

Discussion Paper

The Hidden Workforce: Optimizing Support for Family Caregivers



Caregiver-Centered Care Collaborative Working Group
October 29, 2024

Table of Contents

The Opportunity: Leading the Way in Supporting Alberta’s Family Caregivers.....	3
A Call for Transformation Across Health, Social, and Community Care Systems	3
Catalyzing Change in Alberta’s Health, Social, and Community Systems	3
The Care Challenge	4
Canada’s Health, Social, and Community Care Workforce: A Growing Crisis.....	4
The Role of Family Caregivers: The Largest Care Workforce	5
Caregiving Impacts Caregivers’ Own Health and Wellness	6
Caregiving Increases the Risk of Poverty	6
Employed Family Caregivers: Balancing Work and Care	7
Double-Duty Caregivers: Managing Dual Roles Amid Systemic Workforce Challenges	7
Caregivers are Diverse and Need Person-Centered Support	8
Building a Sustainable Future: An Integrated Care System.....	9
Transformation Opportunities within Health, Social and Community Care Organizations.....	9
Elevate Family Caregiver Support in Alberta.....	10
References	12
Acknowledgements.....	16
Caregiver-Centered Care Collaborative Working Group	16
Honouring the Legacy of Dr. Janet Fast	16
Appendix A Promising Practices, Policies, Resources, and Supports	17
Appendix B Discussion Guide	23
Appendix C – Discussion Guide: Potential Ways to Support Double-duty Caregivers.....	24
Appendix D: Family Caregiver Organizations and Websites.....	25
Glossary of Terms.....	29

The Opportunity: Leading the Way in Supporting Alberta's Family Caregivers

Family caregivers are the backbone of Alberta's health, social and community care systems, providing vital care and support, often without recognition or formal assistance. However, the challenges they face impact not only their own well-being but also the quality of care they can provide. This paper highlights the urgent need to address these challenges and outlines transformative opportunities based on best practices in Alberta and beyond. Our goal is to benefit everyone involved: care recipients, caregivers, the healthcare system, and employers.

A Call for Transformation Across Health, Social, and Community Care Systems

Alberta's health, social, and community care systems must take bold, collaborative action to support caregivers effectively. Caregiver support needs are twofold:

1. Recognizing, valuing, and partnering with family caregivers as integral partners of the care team.
2. Creating a work culture that supports employed family caregivers—enabling them to manage both caregiving and professional responsibilities without compromising their productivity or well-being.

Double-duty caregivers, care providers who balance professional and family caregiving roles, are critical to the system, but they are also at heightened risk of burnout. Addressing their needs is essential to building a sustainable care model that benefits all Albertans.

Catalyzing Change in Alberta's Health, Social, and Community Systems

In this paper, we aim to spark a critical dialogue among Alberta's health, social and community care system's policymakers, healthcare leaders, businesses, and care providers regarding the experiences of family caregivers and double-duty caregiver staff. It presents evidence-based research, promising practices, and emerging opportunities for systemic transformation. Organizations are encouraged to explore these opportunities collaboratively, engaging caregivers and staff in the co-design of innovative solutions. The overarching objective is to elevate awareness and embed sustainable structures that acknowledge, support, and integrate family caregivers into care settings, ensuring their needs and preferences are fully recognized and addressed within health, social, and community care systems.

In Canada, Alberta is already leading the way in supporting caregivers and the individuals they care for through initiatives like the new Continuing Care Act, Caregiver-Centered Care Education, Caregivers Alberta, and the Glenrose Rehabilitation Hospital's Alberta Caregiver College®. Additionally, Norquest College's Alberta Family Wellness Initiative, innovative home care and respite services, and efforts to integrate health, social, and community services by Family and Community Support Services and organizations such as the Alzheimer Societies, CASA, FamilySmart Family Peer Support Program, Huntington Society, Parkinsons Society, Canadian Mental Health Association in Alberta, Cerebral Palsy Alberta, and many others further underscore this commitment.

Together, Albertans can elevate the role of family caregivers by embedding supportive frameworks that ensure they receive the recognition and tools needed to succeed. A future where caregivers thrive benefits not just those providing care, but also care recipients, employers, and the entire healthcare system. By leading with compassion and innovation, Alberta can create a care landscape that sets a new standard for sustainability, equity, and excellence. Join us in shaping a strategy that enables Alberta's family caregivers to thrive! Your insights are essential to strengthening the support systems that sustain both caregivers and the communities they serve.

The Care Challenge

Most Albertans, like Canadians across the country, want to live their entire lives in their homes and communities [4]. However, the rising prevalence of chronic illness and disabilities in the younger populations and the demographic changes, such as growing population of older adults, employed adults, changes in family configurations e.g., smaller families, divorce/ remarriage, adult children who no longer live near parents) present significant challenges. Findings from Alberta’s Tomorrow Project show that multimorbidity—having two or more chronic conditions—has skyrocketed from 3.9% of the population in 2001 to 40.3% in 2017 [5]. This mirrors projections from Ontario, where by 2040, 25% of adults over 30 will live with a major illness [6]. Projections show a 50% rise in diabetes and a 40% increase in conditions like cancer and osteoarthritis by 2040.

With chronic conditions such as diabetes, dementia, and osteoarthritis on the rise, the provinces are facing unprecedented strain on healthcare systems, requiring a bold shift toward community-based care [5,6]. We need systems that enable caregivers to continue their essential roles while maintaining their own well-being. Without adequate community support, caregivers often have no choice but to turn to hospital emergency departments during crises, leading to costly admissions and premature institutionalization—outcomes neither caregivers nor care recipients want.

Managing the growing burden of chronic disease and multimorbidity requires a well-prepared and sustainable health, social, and community care workforce who are educated on how to integrate family caregivers as members of care teams and supported to do so. Person-centered care for caregivers is crucial to fostering empathic communication, collaboration, reducing caregiver stress, and ensuring care aligns with Albertan’s values. This collaborative approach benefits caregivers, Albertans needing care, and healthcare providers alike, creating a more compassionate care environment across health, social and community care sectors.

CHERYL - A NURSE AND CAREGIVER



How do health and social care organizations support someone like Cheryl? Cheryl is struggling to continue as a full-time ICU nurse while balancing all her caregiving roles. Cheryl is a mom to her two young children, a wife and caregiver for her partner who has MS. Her mother lives alone at home in another province and is becoming increasingly frail.

Canada’s Health, Social, and Community Care Workforce: A Growing Crisis

The health [1,7,8], social, and community care [9-11] workforce is under unprecedented strain, with chronic disease, an aging population, and the lingering impacts of the COVID-19 pandemic driving staffing shortages, burnout, and increased service demands. Critical areas like long-term care, primary care, and disability services are struggling to attract and retain workers, jeopardizing access to care [1,7-11].

Shortages are widespread in Canada’s healthcare workforce. Job vacancies doubled during the pandemic, with over 120,000 unfilled positions in 2022-2023 [8]. Personal support workers, health care aides, nurses, and mental health workers accounted for two-thirds of these vacancies [8]. The long-term care sector lost 2,500 nurses in 2022, and hospitals saw 800 fewer nurses in direct care roles, despite surging demand. Burnout remains a critical issue, with hospital staff logging 26 million overtime hours—equivalent to 13,000 full-time positions—particularly in intensive care and mental health units [7,8].

Staffing shortages, high turnover, and burnout are creating significant challenges in the social and community systems too [9-11]. Non-medical support programs like those supported by Healthy Aging Alberta face difficulties recruiting for essential roles such as in-home maintenance, transportation, and community supports [9]. Alberta's community disability services report turnover rates of 23% and burnout as a major operational challenge [10]. Low wages (54% of community disability workers earn under \$20/hour) and limited access to training further hinder recruitment and retention [10]. Volunteer-run services, vital to community care, are also struggling to keep up with demand, resulting in long waitlists for critical services [11].

Family caregivers, who make up over a third (35%) of the Canadian workforce[12], are essential to both paid and unpaid care systems [2,13], yet the demands of caregiving are so overwhelming that in 2023, 30% of employed caregivers considered leaving their jobs, and 10% turned down job opportunities due to caregiving responsibilities [14]. If all caregivers took a week off, *every Canadian would experience the collapse of our care systems* before noon on the first day [13].

The Role of Family Caregivers: The Largest Care Workforce

Caring for a family member, chosen family, friend, or neighbour can bring deep personal fulfillment, fostering stronger connections and offering a sense of purpose [15,16]. Indigenous people view the care and reverence for their elders as the completion of the circle in the life cycle [17-19]. Elders have a mutual desire to share and maintain cultural wisdom, relationships, and the transmission of cultural worldview to successive generations, which is an important factor in successful aging.

Families value the opportunity to enjoy each other's company for as long as possible. Many caregivers report that the experience brings joy and meaning, as they play a vital role in enhancing their loved one's quality of life, helping them achieve personal goals, and maintaining their dignity and independence [20,21].

However, family caregivers are often referred to as the invisible workforce and the backbone of the health system—providing most of the care for individuals with chronic conditions, disabilities, and age-related needs, yet receiving little recognition or formal support.

Alberta relies heavily on caregivers. In 2018, 26% of Albertans—929,000 individuals—provided an estimated 647 million hours of unpaid care annually, equivalent to 317,824 full-time positions. Valued conservatively at \$17 per hour, this contribution amounts to \$11 billion yearly [3,22,23].

The role of family caregivers extends far beyond basic care [22,24]. Caregivers foster well-being, dignity, and social connections, helping individuals pursue personal goals and aspirations [13,22]. They are essential partners in improving patient care, enhancing experiences, and achieving better outcomes [25,26]. Their involvement also improves safety, quality, and continuity of care, benefiting both patients and healthcare systems [27-29].

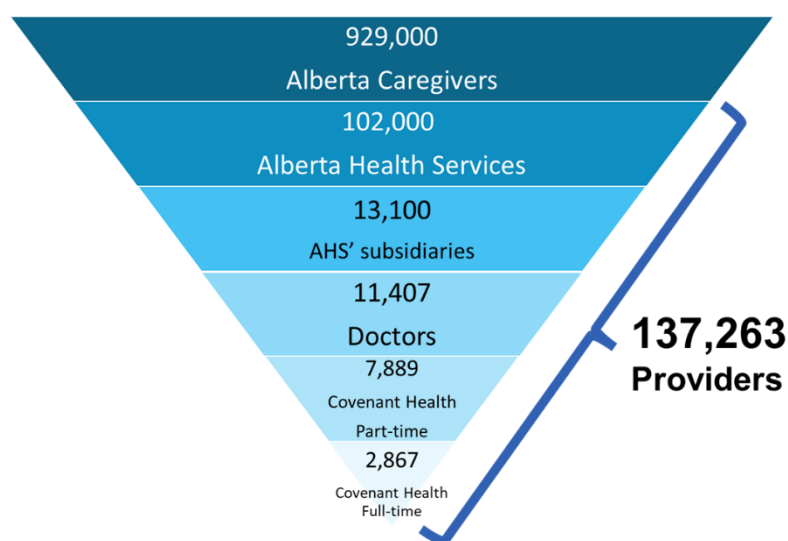


Figure 1, Alberta's healthcare[1] and family caregiver workforce[3]

Increasingly, family caregivers are taking on complex medical tasks at home that were once performed by healthcare professionals in healthcare settings [2,25,30,31]. These responsibilities may include managing medical equipment, wound care, complex medication administration, and catheter care [2]. In addition to these medical duties, caregivers are becoming de facto health system navigators and care coordinators [32,33]—roles that often impose more stress than the physical tasks themselves [34,35]. This growing responsibility places considerable emotional and physical strain on caregivers, who often receive minimal training or support [34,35]. Without proper resources and professional guidance, caregivers risk burnout, which can jeopardize both patient safety [36] and their own well-being. Caregiver support systems that provide adequate training, emotional support, and access to a wide range of resources are crucial to ensuring safe, effective care.

The efforts of family caregivers often reduce the need for institutional care, allowing individuals to remain at home in familiar environments, surrounded by family and friends [37-40]. Family caregivers can facilitate earlier hospital discharges by providing essential support, but their effectiveness is often hindered by factors such as caregiver burnout and the complexity of patient needs [41-43]. Caregiver's personalized care enhances comfort and well-being. Without caregivers, the healthcare system would face overwhelming demand, increased costs, workforce shortages, and diminished continuity of care [2,13,44].

Despite their vital contributions, caregivers are frequently excluded from decision-making processes and treated as secondary to care plans even though family caregivers hold significant responsibility for carrying out the care plan [25,26]. This exclusion not only limits their ability to provide effective care but also disregards the valuable insights they bring to care planning and delivery. A more inclusive approach that integrates caregivers as partners in care is essential to improving outcomes for patients and caregivers alike.

“There are only four kinds of people in the world—those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers.” –

Rosalynn Carter. Former First Lady of the US. Founder – Rosalynn Carter Institute for Caregivers. 1987

Caregiving Impacts Caregivers' Own Health and Wellness

One in four Alberta caregivers report their health has suffered because of their caregiving responsibilities [45]. For example, 44% of family caregivers were stressed—feeling tired (47%), worried or anxious (44%), or overwhelmed (37%) due to caregiving duties [46]. Parents caring for adult children with special needs or older spouses caring for their partners may be as frail as the person they care for [47,48]. Twenty-eight percent of caregivers report having a disability.

It is not giving care per se that is distressing, rather it is being overloaded with work and worry that is distressing [13,14,26,36]. Caregiver burden rises sharply when caregivers are caring over 20 hours a week or caring for a person with severe disability, dementia, depression, or responsive behaviours [36,37,48]. Burnout, emotional exhaustion, reduced job satisfaction, and fewer opportunities to connect with friends and neighbours occur without proper supports in place [49,50].

Caregiving Increases the Risk of Poverty

Unpaid family caregivers are at high risk of poverty. New research shows that rates of poverty are 50% higher for those looking after a friend or family member [2]. Almost a quarter (22%) of caregivers spend \$1,000 + per month on out-of-pocket caregiving expenses [2,51]. Thirty percent of family caregivers struggle to make ends meet [2,51]. There are

four tax credits that can reduce tax paid, 1. Medical expense tax credit, 2. Disability tax credit, 3. Home accessibility tax credit, and 4. Canada Caregiver Credit.

Surprisingly, more than half of the 3,000 caregivers surveyed in Canada said they were not familiar with tax credits related to caregiving and that an income tax credit (87%) or a monthly care allowance (86%) would be helpful [2]. Only 2.5% of caregivers claimed the Canada Caregiver Credit from 2017 to 2019 [52]. Refundable tax credits may help low-income caregivers [2]. The long hours of care, the struggle to balance work and care, and the toll on mental and physical health make it difficult for unpaid family caregivers to stay employed, creating additional financial hardship [2,51,53].

Employed Family Caregivers: Balancing Work and Care

Employed caregivers shoulder the dual responsibility of paid work and unpaid caregiving, often facing significant challenges in maintaining both roles [54-56]. In Canada, 5.2 million people, or one in four working-age adults, combine employment with unpaid care, contributing an estimated \$51.5 billion in labour that would otherwise fall on the healthcare system [54,56]. Typically, unpaid care work becomes more demanding, both emotionally and physically, over time. Individual productivity suffers and their capacity for work diminishes. Many caregivers reduce their work hours, decline promotions, or leave their jobs entirely. The key factors that trigger caregivers to leave the work include:

1. **Lack of Workplace Flexibility:** Without remote work options or flexible schedules, caregivers struggle to manage both job and caregiving responsibilities effectively.
3. **Career Advancement Concerns:** Many caregivers worry that requesting time off or accommodations will hinder their career growth, leading them to seek jobs with more supportive environments.
4. **Financial Strain:** The high costs of caregiving—such as healthcare expenses and paid assistance—can be overwhelming, prompting caregivers to find higher-paying jobs or leave the workforce entirely.
5. **Burnout from Emotional and Physical Exhaustion:** Balancing work and caregiving duties often leads to burnout, pushing caregivers to search for less demanding roles with better work-life balance.

Double-Duty Caregivers: Managing Dual Roles Amid Systemic Workforce Challenges

Double-duty caregivers are healthcare providers who also provide unpaid care outside of work, the caring professionals at all health system organizational level [57]. Frequently, the family selects the health provider as the designated family caregiver (e.g., the sibling who is a nurse) because of their medical knowledge. Indeed, in the most recent UK census, the proportion of NHS staff who were carers (one in three) higher than in the general population (one in 11) [58]. Balancing these roles presents significant challenges, as many caregivers reduce their work hours or miss shifts when community care options are unavailable, leading to workforce shortages and lost income [59,60]. A General Medical Council survey found that 7.8% of doctors left their positions due to caregiving responsibilities [61]. Addressing the needs of these experienced staff is crucial for retaining talent and ensuring quality patient care.

The ongoing health workforce staffing crisis [1], further complicated the situation, creating conditions that heighten the strain on double-duty caregivers [59,60,62]. Double-duty caregivers can feel guilty when prioritizing caregiving over work because they fear letting down their patients, colleagues, or teams in an already strained system [59,60,62,63]. They may also worry about being judged as less committed, feel pressure to meet high personal expectations, and struggle with the emotional toll of balancing both roles.

One key strategy to support double-duty caregivers is implementing flexible work arrangements [59,60,62,63]. By offering flexible hours, remote work options, and adjusted schedules, healthcare organizations can help double-duty caregivers balance their professional responsibilities with caregiving at home. This flexibility can reduce stress and burnout, allowing caregivers to continue contributing effectively in both roles while maintaining their own well-being.

Canada is facing a caregiving crisis that will only get worse without real action. A perfect storm is brewing: demand for care is growing, caregivers are aging, the number of available caregivers is shrinking and care needs are becoming more complex due to our aging population and rising rates of disability and mental health conditions. There is an urgent need to make sure that caregivers and care providers have the resources and services to support their caregiving responsibilities [2].

Caregivers are Diverse and Need Person-Centered Support

Caregiving is as diverse as the people involved—family caregivers, care recipients, and the illnesses or disabilities that prompt caregiving diverse [64,65]. Care journeys vary widely, evolving from basic tasks to intensive personal or medical care depending on illness progression, caregiving duration, and available support[66-68]. Some caregivers start with basic assistance[69,70], while others take on complex care immediately due to sudden health events [69,70].

Women make up nearly 60% of caregivers, with many in their late 50s [2,46], and 1 in 5 Canadian caregivers are over 65, typically caring for an aging partner [2]. Young caregivers, often invisible, contribute significantly[71], with 10% of those aged 15 to 24 providing 20 or more hours of care each week [71]. They can take on more complex tasks like organizing medical appointments or financial planning. Indigenous caregivers carry unique cultural responsibilities, balancing caregiving with the transmission of knowledge and traditions, often with limited formal support due to systemic barriers. Sibling caregivers frequently care for individuals with intellectual or developmental disabilities [2,72]. LGBTQ2S+ caregivers are more likely than heterosexual caregivers to support someone with a mental health condition, with 40% reporting fair or poor mental health themselves compared to 22% of heterosexual caregivers [2]. Immigrant and refugee caregivers face additional challenges, such as language barriers, differing healthcare expectations, and increased mental health risks [2]. Given the complexity and diversity of caregiving, person-centered support is essential [73,74]. Tailoring care to caregivers' unique circumstances enhances their well-being and improves the quality of care they provide. Recognizing and supporting caregivers through person-centered approaches ensures they are not just seen as extensions of the healthcare system or the person they care for, but as individuals with their own needs and contributions [24]. No one person or organization, not even the health system, is able to meet diverse caregivers' needs along the entire care trajectory [69]. The existing care delivery model is unsustainable, we require new, innovative approaches to optimize workforce use and prevent further workforce and caregiver burnout.

"At some point, almost every one of us is going to be a caregiver or a care receiver. We owe it to ourselves to get this right." Andre Picard, Globe and Mail

Building a Sustainable Future: An Integrated Care System

An integrated care system that unifies health, non-medical, and community care services—while actively supporting caregiving in homes and communities—is essential for significantly reducing the pressure on our health and continuing care systems [5,75,76].

An integrated care model benefits everyone:

1. Care recipients experience greater independence, dignity, and quality of life.
2. Caregivers feel empowered and supported, preventing burnout and maintaining their well-being.
3. Healthcare providers experience reduced workload and better care coordination, easing system strain.
4. Hospitals and long-term care homes preserve capacity for those with the most complex needs.

Caregivers need respite time to balance their caregiving duties with work, relationships, and personal well-being to avoid burnout and maintain their health. Flexible work arrangements, respite care, and emotional support are essential to help them manage both roles effectively. Maintaining this balance allows caregivers to provide better care while preserving their own well-being and personal fulfillment.

Early detection, management of chronic conditions, and better access to primary, home, and community care services can help caregivers and the people they care for remain in their community and homes longer [37,38,77]. Home and community care services like Meals on Wheels, transportation services, non-medical home supports, respite services and adult day programs, supportive housing, caregivers can limit the time they need to take off work, and reduce the hours of care they're providing each week, giving them some respite from caregiving duties, prevent burnout and reduce emergency hospital visits [78-80].

Transformation Opportunities within Health, Social and Community Care Organizations

Despite Alberta's wealth of innovative policies, initiatives, services, and supports (see Appendix 2 for examples), a significant gap persists -- many caregivers and providers remain unaware of these resources. This lack of awareness turns navigation into a daunting challenge for both parties. Caregivers often become the de facto care coordinators and navigators, shouldering the overwhelming task of deciphering complex healthcare, education, and legal systems.

Family workloads have surged due to several factors:

- An Aging Population: A large number of older adults require complex care and care trajectories are longer.
- Medical Advancements: Increased survival rates mean longer periods of care are needed.
- Shift to Home and Community Care: Healthcare responsibilities have moved into homes.
- Fewer Available Caregivers: Smaller families, high adult employment, diverse family configurations (divorce, remarriage), mobility, and migration reduce the pool of potential caregivers.

This increased care burden significantly impacts caregivers' health, well-being, and financial stability. Employed family caregivers including double-duty caregivers face compounded challenges balancing paid work and unpaid caregiving. When they reduce work hours, decline promotions, or leave jobs entirely due to caregiving demands, they risk financial hardship and exacerbate the ongoing workforce staffing crisis.

Caregivers are a diverse group, each with unique needs and circumstances. Recognizing them as individuals is essential to prevent burnout and ensure sustainable care delivery models. Innovative approaches are necessary to effectively support both caregivers and the health, social, and community workforce. Caregivers should not be seen merely as extensions of the healthcare system but as vital contributors who require support themselves. The current

care delivery model is unsustainable; we need fresh strategies to prevent further caregiver and workforce burnout and optimize workforce well-being.

Given these challenges, there are opportunities for Alberta's health, social, and community sectors to:

- **Promote Caregiver-Centered Education.** Equip health, social, and community providers with the knowledge and skills to support caregivers by providing caregiver-centered care training. Encourage continuous learning and development to foster better understanding of partnering with family caregivers.
- **Foster a Compassionate, Inclusive Culture.** Build an organizational ethos where caregivers are respected and that addresses the ethical, multicultural, geographic, and generational complexities of caregiving. Actively listen to caregivers, support meaningful connections, and create an environment where caregiving concerns can be openly discussed.
- **Systematically Identify and Support Caregivers.** Establish processes to consistently identify family caregivers, assess their needs, and support family caregivers throughout the care journey. Provide tailored emotional, informational, and practical supports to meet their unique needs.
- **Document the Family Caregiver Identified by the Patient/ Client/ Resident.** Provide patients an opportunity to identify a family caregiver, record their name and role in the health record, and ask the caregiver about their desired level of involvement.
- **Leverage Technology to Enhance Care Coordination.** Utilize digital tools, such as virtual care platforms and caregiver support apps to improve care coordination, communication, and safety. Features might include task tracking, GPS monitoring, and fall detection (e.g., Locator devices, Team CarePal, TELUS Health Medical Alert, Caregiver Mobile app).
- **Enhance Awareness and Access to Caregiver Support Resources.** Increase utilization of available resources, including respite care, support groups, and home care services. Promote awareness of existing policies and programs that offer diverse forms of assistance to caregivers.
- **Support Employed Caregivers Including Double-Duty Caregivers.** Recognize that supporting employees with caregiving responsibilities is essential to workforce productivity. Advocate for caregiver-friendly workplace policies, including flexible work arrangements, and offer benefits that help reduce the impact of caregiving on their professional lives.

Alberta can transform its health and social care organizations to better support caregivers—ensuring they are empowered, recognized, and equipped to continue their vital roles without compromising their own well-being.

Elevate Family Caregiver Support in Alberta

Now is the time for Alberta's health, social, and community services to act decisively and collaboratively to embed caregiver-centered care. When caregivers thrive, the entire community benefits. Let's work together to build better systems that enable Alberta's caregivers to not just survive but thrive. Your participation is crucial in shaping policies, resources, and supports that will make a meaningful difference in the lives of caregivers and those they care for.

We invite all Albertans—family caregivers, patients, clients, residents, citizens, policymakers, healthcare leaders, businesses, care providers, and Canadians nationwide—**to be part of the co-design and co-production process of the Alberta Caregiver Strategy and Action Plan.** Your voice is essential in creating a supportive environment where caregivers are recognized, valued, and empowered.

1. **Engage in Meaningful Conversations:** Start discussions with leaders and colleagues in your organizations, communities, and social networks. Use the **Discussion Guides in Appendix B and C** to explore how we can better support caregivers, caregiving employees, and double-duty caregivers. Share these conversations with your colleagues, staff, family, chosen family, friends, and neighbours to broaden the impact.
2. **Consider Options for Raising Awareness:**
 - Organize webinars where authors can present key findings and engage in discussions with readers, allowing for real-time interaction.
 - Use art Installations: Create an art exhibit that depicts the lives of family caregivers through photography, paintings, or multimedia. This can be a powerful way to visualize their challenges and contributions. The art installation could travel from location to location around the province.
 - Contribute to Caregiver Day (April 8, 2025) and Caregiver Month (May). Get the mayors, premier, key ministers, etc. to bring greetings. Host a photo contest where caregivers can submit pictures that represent their caregiving journey.
3. **Engage on Social Media:** Expand dedicated social media team or develop existing platforms to facilitate discussions, share resources, and allow readers to connect. Use the #CaregiverCare hashtag to share on LinkedIn, X, Instagram, Facebook, etc. sites and or encourage readers to share their thoughts on caregivers and employed caregivers on social media to foster a broader conversation about caregiving.
4. **Hold Discussion Forums:** Create online forum or platform where your audience can discuss this **Discussion Paper**, share insights, and connect with the authors for deeper conversations. Create a “canned” PowerPoint presentation that leaders/community members can use to prompt discussion/conversation.
5. **Share Resources:** Develop a shared repository of resources, articles, or tools related to family caregiving, allowing readers to contribute and engage with the content.
6. **Hold Employer Roundtables:** Facilitate discussions among employers to share best practices and strategies for supporting employees who are also caregivers, creating a collaborative environment for problem-solving.
7. **Provide your Input into Strategic Planning and Pathways:** Your insights and experiences are invaluable. Help shape strategies and care processes that truly reflects the needs of caregivers. Share your thoughts, ideas, and feedback on enhancing support for caregivers.

Help to Co-produce the Leading the Way Alberta Caregiver Strategy and Action Plan.

- **Join the Caregiver-Centered Care Co-Design Team:** to provide advice, co-create solutions, and participate in developing the Alberta Caregiver Strategy and Action Plan.
- **Get More Involved** If you or your organization would like to play a more active role.

Together, we can build a future where caregivers are fully supported, and their contributions are recognized and valued. **Join Us in Shaping the Future of Caregiving in Alberta.**

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“Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has.” **Margaret Mead**

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Acknowledgements

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We extend our sincere gratitude to all the generous reviewers who provided valuable feedback, including patients, family caregivers, representatives from the health, social and community services, and health workforce/human resources professionals from various organizations.

Thank you.

We extend our heartfelt gratitude to all who have taken the time to read this document. Your engagement is instrumental in shaping the Alberta Caregiver Strategy and Action Plan. By investing your time and attention, you are contributing to a collective effort to support family caregivers across Alberta. Your insights, reflections, and willingness to participate are invaluable as we work together to build systems that enable caregivers not just to survive but to thrive. Thank you for joining us on this important journey toward a more compassionate and supportive community for caregivers and those they care for.

Honouring the Legacy of Dr. Janet Fast

In Alberta and in Canada, we stand on the shoulders of giants like Dr. Janet Fast, a pioneering scholar whose research on the economics of work and care illuminated the often-unseen challenges faced by unpaid caregivers. Dr. Fast dedicated her career to exploring the intricate balance between caregiving responsibilities and paid employment. Her groundbreaking work brought to light the significant economic impacts of caregiving on individuals, families, employers, and the broader economy. By quantifying hidden costs—such as lost wages, reduced labour force participation, and out-of-pocket expenses—she provided compelling evidence that caregiving has profound economic and social implications.

Dr. Fast's legacy is one of compassion, intellect, and unwavering dedication to improving the human condition. Her advocacy played a crucial role in informing policymakers and influencing legislation aimed at supporting caregivers economically and socially. She bridged the gap between research and real-world impact by collaborating with government agencies, non-profit organizations, and businesses to translate her findings into actionable strategies. Her work has informed policy development, shaped public discourse on the vital role of caregivers, and inspired future research. We honour and celebrate Dr. Janet Fast's life and legacy; her pioneering work will continue to inspire and guide efforts to support caregivers and build more compassionate and economically sound communities.

Appendix A Promising Practices, Policies, Resources, and Supports

This list is not exhaustive. There are many other resources available. The key will be to ensure that health, social and community providers and organizations are aware of the services and supports available to support family caregivers.

1. Policies to Support Partnering with Caregivers

United States

The United States enacted the **Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act** [81,82] Jan. 22, 2018. It directed the Secretary of Health and Human Services to develop a national strategy to support family caregivers. The result is the **2022 National Strategy to Support Family Caregivers**[83,84] which requires the development of the infrastructure needed to systematically identify and document caregivers, assess caregiver concerns, and provide resources to address needs^{41,42}.

40 US states have enacted the **Caregiver Advise, Record, Enable (CARE) Act** which emphasizes the critical role of family caregivers in strengthening family caregiver involvement in hospitals and healthcare to facilitate care, discharges, and reduce readmissions. The CARE Act requires healthcare providers to (1) allow patients to designate a family caregiver, (2) notify caregivers when the patient is being discharged, and (3) educate caregivers on self-care activities and caregiving tasks necessary for home care. However, implementing these policies across healthcare systems presents challenges, as identifying and engaging family caregivers takes time and effort. While the CARE Act does not provide financial incentives, it aims to improve outcomes by ensuring caregivers are adequately prepared, reducing the likelihood of hospital readmissions, and enhancing care continuity[85-87].

Alberta

The new **Alberta Continuing Care Act** is designed with a strong emphasis on person-centered care, prioritizing the quality of life of residents and clients as its highest focus. It recognizes the critical role of family and friends who act as caregivers, ensuring that they are involved in determining how best to meet the needs of those receiving care. The Act also emphasizes the importance of caregivers and care recipients being able to make informed decisions about care options, and aligned with the Alberta Healthcare Workforce Strategy [1] it highlights the value of well-trained and supported staff in enhancing the quality of life within the continuing care system. Additionally, it supports the desire of residents to age in place or live with companions, treating all with dignity and respect while considering their diverse needs.

Caregiver support assessments in the Alberta Continuing Care Act Regulations

The Alberta Continuing Care Act introduces an innovative approach by offering caregivers of home care clients a dedicated assessment of their own needs for support. This legislation allows family members or friends providing care to receive a "caregiver support assessment" from regional health authorities, identifying whether they would benefit from additional support services. If deemed necessary, caregivers can be enrolled as home care clients themselves, ensuring their own well-being is addressed alongside their caregiving responsibilities. This approach recognizes the critical role of caregivers and ensures that their needs are met, enhancing their ability to provide care.

Nova Scotia

The Caregiver Benefit [88] recognizes the important role of caregivers in their efforts to assist loved ones and friends. The program is intended for caregivers of low-income adults who have a high level of disability or impairment, as determined by a home care assessment. If the caregiver and the care recipient both qualify for the program, the caregiver will receive \$400 per month.

2. Education for Health, Social, and Community Care Workforce to Support Caregivers

Caregiver-Centered Care Education for the Health, Social, and Community Care Workforce

The Alberta co-created, competency-based [73], [Caregiver-Centered Care Education](#) to educate health, social, and community care providers to provide person-centered care to family caregivers. See Appendix b).

The education goes beyond solely focusing on the care recipient's needs and extends support to address the specific challenges, concerns, and well-being of family caregivers[89]. It was co-designed and evaluated by a team of 150 Alberta-based multi-level interdisciplinary health and social care providers, leaders, and family caregivers. There are 4 levels of education, [all free online](#), available at Alberta Health Services My Learning Link, and Covenant Health's CLIC:

- Foundational Caregiver-Centered Care Education
- COVID-19 Caregiver-Centered Care Education
- Advanced Caregiver-Centered Care Education
- Caregiver-Centered Care Champions Education

3. Supports and Services for Caregivers

Caregivers Alberta [Caregivers Alberta](#) strives to empower caregivers and promote their well-being by providing group and one-on-one support services, increasing community capacity, and advocating on behalf of caregivers

- [Work and Care Program](#). Part of Caregivers Alberta's mission is to educate employers about how to build caregiver-friendly company policies and practices. It includes, 1) Executive Work & Care presentation, 2) Online Educational modules: Supporting Caregivers at Work – 3 modules, and 3) Caregiver support – right in the workplace
- Caregivers Alberta has also [compiled resources to help employed caregivers advocate for themselves](#) and help their employers to lead the way in becoming a caregiver-friendly organization.

Norquest College offers a wide range of [Family Caregiver Wellness Workshops](#) taught by experienced healthcare professionals. They are designed to help caregivers gain the knowledge, skills, and confidence they need to care for a loved one at home and/or needing end-of-life care.

Glenrose Rehabilitation Hospital's Alberta Caregiver College is a virtual college dedicated to providing courses to enhance the knowledge and skills of caregivers to provide for their family member. The educational programs were developed by the Glenrose Rehabilitation Hospital, Alberta Health Services, with contributions from other partnering organizations in Alberta. The individuals who developed the programs are educators and professionals in

rehabilitation and geriatrics and include dietitians, nurses, occupational therapists, physical therapists, physicians, psychologists, social workers, and speech language pathologists.

[Calgary Caregiver Centre](#) is an initiative of Alberta Health Services in partnership with the Calgary Health Foundation. They offer information, peer support, mental health supports, coaching, education and support to family caregivers designed to reduce caregiver burnout, increase knowledge, skills, and abilities to manage caregiving responsibility, and develop a caregiver-friendly community.

Care of the Elderly Family Physicians and Geriatric Nurses in Primary Care Networks and Home Care. Care of the Elderly Family Physicians work in the home care with home care teams to support clients with very complex care needs. They do geriatric and palliative care assessments in clients' homes and coordinate care with the homecare team, the clients' primary care team and often social and community resources to enable clients and caregivers to age in the right place. The geriatric Nurses working in primary care networks work with Care of the Elderly Physicians, assist physicians, clients, and family caregivers to navigate HSCC systems and coordinate care, and are resources for family physicians and the PCN team.

Continuing Care Home & Community Care: [Home Care](#)'s focus is creating an environment where you are able to live at home independently for as long as possible. Home Care is publicly funded personal and healthcare services for clients of all ages living in a private residence or another setting, such as suites in a retirement residence. Anyone living in Alberta with a valid healthcare card can receive Home Care services, as long as their needs can be met safely in their place of residence. Home Care philosophy promotes client independence, and supplements care and supports provided by families and community services. While Home Care services are most commonly delivered in your home, flexibility exists to deliver services in a variety of other settings. Home care services can be delivered by home care employees or contracted partners or through self-managed care or the Client Directed Home Care Invoicing program.

AHS Home Care. Home and community care does not provide all services a client may need but can help clients to navigate to other supports provided in your community. A case manager works directly with the client and is responsible for assessing the client's needs and ensuring the overall coordination of care and services. AHS provides healthcare services or contracts other healthcare providers to provide care. Services are provided by a team of skilled individuals who support the client to continue living in the community. Depending on your needs, your care team may include a nurse, social worker, occupational therapist, physiotherapist, recreation therapist, health care aide, personal support worker and others.

Self-managed care is an alternate method of service provision. It provides resources to directly pay for and manage personal care and home care support services. Clients/ caregivers who are willing and able to assume the responsibilities and risks associated with contracting services for the needed personal or home care support services as assessed by the client's case manager. Services include personal care, home support services and respite care. Self-managed care funds cannot be used for any other purposes. Professional services, such as nursing, social work or therapy services cannot be purchased with self-managed care funds but will be arranged by the home care case manager, if needed.

The **Client Directed Home Care Invoicing (CDHCI)** program allows new or current AHS Community Home Care clients to choose an eligible home care provider to deliver personal care services up to AHS-authorized monthly hours. By using the CDHCI program, clients can have more control over scheduling and directing their care while minimizing administrative responsibilities and financial burdens. This program is especially beneficial for clients with short-term intensive needs, cultural considerations, or those living in areas where it is difficult for AHS to arrange services.

- Caregivers can access some **respite services** via home care. Respite provides caregivers a short period of rest or relief from their caregiving responsibilities through overnight, in-home, and adult day programs. A Home Care Case Manager can review respite options available. Overnight respite services are offered in a Continuing Care environment. [In-Home Respite Care](#) provides short-term care in the client's home, allowing them to remain in a familiar environment. [Adult day programs](#) are designed for people over the age of 18 who may have physical and/or memory challenges or are living with chronic illness. Some programs focus primarily on socialization needs and providing respite for the caregiver.

The **Comprehensive Home Option of Integrated Care for the Elderly (CHOICE)** in Edmonton or **Comprehensive Community Care (C3) Program** in Calgary provide integrated care for very frail seniors with complex chronic illnesses who require extra supports to live safely at home. Integrated care is provided by an interdisciplinary health care team, which includes a medical health clinic, day program, home support, transportation assistance, and access to a designated treatment bed. Clients attend adult day centres, one to five days a week, and receive professional services including rehabilitation, social work, nursing and on-site access to physician services in addition to socialization and respite.

4. Condition specific Not-for-profit/ charitable organizations

Not-for-profit and charitable organizations offer many needed services, including but not limited to, education and skills training, peer support, mental health supports, coaching for Albertans with the illness or disability and caregiver supports. There are many other organizations providing services. **This list is not exhaustive.** These are just an example of some of the organizations.

[Alzheimer Society of Alberta and Northwest Territories](#) and [Alzheimer Calgary](#) raise awareness to Alzheimer's disease and other dementias; with education and support programs such as the First Link, education and support programs, and navigators helps to alleviate the personal and social consequences of the disease; and, promotes and funds research into the cause, prevention and cure.

- Dementia in the workplace was developed by the Alzheimer Society to share information and guidance with Alberta-based employers and employees navigating the impacts of dementia in the workplace. The website has content for employers, employees living with dementia, and employees who are care partners.

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[Autism Society Alberta](#) is dedicated to increasing public awareness about autism and the day-to-day issues faced by autistic individuals, their families and the professionals with whom they interact. The Society and its partners share a common mission of providing information and education, as well as supporting research and advocating for programs and supports for the autism community.

Canadian Mental Health Association in Alberta, in partnership with the Government of Alberta, Ministry of Children's Services, has developed the peer-to-peer family support program, [Caregiver Connections](#), to provide peer support for parents and caregivers of individuals with mental health concerns. Caregiver Connections provides peer support services in six Alberta Regions, offering compassionate support and specific information and resources.

[CASA](#) offers the FamilySmart Family Peer Support Program to parents and caregivers of kids who struggle with mental health challenges. How can a family peer support worker help?

- We will listen to you, and we understand what you're going through.
- We can help you navigate the system. We'll connect you to services and supports that are available to you.
- We can help you prepare for meetings with mental health professionals.

[Cerebral Palsy Alberta](#) has a full-time Social Worker & Client and Family Counsellor to help support, enrich and enhance clients and family caregivers' lives.

Huntington Society, [Southern Alberta Chapter](#), [Edmonton Chapter](#), [Camrose](#) provide information and resources, education, counselling, and support groups. In addition the social workers provide assistance to navigate systems and access resources and accompany patients and caregivers to critical healthcare appointments.

[Parkinson Association of Alberta](#) has a range of supports and services for family caregivers including one-on-one/family support counselling, support groups, information and resources, education sessions, and assistance in identifying and locating community and government resources.

5. Access to Non-medical Community Services

The Family and Community Support Services (FCSS) program is unique to Alberta. These programs are designed to **enhance quality of life** and **build capacity** within communities to promote social well-being and sustainable personal growth. They offer [services locally](#) that directly benefit family caregivers. 99% of Albertans live in a municipality or Métis Settlement where an FCSS program is ready to offer preventive services such as: *Access to Social Supports*, helping caregivers connect with community resources; *Volunteer Promotion*, encouraging volunteer involvement to support caregiving efforts; *Skills Development Programs*, offering mentoring and personal development to enhance caregiver resilience. *Senior Support*, helping seniors stay connected to their communities with home support services; and, *Healthy Relationships*, providing tools for building strong interpersonal skills to enhance caregiver and family well-being.

Children and Family Services offers a range of supports and resources for children, youth and families in 5 regions across the province. Children's Services aligned its services under three outcomes 1) Albertans have access to early childhood education and childcare options that enable participation in training, education, or the workforce. 2) The well-being, resiliency, and cultural connections of children, youth and families are supported, and children and youth are protected. 3) Reduction in red tape imposed by legislation, regulations and associated policies and forms improves services for children, youth, and families. This includes Calgary, Central, Edmonton, North, Southeast and Southwest regions.

[Healthy Aging Alberta](#) was established to connect community-based senior-serving (CBSS) organizations with larger systems such as health, housing, and the disabilities sectors. Healthy Aging Alberta does not directly provide services to older adults itself. Through the work of Healthy Aging Alberta, however, organizations in the community-based seniors serving sector will be more connected with each other, more cohesive in their joint messaging, and more effective in getting the value and the needs of the sector better understood within government and among members of the public.

- **CORE Alberta.** [Website](#) is a knowledge hub connecting organizations that support and advance independent living for older Albertans.
- **Provincial Community and Home Supports for Older Adults** See [CORE Alberta](#) The Government of Alberta announced \$3.2 million in funding in June 2022 to Healthy Aging Alberta to enable community-based organizations across the province to offer older adults personal, psychosocial, and mental health supports.
- **Social Prescribing** [Social Prescribing](#) is a holistic, wrap-around approach to healthcare that bridges the gap between medical and social care services. Through this approach, healthcare professionals refer patients to community-based programs to improve their health and enhance their quality of life.

Connecting People & Community for Living Well The [Connecting People and Community](#) team works provincially with rural multi-sector community teams to build and sustain the well-being of local underserved populations such as seniors impacted by dementia, and others who may benefit from enhanced support within their **community**.

Seniors Centres Across Alberta, seniors centres offer Albertans 55 years of age and older a wide range of programs, services and activities including: recreation programs, nutrition services, health and wellness, social services, community development, volunteer opportunities and more. [Alberta, Via 211 Edmonton](#), and [Edmonton, Via Sage Seniors](#)

6. Navigation

211 is available 24/7 by phone, text and chat to help Albertans find the right resource or service for whatever issue they need help with, at the right time. The service is free, confidential and available in over 170 languages over the phone. They also have a [searchable database](#). On a national level, 211 connects people to the right information and services, strengthens Canada's health and human services, and helps Canadians to become more engaged with their communities.

Health Link 811 provides free 24 / 7 advice and general health information for Albertans. Health Link provides a number of clinical services including tele-triage and health advice, assistance finding a health provider, Dementia, Rehabilitation, and Nutrition Advice, and health system navigation services for all Albertans by calling 811 There are 2 searchable databases associated with 811: Inform Alberta and MyHealth.Alberta.ca

Alberta Supports can help you find and apply for more than 30 programs and 120 services for seniors, people with disabilities, job seekers, parents and families, homelessness, financial assistance, abuse, and family violence prevention. All Alberta Support Centre services are available online and by phone. For in-person services, call or visit your local Alberta Supports Office.

Alberta Seniors and Community Housing Association [Seniors Housing Directory](#) The Alberta Seniors and Community Housing Association has a searchable database of housing resources for seniors.

Community Connect YYC Mental Health Support: [Community Connect YYC](#) Finding the right support in times of need can be challenging, but Community Connect YYC is changing that. We are a group of Calgary-based agencies dedicated to helping community members to quickly and easily access mental health supports when they need it most.

The Way In Network Calgary Telephone 403-SENIORS (403-736-4677) The Way In Network offers navigation and connection to services and supports. The Way In is targeted to Calgarians, age 65+ years, living independently in the community, and who need assistance to navigate to and connect with community supports Four Calgary Organizations offer Way In supports: Calgary Chinese Elderly Citizen's Association, Calgary Seniors Resource Society, carya, Jewish Family Service Calgary.

Offers :

- information, referrals, and support with transportation, government programs, and case management;
- application assistance for pensions, benefits, transportation, and housing;
- elder abuse intervention and support;
- caregiver support;
- group activities and workshops;
- Commissioner for Oaths;
- tax preparation assistance in March and April.

Appendix B Discussion Guide

Discussion questions related to family caregivers

1. What have you heard that is important from the perspective of family caregivers within your setting?
2. What role do you play in supporting family caregivers? What types of emotional, practical, informational, decisional, physical and mental supports are part of your role within your setting?
3. What have you found helpful to support family caregivers?
4. How important do you feel family caregivers are to the health of your patients/ clients/ residents?
5. What challenges have you observed and experienced related to family caregivers?
6. Do you feel you have the necessary skills and competencies to support family caregivers?
7. Are you aware of the education modules that are available for health and community/ social care providers?
8. What enhancement would you like to make as a team to help family caregivers best support patients?

Discussion questions related to staff on your team who are double-duty caregivers

1. What have you heard that has been valuable or is an obstacle for team members/staff who are family caregivers (Double-duty caregivers)?
2. What role do you play in supporting staff who are Double-duty caregivers?
3. What types of emotional, practical, informational, decisional, physical and mental supports do you offer within your setting?
5. How well do you feel the staff members on your team who are double-duty family caregivers are supported?
4. What impact from being a Double-duty caregiver have you observe / experienced?
5. Do you feel you have the necessary skills to support Double-duty caregivers?
6. What enhancements would you like to make as a team to help Double-duty caregivers?
7. What changes would you like leadership to advocate for?

Appendix C – Discussion Guide: Potential Ways to Support Double-duty Caregivers

What can you do if you are a Double-duty caregiver?

1. Communicate your needs, concerns, and boundaries.
2. Seek emotional support and practical advice from colleagues, supervisors, or support groups.
3. Look for micro-moments like taking a few deep breaths, stretching, standing outside on outside, looking after a plant, or enjoying a cup of coffee.
4. Prioritize self-care time like exercise, relaxation techniques, hobbies, getting rest, and practising mindfulness.
5. Delegate tasks to other family members or use external support services to lighten your caregiving load.
6. Utilize available resources such as employee assistance programs, counselling services, and community organizations like Caregivers Alberta for extra support.
7. Access information on financial, legal, transportation, and other community supports. such as meal prep, grocery delivery and laundry services.
8. Carve out time for family relationships and daily check-ins with partners such as going for a walk, having regular family meetings and discussing the division of responsibilities.

How can I support a coworker who is a caregiver?

1. Show empathy by recognizing the challenges family caregivers face. Listening can make the workplace more supportive.
2. Offer practical aid like helping with work tasks, covering shifts, or providing emotional support during tough times.
3. Acknowledge and celebrate the contributions and resilience of Double-duty caregivers.
4. Foster a positive and inclusive workplace environment, boosting morale.

How can healthcare leaders help Double-duty caregivers?

1. Enable supportive communication about caregiving responsibilities and work accommodations.
2. Look for ways to manage workload and minimize stress.
3. Support workplace wellness, mental health, stress reduction, and work-life balance.
4. Take training on caregiving support.
5. Encourage the use of employee assistance programs.

Appendix D: Family Caregiver Organizations and Websites

CANADA

[Canadian Caregiver Coalition](#) (CCC). A national body that brings together caregiver organizations and works to promote the well-being of family caregivers

[Veterans Affairs Canada](#). Provides government support to families of veterans, including family caregivers who care for injured or disabled veterans.

[VETS Canada](#). Focuses on supporting veterans and their families with a focus on high risk individuals, including assisting family caregivers.

[Carers Canada/The Caregiver Network](#). Virtual alliance of partners working collectively to respond to the needs of caregivers in Canada.

[Canadian Centre for Caregiving Excellence](#). Brings together caregivers, researchers and allies to advocate for policy solutions across Canada.

[AGEWELL](#). Canadian network to develop technologies and services for healthy aging, including supports for caregivers.

[Canadian Hospice Palliative Care Association](#). Advances quality hospice palliative care including support for caregivers.

[Caregiving Matters](#). Internet based information and education for caregivers.

[Canadian Abilities Foundation](#). Resources, blog and publications including Abilities and Caregiver Solutions.

[The Ontario Caregiver Organization \(OCO\)](#). Provides programs, services, and education for hospitals and caregivers in Ontario, helping them navigate the health system and access resources. They provide guides such as Caregivers in the Workplace: A Guide for Employers Building a resilient and sustainable workforce.

[Family Caregivers of British Columbia](#). Offer support groups, tools, and information for family caregivers in the province of British Columbia.

[Caregivers Nova Scotia](#). Offers resources for friends and families giving care, including a new program for young caregivers.

[Caregivers Alberta](#). Promotes caregiver well-being by providing resources, mental health support and education for family members or friends.

[Caregiver-Centered Care](#). A program of applied research in family caregiving based at the University of Alberta. Specializes in education to staff on working with family caregivers.\

[Family Caregiver Centre](#) AHS initiative in Calgary Zone in partnership with Calgary Health Foundation. Offers information, education and support to family caregivers.

[Caregiver Connect](#) Supports family caregivers of loved ones with mental health concerns. Partnership with CMHA and Alberta government.

[HiMARC](#) is a collaborative initiative and provincial hub that aims to develop, evaluate, and help implement solutions to improve the resilience, readiness and growth, as well as health and well-being, of military members, Veterans, PSP (public safety personnel) and their families.

INTERNATIONAL

[Carers Australia](#). The national voice for unpaid carers, offering advocacy, resources, and support across Australia.

[Young Carers Network](#). An initiative of Carers Australia and a nationally coordinated resource to raise young carer awareness, provide information and direct young carers to resources.

[Carer Gateway](#). A government initiative that provides practical support, services, and advice to unpaid carers.

[Soldier On](#). Supports serving and ex-serving veterans and their families, including providing programs for family carers.

[Legacy Australia](#). Supports the families of veterans, especially widows and children, through welfare services and support for carers.

[The Carers Foundation Australia](#). Provides family carers with well-being programs to prevent health crisis breakdown from the impact of caring. Includes a teen program.

[National Organisation for Fetal Alcohol Spectrum Disorders](#). Support for caregivers and families including a confidential toll-free line.

[National Carer Strategy](#). Launched in 2023, strategy will recognize carer contributions across government portfolios and implement actions. Consultation currently underway.

[International Alliance of Carer Organizations](#). Network of carer organizations to recognize the essential role of carers, advocate, share best practices and assist in establishing carer organizations.

[Carers UK](#). A national membership charity that supports unpaid carers through information, advice, and policy advocacy.

[The Carers Trust](#). Provides financial and practical support to unpaid carers, including young carers and carers of the elderly.

[Care for the Family](#). Offers programs that support family members and carers, including those dealing with illness, disability, or the aging process.

[Help for Heroes](#) Provides a network of support for family members of veterans and those injured or affected by military service.

[Help for Heroes Band of Sisters](#). Open to males and females, a support group for caregivers of military service members who have sustained significant injuries or illness related to their service.

[Royal British Legion – Admiral Nurses Service](#). Work with Dementia UK to offer specialized dementia care support, information and advice for veterans and their families.

[AgeUK](#). Provides emotional, practical help and advice on available financial support.

[Carents Room](#). Website for supporting “carents” (mid life children providing care for elderly relatives)

[Embracing Carers](#) Focused on improving carers' health and wellness while increasing awareness and support for them across the globe.

[Mind](#). Information and support for carers including help looking after people with mental health problems.

[Family Caregiver Alliance](#) (FCA). Provides information, services, and support for family caregivers of adults with physical and cognitive impairments.

[AARP Family Caregiving](#). Offers resources, tools, and community support to caregivers across the US (one of many roles of the AARP)

[National Alliance for Caregiving](#) (NAC). Focuses on advancing family caregiving through research, advocacy, and innovation. National strategy underway.

[Caregiver Action Network](#) (CAN). A non-profit organization that provides education, peer support, and resources to family caregivers.

[Elizabeth Dole Foundation](#) – Hidden Heroes. Focuses on military and veteran caregivers, providing resources, advocacy, and support.

[The Wounded Warrior Project](#). As part of its mission to serve veterans, provides assistance and support for military caregivers through various resources and advocacy programs.

[Rosalynn Carter Institute for Caregivers](#). Promotes caregiver health, strength and resilience.

[EngAGED](#): The National Resource Center for Engaging Older Adults. National effort that identifies and disseminates information and develops resources to increase the social engagement of older adults, people with disabilities and caregivers.

[National Family Caregiver Support Program](#). Designed by the Administration on Aging, the aim of the program is to help family members care for older adults at home. Funding requires states to work with local area agencies and service providers.

[American Association of Caregiving Youth](#). Offers support services for individuals 18 and younger who provide significant assistance to a family member with a chronic illness, disability or frailty.

[Brain Injury Association of America Caregiver Information Center](#). Provides tools and resources to caregivers of loved ones with a brain injury.

[Alzheimer's Association Caregiving](#). Resources including 24/7 national helpline for caregivers of those with AD.

[National Strategy to Support Caregivers](#). Provides guides to help states, communities and organizations help caregivers to achieve balance and stability (lighten the load)

Caregiver Support Apps

[Team CarePal](#)

[Caring Bridge](#)

[ianacare](#)

[Watch Our Own](#)

[eCare21](#)

[Medisafe](#)

Glossary of Terms

Family Caregiver (carer, care-partner, support person) is any person (family, friend, neighbour or chosen family) who takes on a generally unpaid caring role and provides emotional, physical, or practical support in response to physical and mental illnesses, disabilities, and/or age-related needs.

Caregiver in Continuing Care Act Ministerial Regulations “caregiver” means a family member or friend who provides support or assistance to an eligible individual with respect to the eligible individual’s needs relating to home and community care but does not include a home and community care provider.

Designated Family/Support Person is an individual identified by the patient as an essential support, and who the patient wants included in care planning and decision-making. Patients must communicate any changes to their Designated Family/Support Person to the care team⁵⁸

Double-duty Caregiver refers to a portion of the health, social, and community care labour force who double up as unpaid family caregivers to people needing care for mental or physical illness, disabilities, and/or frailty and provide care at work.

Caregiver-centered care is an approach that acknowledges and supports the unique needs, roles, and contributions of family caregivers within the broader context of the health and community/social care systems. Unlike traditional models that focus primarily on the patient or care recipient, caregiver-centered care explicitly integrates the well-being, experiences, and insights of family caregivers into care planning and delivery.

Caregiver-centered education is an approach to training and education that focuses on equipping health, community/ social care providers with the knowledge, skills, and attitudes needed to effectively recognize, support, and collaborate with family caregivers. It emphasizes understanding the unique needs, challenges, and contributions of caregivers, ensuring that their roles are acknowledged and respected within care teams.

Caregiver-centered Competency Framework are the competencies -- the structured set of skills, knowledge, and attitudes that health and community/social care providers need to effectively engage with and support family caregivers as essential partners in the care process. The competency framework is designed to guide training, assessment, and professional development, ensuring that care practices are inclusive of the needs and contributions of family caregivers.

Continuing Care Home: Continuing care home means a facility or part of a facility where facility-based care is provided to residents, some of whom must be eligible residents. Continuing care homes are publicly funded facility-based accommodations that provide care (health and support services) appropriate to meet the resident’s assessed needs. The type of care needed is determined through a standardized assessment and single point of entry process and consists of Type A, Type B and Type C. Individuals admitted into Continuing Care Homes Type A and B are required to pay accommodation fees (room and board and other costs associated) as set by Alberta Health.