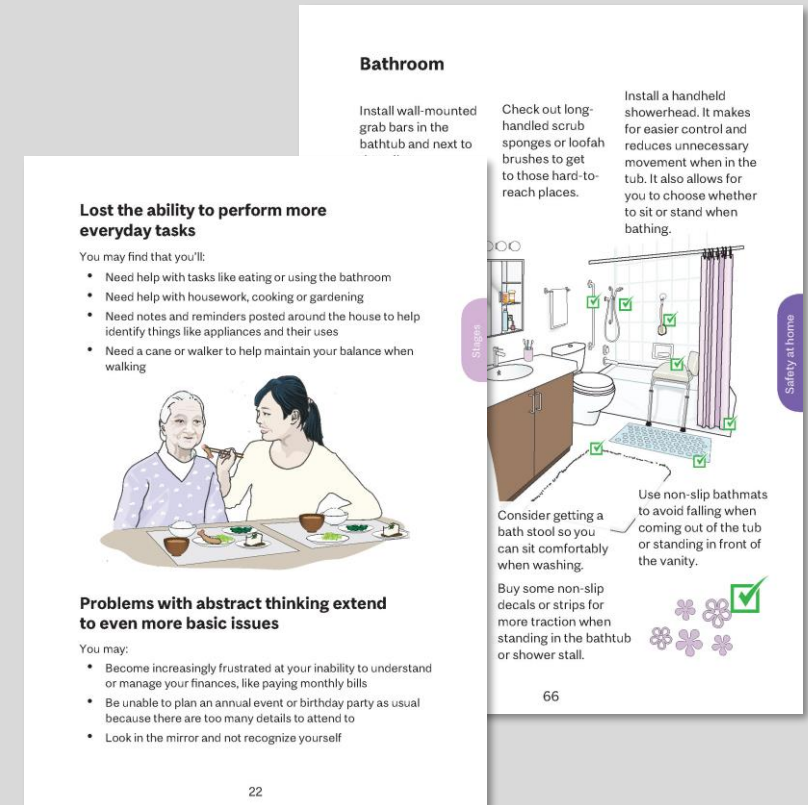


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QUESTIONS?