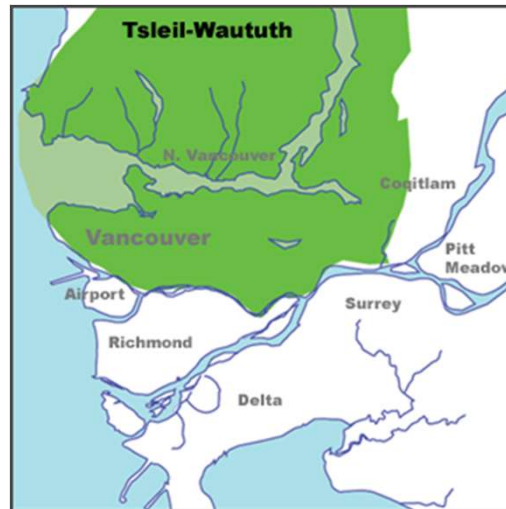


We would like to acknowledge that we are gathered today on the traditional territories of the Musqueam, Squamish and Tsleil-Waututh peoples.

Source: [www.ijohomaps.net/na/canada/bc/vancouver/firstnations/firstnations.html](http://www.ijohomaps.net/na/canada/bc/vancouver/firstnations/firstnations.html)





**Providence  
Health Care**



# Care for the Dementia Caregiver

Dr. Susan More  
Karen Gilbert OT  
Dementia Caregiver Resilience Clinic  
St. Paul's Hospital

# Learning Objectives:

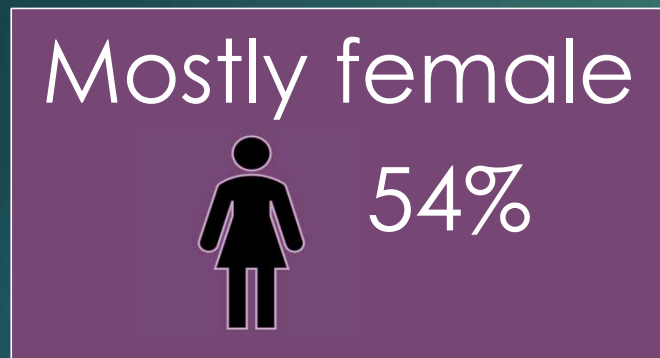
1. Identify dementia caregiving variables that increase the risk of caregiver distress.
2. Discuss negative outcomes of caregiver distress for both the person living with dementia and the care partner.
3. Describe key inner resources to optimize resilience of dementia caregivers
4. Describe 'in the moment' strategies to support dementia caregivers in your patient sessions and when to refer for more support

# Dementia Caregiving in Canada

350,000 caregivers in 2020	Average of 26 hours/week = 470 million hours/year	Equivalent to 235,000 FT jobs = 7.3 billion/year at min wage
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Landmark Study- Alzheimer's Society of  
Canada 2022

# Dementia Caregiving in Canada



12% 65 and older  
44 % 45-65  
14 % 35-45  
30% Under 30 years

# Dementia Caregiving in Canada

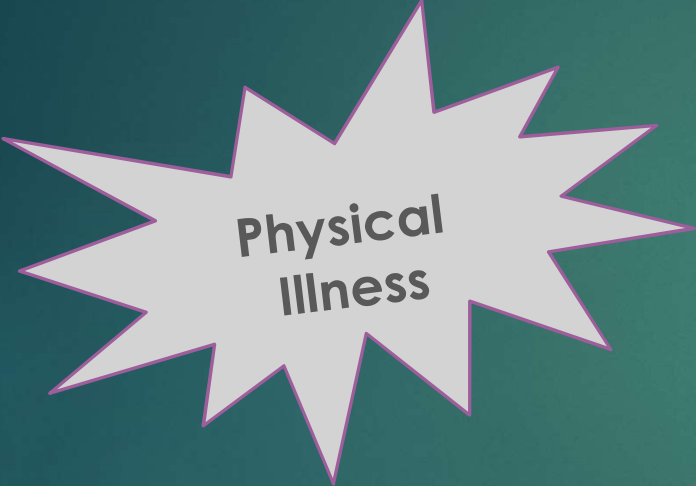
Most PWD  
live at



Who are the caregivers?  
58% children  
32% spouses  
10% neighbors and  
friends

Landmark Study- Alzheimer's Society of  
Canada 2022

# How Does Dementia Caregiver Distress Show Up?



**Physical  
Illness**



**Psychological  
Symptoms**

In complex situations, we can end up with two identified patients instead of one.



# Pearlin model of caregiver stress

- ▶ 4 main contributing areas:
  - ▶ **Background context** (premorbid quality of relationship, level of support & impact of other life events)
  - ▶ **Primary stresses of the illness** (dependency & behaviour)
  - ▶ **Secondary role strains** (family conflict, support network, social life/isolation, excess responsibility, identity)
  - ▶ **Intrapsychic factors** (personality, competence, and role captivity, hx of mental health challenges, trauma)



# Risk Factors for Dementia Caregiver Distress

## Situational Factors

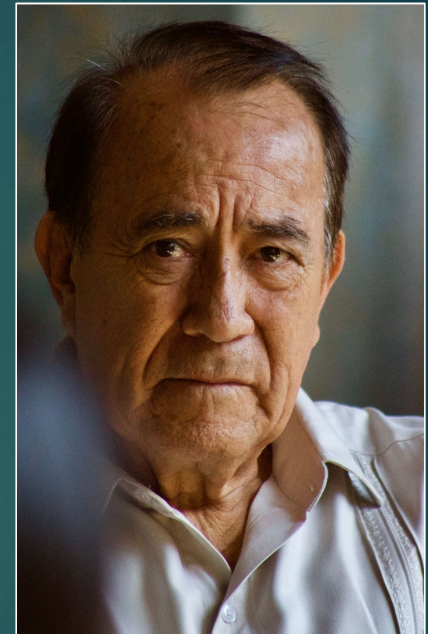
- ▶ Cohabitation
- ▶ Younger spousal partners
- ▶ Lower income
- ▶ Type of Dementia – e.g. Frontotemporal Dementia
- ▶ Poorer relationship quality

## Caregiver factors

- ▶ History of mental health challenges
- ▶ Poor emotional regulation
- ▶ Low sense of confidence/mastery
- ▶ High sense of “role captivity”
- ▶ Confrontative coping strategies

# Is caregiving a health hazard?

- ▶ Affects both physical and emotional health
- ▶ Increased hospitalization for the caregivers
- ▶ Increased medication usage
- ▶ Increased mortality
- ▶ Increased risk of dementia



Fonareva International  
Psychogeriatrics 2014

# Physiological effects of caregiving

- ▶ Dyscoagulation - increased d-dimer, increased t-PA
- ▶ Inflammation- Increased CRP
- ▶ Shortened telomeres
- ▶ Decreased immune function
- ▶ Increased systolic and diastolic BP
- ▶ Increased carotid plaque



Fonareva 2014  
International Psychogeriatrics

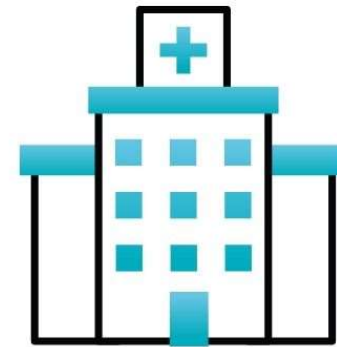
# Cognitive changes in caregivers

- ▶ Decreased processing speed
- ▶ Decreased attention
- ▶ Decreased memory
- ▶ Decreased executive function
- ▶ Increased risk for dementia



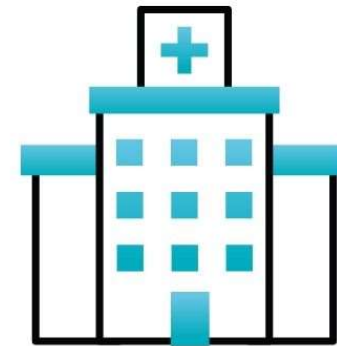
Fonareva 2014 International  
Psychogeriatrics

Dementia-related  
behaviours



Emergency  
Department  
Admissions

Dementia-related  
behaviours ~~X~~

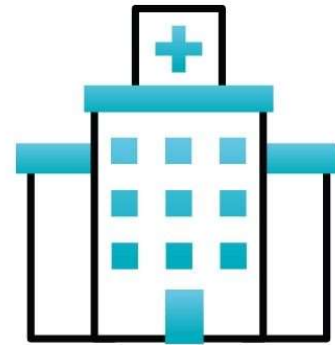
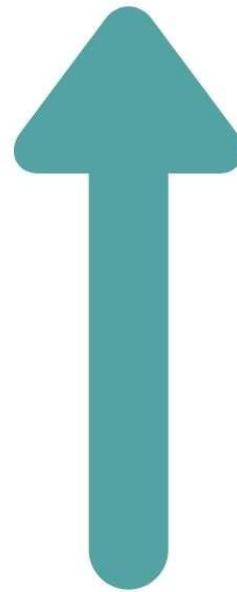


Emergency  
Department  
Admissions

Dementia-related behaviours ~~X~~

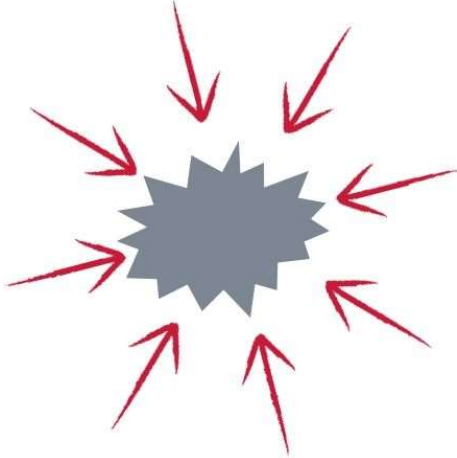


Caregiver distress  
resulting from  
the behaviours

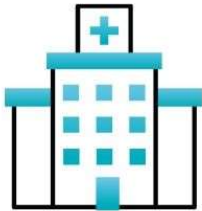


Emergency  
Department  
Admissions





This suggests that interventions targeting caregiver distress stand to:



healthcare expenditures



better support both caregivers and people living with dementia

# Supporting Dementia Care Partner Well-being

## External Resources

- ▶ Physical assistance
- ▶ Financial Assistance
- ▶ Respite
- ▶ Adult Day Programs
- ▶ Supportive working environments

## Internal Resources

- ▶ Knowledge
- ▶ Awareness
- ▶ Problem-solving skills
- ▶ Restorative self-care practices
- ▶ Mindful communication skills
- ▶ Confidence in caregiving role

### The Zarit 4 Item Burden Interview

Circle the response that best describes how you feel.

	Never	Rarely	Sometimes	Quite frequently	Nearly always
Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4
Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
Do you feel strained when you are around your relative?	0	1	2	3	4
Do you feel uncertain about what to do about your relative?	0	1	2	3	4

Instructions for caregiver: The questions above reflect how persons sometimes feel when they are taking care of another person. After each statement, circle the word that best describes how often you feel that way. There are no right or wrong answers.

. Copyright© 1983 Steven Zarit. Used with permission.

# Supporting Family Caregivers Improves Outcomes for Person Receiving Care, FCGs, and Healthcare Providers

- ▶ Promotes effective communication  
(Gonella et al., 2022; Pop et al., 2022)
- ▶ Improves patient care, health, and wellbeing  
(Maxwell et al., 2018; Schulz et al., 2021)
- ▶ Supports aging in the right place  
(Holland, 2022; Wagner, 2021)
- ▶ Reduces length of hospital stays  
(Glose, 2020; Yasmeen et al., 2020)
- ▶ Reduces hospital readmissions  
(Beach et al., 2020; Ma et al., 2019; Morkisch et al., 2020)
- ▶ Reduces healthcare providers' workload  
(Morton-Chang et al., 2016; Schulz & Czaja, 2018)

# Interventions that help - it's complicated

- ▶ Very heterogeneous group- gender, age, SES, culture, work status, other roles
- ▶ Course of dementia is long - needs are different at different times
- ▶ No one size fits all

# Research summary

- ▶ Multicomponent interventions seem to work best
- ▶ Depression: treatment as usual with medication and CBT, ACT, behavioral activation, psychoeducation have all been shown to help
- ▶ Caregiver Burden- case management, psychoeducation, multicomponent intervention have all helped
- ▶ Quality of Life- support group intervention

Yue, S 2021 International Journal of Nursing Studies

# How do we support care partner resilience?

- ▶ Assessment of the care partner's own needs, struggles, concerns as part of assessment/treatment approach.
- ▶ Ensure education and skill development offered
- ▶ Review their health and wellness throughout the illness of their care partner
- ▶ Partner and collaborate **with** them as key members of the health care team
- ▶ Emphasize that self-care is not selfish, it's essential!





# Refer dementia caregivers

## When?

- At the time of diagnosis or soon after
- At the earliest signs of distress arising
- If you observe red flags of lack of understanding or relational tension

## Where?

- Alzheimer Society of BC
- Family Caregivers of BC
- Dementia Caregiver Resilience Clinic for moderate-high risk
- Disease specific organizations
- [Dementiacarers.ca](http://Dementiacarers.ca) website

## How?

- Provide resource contact info
- Connect them with social work if available
- Access caregiver specific assessment if available
- Follow-up with caregiver to ensure they have made connection

# Dementia Caregiver Resilience Clinic

## ▶ Individual interventions

- ▶ Skill-building
- ▶ Connecting with resources
- ▶ Counselling & Psychotherapy, Psychiatric support

## ▶ Group interventions

- ▶ CARERS program
- ▶ Mindfulness Based Dementia Care
- ▶ MBDC Alumni group
- ▶ Bereavement group

dementiacaregiver.providencehealthcare.org



HOME

FOR GROUP PARTICIPANTS

RESOURCES

REFERRALS



How you want to be treated.

**DEMENTIA CAREGIVER  
RESILIENCE CLINIC**

Currently caregiver completes personal info and screening tool and brings to family physician

Self-referral to begin in 2024.

# In-the moment strategies

- ▶ Dementia education
- ▶ Problem Solving
- ▶ Communication approaches
- ▶ Self-care



# Dementia education

- ▶ Be clear about diagnosis
- ▶ Repeat diagnosis and check-in about understanding on follow-up.
- ▶ Help adjust to having realistic expectations based on abilities
- ▶ Connect to resources who can reinforce education and expand on over time (Alzheimer Society, OT, SW, DCRC)

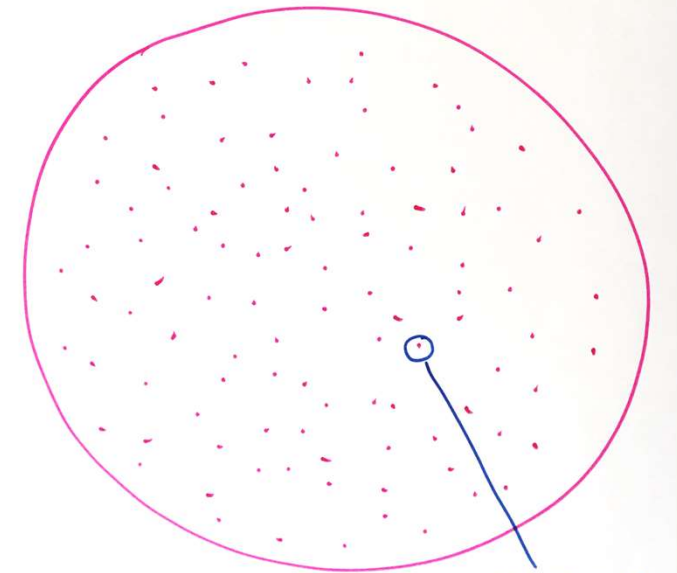




# Problem-solving strategies

- ▶ What is the problem for me? (the caregiver)
- ▶ Focus on one piece of the dust cloud
- ▶ Brainstorm solutions
- ▶ Identify an achievable action plan
- ▶ What is the first step? (i.e. make a phone call)

When we can handle something differently and with some success, it changes how we feel and how we approach other problems



We are identifying one piece of the "dust cloud"

# Problem-solving strategies

- ▶ When an issue arises, leave it – and return a few minutes later, it may have changed
- ▶ Is it a safety issue? Don't sweat the small stuff.
- ▶ Approach situations with curiosity





# Communication strategies

## Model and educate

- ▶ Inclusion of person with dementia (eye contact, ask permission, ask for their input, adjust to yes/no if needed)
- ▶ Monitor tone/volume of voice – co-regulation
- ▶ Entering person's reality; Speak to emotions
- ▶ Avoid rationalizing and arguing “Connect don't correct”



# Communication strategies

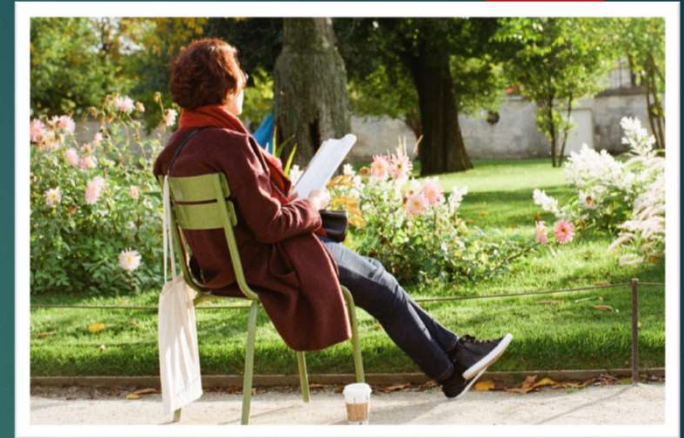
## Model and educate

- ▶ Use less words
- ▶ Create pauses in conversation
- ▶ Gentle physical or gesture cues
- ▶ Learn to recognize triggers and try to avoid



# Self-care strategies

- ▶ Validate that self-care is not selfish
- ▶ Give people permission to “ask for what you need”
- ▶ Give yourself permission to \_\_\_\_\_ (rest, be less productive, do something for you, set boundaries, not consult my partner on everything etc)
- ▶ Encourage acceptance of help earlier than you think you need it.



# Self-care strategies

- ▶ Encourage using respite care – book early in trajectory of illness
- ▶ STOP practice – good for identifying OWN needs as well!
- ▶ Self-compassion, self-compassion, self-compassion!



The simplest and most effective way I know how to step into the pause of life is simply to STOP. **Put any judgements aside and see what you notice.**

- S** Stop what you are doing
- T** Take a few deep breaths and pay attention to each one as if it were a new experience.
- O** Observe your
  - Body sensations (toes up to your head),
  - Thoughts (gently name....thinking, planning, replaying...)
  - Emotions (“name it to tame it”)
- P** Proceed by asking the question, “What is most important to pay attention to right now?” or based on what I observed, “What am I needing right now”

Source: Elisha Goldstein <http://elishagoldstein.com/videos/the-stop-practice/>

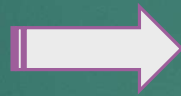
# Shifting from Caregiver Risk to Resilience:

Lack of confidence  
in caregiver role



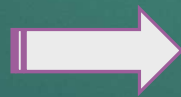
Confidence and competence in  
caregiver skills

Limited understanding  
of dementia



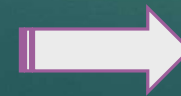
Deeper understanding of how  
dementia affects their partner

Overwhelmed by  
emotions



Increased ability to regulate emotions

Strained interactions

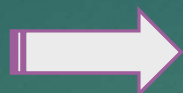


Mindful communication skills



# Shifting from Caregiver Risk to Resilience:

Self-criticism



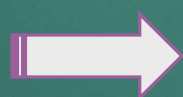
Self-compassion

Exhaustion  
Hopelessness



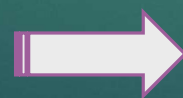
Self-care  
Remaining open to possibility and growth

Trying to control  
the uncontrollable



Embracing grief and accepting change

Unmet needs of caregiver  
and person with dementia



Recognizing and addressing needs of **both** person with dementia and caregiver





Thank you!

Questions?