Leading Change in a Caring Environment through Partnership with Family Caregivers: Competency-based Education for Interdisciplinary Healthcare Providers

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The University of Alberta, its buildings, labs and research stations are primarily located on the territory of the Néhiyaw (Cree), Niitsitapi (Blackfoot), Métis, Nakoda (Stoney), Dene, Haudenosaunee (Iroquois) and Anishinaabe (Ojibway/Saulteaux), lands that are now known as part of Treaties 6, 7 and 8 and homeland of the Métis. The University of Alberta respects the sovereignty, lands, histories, languages, knowledge systems and cultures of all First Nations, Métis and Inuit nations.

To acknowledge the territory is to recognize the longer history of these lands. The acknowledgment signifies the University of Alberta's commitment to working in Good Relations with First Nations, Métis and Inuit peoples as we engage in our institutional work, uplifting the whole people.

Have you thought about the prospect….?

“There are only four kinds of people in the world —

those that have been caregivers, those that are caregivers, those who will be caregivers, and those who will need caregivers.”

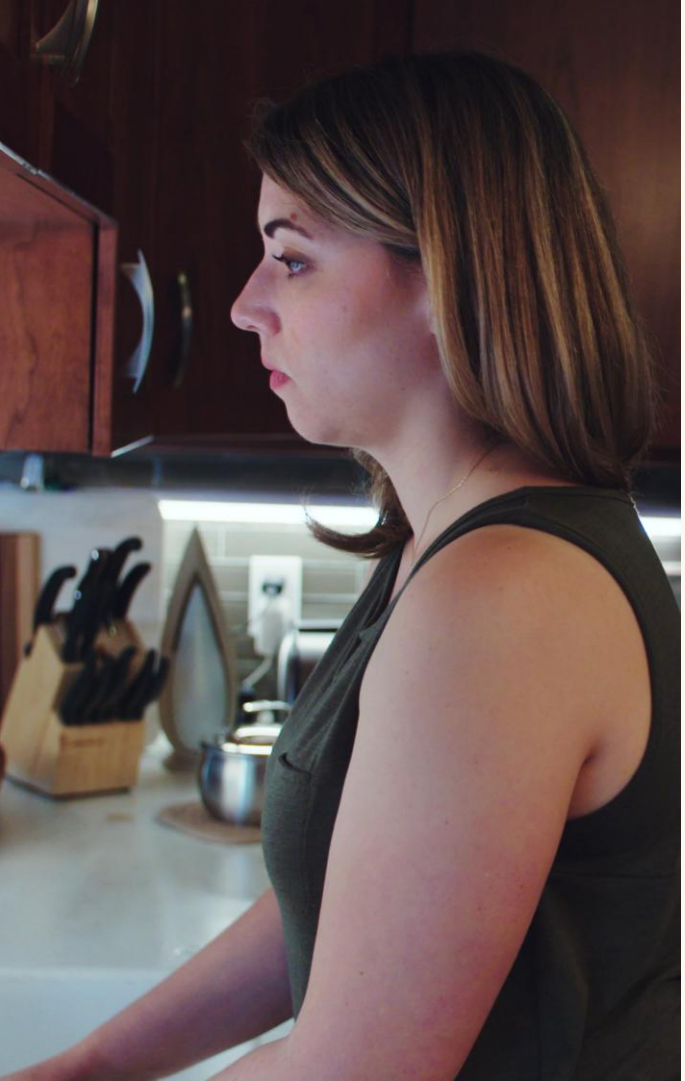
First Lady Rosalynn Carter.

Exploring A Collaborative Approach for Change

Today we'll explore….

- Identifying the issue - What's the challenge?
- What the research tells us
- Designing based on a creative and emergent process
- Sharing the insights of an equity-focused co-design experience
- Answering your questions
- How you can become a partner in health system transformation!

VIDEO LINK



Caregiving is a normative life course experience

1 in 4 Canadians are caregivers

- Provide care to others with chronic health conditions, disabilities, and/or functional limitations
- Have a personal connection to those they support: family members (84%) and non-family (16%)
- All ages, including young caregivers (under age 15)
- Have different patterns of moving in and out of providing care across their life courses

Source: Dr. Janet Fast Caregivers in Alberta: impact of caregiving on well-being based on analysis of 2018 GSS

Caregiving in Canada

Canadian family caregivers:

- Collectively provide **5.7 billion hours** of care annually
- Equivalent to **2.8 million FTE's**
- Valued at **~$97.1 billion** annually (@ $17/hr)
- Representative of **3 times** the national expenditures on home, community, & long-term care combined.

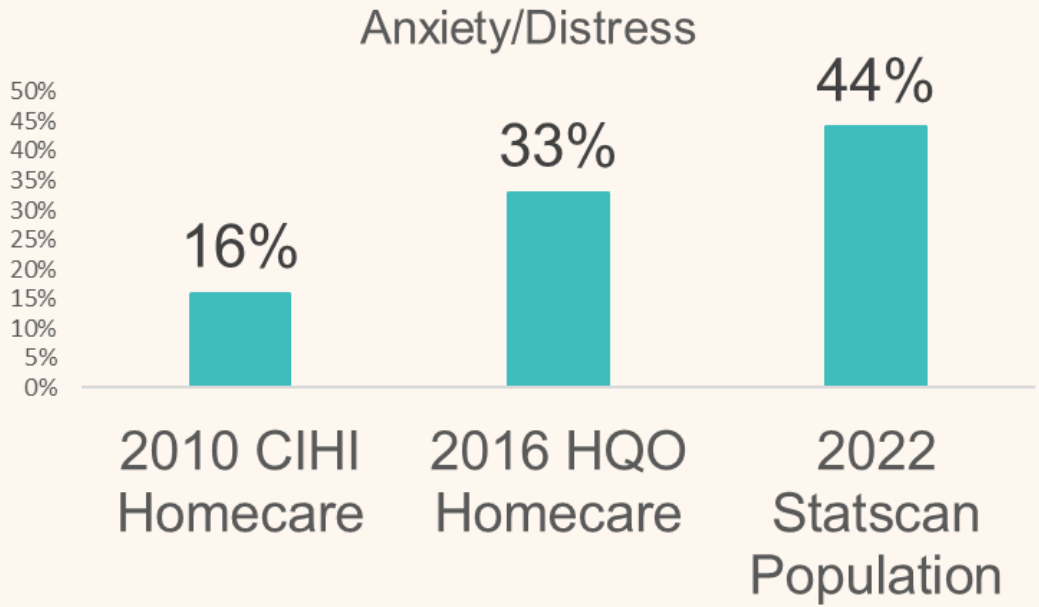
Fast et al. 2022 https://bit.ly/3yCh735

Implications of invisibility

- Family care is often viewed as “free” labour that helps contain costs in the formal care sector
- But it’s seen as “supplemental” to formal care (when really it’s formal care that’s supplemental)
- Care contributions are distributed inequitably; inequities are also invisible
- Reluctance to ‘account for’ the contributions of the family care sector

Janet Fast, January 18, 2023

Rising Family Caregiver Distress



- rises as care increases & energy is depleted.
- 21+ Hrs /weekly, Lives with receiver, dementia, depression, severe disability, medical care tasks
- higher (re) hospitalization rates (receiver)
- poorer health outcomes (receiver)
- increases risk of heart disease, dementia, premature mortality.

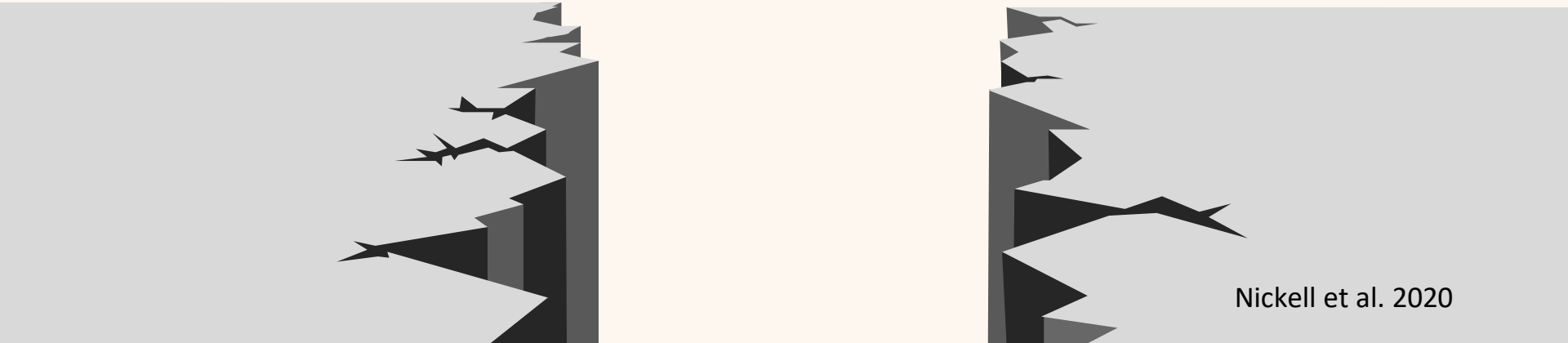
Supporting Family Caregivers Improves Outcomes

- Promotes effective communication[1]
- Improves patient care, health, and wellbeing[2]
- Supports aging in the right place[3]
- Reduces length of hospital stays[4]
- Reduces hospital readmissions[5]
- Reduces healthcare providers' workload[6]

[1] Gonella et al., 2022; Pop et al., 2022 , [2] Maxwell et al., 2018; Schulz et al., 2021, [3] Holland, 2022; Wagner, 2021
[4] Glose, 2020; Yasmeen et al., 2020 [5] Beach et al., 2020; Ma et al., 2019; Morkisch et al., 2020
[6] Aoun et al., 2015; Morton-Chang et al., 2016; Schulz & Czaja, 2018

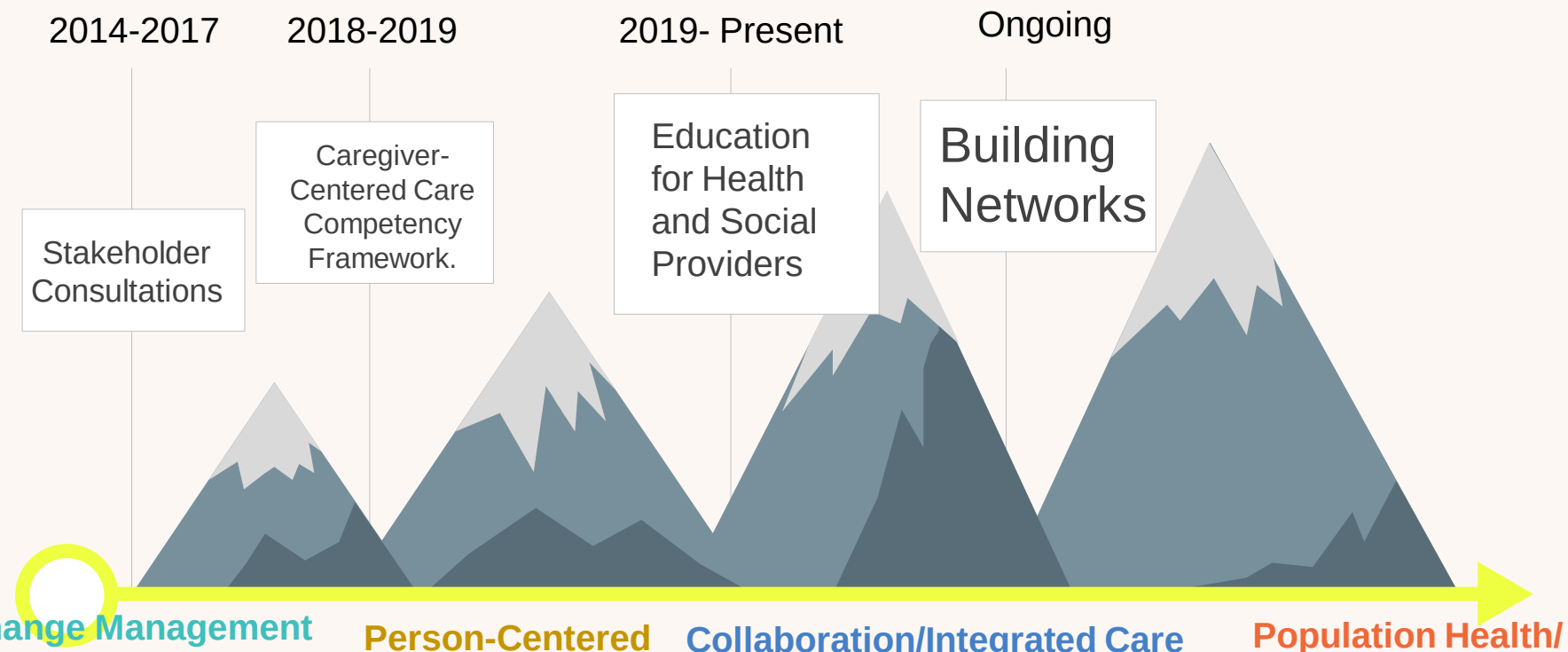
Who is caring for Family Caregivers?

In most models of family practice, family caregivers are under recognized, under supported, and under used.
Few health care professionals have received training in caregiver engagement, and typically there is a reluctance to collaborate with caregivers and an unwillingness to involve caregivers in the care process in a meaningful fashion.

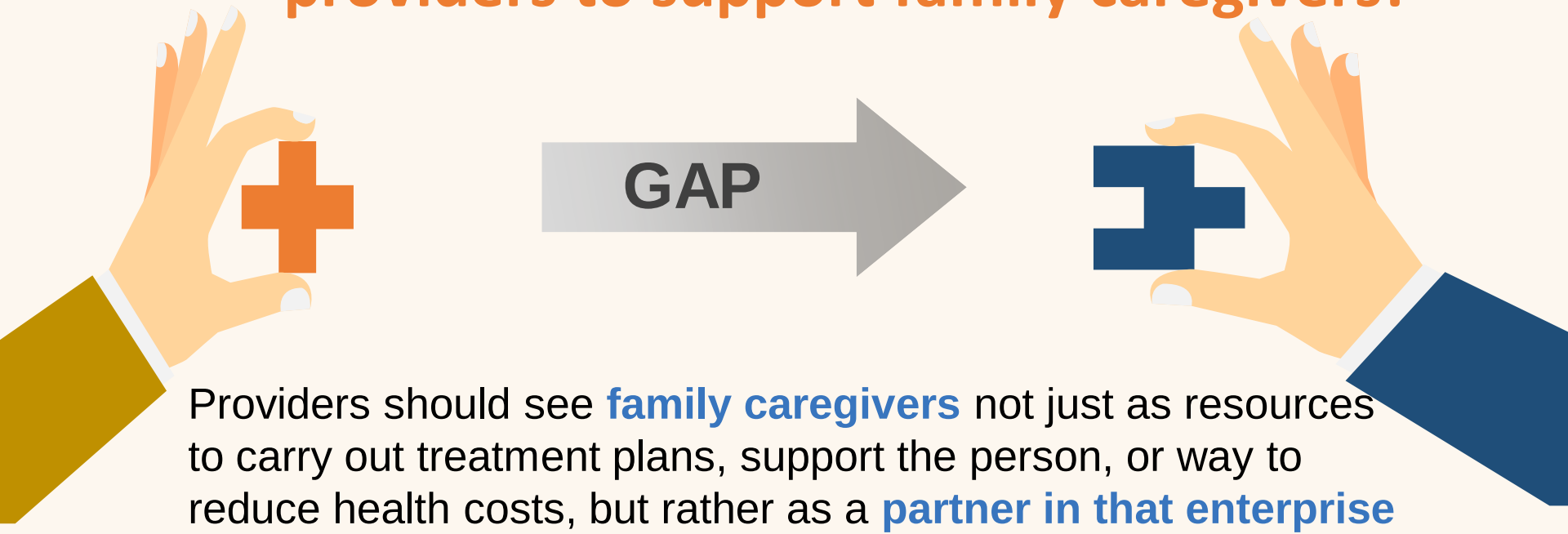


Nickell et al. 2020

Health & Social Care Partnerships



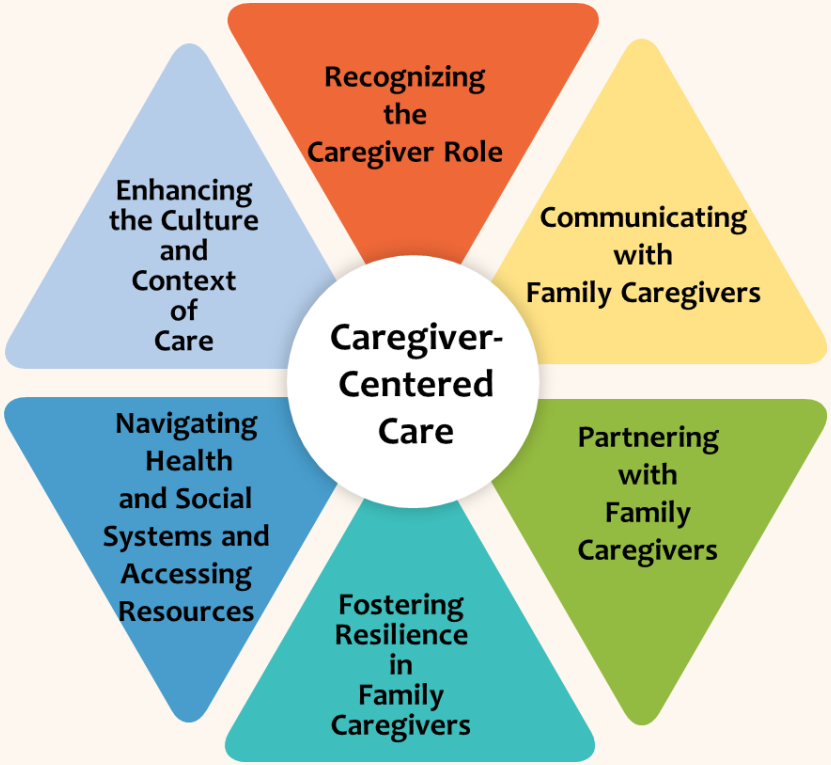
Enhance the competencies of healthcare providers to support family caregivers!



Providers should see **family caregivers** not just as resources to carry out treatment plans, support the person, or way to reduce health costs, but rather as a **partner in that enterprise who may need information, training, care, and support.**

Schulz et al, 2018

Caregiver Centered Care: Competency Framework



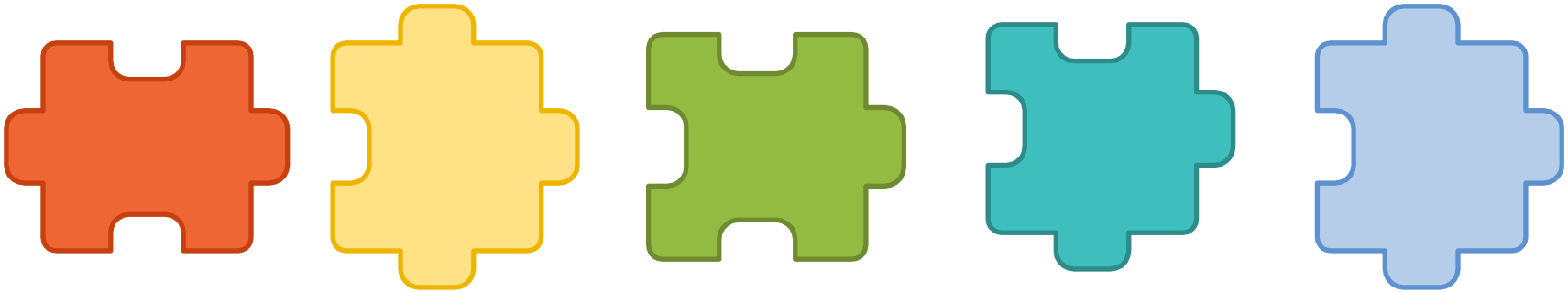
Family Caregivers = family, friends, partners, neighbours, and others deemed by the receiver of care as fulfilling the care role.

Co-Designing the Competency Based Education

Challenges: What is our Goal?

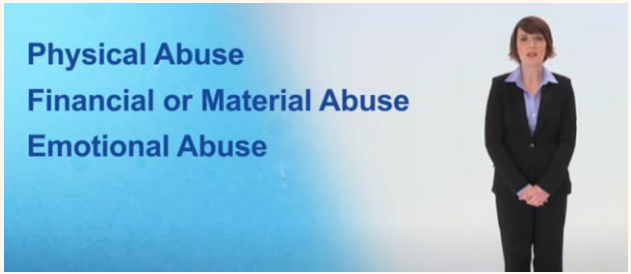
“That family caregivers feel supported by the healthcare system throughout their care giving journey”

Co-Design: Stakeholder Collaboration



Person Centered	Desired Results	Multiple Perspectives	Tangible Possibilities	Practical Solutions

Original Idea - “Can you do this?”



Talking Head with Text

Documentary Inserts

Illustrative Vignettes

“It helped me realize how important the role of a caregiver to the health care system and their need to be looked after too aside from the person they are taking care of.”

Engaging Education Based on Real-Life Experiences

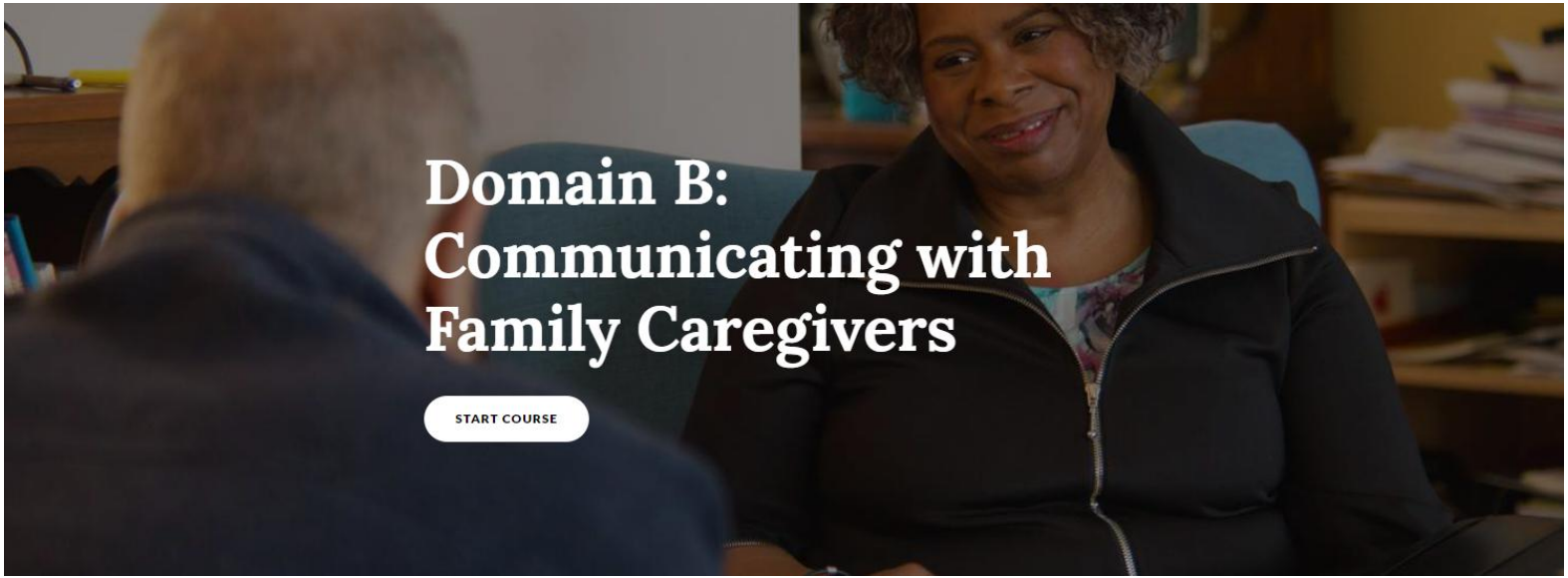
Foundational

Covid-19

Advanced

What happens when caregivers share about their challenges?

VIDEO LINK



- ❖ Introduction – Communicating with Family Caregivers
- ❖ Goals of Effective Communication with Family Caregivers
- ❖ Self-Assessment: Person-centered Care
- ❖ The OARS Communication Framework
- ❖ Self-Reflection
- ❖ Perspective Taking
- ❖ Curiosity – Digging Deeper
- ❖ Therapeutic Relationships
- ❖ Supporting the Coordination of Care
- ❖ Tools for the Healthcare Provider’s Toolkit
- ❖ Set Goals
- ❖ Conclusion & Certificate of Completion

Why is Changing the Culture and Context of Care so important?

VIDEO LINK

Recognizing & Overcoming

“Navigating uncertainty and relationship dynamics together”

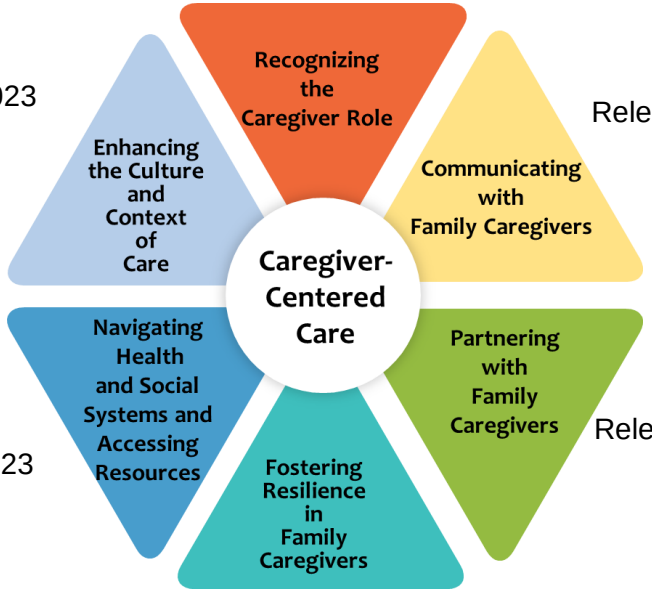
Possibilities & Positive Outcomes!

“The unexpected, expected outcome”

Release of Advanced Education

Released Oct 2022

Released May 2023



Released Nov 2022

Released Jan 2023

Released Mar 2023

Released Nov 2022

Honestly, I've had years of experience working with caregivers in a Home Care environment and in the child protection system (foster parents and parents), and I still found these courses helpful. Helpful in that it cues you to slow down a bit and be present, even when our caseloads are nuts, no matter how experienced you are. I really liked the teaching about communication, open-ended questions, curious discovery, etc. in each module, that other disciplines aside from social workers may not be getting training in. The videos are really well done too – you know how some training videos can be. Great work, everyone!

Social Worker & Case Management Practice Lead

caregivercare.ca

Caregiver-Centered Care Champions

COMING SOON!

Champions Education – A Quick Overview

Target Audience:

- completed all other Caregiver-Centered Care Education modules
- ability and willingness (enthusiasm, dedication, and commitment) to contribute to building/improving cultures of Caregiver-Centered Care.

Delivery Options:

- 3-hour asynchronous, interactive online module, or
- In-person facilitated training

Draft Outline:

- Previous Co-Design Team Meetings (reviewing of transcripts)
- Existing Champions Education (e.g. CSNAT-I, Esther, Scottish Dementia)
- Quality Improvement/Change Management Models/Approaches
- Champions Education Literature

Draft Learning Outcomes

Champion learners will be equipped to:

1. Reflect upon, integrate, and build on their personal leadership capabilities and strengths.
2. Identify and apply change management and quality improvement principles and practices to improve experiences of family caregivers.
3. Engage in solution-focused approaches that spread, enhance, scale-up, & sustain Caregiver-Centered Care education and initiatives.

Very High Level Outline
What is a Champion? (Review of Leadership/Champion Qualities & Self-Development Plan)
Intro to Quality Improvement/ Change Management (Review barriers/enablers to change; current state assessment)
Raising Awareness & Desire for Caregiver-Centered Care (Building a Communication Plan)
Building Capacity – Educating Others (Building a Training & Evaluation Plan)
Building Capacity – Supporting & Reinforcing Practice Change (Create Action Plan & CoP, Return to Self-Development Plan)

Building a Better System to Support Caregivers

1. Recognize Caregivers

Health systems must support system-level changes to formally recognize caregivers, incorporate them into care plans, & document this information in health records.

2. Health & Social Care

Health systems must develop robust partnerships with community programs & organizations that support caregivers.

3. Education

Incorporate topics of caregiving & integrated care into health professions' education.

4. Policy

Need broad, coordinated scale-up of policies to support caregivers as part of strategy to improve caregivers and recipient wellbeing outcomes.

Leykum et al. 2022 Recommendations to Improve Health Outcomes Through Recognizing and Supporting Caregivers https://bit.ly/3NWSupn

Pair + Share + Padlet Activity

https://tinyurl.com/CCHL123

Padlet QR Code

1. Are we on the right track? What are your initial impressions of the Caregiver-Centered Care Education?

Pair + Share + Padlet Activity

https://tinyurl.com/CCHL123

Padlet QR Code

2. What would be your ideas to scale & spread the education in the healthcare systems across Canada (and beyond).

Pair + Share + Padlet Activity

https://tinyurl.com/CCHL123

Padlet QR Code

3. As Healthcare leaders how can we collectively advocate to engage our healthcare system in supporting family caregivers. (Call To Action)

Takeaways Based on Our Experience

Dedication, vision, and tenacity

Designing for systems change is a marathon, not a sprint.

Capacity-building

Strengths focused

Deep trust and respect

Creative humility

If you want to go fast, go alone. If you want to go far, go with others.

www.caregivercare.ca

Questions ?

Contact us:

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Dr. Sharon Anderson, Research: sdanders@ualberta.ca

Caregiver Centered Care is a Program of Applied Research & Innovation in Health Services Delivery in Family Caregiving, led by Dr. Jasneet Parmar, University of Alberta, Department of Family Medicine.

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Additional References & Resources

Anderson , G. O., & Thayer, C. E. (2018). *Loneliness and social connections: A survey of adults 45 and older.* . Retrieved from Washington, DC https://www.aarp.org/content/dam/aarp/research/surveys_statistics/life-leisure/2018/loneliness-social-connections-2018.doi.10.26419-2Fres.00246.001.pdf

Holt-Lunstad J, Smith TB, Baker M, Harris T, Stephenson D: **Loneliness and Social Isolation as Risk Factors for Mortality: A Meta-Analytic Review**. *Perspectives on Psychological Science* 2015, **10**(2):227-237. https://bit.ly/3kO31CG

Holt-Lunstad J, Smith TB, Layton JB: **Social Relationships and Mortality Risk: A Meta-analytic Review**. *Plos Medicine* 2010, **7**(7).

Kaddour L, Kishita N: **Anxiety in Informal Dementia Carers: A Meta-Analysis of Prevalence**. *Journal of Geriatric Psychiatry and Neurology* 2020, **33**(3):161-172.

Loh AZ, Tan JS, Zhang MW, Ho RC: **The Global Prevalence of Anxiety and Depressive Symptoms Among Caregivers of Stroke Survivors**. *Journal of the American Medical Directors Association* 2017, **18**(2):111-116.

Magnaye A, Fast J, Eales J, Stolow M, Leslie M: **Caregivers' failure to thrive: A case for health and continuing care systems transformation**. *Healthcare Management Forum* 2020. https://bit.ly/3bJ8xnb

Nickell et al. 2020 Effect of an innovative model of complexity care on family caregiver experience Canadian Family Physician https://www.cfp.ca/content/cfp/66/3/194.full.pdf

Additional References & Resources

Seeher K, Low LF, Reppermund S, Brodaty H: **Predictors and outcomes for caregivers of people with mild cognitive impairment: A systematic literature review**. *Alzheimer's and Dementia* 2013, **9**(3):346-355.

Schulz R, Beach SR, Friedman EM, Martsolf GR, Rodakowski J, Everette James A: **Changing Structures and Processes to Support Family Caregivers of Seriously Ill Patients**. *Journal of Palliative Medicine* 2018, **21**(S2):S36-S42. https://bit.ly/3a8fEVq

Victor, C. R., Rippon, I., Quinn, C., Nelis, S. M., Martyr, A., Hart, N., . . . on behalf of the, I. P. T. (2020). The prevalence and predictors of loneliness in caregivers of people with dementia: findings from the IDEAL programme. *Aging and Mental Health*. doi:10.1080/13607863.2020.1753014

Dr. Janet Fast's Research on Aging Policies and Practice Fact sheets

Caregivers in Alberta: Economic costs and contributions, 2019

The importance of connecting carers through health care connections, 2018

A snapshot of Canadians caring for persons with dementia: The toll it takes, 2015