

Caregivers and Care Partners – Reducing Burden



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CLINICAL
NEURO
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CALGARY + CANADA



UNIVERSITY OF CALGARY
O'Brien Institute for Public Health

Disclosures

- No relevant conflicts for this topic

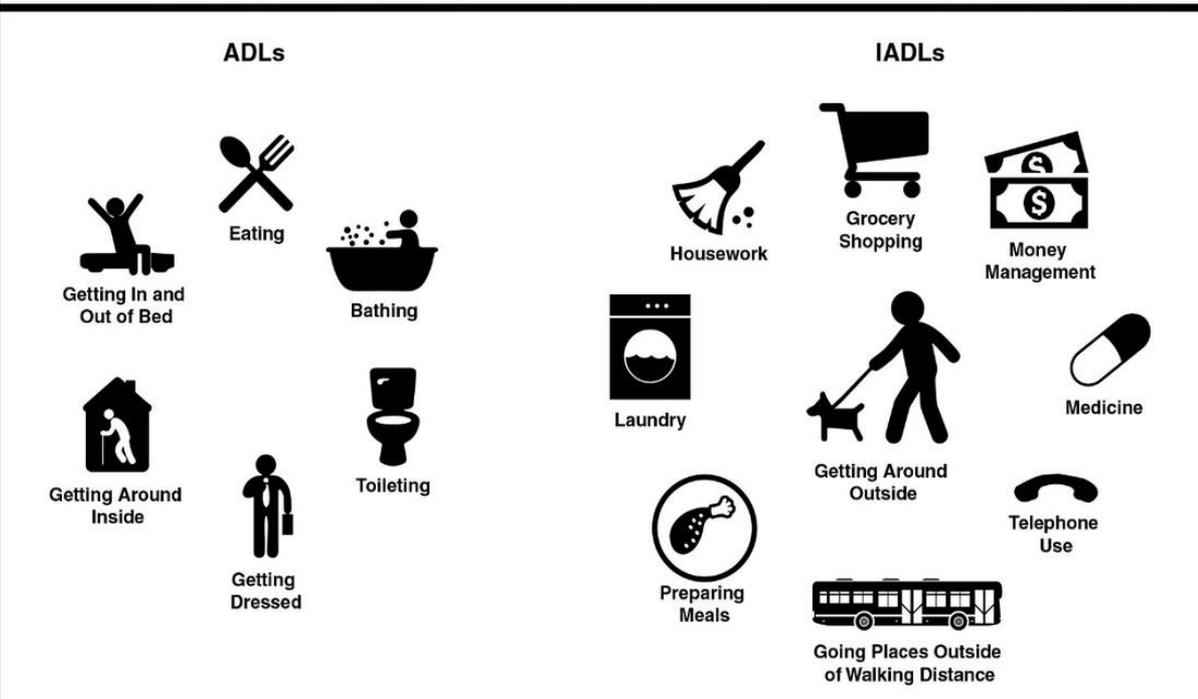
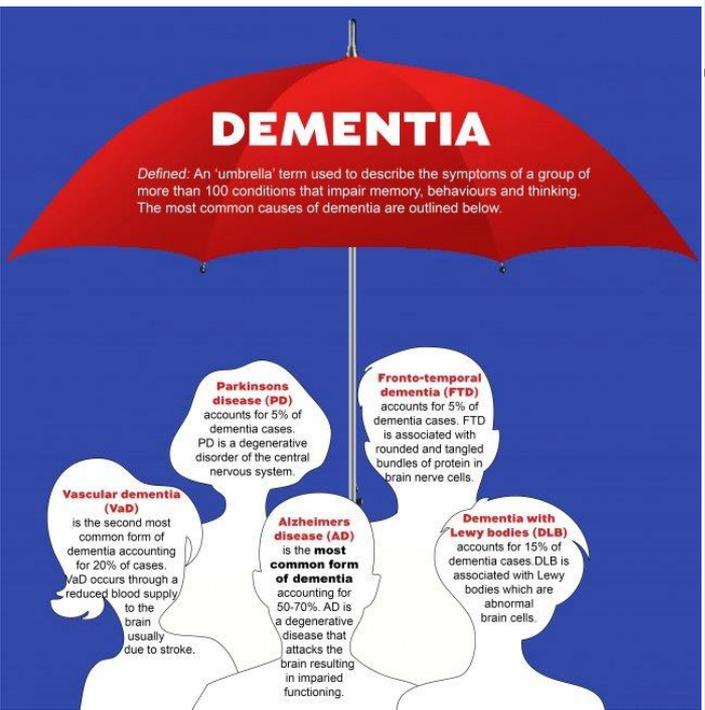
Objectives

- 1) describe an overall framework for assessing stress
- 2) provide clinical examples of contributors to stress
- 3) review preliminary data from formal and informal Canadian caregivers

Dementia: a clinical syndrome marked by progressive decline in memory, thinking, and behaviour that interferes with function

Figure 1

Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs)



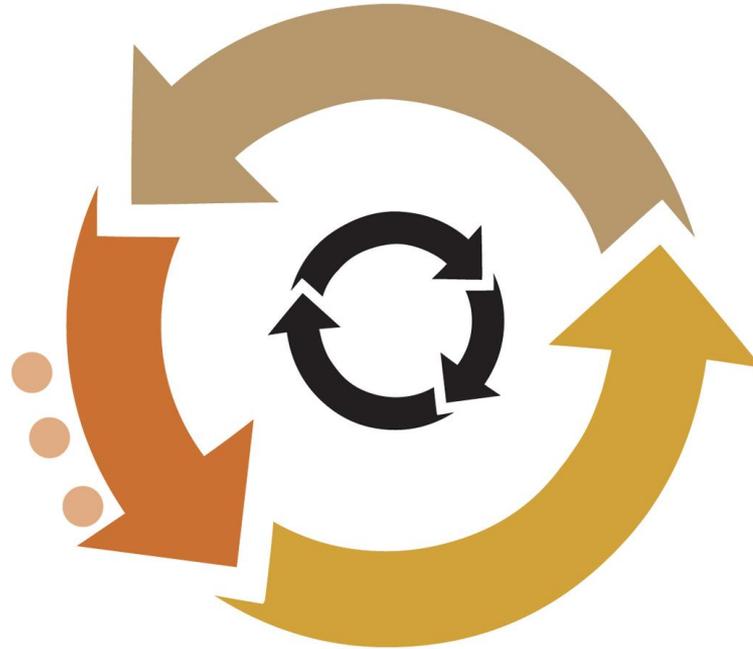
Attendant with progressive impairment of cognition, behaviour, and function is a need for caregiving



Stress: synonymous with distress: “a condition or feeling experienced when a person perceives that **demands** exceed the personal and social **resources** the individual is able to mobilize”

Attendant with progressive impairment of cognition, behaviour, and function is a need for **caregiving**

Fewer services and reduced provision of support result in more care responsibilities falling on **family/friend care partners**, greater stress and burden, and a greater need for dementia services



Greater stress, burnout, and turnover in **formal caregivers** results in higher turnover and poorer services provided to PWD and their care partners

Caregiver burden statistics

- Working Dementia Care Partners: Challenges and Needs
 - 73.7% of working care partners are exposed to **high levels of caregiver stress**
 - 46.2% of working caregivers have symptoms of **depression**

Critical shortage of dementia caregivers

- **Demand and Supply of PSWs:** The number of seniors requiring care is expected to double in 20 years. However, there is a shortage of PSWs to meet this demand, resulting in long wait times for home care services
- Post-COVID effects
- Studies are few on formal caregiver stress

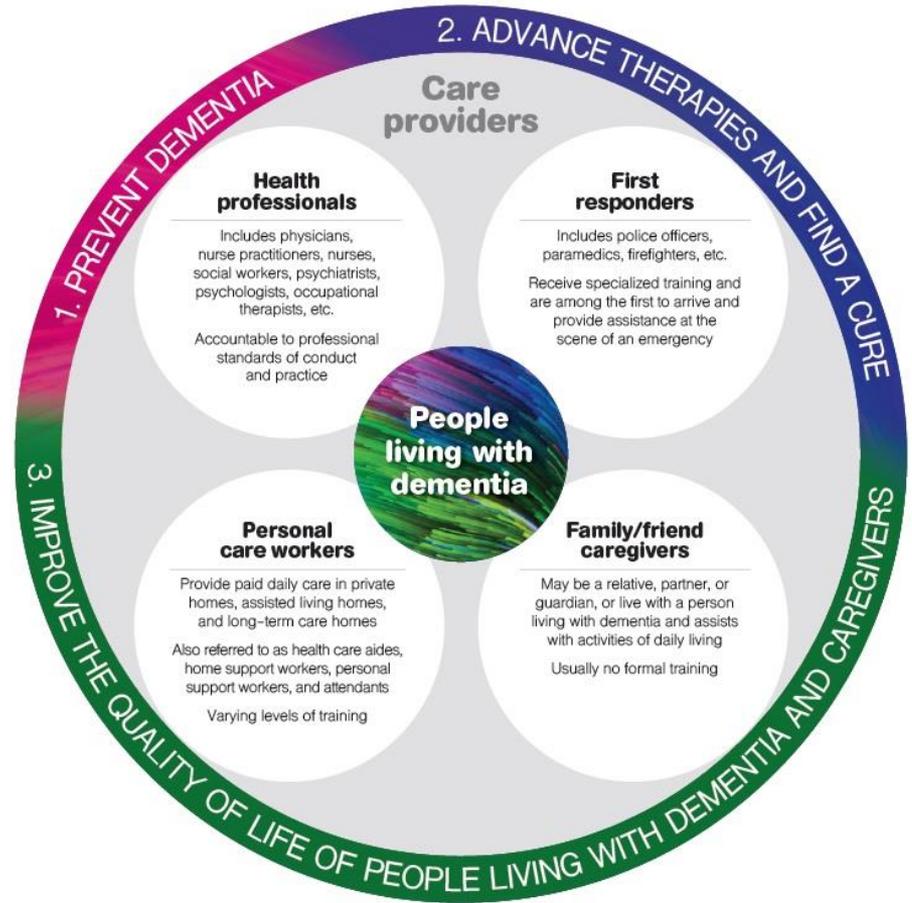
Resilience

Three inter-related domains of factors influence carers resilience:

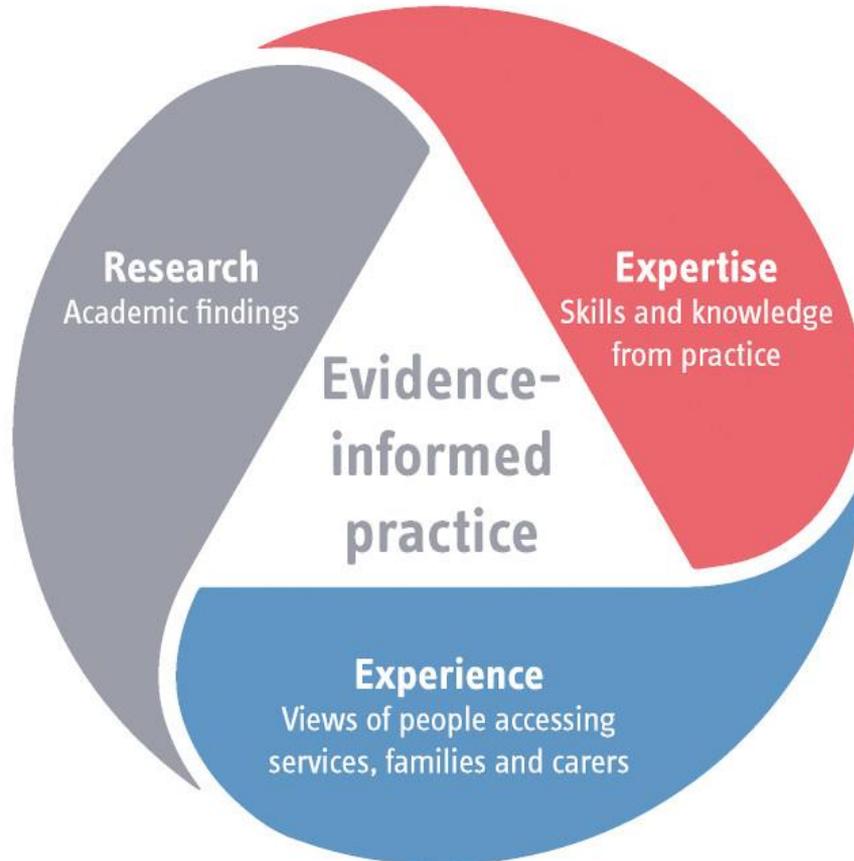
- social and cultural factors
- properties of the care relationship
- carer psychological factors

National Dementia Strategy

Ministerial Advisory
Board for Dementia
provides **evidenced-informed**
input on the strategy



There are many unanswered questions



- Online study of brain aging
- Canada-wide
- Annual assessments
 - Cognition, Function, Behaviour
 - Lifestyle, Quality of Life
 - Demographics (sex, gender, ethnocultural background, cognitive reserve)
 - Vitamin D, menopause, exercise, etc.
 - Brain Training Games
 - Newsletter
 - YouTube channel
- Nested **caregiver** sub-study
 - Family caregivers
 - Professional/paid caregivers (e.g., PCA, LPN, RNs, Physicians, SW, RT, OT etc.)

CAN⁺PROTECT

Are you or have you been a caregiver for someone with dementia, either as a friend/family member or as a professional?

CAN-PROTECT is an **online study of brain aging** that explores the health and wellness of all Canadians.

We are also looking for participants who are **current or past caregivers**, who can be:

- Health care or personal care aids
- Friends or family
- Physicians
- Home care staff
- Paid companions
- Nurses
- Long-term care staff
- Recreational therapists
- Etc.
- Occupational therapists

For more information, please visit www.can-protect.ca or scan the QR code below. You can also email us with questions at CAN.PROTECT@ucalgary.ca



CAN-PROTECT BASELINE

Data from March – May
2023

2150 participants

637 study partners

Every Canadian province
and territory represented

Meaningfully identifies the
broad Canadian
ethnocultural landscape

Aging and Health Research

CAN-PROTECT: an online nation-wide cohort study of health, quality of life, cognition, behaviour, function, and aging
--Manuscript Draft--

Manuscript Number:	
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Measuring caregiver stress in CAN-PROTECT

Informal, i.e., friend and family care partners

INFORMAL CAREGIVER EXPERIENCE IN DEMENTIA SCALE (ICED)

For all the questions below, please answer the following question and score each from 1-7.

With respect to being responsible for, or caring for a person with a cognitive or neurological disorder in the last month, how often did any of the following contribute to your level of stress?



- Assess stress in domains of:
- 1) cognition
 - 2) behaviour
 - 3) function
 - 4) unmet needs/emotional impact on caregiver
 - 5) work interference/financial strain
 - 6) family interference/conflict
 - 7) situational perception

Measuring caregiver stress in CAN-PROTECT

Formal, i.e., health care aids/ PSWs, nurses, companions, home care, LTC staff

FORMAL CAREGIVER EXPERIENCE IN DEMENTIA SCALE (FCE-D)

For all the questions below, please answer the following question and score each from 1-7.

With respect to your occupation in which you are responsible or caring for persons with a cognitive or neurological disorder, **in the last month**, how often did the following contribute to your level of stress?



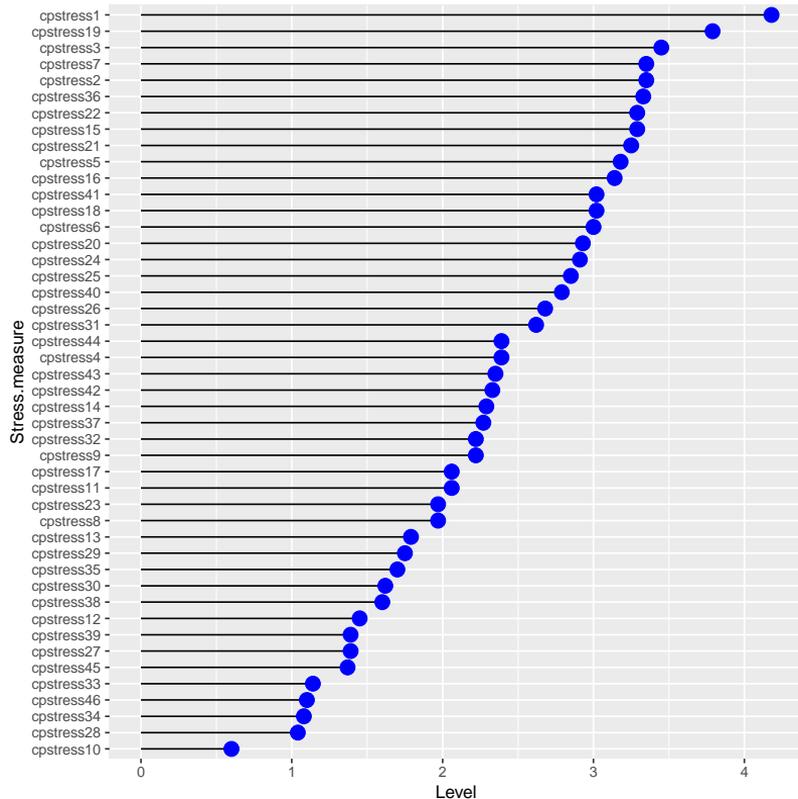
- Assess stress in domains of:
- 1) patient/resident factors
 - 2) family factors
 - 3) environment/workplace factors
 - 4) psychological/emotional factors
 - 5) interpersonal factors

Family/friend care partner experiences

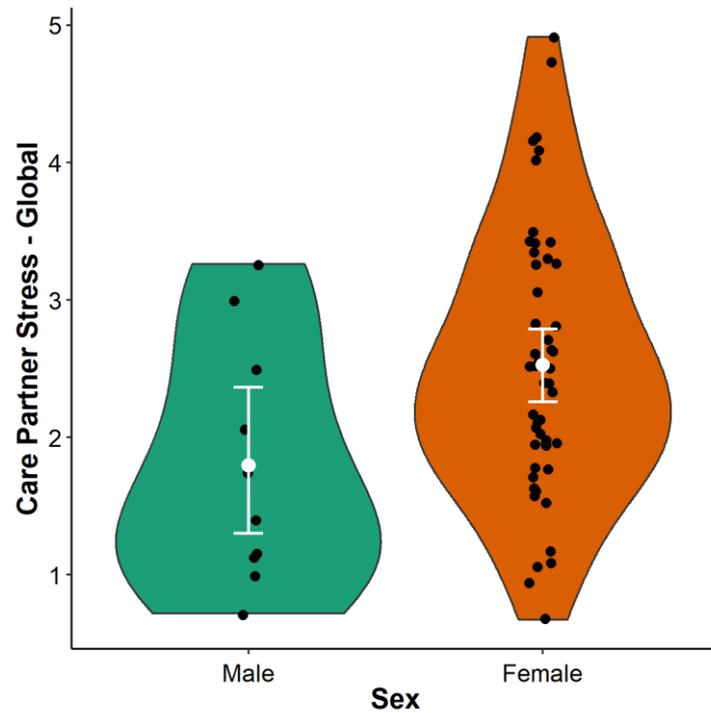
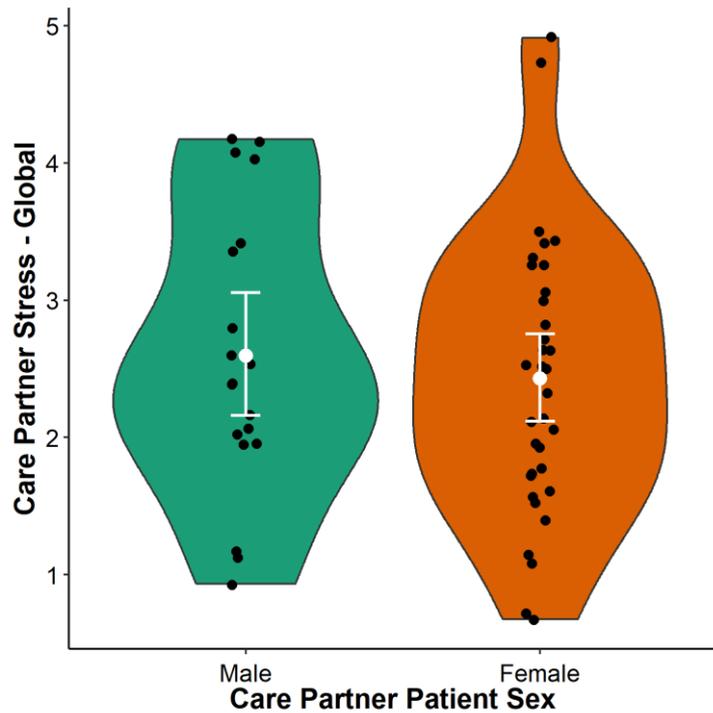
Cognitive Decline	Score
1. Forgetfulness or difficulties learning (e.g., having to repeat yourself, hearing repetitive stories or instructions, looking for lost items, teaching how to use technology, collectively making decisions based on conversations which are later forgotten, dealing with factual inconsistencies or made-up conversations)	_____
2. Inattention (e.g., unable to focus, pay attention, or stay alert)	_____
3. Difficulties with communication due to decline in language abilities (understanding or making yourself understood)	_____
4. Recognition (e.g., not recognizing places and easily getting lost or wandering off, not recognizing familiar people)	_____
5. Decision making (e.g., poor planning and organization)	_____
Behaviour Changes	
1. Apathy (loss of interest, drive, motivation, or emotional reactivity)	_____
2. Emotional symptoms (low mood, anxiety, worry)	_____
3. Excessive motor activity (e.g., pacing, rummaging, trying to leave)	_____
4. Verbal aggression (e.g., being argumentative, having a bad temper, poor frustration tolerance, verbal outbursts, rudeness)	_____
5. Physical aggression (e.g., resisting care, grabbing, pushing, hitting, scratching)	_____
6. Hoarding or repetitive behaviours	_____
7. Disinhibited or socially inappropriate behaviour (e.g., loss of tact, empathy, or social graces, disclosing personal or intimate details, intruding on others, sexually inappropriate behaviour, or uncomfortable discussions about sex)	_____
8. Psychotic symptoms (e.g., suspiciousness, paranoid thinking, seeing/hearing things)	_____
Functional Impairment	
1. Assisting with activities of daily living (bathing, dressing, eating, transferring, toileting, incontinence)	_____
8. Not having enough formal supports (e.g., home care, day program, or respite care)	_____
9. Not feeling on top of things because of caregiving obligations	_____
10. Having to be responsible due to gender role expectations	_____
11. Cultural expectations to take on the caregiver role	_____

2. Managing instrumental activities of daily living (e.g., finances, transportation, shopping and/or meal preparation, housecleaning and/or home maintenance, managing communication (telephone, mail, email), medication management)	_____
3. Attending or assisting with medical appointments	_____
4. Dealing with legal issues	_____
5. Overwhelming number of tasks involved in caregiving	_____
6. Amount of time every week spent on caregiving obligations	_____
7. Loss of insight into changes in function (or cognition or behaviour)	_____
Unmet needs and emotional impact on caregiver	
1. Not having your own needs met	_____
2. Not enough time for yourself or your interests	_____
3. Not being able to take care of yourself	_____
4. Limited social life	_____
5. Feeling like you are missing out on other things	_____
6. Feelings of guilt or inadequacy to provide care	_____
Work interference/ financial strain	
1. Missing work or poorer work quality due to caregiving obligations	_____
2. Financial hardship related to current caregiving	_____
3. Concerns over how to pay for future caregiving needs	_____
4. Safeguarding the person from financial exploitation or scams	_____
Family interference/ interpersonal conflict	
1. Detrimental effect of caregiving on your own personal relationships	_____
2. Not having enough time for your own family	_____
3. Conflict with family over how to provide care	_____
4. Conflict with family over time spent caregiving	_____
5. Feeling underappreciated by family members for efforts in providing care	_____
Situational Perception	
1. Feeling unable to control the situation	_____
2. Not knowing enough about the disease or condition	_____
3. Being unprepared for new roles/responsibilities (e.g., managing finances)	_____
4. Feeling like this responsibility should not be yours	_____
5. Feeling stuck or trapped in this role of caregiver	_____
6. Not seeing an end to caregiving	_____
7. Not having enough family support or help for caregiving duties	_____

Family/ Friend Care Partners



- Forgetfulness
- Caregiving time
- Communication difficulties
- Unmet needs
- Unable to control



We must learn more about carer experiences

Patient/Resident factors

1. Physical demands due to impaired activities of daily living (e.g., transfers, incontinence care, feeds, etc.)
2. Cognitive impairment (e.g., forgetfulness, confusion)
3. Apathy (e.g., lack of interest, initiative, or emotional reactivity)
4. Mood and anxiety symptoms (e.g., depressed mood, worry, panic)
5. Agitation behaviours (excessive motor activity, verbal aggression, physical aggression)
6. Socially inappropriate behaviour (e.g., disclosing personal or intimate details, intruding on others, treating strangers as if familiar, sexually inappropriate behaviour)
7. Psychotic symptoms (e.g., suspiciousness, paranoid thinking, seeing/hearing things)
8. Behaviours interfering with other patients
9. Lack of insight into impairment

Family factors

1. Lack of understanding of patient's family of disease and management
2. Different family perceptions of challenging behaviours
3. Unrealistic family expectations
4. Conflict or disagreement between family members
5. Not having answers to family questions
6. Lack of respect or rudeness from family members

Environmental/Workplace factors

1. Heavy workload
2. Long hours
3. Lack of backup or support from other healthcare professionals (e.g., colleague support, physician support to nursing, nursing support to care aids, etc.)
4. Lack of adequate training
5. Impact of shut-downs or restricted visitation
6. Unrealistic demands from management/ownership
7. Regulatory issues (e.g., accreditation, infection control)

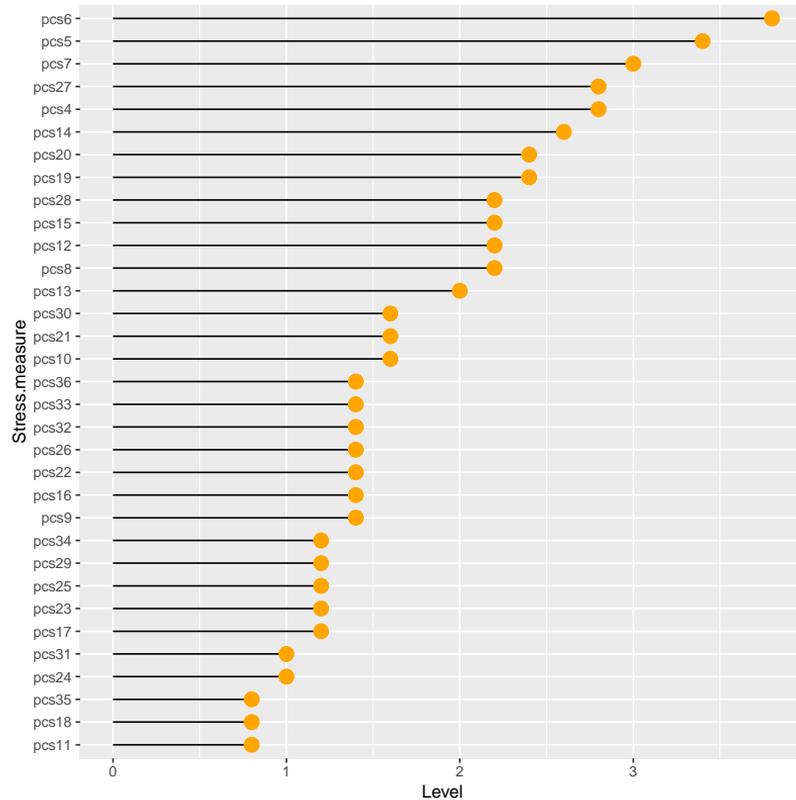
Psychological/Emotional factors

1. Internal conflict, guilt or helplessness in providing care
2. Exhaustion or burnout
3. Witnessing cognitive and functional decline
4. Death of the patient to whom you were attached
5. Witnessing suffering
6. Inadequate preparation to deal with the emotional needs of patient or family
Embarrassment or shame about patient when in public

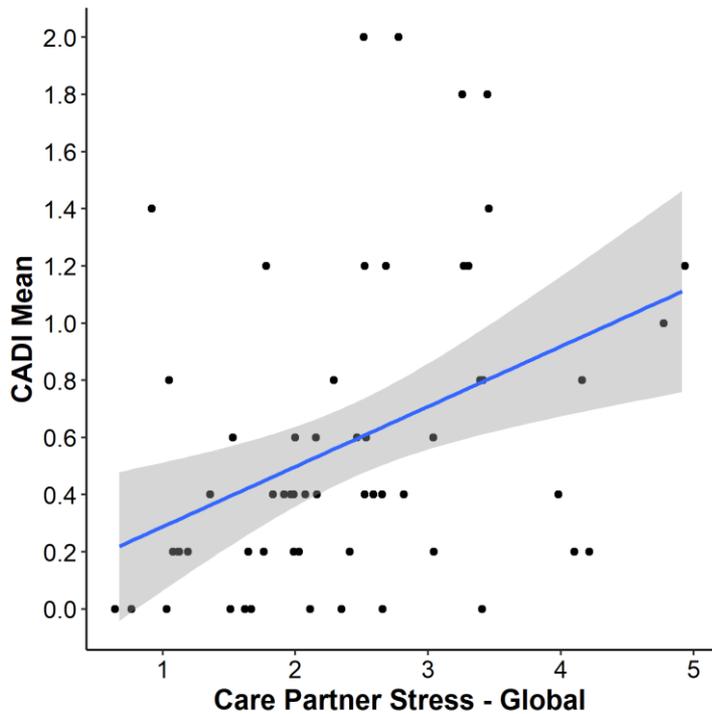
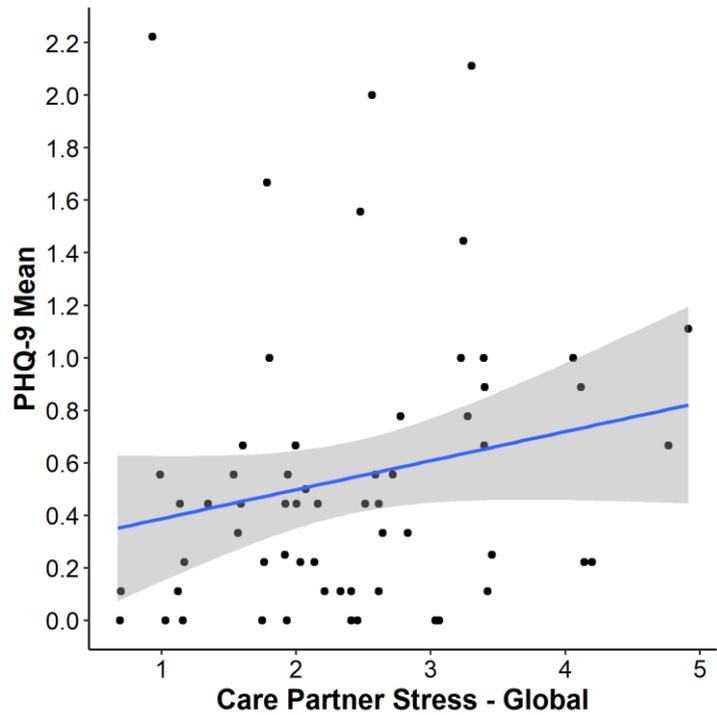
Interpersonal factors

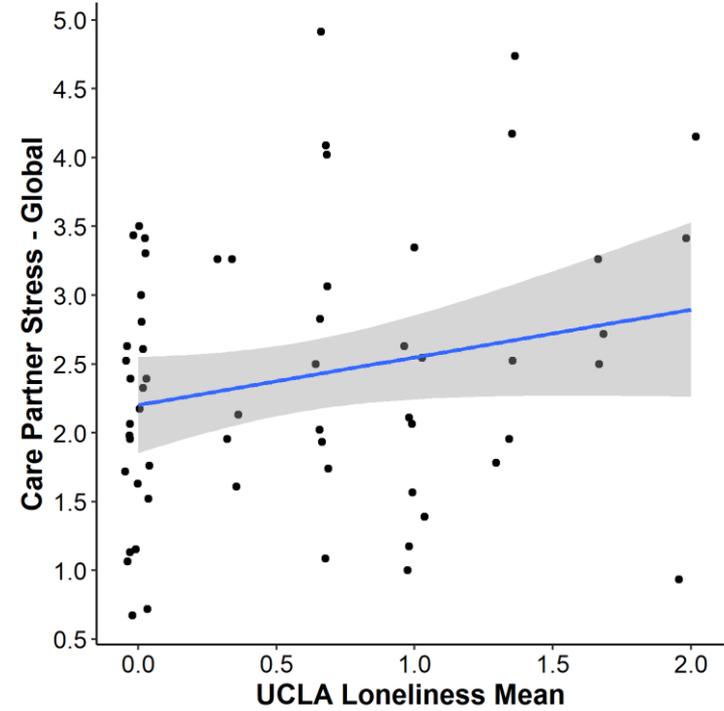
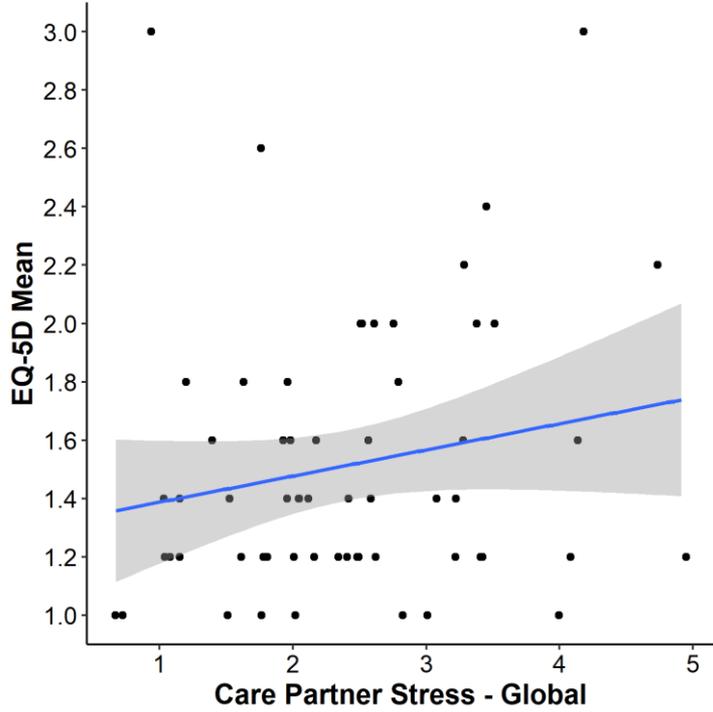
1. Difference in caregiving approach and/or conflict amongst team members
2. Language and/or cultural differences between caregiver and patient
3. Perception of racial prejudice from patient or family or others
4. Perception of different levels of commitment or work ethic of different team members

Formal Caregivers (e.g., PSWs, etc.)



- Apathy
- Agitation
- Exhaustion
- Physical demands
- Family expectations

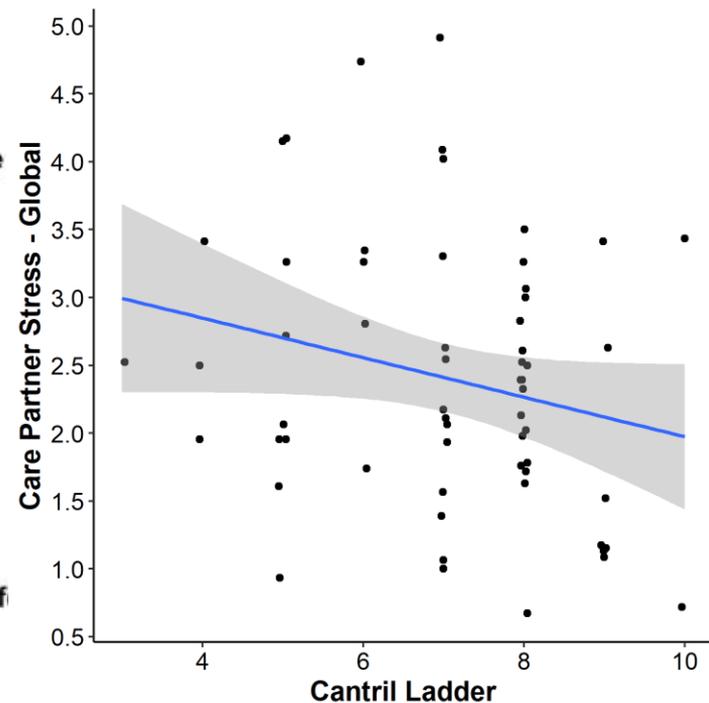
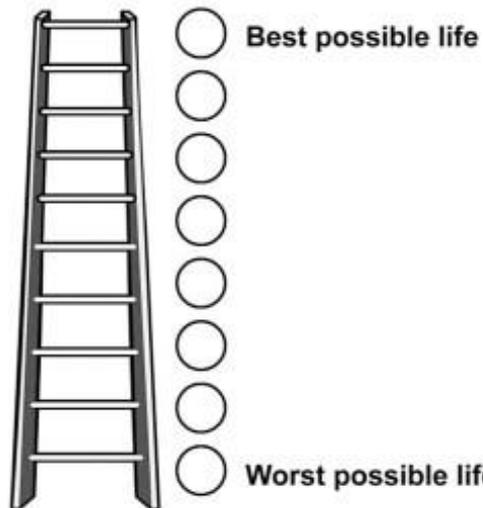




Cantril ladder question of life satisfaction

Assume that this ladder is a way of picturing your life. The top of the ladder represents the best possible life for you. The bottom rung of the ladder represents the worst possible life for you.

Indicate where on the ladder you feel you personally stand right now by marking the circle.

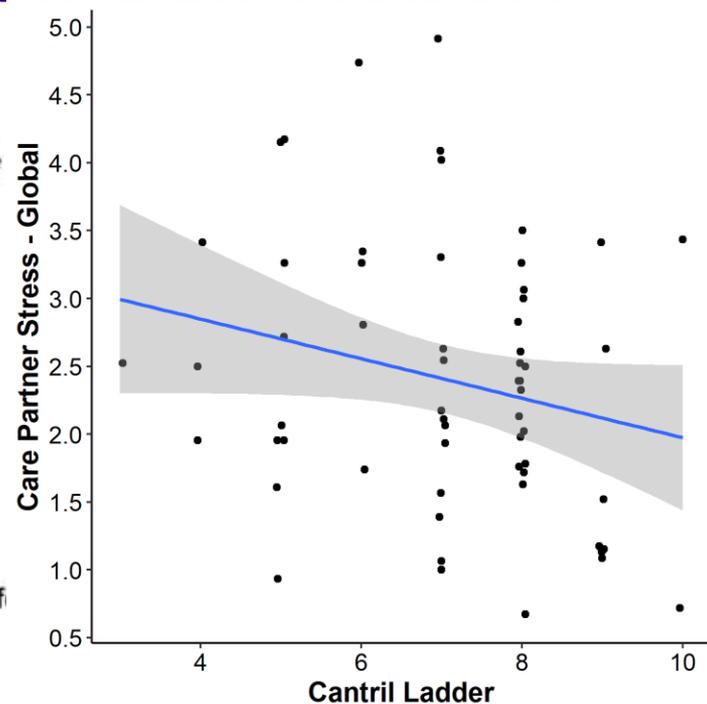
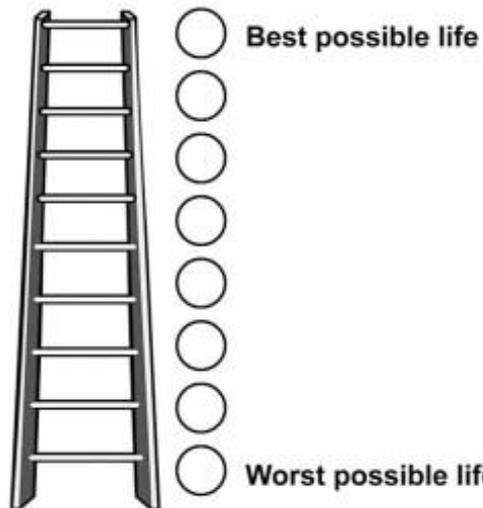


Cantril ladder question of life satisfaction

QSF-5 (QoL and Function Self-Report)

Assume that this ladder is a way of picturing your life. The top of the ladder represents the best possible life for you. The bottom rung of the ladder represents the worst possible life for you.

Indicate where on the ladder you feel you personally stand right now by marking the circle.



How do carers cope?



4 KINDS OF GRIEF

That Should Be Discussed More Often

<h3>Loss Of Identity</h3> <ul style="list-style-type: none"> When you lose your primary identity Mourning the person you thought you were A lost role or affiliation 	<h3>Loss Of Dreams</h3> <ul style="list-style-type: none"> Suffering from a deep sense of disorientation Trying to deal with unfulfilled hopes and dreams
<h3>Loss Of Autonomy</h3> <ul style="list-style-type: none"> Losing control on oneself Losing the ability to manage one's life Loss of independence 	<h3>Loss Of Safety</h3> <ul style="list-style-type: none"> Feeling emotionally and physically unsafe Absence of mental, physical & emotional well-being

SYMPTOMS OF BURNOUT

- Physical and mental exhaustion
- Lowered immunity, falling sick more often
- Frequent headaches, back pain, or muscle aches
- Change in appetite or sleep habits
- Feeling impending dread about work
- Cynicism, anger and irritability
- Feeling helpless, trapped and/or defeated
- Procrastinating & taking longer to get things done



Today is one of those days I feel like screaming! Actually, every day is like that...

I am a caregiver.

someecards user card





9 WAYS TO REDUCE STRESS FOR CAREGIVERS



Healthy habits, strong connections and resources are important for the well-being of caregivers.

by Yvonne M. Feltman

STAY CONNECTED TO OTHERS



Sharing experiences with others can help caregivers manage stress, reduce feelings of isolation, and recognize that they are not alone. Caregivers should find someone they can talk to about their feelings like a therapist, a fellow caregiver, clergy, friend or family member.

SEEK AND ACCEPT HELP



Speak up when you need support or assistance. Join a support network. Help can come from community resources, online support forums, local groups and professionals. Consider getting help to manage meals, transportation, social activities, and services to assist with other daily needs.

GET EDUCATED



It can help to talk to medical staff about options that are available for every stage of aging or disease. Area Agencies on Aging, Aging and Disability Resources Centers, Aging Info and Referral services, and other programs are trusted community links to information and services for older adults and their caregivers.

FIND RESPITE SOLUTIONS

Get a break for a few hours, a few days or even longer. Respite is offered in or outside the home, in a community or faith-based agency or organization, at an adult day care program, in a hospital or healthcare facility, a nursing home, an assisted living facility, or adult foster home. Family members, friends or neighbors may also be available to act as a respite provider.



PRACTICE SELF-CARE



Don't forget to participate in enjoyable or relaxing activities. Partake in a social outing or a hobby such as art or another creative endeavor. Read a good book, listen to music, watch a movie or relax in a warm bath. Regular self-care is a must for caregivers!

EXERCISE REGULARLY



A quick 10-minute walk outside can help improve mood, offer fresh air and a change of scenery. Daily exercise breaks can change a hectic pace & mindset. Yoga and stretching can also relax the mind and reduce the feeling of overwhelm & stress.

STAY HEALTHY

Reactions to stress can include lack of sleep, overeating, undereating, increased alcohol consumption and smoking. Be aware of these detrimental responses and receive regular health check-ups to ensure good health practices.



KEEP A POSITIVE PERSPECTIVE

Striving to maintain a positive outlook can make a real difference. Writing in a gratitude journal or simply choosing to focus on the good in daily situations can help to reduce negative thoughts and feelings resulting from stress or overwhelm.



MEDITATION & BREATHING PRACTICES



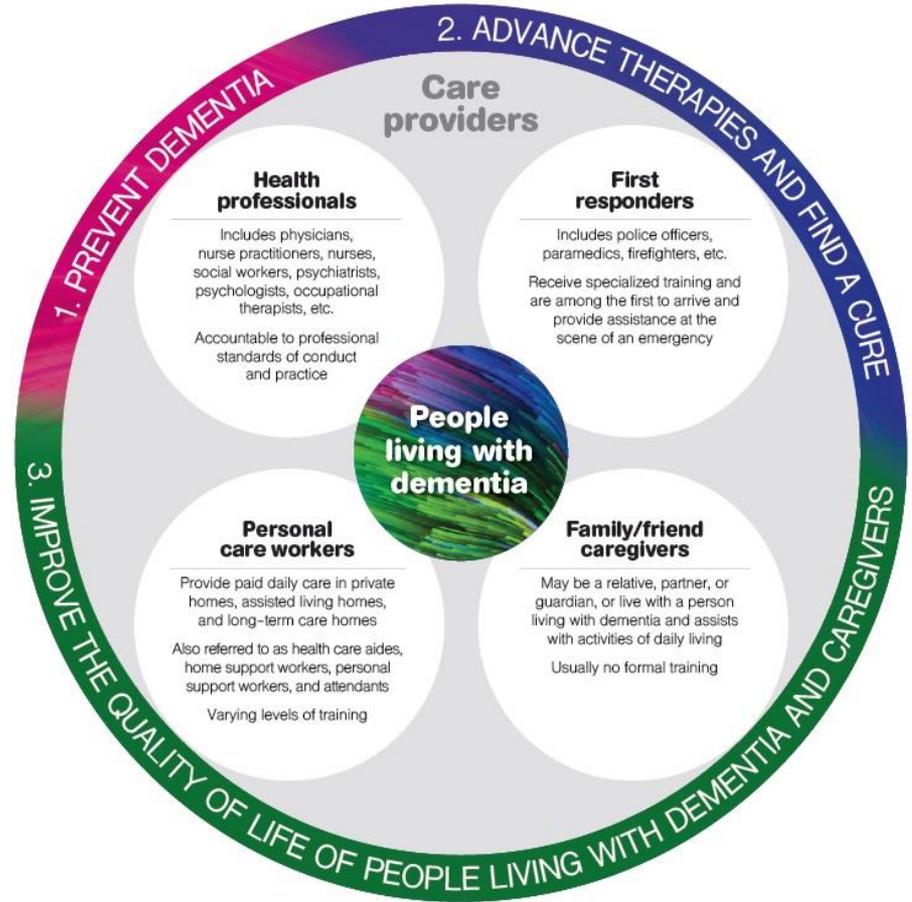
There is increasing evidence that mindful meditation can help ease psychological stresses like anxiety, depression, and pain. An effective relaxation method developed at Harvard Medical school involves deep breathing exercises.



<https://www.aginganddisabilityresources.org/files/downloads/caregiver-fact-sheet.pdf> and <https://www.caregiver.org/taking-care-of-yourself-care-family-caregiver>
<https://www.aging.org/Outreach-and-Education/Outreach/Partnerships/Downloads/AskMedicareTipsForCaregiversCareForYou.pdf>
<https://pubmed.ncbi.nlm.nih.gov/public/respite-care/Caregiver.aspx> and <http://www.caregiveraction.org/family-caregiver-trail-kit>
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National Dementia Strategy



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**GORDIE
HOWE**
CARES



The CAN-PROTECT Study

CAN-PROTECT is an exciting opportunity to take part in a major Canadian research study on how the brain ages. Features like brain training games were developed for participants >40 years of age.

www.can-protect.ca



If you have questions, want to participate, or know someone who might want to participate, you can visit the website, scan scan the code, or phone/email

This study has been approved by the University of Calgary Conjoint Health Research Ethics Board, Ethics ID# REB21-1065