



NATIONAL CONFERENCE
CONFÉRENCE NATIONALE

@CCHL_CCLS
#CCHLUnstoppable



Re-imagining care through health, community, and family caregiver partnerships: Forging a future of integrated care, together

Jasneet Parmar MBBS, MSc, MCFP (COE)

Helen Lightfoot BSW, RSW, MACE.

CANADIAN COLLEGE OF
HEALTH LEADERS



COLLÈGE CANADIEN DES
LEADERS EN SANTÉ

TITLE
SPONSOR



Agenda and Learning Outcomes

At the end of this session, participants will be able to:



1

Recognizing Family Caregivers as Integral Members of Care Teams

2

Explore How We Can Accelerate Caregiver-Centered and Asset-Based Community Strategies

3

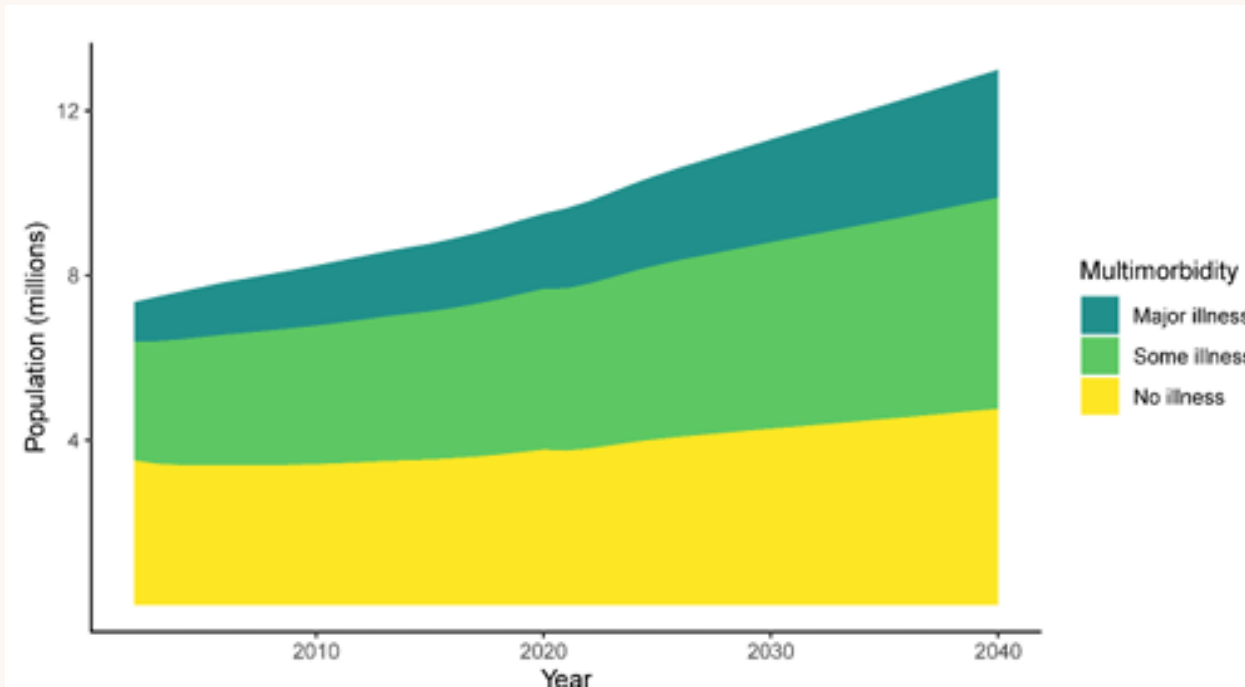
Co-produce a forward-looking action plan for scaling caregiver-centered initiatives provincially and nationally.

1. Recognizing Family Caregivers as Integral Members of Care Teams



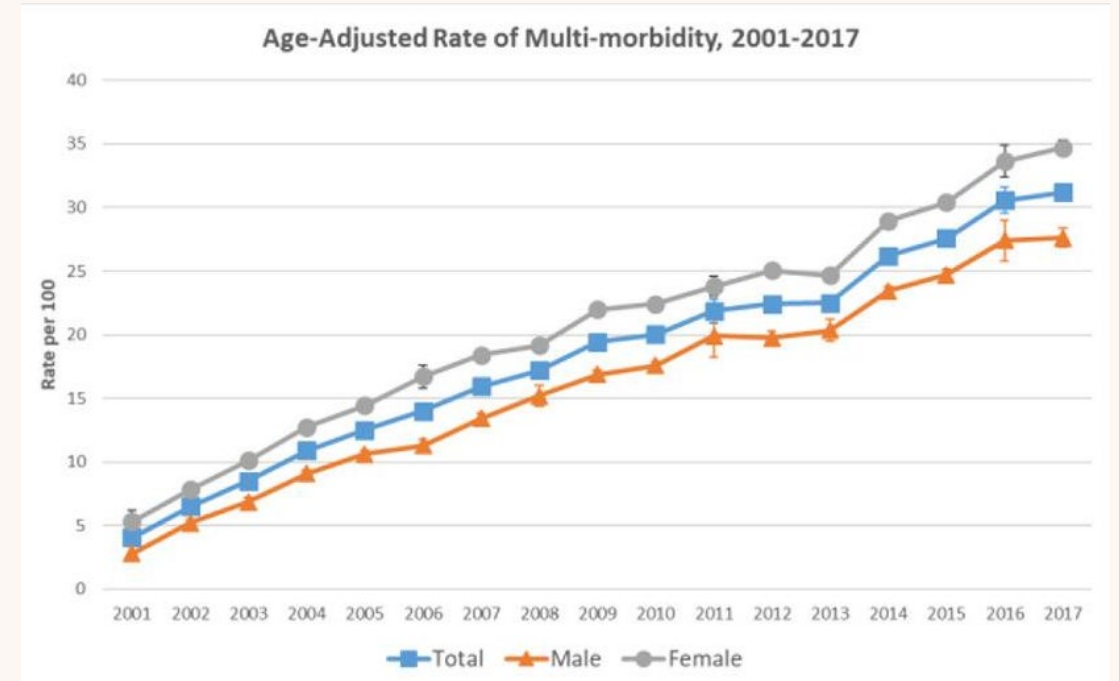
“Substantial Increases” in Chronic Diseases

Projected patterns of illness in Ontario (2024)



Rosella, L. C., Buajitti, E., Daniel, I., Alexander, M., & Brown, A. (2024). Projected patterns of illness in Ontario. Retrieved October 17, 2024, from <https://pophealthanalytics.com/wp-content/uploads/2024/10/Study-Projected-Patterns-of-Illness-in-Ontario-Released-October-16-Final.pdf>

Chronic disease surveillance in Alberta’s tomorrow project using administrative health data (2022)



Ye, M., Vena, J. E., Johnson, J. A., Shen-Tu, G., & Eurich, D. T. (2021). Chronic disease surveillance in Alberta's tomorrow project using administrative health data. *Int J Popul Data Sci*, 6(1), 1672. <https://doi.org/10.23889/ijpds.v6i1.1672>

A Turning Point: Need for New Thinking in Health Care

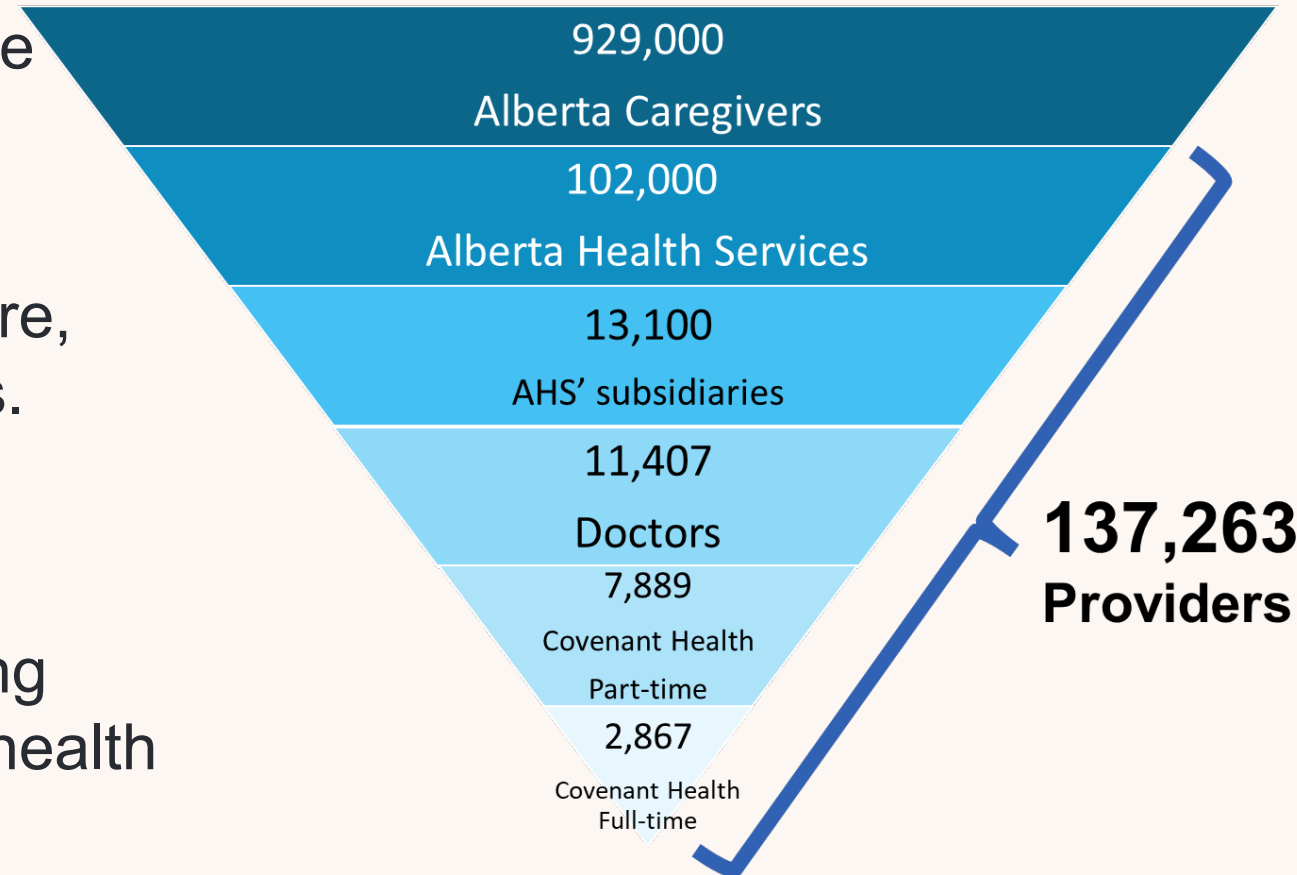
Health Systems Grappling with Intense Pressures on Existing System Capacity:

- Rapid population growth,
- Increasingly complex health needs,
- Workforce shortages, and
- **Urgent need for a long-term health services capacity plan**

“Expanding services that support and encourage seniors to age at home, such as access to home and community support services, primary care and supportive housing, will also ensure that long-term care and hospital capacity are available for people with the most complex and serious needs.” (Rosella et al. 2024)

Family Caregivers: The Largest Care Workforce

- Provide 75- 90% of the care in the community & assist with 15 - 40% of the care in continuing care
- In 2018, Alberta's 1 million caregivers provided 647 million hours of unpaid care, equivalent to 317,824 full-time positions.
- Unpaid care worth \$12 billion yearly
- Caregivers play a critical role in reducing safety incidents and improving patient health outcomes and experiences



Klingbaum, A et. al. Caring in Canada: Survey insights from caregivers and care providers across Canada. **2024**.

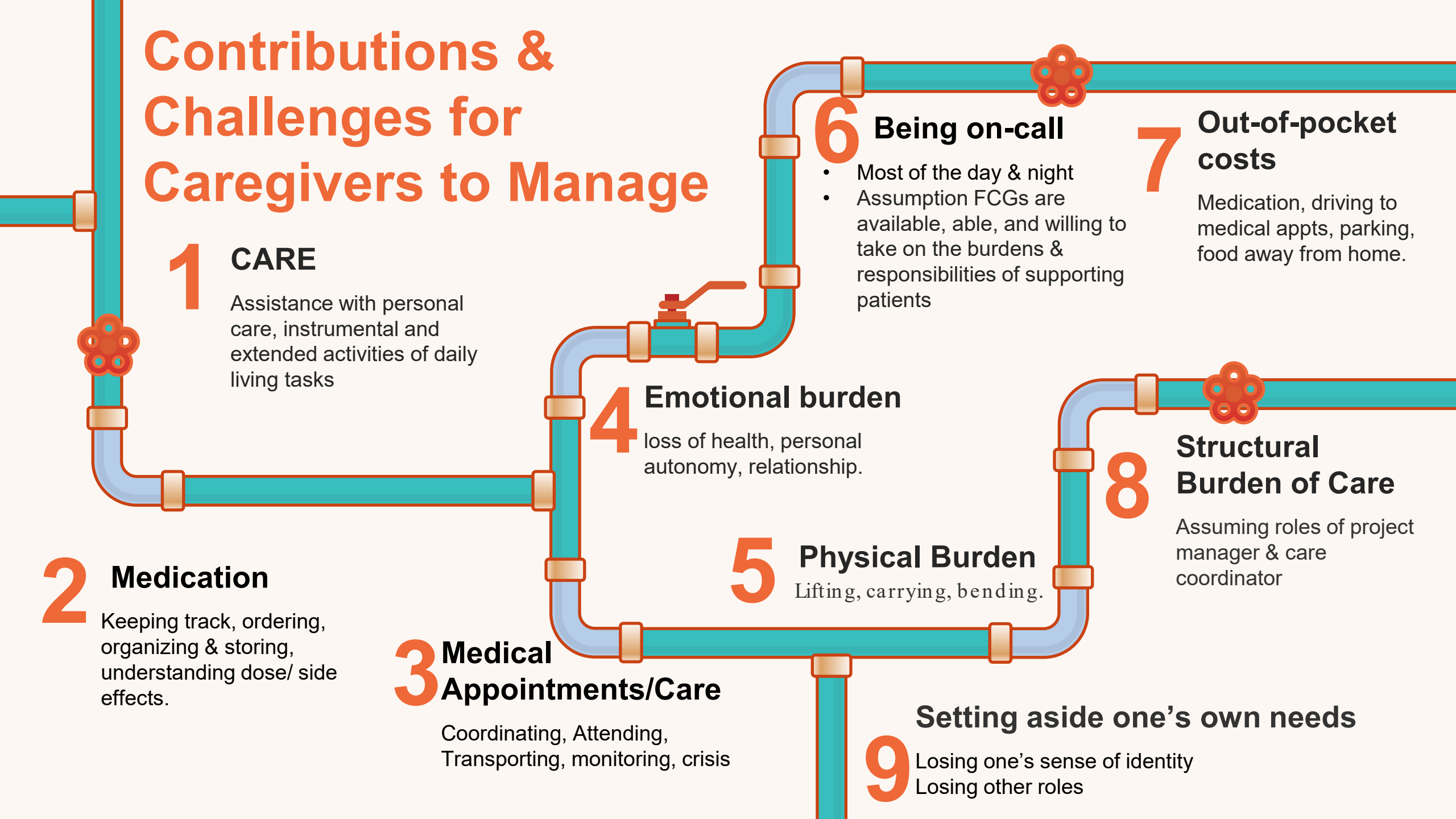
Fenc, L. et al., Caregiving in Canada: Challenges and opportunities shaping a national conversation. **2020**, 22.

Coe, N.B.; Werner, R.M. Informal caregivers provide considerable front-line support in residential care facilities and nursing homes. *Health Affairs* **2022**, 41, 105-111, doi:10.1377/hlthaff.2021.01239.

Fast, J. *Value of family caregiving in Canada*; University of Alberta: Edmonton, 2022; p. 2.

Alberta Healthcare Workforce Strategy, 2023 <https://open.alberta.ca/dataset/212201d6-7780-4111-ae2d-da4c487bfef9/resource/20f3f48b-1bec-4fab-a6b8-d5b24bdf6fef/download/hlth-health-workforce-strategy-2023.pdf>

Contributions & 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 are doing nursing and medical tasks

- 70% perform medical/ nursing tasks to help care receiver manage pain and/or discomfort, including opioid injections such as morphine
- 82% manage medications including for insulin, antibiotics,
- 37% deal with wound care (surgical wounds, ulcers, rashes, or sores)
 - cleaning wounds,
 - ordering wound care supplies,
 - monitoring wound conditions for infection and healing, changing dressings
- Managing respiratory equipment: oxygen therapy, (including continuous positive airway pressure [CPAP] units), spirometers,
- Managing drains and drainage bags including ostomy bags.
- 30% manage incontinence
- Managing and arranging for medical equipment,
- Half (51%) assist with canes, walkers, wheelchairs, scooters, or other mobility devices
- Coordinating care.

Caregivers who perform medical or nursing tasks worry about making a mistake and the more complex the task, the greater the worry.

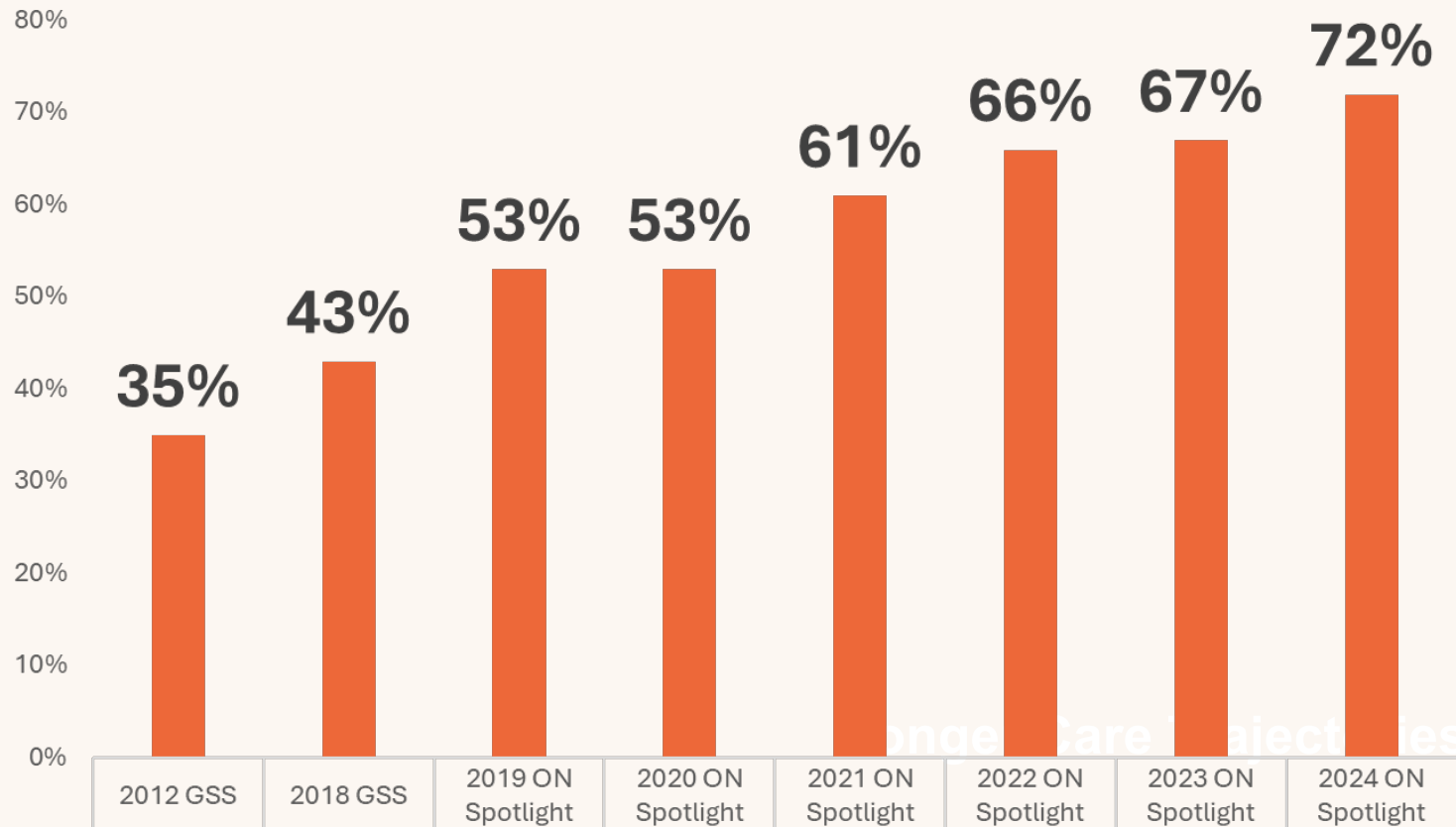
Choula, R.B.; Accius, J.C. Home alone revisited: Family caregiver providing complex care. 2019, 63.

Allen, J.; Woolford, M.; Livingston, P.M.; Lobchuk, M.; Muldowney, A.; Hutchinson, A.M. Informal carer support needs, facilitators and barriers in transitional care for older adults from hospital to home: A scoping review. *Journal of Clinical Nursing* 2023, 32, 6773-6795, doi:10.1111/jocn.16767.

Chase, J.A.D.; Russell, D.; Kaplan, D.B.; Bueno, M.V.; Khiewchaum, R.; Feldman, P.H. "Doing the Right Thing": Family Caregivers Managing Medical and Nursing Tasks in the Postacute Home Health Care Setting. *Journal of Applied Gerontology* 2021, 40, 1786-1795, doi:10.1177/0733464820961259.

Rising Family Caregiver Anxiety, Distress, Burnout

Family Caregivers: Feeling Overwhelmed



Anxiety most frequently occurring disorder in caregiving

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

Fewer Family Caregivers

Longer Care Trajectories

Aging in Place

Invisible Caregivers

“Healthcare delivery simultaneously ignores and relies heavily on family caregivers to provide ongoing support to older adults with cognitive issues, physical impairments, and/or advancing complex conditions.” (Schulz and Czaja 2018)



Walk with me: Caregiver Linda Powell



Supporting Family Caregivers Improves Care

- **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**

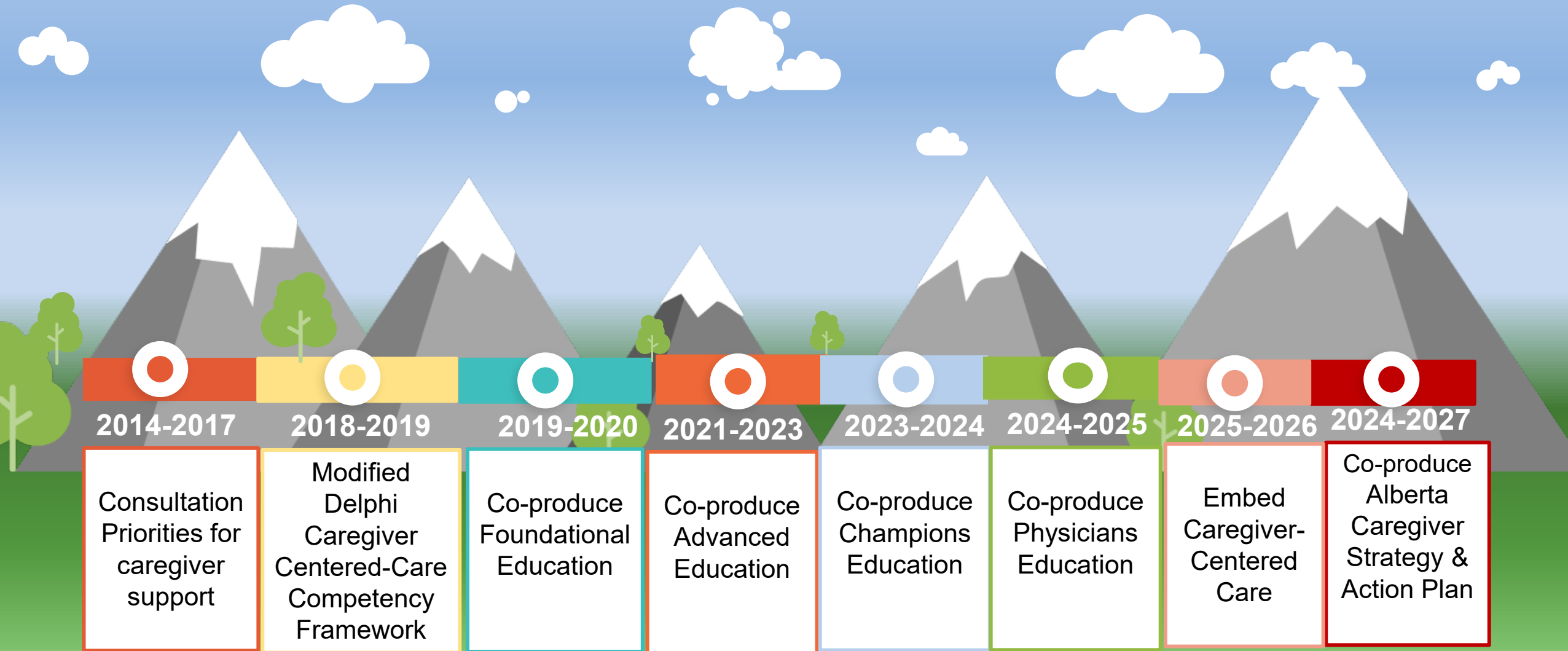
- Reduces healthcare providers' workload/stress ([Morton-Chang et al 2016](#) | [Schulz & Czaja 2018](#))
- Increase healthcare provider satisfaction ([Brannelly et al 2019](#) | [Griffin et al 2021](#) | [Reinhard et al 2019](#))

An orange, irregular, blob-like shape with a soft, organic edge, serving as a background for the title text.

Paradigm Shift required:

- The work of family caregivers is NOT simply to implement the health, social, or community care team's plan of care for their family member.
- The work of health, social, and community care teams is to recognize, support, enrich, and augment the care that family caregivers already provide to their family members.
- **Family caregivers are the most valuable health, social, and community care team member we have.**

Changing Mindsets: Making Caregivers Visible & Valued



Caregiver-Centered Care

FOUNDATIONAL COURSE

ADVANCED EDUCATION

CHAMPIONS EDUCATION

PHYSICIANS EDUCATION



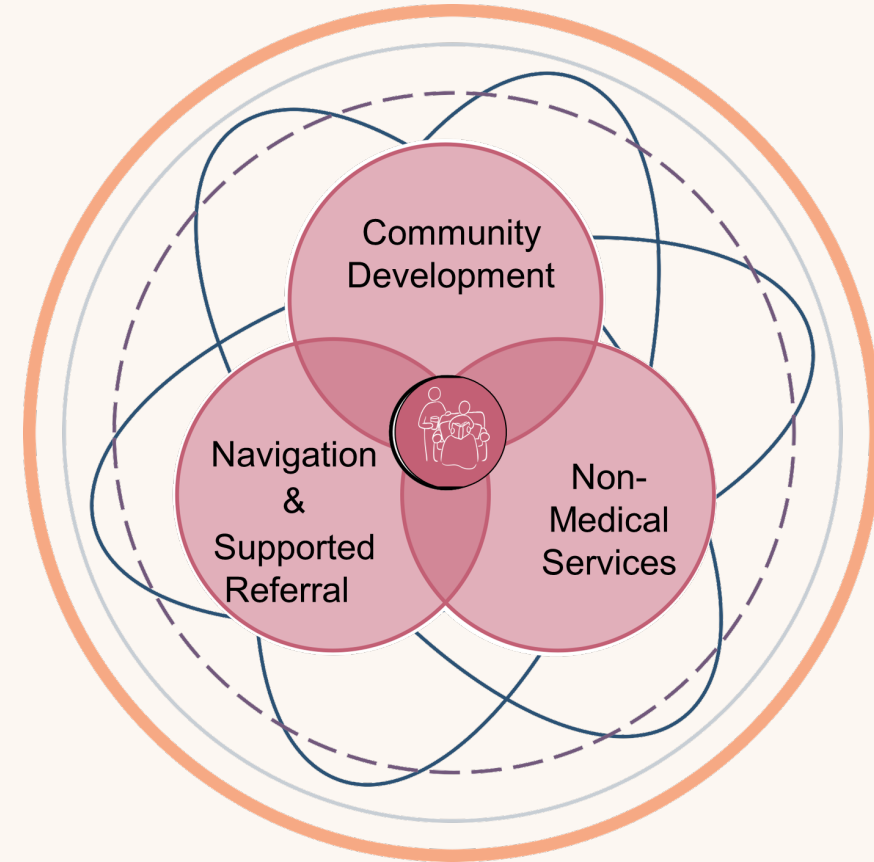
Education for Health, Social and Community Care Providers:
www.caregivercare.ca

Family Caregivers as Care Integrators

Health Care

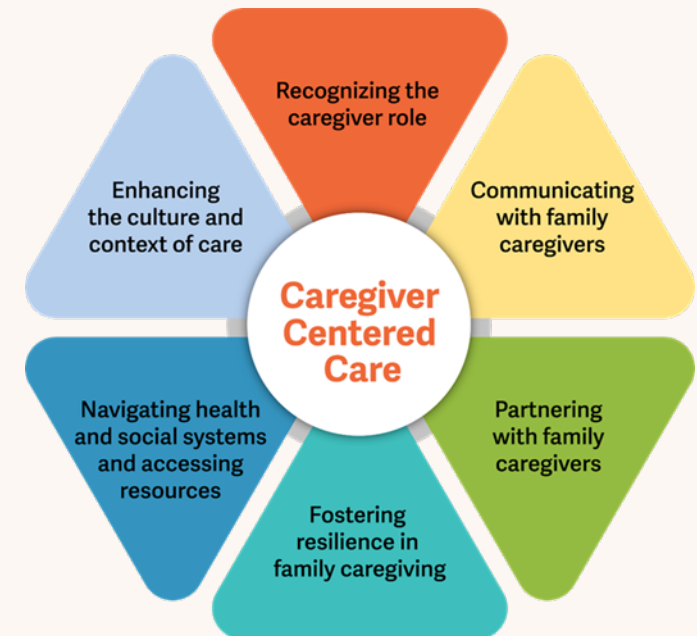
- Primary and Preventative Health Services
- Assisted Living and Social Services
- Hospital and Surgical Health Services
- Mental Health and Addictions

Community Care



Think, Pair, Share

- How does your program incorporate caregivers into service delivery?
- What approaches are used in your work to enhance collaboration across silos?



2. Explore How We Can Accelerate Caregiver-Centered and Asset-Based Community Strategies



Building a Better System to Support Family Caregivers and the People they care for: Integrating Health, Social, and Community Care

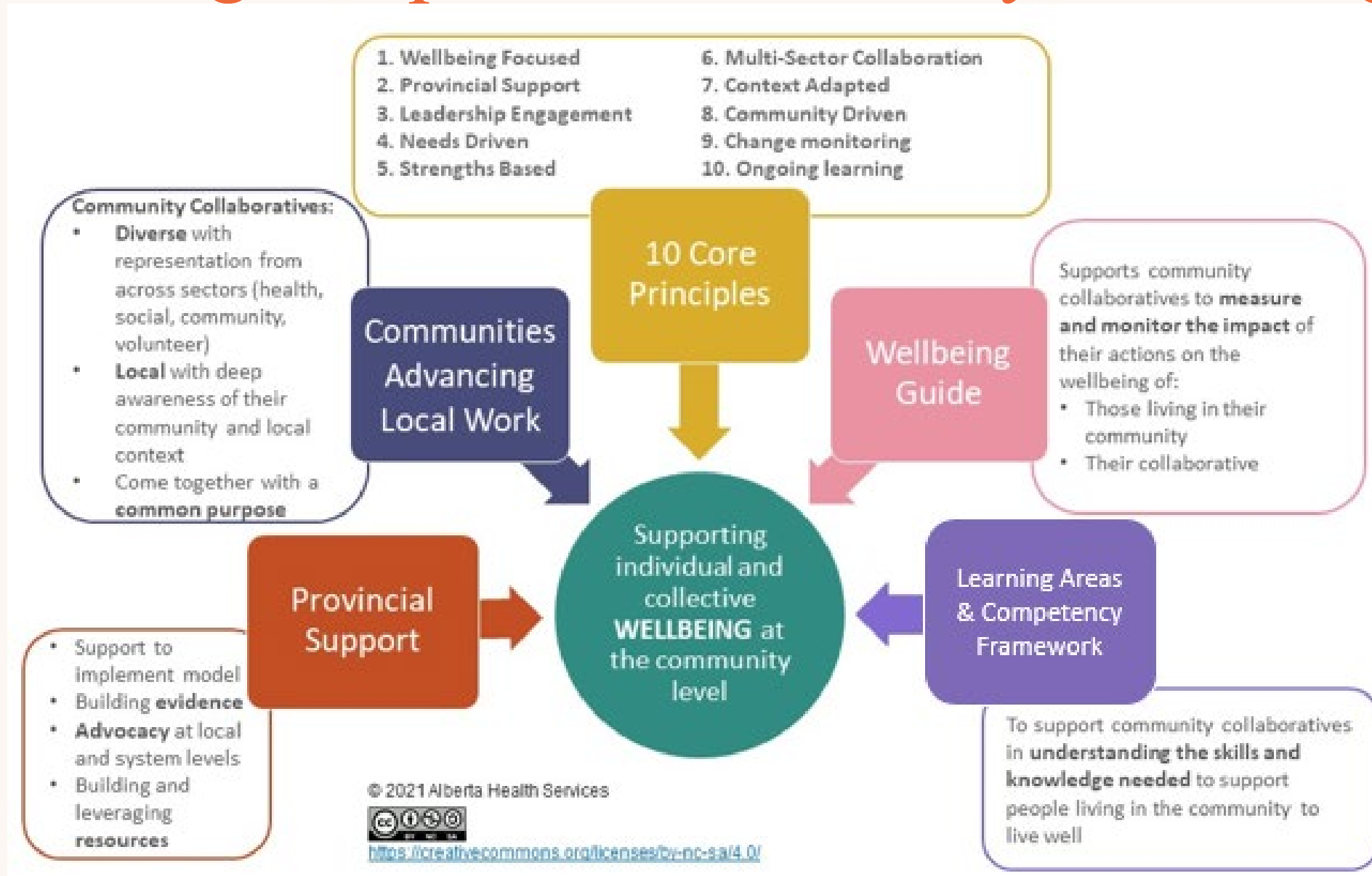
Caregiver support **spans healthcare, social care, community services, and workplaces.**

Collective Impact brings sectors together to build sustainable, system-level support for family caregivers — aligning policies, services, and care practices around a shared vision.

- Ensures sectors move together, not in silos.
- Builds a sustainable system of support, rather than a patchwork of programs.



Connecting People & Community for Living Well

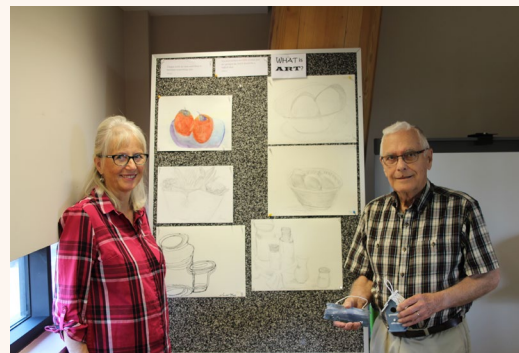




Drumheller Community Seniors Coalition

- Circle of Connection program
 - Volunteers
 - Transportation
- Caregivers Support Group
- Frozen and hot meal deliveries
- Grocery delivery
- In home support/Housekeeping
- Annual Seniors Fair
- Opening Minds through Art





CPIA- Community Partners in Action Innisfail



- Falls Prevention
- Community Kitchen
- Let's Connect
- Caregiver Information Fair
- Dementia Friendly Community
- Business Dementia Friendly Certification
- Memory Café
- Social Prescribing
- Art from the Heart
- Men's Sheds





Westview Dementia Collaborative

Stony Plain, Spruce Grove, Parkland County



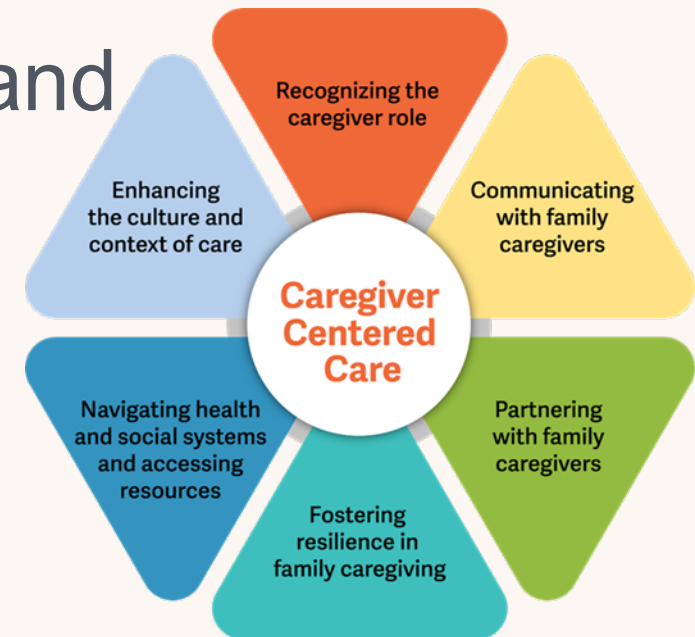
- Community Connector
- Memory Café
- Caregiver support group
- Education Series
- Trail Explorers
- Alzheimers Awareness event
- Business Dementia Friendly Videos
- Home Support
- Music program
- Art program



Think, Pair, Share

What opportunities do you see in your work for collaboration to:

- Enhance how caregivers are supported and listened to?
- Build partnerships across health, social and community sectors?



3. Co-produce a forward-looking action plan for scaling caregiver-centered initiatives provincially and nationally.



High Level Bridge / Lethbridge Viaduct

SET FOUNDATION

CONSISTENTLY RECOGNIZE FAMILY CAREGIVERS

Recognize family caregivers as essential members in care teams
Identify caregivers in health and social/community care planning and service provision
Document family caregiver involvement in care recipient/caregiver records

MEANINGFULLY PARTNER WITH FAMILY CAREGIVERS

Include family caregivers care planning, decision-making and transitions across health and social/ community care settings
Define and clarify family caregivers' roles on care teams
Embed equity, diversity and inclusion principles in caregiver-centered care

SUPPORT

ASSESS AND ADDRESS FAMILY CAREGIVER NEEDS

Engage family caregivers in conversations about their realities, needs in providing care and maintaining their wellbeing
Identify family caregivers' needs and risks early and provide timely access to supports and services
Strengthen mental health supports
Provide information about financial support
Enhance access to flexible services—respite care and day programs

SUSTAIN

ENABLE SEAMLESS NAVIGATION

Equip individuals who play a formal or informal navigation role with the knowledge, tools and training needed to guide caregivers to supports
Define and communicate provider responsibilities for co-ordinated navigation across health and social/community services
Enhance communication among providers and caregivers, including referral outcomes, to reduce challenges in navigation and co-ordination.
Develop and use community-based assets of caregivers' resources and update them regularly

ESSENTIAL ENABLERS

AMPLIFY EDUCATION

Equip health and social/community care providers and trainees with knowledge, skills, approaches and best practices to engage and support family caregivers

Integrate caregiver-centered care education in post-secondary health workforce curricula and accreditation standards

Increase preparedness of family caregivers to engage and partner with health and social/community care providers

ENSURE WORKPLACE SUPPORTS FOR EMPLOYED FAMILY CAREGIVERS

Identify organizational approaches to foster healthy workplaces for family caregivers

Embed caregiver supports into Employee Assistance Programs

FORTIFY POLICY FOUNDATIONS

Develop consistent policies and practices for caregiver identification, partnership and support.

Identify and scale policies for flexible services

Expand effective policies to reduce the financial burden on caregivers

Clarify policies on access to information and consent processes to support caregiver involvement

ENHANCE RESEARCH AND EVALUATION

Develop a robust research and evaluation framework to measure the impact of support initiatives

Enhance data collection for care co-ordination and evaluation/research



Five Pillars of a National Caregiving Strategy for Canada

1. Improving supports, programs, and services for caregivers

- Canada Caregiving Credit, Caregiving Benefit, Care insurance, Mental health supports

2. Supporting caregivers in work and education

- EI reform, care in federally-regulated workplaces, CPP reform

3. Support for recipients of care

- DTC reform, medical expenses tax credit, RDSP, implement Canada Disability Benefit

4. Sustainable care provider workforce

- \$25 minimum wage, immigration reform

5. Government and leadership recognition

- Legislation, standing advisory council, military and veteran caregivers



Canadian Centre for
Caregiving Excellence

Centre canadien d'excellence
pour les aidants

Build a Better System to Support Family Caregivers: Integrating Care Supports

Health Care Settings

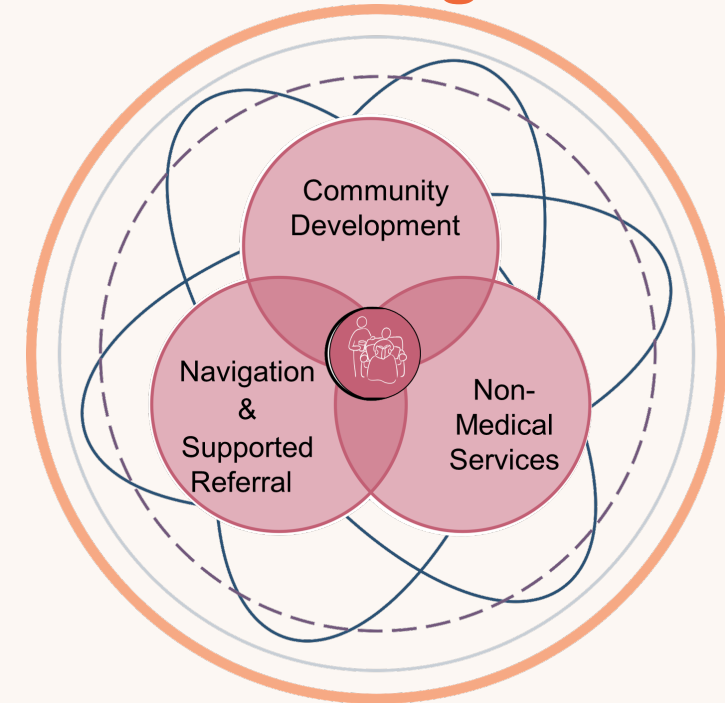
- Primary Care
- Home Care
- Hospitals
- Transitions/Alternative Level of Care
- Supportive/ Assisted Living
- Long-term Care/ Continuing Care Homes
- Palliative Care
- Hospice



Family Caregivers



Community Care Settings



Think, Pair, Share

What immediate, short term, and longer-term actions are you able to take to increase visibility of the family caregiver role and how you can partner with caregivers to support them to sustain care and maintain their wellbeing?

What can you do in:

- your setting?
- your community?
- your Province?



SET FOUNDATION

CONSISTENTLY RECOGNIZE FAMILY CAREGIVERS

Recognize family caregivers as essential members in care teams
Identify caregivers in health and social/community care planning and service provision
Document family caregiver involvement in care recipient/caregiver records

MEANINGFULLY PARTNER WITH FAMILY CAREGIVERS

Include family caregivers care planning, decision-making and transitions across health and social/ community care settings
Define and clarify family caregivers' roles on care teams
Embed equity, diversity and inclusion principles in caregiver-centered care

SUPPORT

ASSESS AND ADDRESS FAMILY CAREGIVER NEEDS

Engage family caregivers in conversations about their realities, needs in providing care and maintaining their wellbeing
Identify family caregivers' needs and risks early and provide timely access to supports and services
Strengthen mental health supports
Provide information about financial support
Enhance access to flexible services—respite care and day programs

SUSTAIN

ENABLE SEAMLESS NAVIGATION

Equip individuals who play a formal or informal navigation role with the knowledge, tools and training needed to guide caregivers to supports
Define and communicate provider responsibilities for co-ordinated navigation across health and social/community services
Enhance communication among providers and caregivers, including referral outcomes, to reduce challenges in navigation and co-ordination.
Develop and use community-based assets of caregivers' resources and update them regularly

ESSENTIAL ENABLERS

AMPLIFY EDUCATION

Equip health and social/community care providers and trainees with knowledge, skills, approaches and best practices to engage and support family caregivers

Integrate caregiver-centered care education in post-secondary health workforce curricula and accreditation standards

Increase preparedness of family caregivers to engage and partner with health and social/community care providers

ENSURE WORKPLACE SUPPORTS FOR EMPLOYED FAMILY CAREGIVERS

Identify organizational approaches to foster healthy workplaces for family caregivers

Embed caregiver supports into Employee Assistance Programs

FORTIFY POLICY FOUNDATIONS

Develop consistent policies and practices for caregiver identification, partnership and support.

Identify and scale policies for flexible services

Expand effective policies to reduce the financial burden on caregivers

Clarify policies on access to information and consent processes to support caregiver involvement

ENHANCE RESEARCH AND EVALUATION

Develop a robust research and evaluation framework to measure the impact of support initiatives

Enhance data collection for care co-ordination and evaluation/research



- Let's build a community of care for our family caregivers.
- Become a Caregiver-Centered Care Champion: Embrace Caregiver-Centered Care to shift mindsets.
- Bring about the change needed to partner with and support family caregivers where you work, live, and play.

Thank you!

Caregiver-Centered Care

www.caregivercare.ca

Dr. Jasneet Parmar Jasneet.Parmar@albertahealthservices.ca

Dr. Sharon Anderson sdanders@ualberta.ca

Connecting People and Communities for Living Well

www.albertahealthservices.ca/scns/Page13526.aspx

Connecting People and Communities for Living Well

Helen Lightfoot Helen.Lightfoot@albertahealthservices.ca

Caregiver-
Centered
Care



Supporting
Family
Caregivers
in Healthcare