



Palliative Institute

Recognizing and Realizing the Value Family Caregivers Bring to Palliative Care

January 8, 2026

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Palliative Institute



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- Please do not disclose any personal health information during the session.
- Your microphones are muted. When we invite participation, please unmute yourself if you'd like to speak at that time.
- If you experience technical difficulties, please let us know in the chat.



Land Acknowledgement



Recognizing and Realizing the Value Family Caregivers Bring to Palliative Care

Sharon Anderson MEd., MSc., PhD
Jasneet Parmar MBBS, MSc, MCFP(COE)

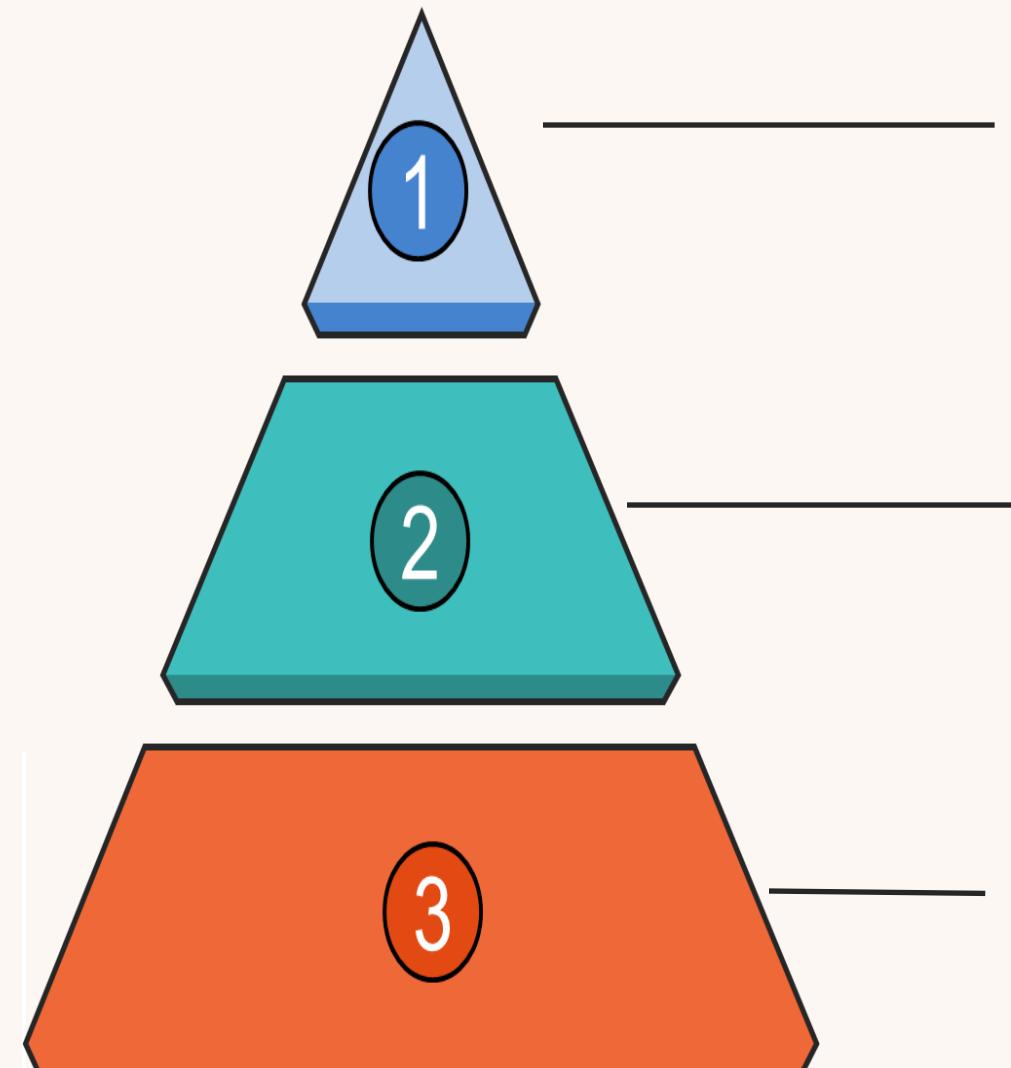
Psychosocial Spiritual Alberta Community of Practice 2025-26
January 8, 2026



Caregiver-Centered Care Health Workforce Education is a Program of Applied Research & Innovation in Health Services Delivery in Family Caregiving, Department of Family Medicine, University of Alberta



Objectives



- 1. Understand caregivers' value as essential partners in care.**
- 2. What matters to family caregivers in palliative care.**
- 3. Explore ways to include and support caregivers.**

“Caregivers are essential to palliative care — but they are not always cared for.”

1. Understand caregivers' value as essential partners in care.





Two Workforces, One System of Care

Alberta's Paid health & social care providers & Unpaid family caregivers

Family Caregivers

(Most recent data: 2018 General Social Survey)

- **~1 million caregivers**
- Provide: **647 million hours of unpaid care annually**
 - 75–90% of care in the community
 - 15–40% of care in continuing care
- Equivalent to **317,824 full-time positions**
- Estimated value: **\$12 billion yearly**

Health & Social Care Workforce

Includes paid workforce in: Hospitals, Ambulatory care, Nursing & residential care, & Social assistance

929,000

Alberta Family
Caregivers

Health & Social
Care Workforce

326,700
workers

Challenges for Caregivers to Manage

1 CARE

Assistance with personal care, instrumental and extended activities of daily living tasks

2 Medication

Keeping track, ordering, organizing & storing, understanding dose/ side effects.

3 Medical Appointments/Care

Coordinating, Attending, Transporting, monitoring, crisis

4 Emotional burden

loss of health, personal autonomy, relationship.

5 Physical Burden

Lifting, carrying, bending.

6 Being on-call

- Most of the day & night
- Assumption FCGs are available, able, and willing to take on the burdens & responsibilities of supporting patients

7 Out-of-pocket costs

Medication, driving to medical appts, parking, food away from home.

8 Structural Burden of Care

Assuming roles of project manager & care coordinator

9 Setting aside one's own needs

Losing one's sense of identity
Losing other roles

Family Caregivers: De facto System Navigators & Care Coordinators

- Heavy reliance on Family Caregivers to offset the need for and costs of continuing care services and support.
- Family caregivers rely on a patchwork of community services and supports that allow them to provide care at home

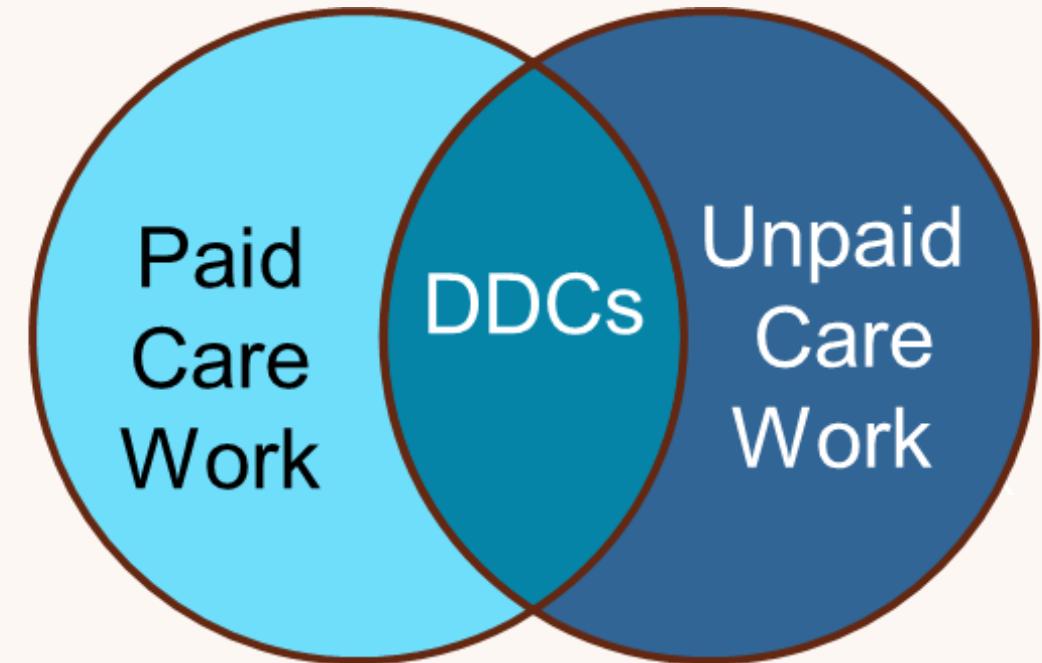


Kim, B., Wister, A., Mitchell, B., Li, L., & Kadowaki, L. (2024). Healthcare system navigation difficulties among informal caregivers of older adults: a logistic regression analysis of social capital, caregiving support and utilization factors. *BMC Health Serv Res*, 24(1), 1159. <https://doi.org/10.1186/s12913-024-11549-0>

Gaugler, J.E.; Marx, K.; Dabelko-Schoeny, H.; Parker, L.; Anderson, K.A.; Albers, E.; Gitlin, L.N. COVID-19 and the Need for Adult Day Services. *Journal of the American Medical Directors Association* 2021, 22, 1333-1337, doi:10.1016/j.jamda.2021.04.025.

Employed & Double-Duty Family Caregivers: *Key Facts*

- 62% of caregivers are employed.
- **56.1% of Alberta CC staff are Double-duty caregivers** (care work& at home)
- **Average of 20 hrs/week** unpaid care on top of employment
- **>10 hrs/week** care → higher risk of poor work–life balance and job insecurity.
- **Flexible work schedules helps,**
 - but ~50% who have it worry using it will hurt their careers.



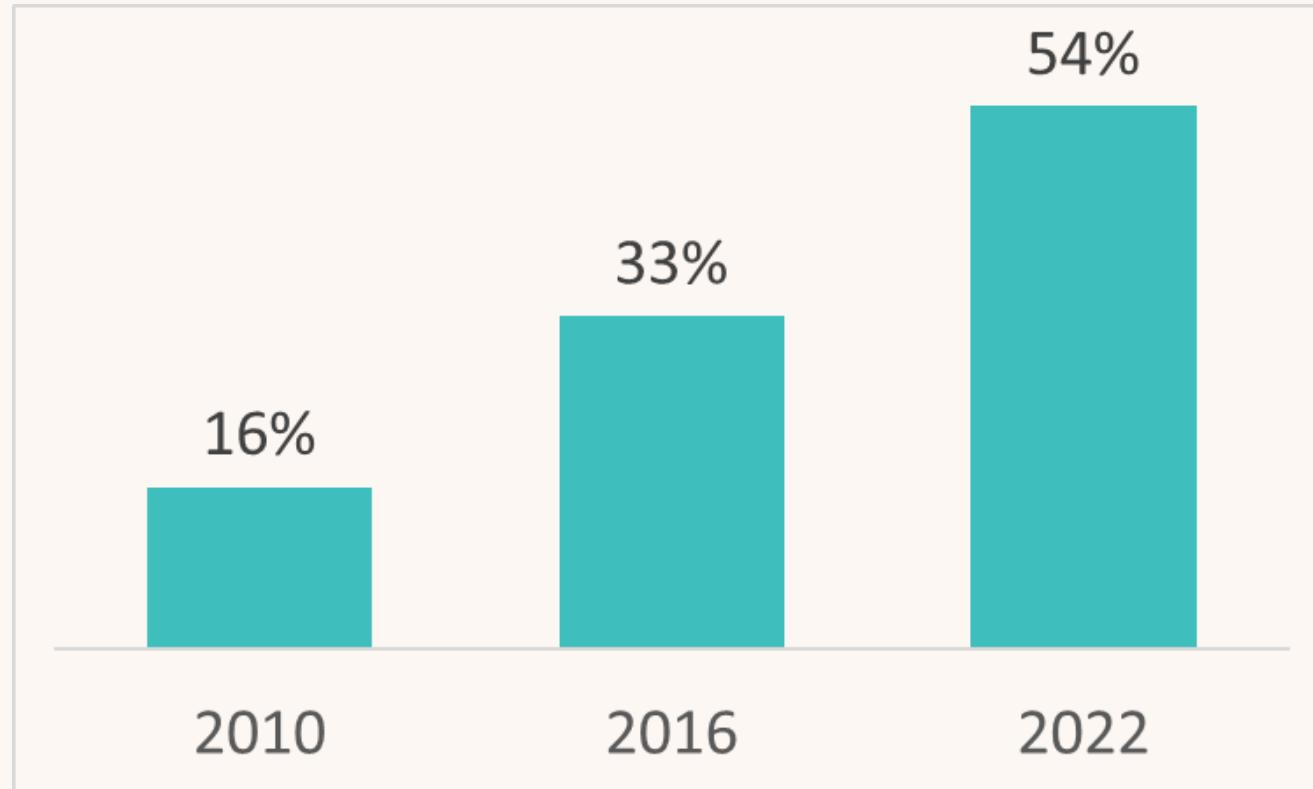
Lived Experience: Caregiving

Linda Powell

Family Caregiver



Rising Family Caregiver Distress



- Anxiety typically rises as care responsibilities increase & energy is depleted.
- Increases risk of heart disease, dementia, & premature mortality.**

Fewer Family Caregivers

- Smaller Families
- Changed family structure

Longer Care Trajectories

- Longer lives
- More chronic conditions

Aging in Place

- Prefer community homes
- Fewer long-term care beds

** Moukarzel, et al., [Sex Differences in the Relationship Between Psychosocial Stress and Myocardial Tissue Characteristics: A CMR Imaging Study](#). 2025, 18, doi:10.1161/circimaging.124.017667.

Hays, A.; Kelle, S. [Mental Stress, Significant Sex Differences, and the Substrate for Cardiovascular Disease: Early Insights From CMR](#) doi:10.1161/circimaging.125.019081.

New Evidence: Caregiving Stress Gets “Under the Skin”

Key findings from recent cardiovascular magnetic resonance imaging research:

- Psychosocial stress is linked to early myocardial changes in women, without diagnosed heart disease
- Caregiving burden independently predicts cardiac tissue changes in female participants

Lower emotional support amplifies biological stress effects

- No comparable effects were seen in men, despite similar reported stress levels

Why this matters for caregivers:

- Caregiving stress is not only psychological, it is biologically embedded, placing women caregivers at increased cardiovascular risk.



** Moukarzel, et al., [Sex Differences in the Relationship Between Psychosocial Stress and Myocardial Tissue Characteristics: A CMR Imaging Study](#). 2025, 18, doi:10.1161/circimaging.124.017667.

What benefits do you see of engaging family caregivers in your program?

Supporting Family Caregivers Improves Healthcare

- **Enhances Population Health**
 - Improves caregiver well-being ([Roberts et al 2020](#) | [Tan et al 2023](#))
 - Improves care recipients' health and well-being ([Schulz et al 2018](#))
- **Contributes to Healthcare Cost Savings**
 - Prevents unnecessary hospitalizations, emergency room visits, and medical interventions ([Griffin et al 2022](#) | [Sawan et al 2021](#) | [Schulz et al 2018](#))
 - Reduces readmissions and length of hospital stays ([Beach et al 2020](#) | [Glose 2020](#) | [Yasmeen et al 2020](#))
- **Enhances Experiences of Care**
 - Supports aging in the right place ([Holland 2022](#) | [Wagner 2021](#))
 - Enhances safety, quality, and continuity of care ([Beach et al 2018](#) | [Griffin et al 2019](#) | [Griffin et al 2022](#) | [Levine et al 2010](#) | [O'Hara & Canfield 2023](#) | [Schulz et al 2021](#))
- **Enhances Workforce Wellbeing/Joy**
 - Reduces healthcare providers' workload/stress ([Morton-Chang et al 2016](#) | [Schulz & Czaja 2018](#))
 - Increase healthcare provider satisfaction ([Brannely et al 2019](#) | [Griffin et al 2021](#) | [Reinhard et al 2019](#))
- **Contributes to health equity**
 - Guides prioritization of efforts to address support needs for equity-denied populations of caregivers ([2022 National Strategy to Support Family Caregivers](#))

2. What matters to family caregivers in palliative care.



What Caregivers of people with Parkinson's & Alzheimer's want

- **Recognition as partners** in the care team
- **Shared decision-making** as goals and capacity change
- **Clear pathways** and predictable access to help
- **Regular check-ins** for distress and anticipatory grief
- **Practical supports** to sustain caregiving
- **Respect and flexibility** across care, work, and community



Garon, M. et al., (2024). A systematic practice review: Providing palliative care for people with Parkinson's disease and their caregivers.

Palliat Med, 38(1), 57–68. <https://doi.org/10.1177/02692163231214408>

Lemos Dekker, N., & Bolt, S. R. (2022). Relating to the end of life through advance care planning: Expectations and experiences of people with dementia and their family caregivers. *Dementia (London)*, 21(3), 918–933. <https://doi.org/10.1177/14713012211066370>

Moments to Add Value in Advancing Conditions & Palliative Care

- New diagnosis of a progressive condition
 - Many unmet physical, cognitive, psychosocial, and spiritual needs
 - experience problems in coordination and continuity of care
 - Early integration of a palliative approach improves symptom control and the quality of life
- Repeat admissions or multiple settings in 90 days
- Complex regimens/equipment or caregiver questions like “What do I do if...?”
- More than one care partner, eager to be involved

Lemos Dekker, N., & Bolt, S. R. (2022). [Relating to the end of life through advance care planning: Expectations and experiences of people with dementia and their family caregivers](#). *Dementia (London)*, 21(3), 918–933.

Walter, H. A. W., et al., (2018). [The Role of Palliative Care in Chronic Progressive Neurological Diseases-A Survey Amongst Neurologists in the Netherlands](#). *Front Neurol*, 9, 1157. <https://doi.org/10.3389/fneur.2018.01157>



**What do caregivers tell you about their
needs?**

What caregivers' psychosocial, spiritual, and religious needs can look like:

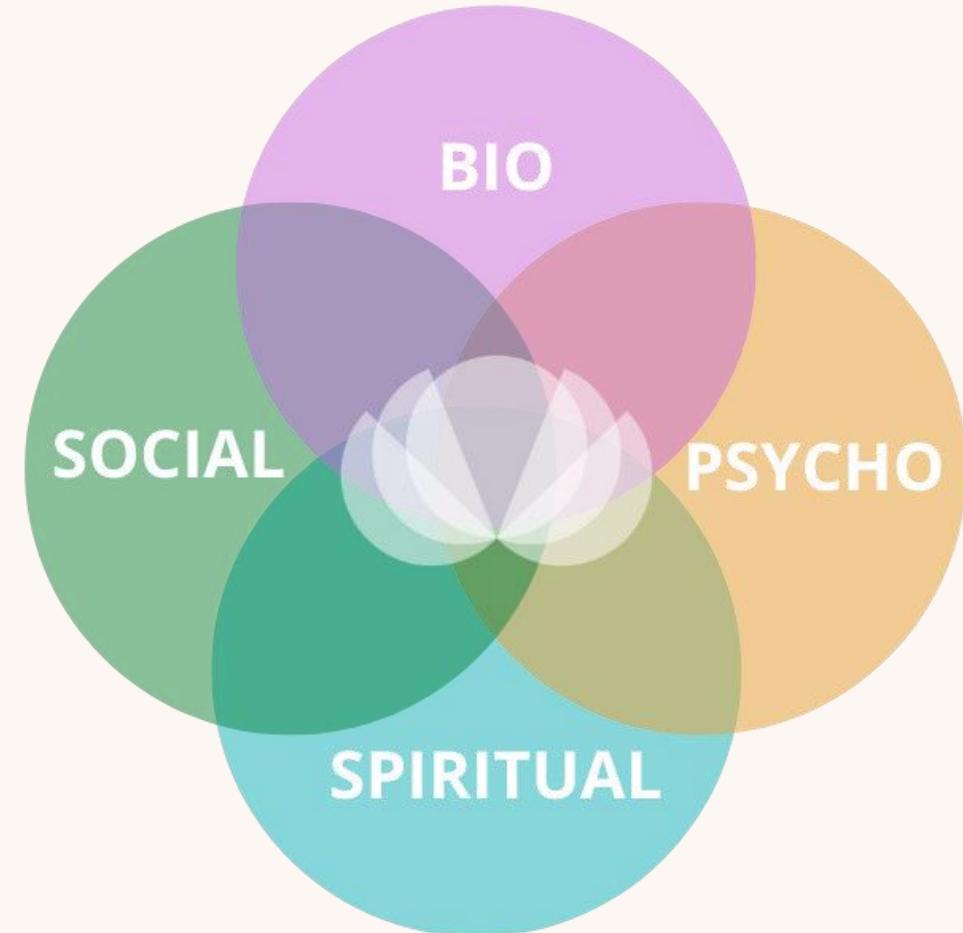
1. **Big questions:** Why is this happening? Why now? What does this mean?
2. **Moral weight:** guilt, fairness, "Am I making the right decisions?"
3. **Anticipatory grief:** Losses piling up before death
4. **Feeling alone or unseen:** Carrying the load quietly
5. **Strained relationships:** Family conflict, disconnection, role changes
6. **Faith/spiritual struggle:** Comfort for some; anger, doubt, or burden for others
7. **Need for connection:** Community, ritual, prayer/meditation, nature, or quiet, or the need to be free from unwanted religious pressure



Why Psychosocial & Spiritual Practitioners Are Essential to Care Teams

Psychosocial and spiritual practitioners play a unique, irreplaceable role in supporting family caregivers. **Your critical contributions include:**

- Protecting caregiver well-being
- Holding the triadic relationship
- Supporting decision-making under uncertainty
- Addressing cumulative loss and meaning disruption
- Stabilizing care continuity



How spiritual practices may support cognitive health

~73% of RCTs reported better cognitive outcomes among people engaging in spiritual practices (e.g., meditation, yoga, tai chi)

Spiritual practices may support cognitive health through three connected pathways

1) Psychosocial pathways (mind + relationships)

- More social connection/support (often through community)
- More positive emotions (meaning, purpose, optimism)
- Less stress, anxiety, and depression (key risks for cognitive decline)

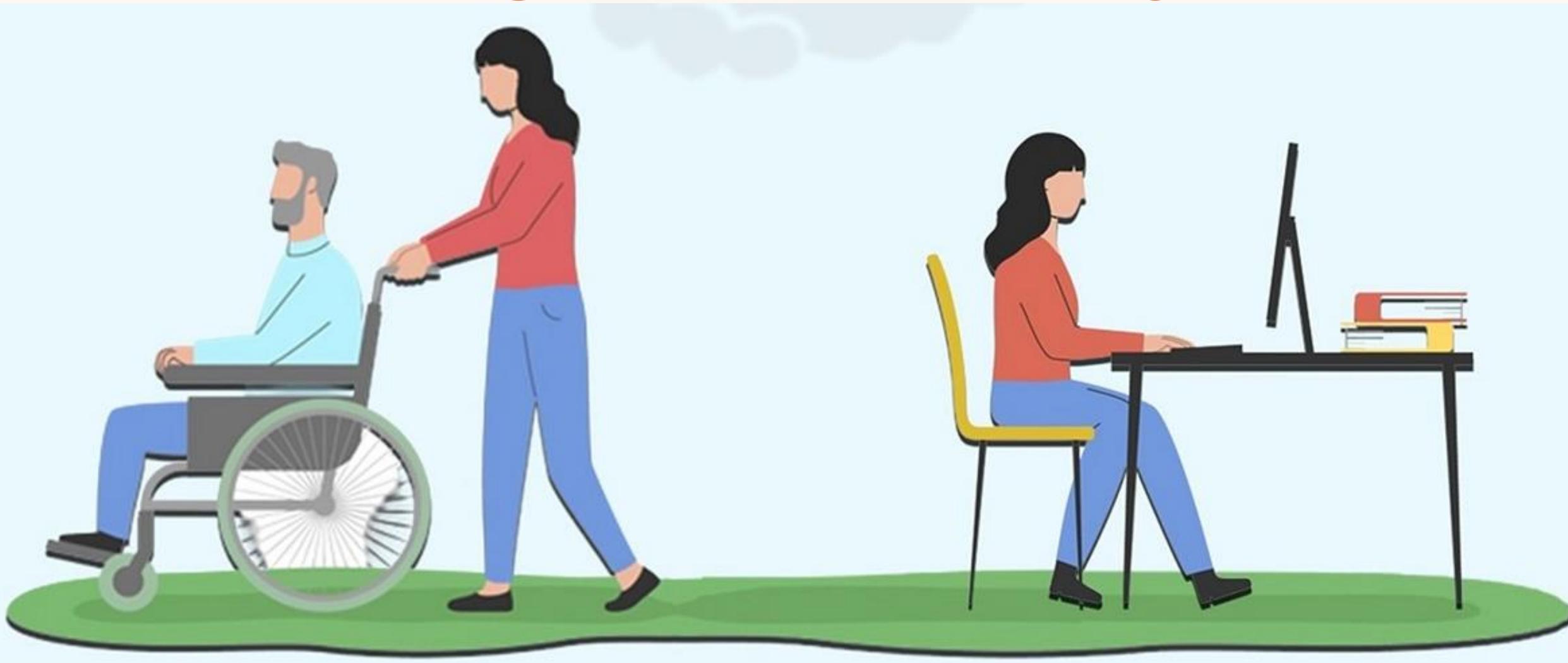
2) Behavioral pathways (daily rhythms + functioning)

- Healthier behaviors (e.g., less smoking/alcohol; more activity; healthier eating—varies by practice)
- Better sleep (quality and quantity)
- Better daily functioning (strength, balance, ability to do everyday tasks)

3) Neurobiological pathways (body + brain biology)

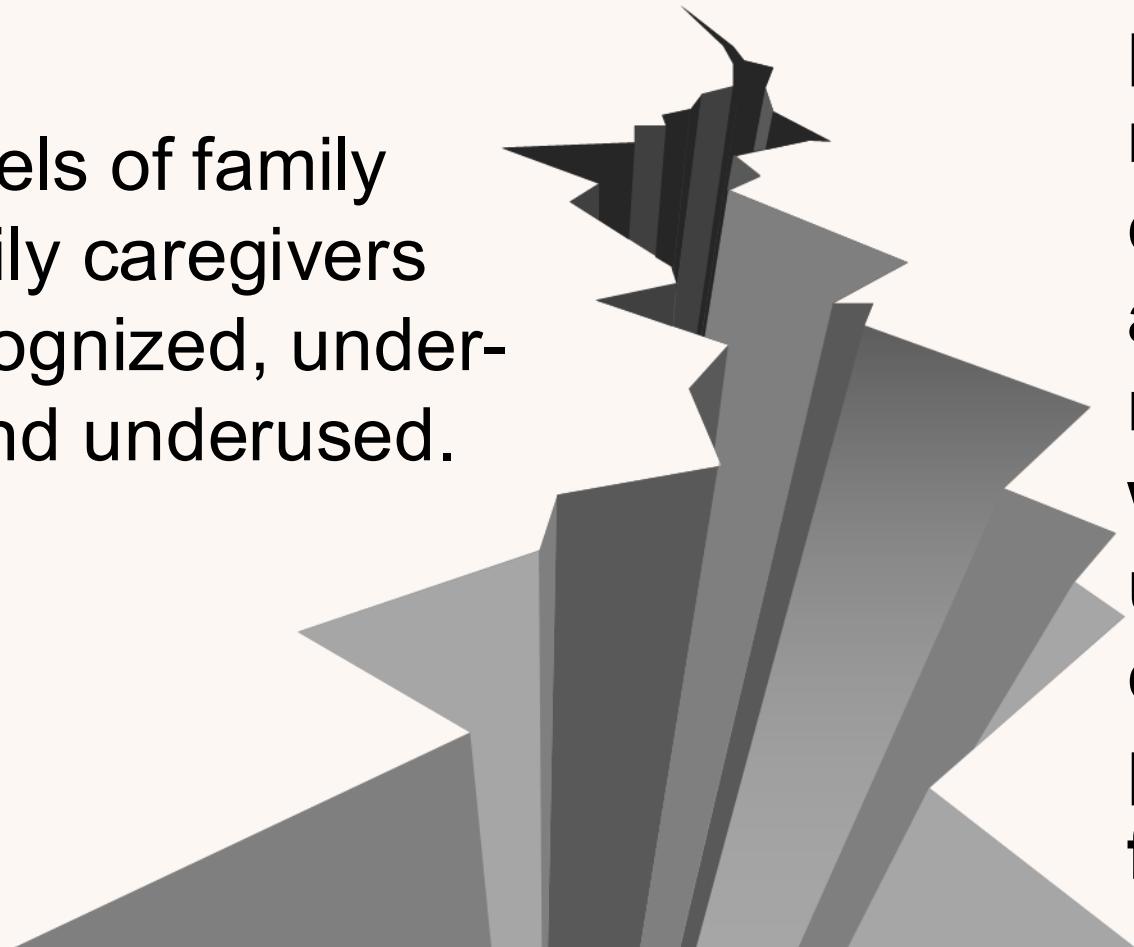
- **Lower inflammation and better immune regulation**
- Better stress biology (e.g., cortisol/stress response)
- Possible brain changes (e.g., brain network efficiency/structure), but more research is needed

3. Explore ways to include and support caregivers across settings.



Biggest Gap in Support for Family Caregivers: the Healthcare System

In most models of family practice, family caregivers are underrecognized, under-supported, and underused.



Few healthcare 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.



2018: Changing Structures & Processes to Support Family Caregivers

“Providers should see family caregivers not just as the person who comes with the client, but rather as a partner in that enterprise who may need information, training, care, and support. “

Recommendation:

Enhance healthcare providers' competencies to support family caregivers!

Schulz, R. et al, 2018 Changing Structures & Processes to Support Family Caregivers

Multiple Complex Chronic Conditions

22.2% of Canadians aged 12 + have two or more chronic conditions

(Chronic conditions: 67% of all deaths in Canada)

What Good Practice Looks Like

Early, inclusive triadic conversations turns transitions into touchpoints and caregivers into confident partners.

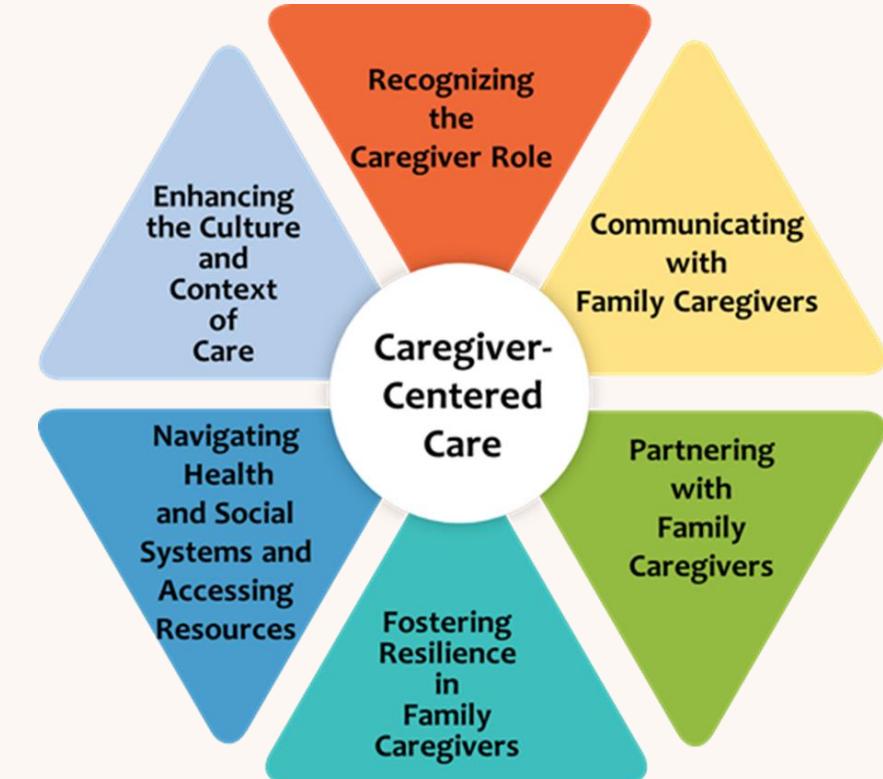
1. Patients and caregivers flag challenges and what matters most to them
2. Caregiver Needs Assessment
3. Team addresses needs

Better outcomes for Patient and Family Caregiver, Healthcare providers, and System

Caregiver-Centered Care Education: Enabler of Best Practice

CCCE strengthens health, social, and community care providers' role by:

- Formalizing caregiver recognition
- Strengthening triadic communication
- Normalizing anticipatory grief and distress
- Embedding routine caregiver assessment
- Improving team integration and influence
- Supporting sustainability of the caregiving role



Caregiver-Centered Care Education makes caregiver support visible, valued, and actionable within teams.



Caregiver-centered care is person-centered care for family caregivers.

It is a collaborative relationship between family caregivers and care providers which engages family caregivers as partners in care. It meaningfully involves them in planning and delivery of supportive services and recognizes and addresses their needs and preferences.

Parmar, J. et al. Developing person-centred care competencies for the healthcare workforce to support family caregivers: Caregiver centred care. *Health Soc Care Community* 2021, 29, 1327-1338, doi:10.1111/hsc.13173. (email us for the paper, it is not open source)

Three Competency Levels

Champions Education for Healthcare Providers who model and mentor Caregiver-Centered Care.

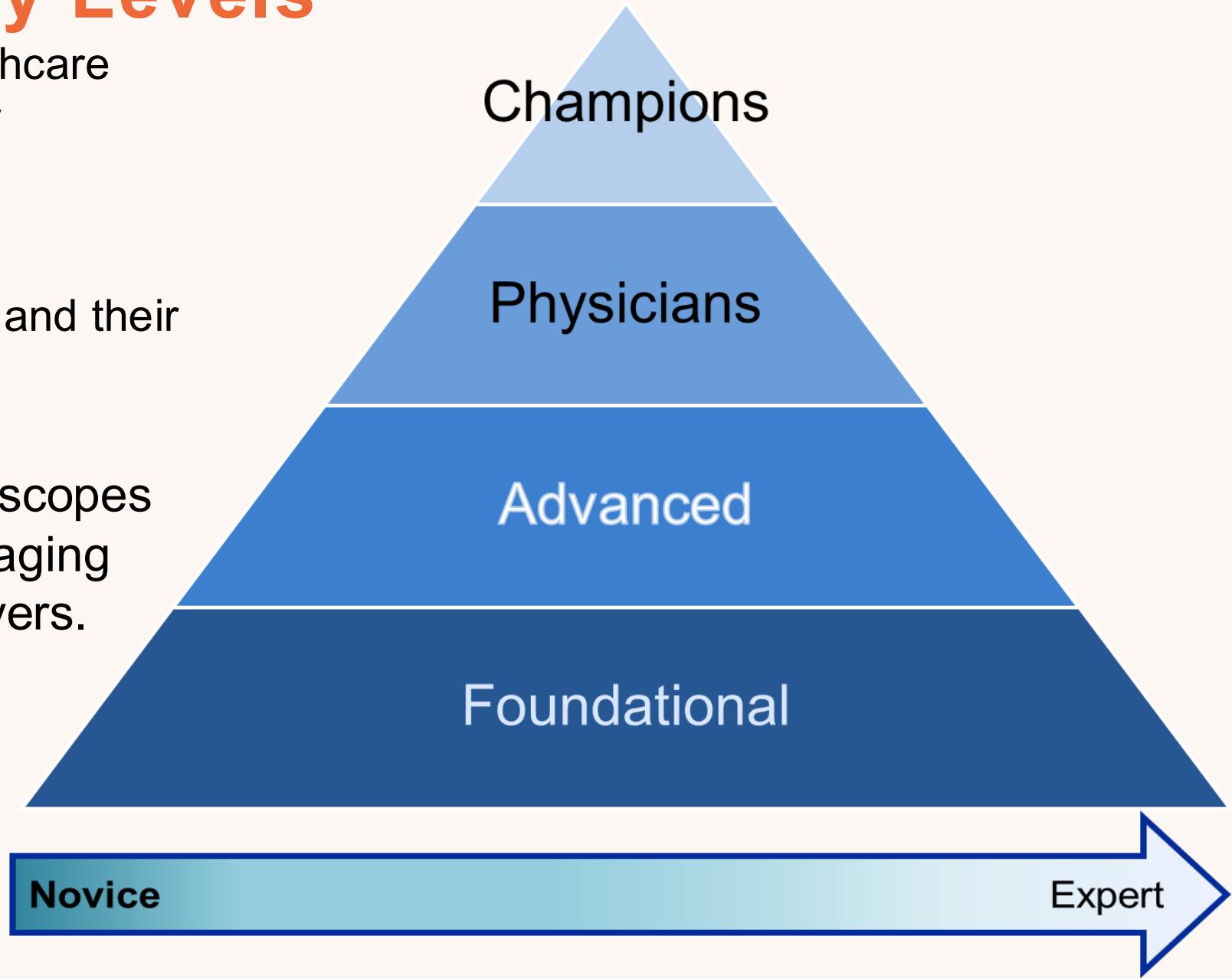
Physicians' Education

For physicians, fellows, trainees, and their teams

Advanced Education

For healthcare providers whose scopes of practice should include engaging and supporting Family Caregivers.

Foundational Education for Healthcare Providers who interact with family caregivers in their roles and contexts.





Caregiver-Centered Care

FOUNDATIONAL COURSE

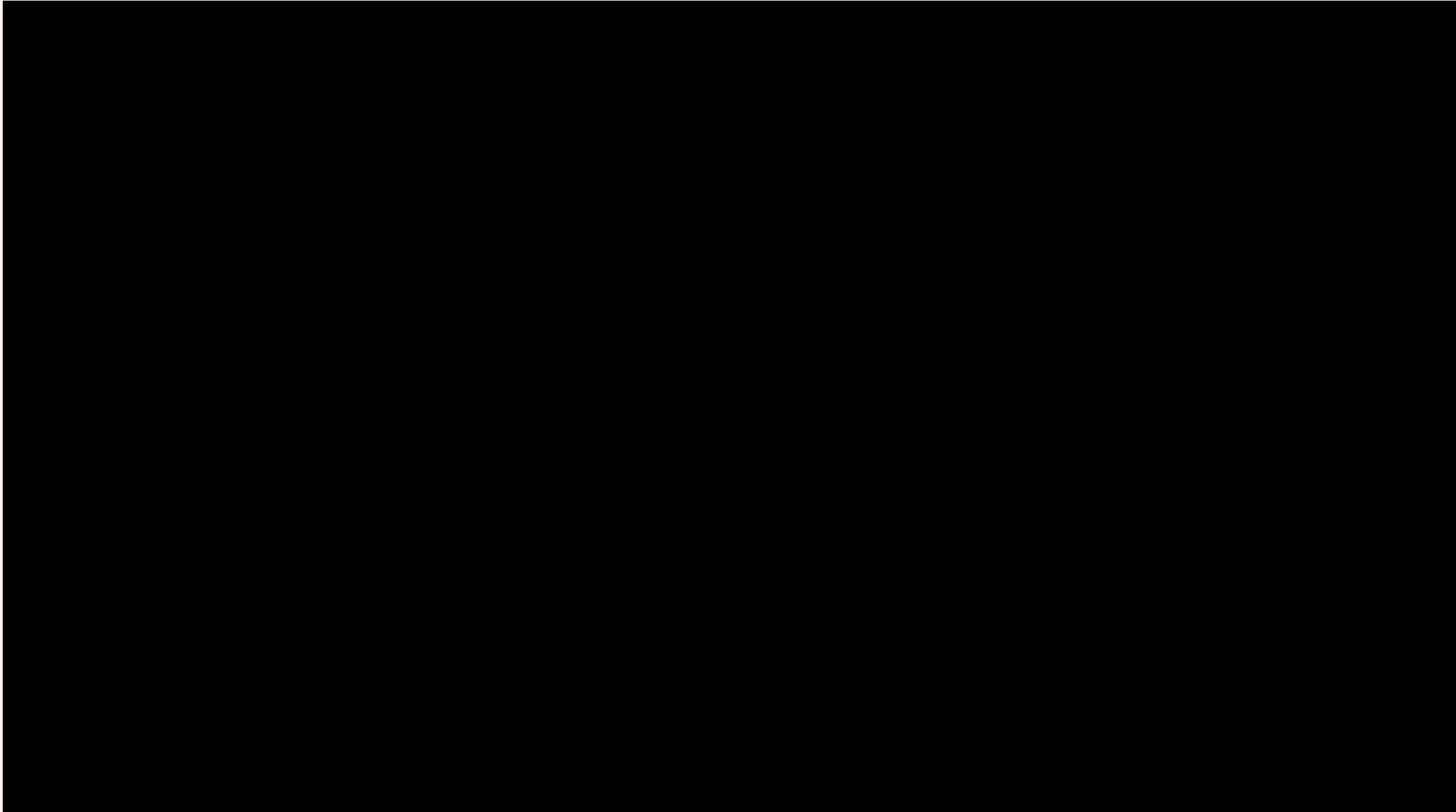
ADVANCED EDUCATION

CHAMPIONS EDUCATION

PHYSICIANS EDUCATION

Free online at Caregivercare.ca

Foundational Education for All Care Providers who interact with family caregivers



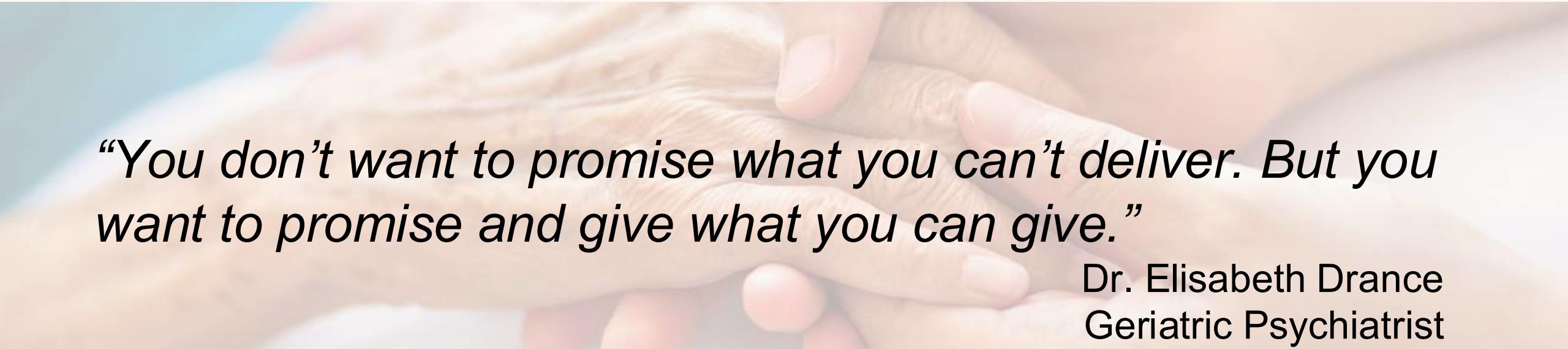
Foundational Results

This module has increased the confidence I have with regards to caregiving centered care. The key points that were discussed on this module were so clear and precise and I would highly recommend for my colleagues to take this course as well. (Occupational therapist)

The videos weren't fake looking. I could actually believe the story you were telling. As a future social worker and current homecare staff I am very thankful for the course and I know I will utilize these steps. It has given me a solid foundation to build more knowledge since you don't know what you don't know! (Social work student)

Parmar, J.K.; L'Heureux, T.; Anderson, S.; Duggleby, W.; Pollard, C.; Poole, L.; Charles, L.; Sonnenberg, L.K.; Leslie, M.; McGhan, G.; et al. Optimizing the integration of family caregivers in the delivery of person-centered care: evaluation of an educational program for the healthcare workforce. *BMC Health Services Research* 2022, 22, [doi:10.1186/s12913-022-07689-w](https://doi.org/10.1186/s12913-022-07689-w).

Advanced Caregiver-Centered Care Education: for Health Care Providers whose roles should include engaging and supporting Family Caregivers



“You don’t want to promise what you can’t deliver. But you want to promise and give what you can give.”

Dr. Elisabeth Drance
Geriatric Psychiatrist

Partnering with family caregivers

DOMAIN C: ELISABETH DRANCE

Compassion and Curiosity

Advanced health workforce education to support family caregivers

Advanced Education: Results

“These learning videos highlighted the importance of the work that I do as a health care provider. I am confident that I provide support in many ways that these videos show—I am now able to put a name to some of the concepts and strategies utilized in my practice.”

“This course helped me better understand how to approach speaking about self-care and helped me understand that self-care not only lies with the caregiver but also has to be planned and executed with the help of a provider.”

Caregiver-Centered Care Champions

Someone's sitting in the shade
today because someone planted a
tree a long time ago.

- Warren Buffet

Caregiver-Centered Care Champions courageously engage in change because they believe that something different is possible.

Champions Results

“It reminded me to listen closely and ensure I paraphrased the need. It helped me recognize strengths and encouraged me to stretch my thinking about what I or others can do.”

“I work in the community setting, so the course gave more concrete examples of how different healthcare professionals could realistically be actively supporting caregivers.”

“I now step back and ask what the caregiver thinks they may need instead of overwhelming them with information.”

Tanya L’Heureux, Jasneet Parmar, David Nicholas et al., (In Review) Equipping Change Agents: Applying mixed-methods to learn about the outcomes of the Co-Designed Caregiver-Centered Care Champions Education Program

Small Shifts, Meaningful Impact

- Seeing and naming the caregiver
- Getting curious before assuming
- Clarifying pathways and limits
- Checking in on the caregiver
- Making space for grief
- Strengthening practice through shared learning



www.caregivercare.ca

Caregiver-centered care grows through practice, reflection, and community.



Questions?



Thank You

Caregiver-Centered Care
Caregivercare.ca

Contact
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Sharon Anderson: sdanders@ualberta.ca



From Hospital Wards to Living Rooms: How Calgary Is Stitching Health & Community Care Together

CAREGIVER-CENTERED CARE CHAMPIONS COMMUNITY OF PRACTICE

12 Noon to 1 PM
22 JAN 26



DR. MICHELLE GRINMAN

Clinical Associate Professor,
Deputy Section Lead,
General Internal Medicine
Chair, Canadian Hospital at
Home Working Group.



FARAH VISRAM

Unit Manager,
Calgary Zone
Virtual Home Hospital



**ALISON MCKELVEY-
JOZSA**

Social Worker
Calgary Specialized
Geriatrics



**JOCELYN CUTHERBERT
MORA**

Manager
Aging Well in Community
Carya

WHAT'S IN THIS SESSION

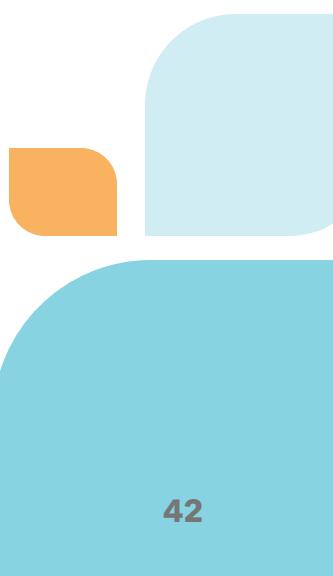
REGISTER

SCAN ME

Evaluation



<https://redcap.albertahealthservices.ca/surveys/?s=A8YCPXM4EMYDKJT3>



Covenant Health
Palliative Institute

Upcoming Session

Session #4: Children's Grief and Psychosocial Support

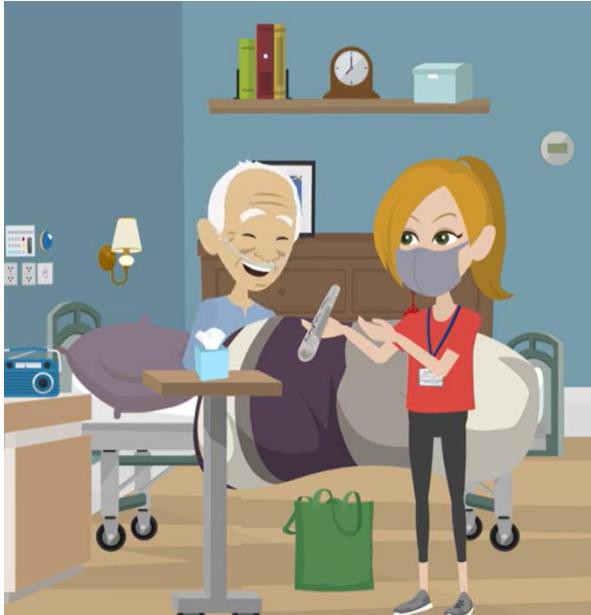
Date: February 12, 2026

Presenter: Debbie Rudd, Certified Child Life Specialist, Children's Hospice and Palliative Support Team, Alberta Children's Hospital, Calgary, AB

This session introduces knowledge and practical tools needed to support children and adolescents experiencing grief. Participants will explore developmental aspects of grief, learn effective psychosocial support techniques, and strengthen their ability to communicate and collaborate with families and care teams.

PalliPro

PalliPro: Palliative Care
Interprofessional
Education | Rise 360



PalliLearn Facilitation Training

- New training sessions coming!
February, 4,11,18, 25th, 12-1:15PM
Facilitator training March 4th, 9-12
- Call for volunteer facilitators:
 - Palliative Care, Health Care Professional
 - Facilitation experience
 - Interested to volunteer to host sessions educating the public
- Contact Mary-Ann Shantz for details
mary-ann.shantz@covenanthealth.ca

Thank You!

Stay Connected

- Visit [Palliative Institute | Covenant Health](http://Palliative.Institute | Covenant Health) (covenanthealth.ca) to access all our tools and resources.
- Contact us at: Palliative.Institute@covenanthealth.ca



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