Canadian Caregiving Summit 2025

Act on Care

Canadian Centre for Caregiving Excellence
A program of the Azrieli Foundation

Fondation Azrieli Foundation

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The Canadian Centre for Caregiving Excellence supports and empowers family caregivers and care providers, advances the knowledge and capacity of the caregiving field and advocates for effective and visionary social policy with a disability-informed approach. The Canadian Centre for Caregiving Excellence is a program of the Azrieli Foundation, which has long supported innovative initiatives to improve access to quality care.

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Act on Care

Insights and Actions From the 2025 Canadian Caregiving Summit

A movement is underway. The second Canadian Caregiving Summit, held in Ottawa in November 2025, made that unmistakable. From the moment participants gathered, the shared understanding was clear: we must recognize care as not only a private act, but the infrastructure that makes all other work possible, including our participation in family, community and public life.

Care providers across Canada work on the frontlines of care each day. Caregivers anchor the health system by supporting family and friends through the most vulnerable periods of their lives. Caregivers and care providers have always been the backbone of our systems – essential, skilled and indispensable – but only now is Canada beginning to recognize their true value.

Caregivers are constantly asked to do more. More care is happening at home and in the community, as hospitals, health and social care organizations and long-term care homes face growing volumes and more complexity than ever before.

These growing pressures led the Azrieli Foundation to create the Canadian Centre for Caregiving Excellence (CCCE) in 2022. In November 2025, more than 500 delegates, in person and online, gathered for the second Canadian Caregiving Summit to advance this work together.

Over two days, Canadians from every region demonstrated that care is the foundation that holds our families, communities, workforce and economy together. Leaders, advocates, caregivers, care providers, policymakers, employers and researchers described a landscape filled with innovation and possibility, yet still constrained by fragmentation, lack of recognition and insufficient supports. One in four Canadians is a caregiver today, while one in two will be one in their lifetime. Care binds us together, no matter how we get there.

> “Every single day in Canada, nearly eight million people wake up and provide care for someone they love. Caregiving is not a fringe issue — it is a shared human experience.” — Dr. Naomi Azrieli, Azrieli Foundation

> “Caregiving should be recognized not as a private burden, but as a public contribution.” — Colonel (ret) Russell Mann, Military Veteran and Caregiver

Canadian Caregiving Summit by the Numbers

502

caregivers, advocates and leaders showed up to act on care.

They didn't just attend – they left energized and ready to act.

70%

said the Summit inspired them

65%

reported they are ready to take action to advance the National Caregiving Strategy

Overview

Overview

Delegates shared stories of struggle and resilience, exchanged practical solutions and learned from emerging research, cross-sector models and real-world innovations. From national organizations to local initiatives, the Summit reflected the breadth and diversity of caregiving in Canada.

Lived experience was at the centre of the Summit. Summit emcee, Stephanie Muskat, bravely shared her personal caregiving story during the welcome remarks. Her reflection on how care for the caregiver is care for the whole system became a grounding theme for the two days of dialogue.

The call to action was clear. Canada has defined the challenges. We now need to move toward implementation, building a coordinated, equitable national approach to supporting caregivers that reflects our values. The National Caregiving Strategy, released in early 2025 by CCCE outlines the steps. Now we need the will, leadership and collective resolve to carry them out.

Delegates confirmed that the foundation for change is ready:

- We have the research
- We have the data
- We have champions
- We have breakthrough innovations
- We have people sharing their stories that move both hearts and systems

> "This is our moment to build a Canada that truly cares. The time to act on care is now." — Liv Mendelsohn, CCCE

> "Care is infrastructure. Like roads, bridges and systems, it is what holds up our economy, our families and our collective well-being."— Liv Mendelsohn, CCCE

During the Canadian Caregiving Summit, we asked attendees to reflect and share **"What I Wish You Knew,"** an opportunity to share joys, triumphs and challenges experienced along their caregiver journey.

What I Wish You Knew

Caregiving is, at its core, an expression of being human. It is profoundly humbling and vital.

Keynote Spotlight: Arlene Dickinson

Entrepreneur and advocate Arlene Dickinson brought humour, honesty and hard-earned wisdom to her keynote, *Advocacy, Aging and the Heart of Care*. She spoke candidly about caring for her mother through dementia, a journey that reshaped her understanding of success, aging and responsibility.

Her insights explored aging as an awakening, caregiving as moral advocacy and society's tendency to glorify productivity while overlooking "the most human act there is."

She urged delegates to view advocacy as legacy, while building a nation that does not discard its seniors.

> "We talk about innovation and growth, but what does it say about a nation if we can't care for the people who raised us?"

Arlene's message to employers was clear: caring for employees who are caregivers requires more than sympathy. It means giving them real flexibility, time and practical support through benefits and total reward offerings. Start by asking directly what they need. Workplaces must back that compassion with policies that relieve pressure, not add to it, because caregivers already carry an enormous, invisible load.

She declared that a caring country is one where the systems we build match the love, labour and courage caregivers bring every day.

Her keynote ended with a standing ovation: "Leadership isn't just scaling companies; it's scaling compassion."

> "If you're an employer, please make sure that your policies take care of those who are working for you."

What We Learned Together

What We Learned Together

Perspectives From the Caregiving Community

Across two days, in 15 breakout sessions and 10 plenaries, caregivers, care providers, advocates, policy leaders and researchers shared ideas that challenged assumptions and sparked practical solutions.

Together, we saw more clearly that care is no longer a private struggle; it is shared work that shapes our families, communities and economy. We heard about gaps that must be closed, and concrete models already working in Canada and around the world.

> “All the stories made me feel like I am not in the fight alone!!” — Summit Participant

The Summit’s proceedings yielded key takeaways organized around five central themes. Each theme reflects what we heard from lived experience, practice, policy and research. Together, they point towards a future Canada that recognizes care as core national infrastructure and acts with urgency to strengthen it.

THEME 1.

Provinces, Territories and Global Peers: Policy Leadership on Care

> "We need to move out of silos and engage in a national, collaborative strategy." — Summit Participant

Across the country and around the world, governments are experimenting with new ways to support caregivers. These choices shape what families can expect, who gets help and how care systems will evolve over the next decade.

Atlantic Canada: Leading the Way with Caregiver Benefits

Canada's Atlantic provinces are emerging as national leaders in caregiver benefit design. Nova Scotia, Newfoundland and Labrador and Prince Edward Island have financial supports that, while modest, send a powerful message: We see you. Care matters, and caregivers must be recognized.

Across these models, several principles stand out:

- Simplicity matters
- Navigation must accompany benefits
- Eligibility should expand over time

These provincial experiments contrast with Canada's federal supports through Employment Insurance (EI), Canada Pension Plan (CPP) and existing tax credits, as highlighted at the *Financial Security: Strengthening EI and CPP to Better Support Caregivers* session. These approaches remain outdated, fragmented and often inaccessible. Long-term caregivers, low-income families, young caregivers and those who are self-employed or who leave the workforce remain largely unprotected.

> "We put so many barriers to access that, in the end, very few people can actually benefit. Complexity becomes the gatekeeper." — Pascale Pilon, Finautonome

> "I chose my family over my career, and now I am paying the financial price for my long-term unpaid caregiving roles." — Pamela Barkhouse, Caregiver

Delegates had a clear message: Canada must modernize its support architecture by simplifying eligibility, making tax credits refundable, fixing CPP penalties and designing a national caregiver benefit that reflects real caregiving timelines.

These reforms directly echo the Summit's message of supporting care as an investment that strengthens the economy, labour force participation and national resilience rather than a pure cost.

Global Models: Long-Term Care Insurance as Social Infrastructure

Countries such as Japan, South Korea and Germany treat long-term care insurance as a universal, risk-sharing infrastructure. Despite different designs, they share core principles:

- Mandatory participation
- Shared financing
- Universal protections
- Care as a social right

Each country offers valuable lessons:

- **Japan** introduced mandatory long-term care insurance in the late 1990s, when 14% of its population was already over 65. Contributions begin at age 40. Coverage is designed to keep people at home and in the community - ranging from light supports to 24/7 assistance - so institutional long-term care is comparatively rare. Eligibility is primarily for ages 65+, with limited access for ages 40 - 64 when needs are tied to aging-related conditions (e.g., Parkinson's). The system is built around early, community-based support and very low institutionalization.
- **South Korea** also uses universal contributions, but with a stronger emphasis on long-term care supports for people over 65. Contributions start as soon as someone earns income, effectively creating an intergenerational model in which working-age adults help finance care for older relatives. As in Japan, people aged 40–64 can qualify only under strict criteria tied to aging-related conditions. Panelists noted that the policy was enacted when demand was still relatively low and the political window was favourable - underscoring that timing and political feasibility can shape reform as much as program design.
- **Germany** introduced a disability-based care insurance that is not age-restricted, distinguishing it from Japan and South Korea. People can choose either a cash benefit to arrange care themselves or in-kind publicly provided services. In practice, many opt for cash, even though it is less value, contributing to a greater reliance on informal arrangements and dependence on migrant care labour. The insurance supports home-based care in particular (roughly 70% of usage) offering families flexibility and choice.

Intergenerational models also demonstrate how design choices strengthen culture and community. For example, in Denmark they co-locate care homes with daycares and Ottawa's Perley Health has embedded childcare in long-term care.

The Canadian system is much more reliant on institutional care than these other countries. Canada spends half of what leading countries in the OECD invest in long-term care, has one of the highest institutionalization rates in the world and lacks a universal home care system.

These international and provincial examples point to the same conclusion: policy design shapes outcomes. Canada must act boldly to ensure nobody gets left behind.

> "We've been thinking about care and long-term care as a kind of public drain, like a burden. I think the government needs to think of long-term care and care and the care economy as an investment source, a pathway to the new economy."
> — Dr. Ito Peng, University of Toronto

What I Wish You Knew

How many caregivers out there don't realize they are caregivers because they are providing the emotional and often invisible support and as such- don't see themselves as a "caregiver."

THEME 2.

Community and Culture: Local Solutions That Work

Communities across Canada are building care models grounded in relationship, culture and real-world experience. These approaches respond to needs that large systems often miss and show what care can look like when rooted in place, identity and trust.

Indigenous Caregiving: A Sacred, Relational Responsibility

Dr. Grant Bruno and the Indigenous Care Collective panelists emphasized that caregiving in Indigenous Nations is a sacred, community-held responsibility shaped by kinship, language, land and ceremony. Colonial policies fractured these care systems, and rebuilding trust requires humility, presence and consistency from service providers.

The message was clear: Canada must partner with Indigenous communities rather than stipulate solutions. Successful programs ground care in ceremony, Elders, language and kinship, and recognize Indigenous caregiving expertise as a core strength.

> “The sensory teepee is a really grounding, safe space. You can physically see people’s shoulders drop. Ceremony is where caregivers say they feel grounded, peaceful and not alone.”
> — Dr. Grant Bruno, University of Alberta

> “Even the language within our kinship system shows how the burden of caring doesn’t fall on one person. Your auntie is your ‘other mother.’ Those kinship terms come with roles and responsibilities.” — Tierney Littlechild, University of Alberta

> “The Indian Act enacted residential schools - tearing apart families and kin, destroying language, culture and teachings. These colonial systems replaced relational care with institutional control.” — Mariam Ahmad, University of Alberta

What I Wish You Knew

Caregivers deserve so much more respect than they receive.

Young Caregivers: Hiding in Plain Sight

The young caregiver movement has introduced the caregiving sector to a population almost invisible in research, policy and practice. Borrowing a phrase from Rhiannon Satherly from BC Women and Children's Hospital, Rebekah Gold urged professionals to "tilt the gaze down" so young carers are seen and treated as wisdom-holders and decision makers.

The *Supporting Young Caregivers: Resources, Rights and Resilience* panelists stressed the need for national data, particularly for children under 15, as well as those in underserved regions. Youth-friendly tools such as magazines, comics and storytelling resources help children explain their caregiving roles to teachers and peers. These should be scaled across systems.

> "It's wonderful to see more organizations being created, especially the Indigenous Caregiving Collective and the Young Caregiver Council of Canada." – Summit Participant

What I Wish You Knew

Young caregiving is not an exception it is a norm and a growing one as disability and chronic illness becomes more prevalent, and as the youth mental health crisis means that youth have to support one another.

Military and Veteran Caregivers

The panelists at the *Military and Veteran Caregiving* session emphasized that military and Veteran families experience unique caregiving pressures driven by the realities of mobility, deployment and risk inherent in military life. With frequent relocations, military families cannot rely on traditional circles of care, leaving families to navigate health, mental health and childcare systems without stable local supports.

The realities for military families was ignored for many years, but more recently, through research and people with lived experience sharing their stories, tailored supports are emerging. The Military Family Resource Centre offers navigation, mental health supports and education for communities where military families live. Julie Drury from Veteran Affairs Canada also shared updates about targeted Veterans Affairs programs such as monthly caregiver benefits, the Veteran Independence Program and peer-support initiatives that are emerging.

Panelists recognized the progress, but also called for greater awareness, broader eligibility and seamless coordination across systems so military and Veteran caregivers are supported consistently - not conditionally.

> "Caregiving in military families is far more complex than the stereotype of an older spouse caring for an older veteran."
> — Nora Spinks, Work-Life Harmony

> "Caregiver benefits are not charity — they are recognition of a real and essential role." — Julie Drury, Veterans Affairs Canada

> "This lifestyle requires an economy of care within the family that is fundamentally different." — Dr. Heidi Cramm, Queen's University

Community-Driven Models Show the Way Forward

Families with complex needs are often failed by large, siloed systems. Community-led models like Nursing Home Without Walls and dementia cafés succeed because they respond to local needs and draw on local strengths. The call was unified: scale person-centred, community-driven models, not top-down approaches.

THEME 3.

Stories Are Shaping Canada’s Care Agenda

Care is infrastructure, and storytelling is one of the tools that makes the infrastructure visible.

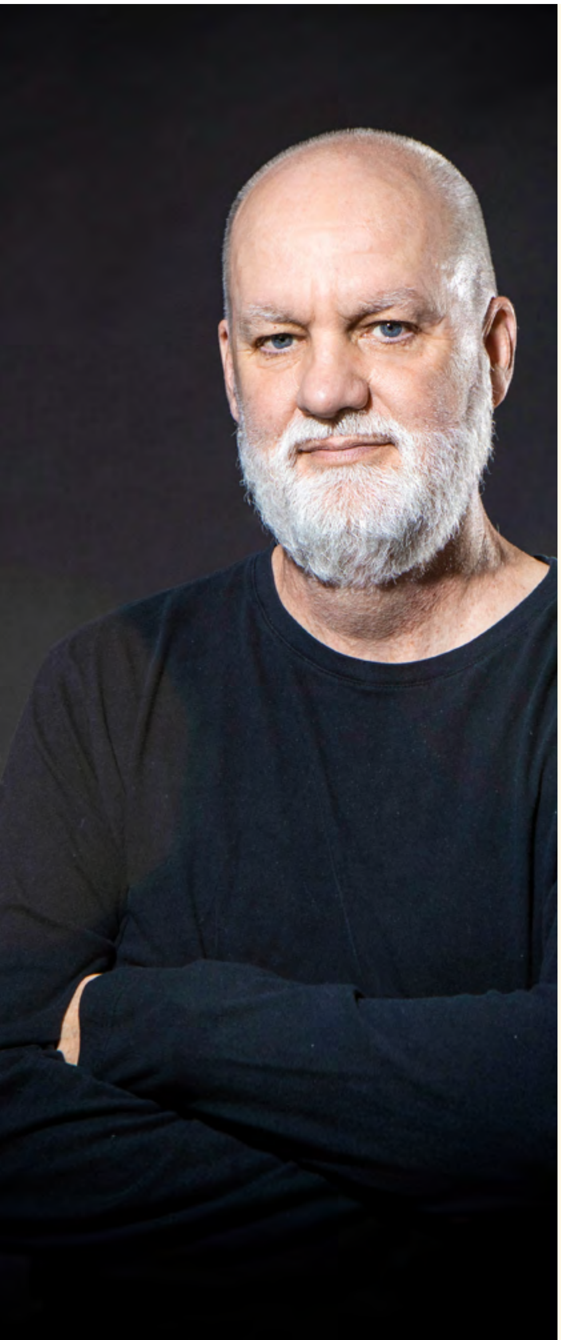
Across Canada, lived experience is shifting caregiving from a private struggle to a collective responsibility.

Stories That Reveal System Gaps

Journalists who have become caregivers themselves are making system failures visible in ways data alone cannot.

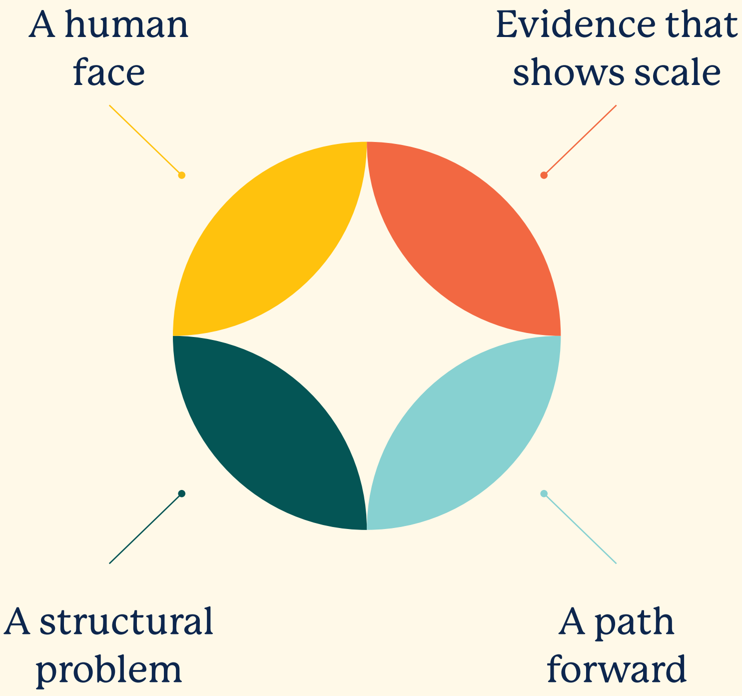
Elizabeth Payne described realizing how “no one’s job” was ensuring patients did not leave the hospital in worse condition, a gap instantly recognizable to families across Canada.

André Picard reflected on the pandemic as the “spotlight moment” for long-term care, noting that one per cent of Canadians live in institutions yet about half of COVID-19 deaths occurred there - a stark illustration of neglect hidden in plain sight.



André Picard’s ideal story

Picard shared what makes a caregiving story powerful:



What I Wish You Knew

That I would get so little sleep for so long and no one would ask what I needed. The assumption was that I would magically be resilient. And if you're not, you've failed somehow.

Caregivers Speak for Themselves: Choosing Where Their Story Lands

Caregivers are increasingly using social media platforms like TikTok, Instagram, YouTube as well as podcasts to show what care really looks like: dementia support, complex children's needs and balancing care for multiple family members. These platforms have become informal peer networks, especially for rural and isolated caregivers. Users want honest stories, diverse voices and practical solutions, not just feel-good moments.

Mainstream outlets, by contrast, reach policymakers and leaders. Panelists encouraged advocates to choose platforms based on who they want to reach, while pairing lived experience with evidence and a hopeful idea for change.

Together, these shifts signal a cultural turning point where caregiving stories move to the centre of Canada's national conversation.

> "Caregivers will tell us what they need. We need to listen to and support them in creating plans that work for them." — Summit Participant

Lived Experience Driving Policy and Workplace Change

The session *Canadian Firsts: Innovations Supporting Working Caregivers* showcased how caregiving is a workforce asset. With over six million Canadians balancing paid employment with caregiving responsibilities, workplaces that proactively consider how to support working caregivers through policies, benefits and culture have a competitive advantage.

Certain Canadian organizations are leading the way by reshaping workplaces and professional norms.

Engineers Yukon now counts caregiving as professional development, recognizing the skills it builds and removing barriers for women and early-career engineers.

SE Health and GreenShield introduced a first-of-its-kind respite benefit that gives employee caregivers a paid benefit that covers the cost of respite care with a qualified provider.

When organizations design supports with caregivers, they create stronger workplaces and set new national standards.

> "Caregiving is work. Not only does it take time and energy, but it develops important skills." — Angel Henchey, Carleton University

> "We want to remove a barrier to keeping caregivers in the workforce and in the profession." — Alison Anderson, Engineers Yukon

> "Caregivers want and need to work. Caregivers are bringing the skills to the workforce that we are looking for in today's environment. This is where that win-win argument comes into play." — Christa Haanstra, CCCE Working Caregivers initiative

> "People will work ten times harder if they know that when they need flexibility to care for someone they love, it will be there." — Colonel (ret) Russell Mann, Military Veteran and Caregiver

THEME 4.

Removing Barriers for Caregivers and Care Providers

> “You are the backbone of this country. Your care sustains lives, families and communities. You deserve recognition, respect and rest.” — Liv Mendelsohn, CCCE

Across Canada, caregivers and care providers face structural barriers that make care harder than it needs to be. Addressing these gaps is essential to building a system that supports families and strengthens the workforce. When we support care, our entire economy grows. When we neglect it, everyone pays the price.

Caregiver Mental Health: The Invisible Load

The theme of mental health came up frequently but was the sole focus of the session *Mental Health and Care: Developing Support Models for Caregivers and Care Providers*. All panelists agreed that caregiver mental health remains one of the most overlooked dimensions of care. Many experience emotional strain equal to or greater than the person they support, yet mental health systems remain fragmented and hard to reach.

Delegates emphasized that effective mental health supports must be co-designed with caregivers, include peer workers, offer flexible access and be backed by sustainable funding.

Canada must embed caregiver mental health into the core architecture of care by:

- Routinely asking about caregiver distress
- Scaling peer-led and co-designed programs
- Creating multiple low-barrier access pathways

> "Clinicians are afraid to ask caregivers how they're doing because they don't know what to do with the answer, especially if there's a two-month waitlist and no solution to offer."
> — Dr. Rinat Nissim, Princess Margaret Cancer Centre

> "We give caregivers very little space. We don't recognize and validate all that they do — and that has a heavy toll on their mental health." — Zelda Freitas, McGill University

What I Wish You Knew

Poverty isn't a reason to take caregiving responsibility away, it's a reason to provide family support to lift caregivers and the people they care for up and out of poverty.

Respite: Essential Yet Insufficient

Families caring for medically complex children shared a stark truth at the *Give me a Break! Respite in Canada Today* session, facilitated by Donna Thomson, a long-term caregiver advocate.

Respite is profoundly inadequate across Canada. Many parents face years of fatigue, significant financial barriers and moments where relinquishing care feels like the only option left. The evidence proves it. Donna quoted Dr. Jane Barratt, global thought leader on aging, saying "Without respite, caregiving erodes health, limits opportunity, and in many cases, shortens lives."

Respite is a lifeline that keeps families whole. Delegates called for predictable, rights-based access, sustainable funding and a skilled workforce to deliver safe, reliable respite across communities.

> "We're seeing that respite is not a universal, accessible program." — Susan Bisaillon, Safehaven

> "When we walk into a space, the first thing that is seen is the colour of our skin — and unfortunately that can present barriers to getting the support that we need." — Sherron Grant, Sawubona Africentric Circle of Support

> "A real mental and physical rest can only happen when your basic supports are in place. Families need inclusive childcare, fully supported school days, or appropriate support for home learning. Many families rely on nursing care, whether in school or at home. And across the country, access to these supports is deeply inequitable. Some jurisdictions do certain things well, others do not, and everywhere there are cracks." — Brenda Lenahan, BC Complex Kids Society

What I Wish You Knew

We are always ON … no downtime from ensuring day runs without incidence, organizing support, interviewing potential staff, completing funding paperwork, emails galore and more. Then people comment how I'm organized and always planning in advance. It's a must to keep my head above water.

Double-Duty Caregivers: Supporting the Workforce Behind the Workforce

Double-duty caregivers, those providing paid care at work and unpaid care at home, carry extra strain. As Dr. Bharati Sethi of Trent University explained, the burden is especially heavy for racialized, immigrant and newcomer workers who often navigate structural inequities and workplaces not designed with caregiving in mind.

During the *On Both Frontlines: Double Duty Caregivers Risk and Resilience* session, panelists talked about the fact that supporting these workers requires workplace redesign grounded in real human lives: flexible schedules, paid caregiver leave, culturally responsive supports and anti-racism practices.

> “Expertise does not replace exhaustion. And compassion is not infinite.” – Dr. Agnes Chinelo Iwegbu, Dalhousie University

> “There’s this perception that seeking help could be seen as a sign of weakness instead of a sign of strength.” – Dr. Agnes Chinelo Iwegbu, Dalhousie University

> “Dignity at work goes beyond economics. It is the very human right of every employee.” – Dr. Bharati Sethi, Trent University

Paid Care Providers: The Backbone of the System

Paid caregivers including Personal Support Workers (PSWs), Health Care Aides (HCAs), home care workers and direct support professionals are foundational to Canada's care system yet remain undervalued. Panelists at the *Strengthening Care Delivery: Paid Care Providers on the Frontlines* session stressed the need for:

- Wage justice
- Fair working conditions
- Credential pathways
- Professional recognition
- Strong cross-sector partnerships
- Government support for retirement security, such as funding for the new Service Employees International Union Healthcare retirement savings program for Personal Support Workers.

Paid caregivers often become "family," providing continuity and connection that allow people to age in place with dignity. A resilient care system requires investing in this workforce.

> "If we're not well, we cannot take care of somebody else."
> — Fredrica Pottinger, Frontline Care Provider

> "Caregivers wear multiple hats. We're their provider, friend, confidante, guide and teacher." — Fredrica Pottinger, Frontline Care Provider

> "These are the people who lift up our economy. They are the ones who ensure that the economy works. (Yet) we're finding now that more and more of them have to access food banks."
> — Tyler Downey, SEIU Healthcare

> "We cannot expect people to be good paid caregivers if they don't feel empowered in their own lives." — Kumaran Nadesan, Computek College

> "We know there's a high level of burnout, that these are often lower-paid jobs, and that there isn't necessarily retirement security." — The Honourable Stephanie McLean, Secretary of State for Seniors

Francophone Caregivers: Language as a Barrier to Safety, Dignity and Access

The session *Resources for Francophone Caregivers in Quebec and Outside Quebec* underscored how language remains a structural barrier that intensifies every other caregiving challenge. Francophone caregivers face the same demands as all caregivers, but language barriers compound stress, delay care and compromise safety – particularly outside Quebec. Panelists described a persistent gap between legal rights to French-language services and real-world access, even in designated facilities.

Caregivers shared how language barriers force them to become interpreters, advocates and system navigators, increasing exhaustion and emotional strain while undermining informed consent and trust. Distance caregiving in minority-language communities further amplifies financial pressure and isolation, especially for older women caring for aging parents or spouses. Delegates pointed to coordinated referral pathways, peer support, “active offer” training and professional interpreters as practical solutions. The message was clear: language access is not a preference – it is essential to safe, dignified care.

> “When we are vulnerable and in crisis, trying to communicate in your second language is not easy.” — Norma Dubé, Association francophone des aînés du Nouveau-Brunswick

> “Access to services in our language changes everything — trust, understanding and safety.” — Sylvie Sylvestre, Réseau francophone des Conseils de familles Ontario

What I Wish You Knew

Caregivers’ expertise as equal members of healthcare teams is essential.

THEME 5.

Valuing Home, Community and Family Care

> “The Canadian Caregiving Summit highlighted the vital role of caregivers in Canada, emphasizing their need for support, recognition and inclusion in policy decisions, and recognition of caregivers as essential partners in care.”
> — Summit Participant

Canada’s health and social systems work only because caregivers hold up the parts that services cannot reach. To build a resilient future, we must redesign care around the places where people live, the communities they rely on and the families who sustain them.

Caregivers as Essential Partners in Care

The *Collaborative Care in Action* session described how caregivers provide daily expertise and continuity across care settings, but collaboration often breaks down due to power imbalances and inconsistent communication. High-quality care requires a cultural shift of moving from allowing caregiver involvement to embedding a predictable partnership into care delivery.

Organizations must establish clear communication pathways, staff training and practical tools that make caregiver partnership the norm.

> “No matter how thorough an interview we do, there is information that the family can give us as health care providers that we just won’t get otherwise.” — Dr. Karina J. Igartua, Conseil d’administration de la Fondation de la FMSQ

> “We see people as a snapshot in time. The care provider has them at home twenty-four seven, and they understand when things are slightly off well before we would ever pick it up.” — Dr. Margot Burnell, Canadian Medical Association

> The interprofessional team should include the caregiver and the patient. It shouldn’t be us versus them.” — Stephanie Muskat, Compassion in Caregiving

A Health System Shifting Toward Home and Community

A country that values care builds systems that honour the lives, dignity and interdependence of its people. As Dr. Richard Lewanczuk from Primary Care Alberta reflected in the *Health System Reform in Practice: Models that Support And Sustain Care* session, “Health care is a team sport, yet caregivers are often treated as spectators.”

Hospitals are points of need, but the true point of care is people’s homes and communities. Nearly 90 per cent of care is managed by the recipient of care or their caregivers. Caregivers sustain the healthcare system yet are often kept at arm’s length from planning and support.

Real and meaningful change requires structures, funding and accountability built around home-centred, community-based care.

> “Caregivers are confused and frustrated because they don’t know when their loved one is going to be discharged, or what supports will be there.” — Dr. Kerry Kuluski, Trillium Health Partners

From Token Engagement to True Co-Design

Traditional engagement methods, such as advisory panels and consultations, often preserve institutional power. True co-design means shared power in priority setting, solution development and evaluation.

Learning health systems offer a model: shared questions, shared data, shared solutions, shared improvement.

> “If you’re designing something for caregivers, caregivers have to be involved from the start — not in a tokenistic way. That means paying them, giving them flexibility, and being willing to change your plans.” — Dr. Yona Lunsky, Centre for Addiction and Mental Health

> “Designing programs with the help of our caregivers and considering their needs in project design.” — Summit Participant

Community Strength and Determinants of Health

"Aging in place depends on more than clinical care," explained Dr. Suzanne Dupuis-Blanchard from the Université de Moncton. Housing, heat, transportation, language and practical help make independence possible. Many regions have unaddressed needs because structural determinants, including racism and inequity, remain intact.

Dr. Richard Lewanczuk spoke about how asset-based community development reframes communities as holders of solutions. He shared local Alberta examples such as community-built swimming pools and caregiver dinners hosted by Legions.

Technology, Access and High-Intensity Home Care

Donna Thomson shared her personal experience of extreme caregiving, revealing the gaps between health care appointments and the pressure that families feel. Caregivers need reliable access to care teams and communication tools that treat them as partners. Some clinicians use email and text informally. Scaling these practices would improve safety and quality of life. Solving these challenges for the most complex cases will make the system better for everyone.

Care is infrastructure, and infrastructure requires accessibility - real-time communication, predictable support and systems designed around the realities of care at home.

> "Caregiving doesn't happen in scheduled appointments. Crises don't wait until Monday at nine." — Summit Participant

What I Wish You Knew

Caregivers are very much part of the interprofessional team. Not separate from, but part of.

Looking Forward

Turning Our Shared Vision Into Action

Across two days, the Summit moved decisively from inspiration to implementation. Policy leaders, researchers, employers, caregivers and community advocates turned their attention to the National Caregiving Strategy and focused on what it will take to bring it fully to life.

Discussions centred on:

- Federal-provincial coordination
- Integrated supports
- Embedding cultural humility in system design
- Delegates emphasized that the strategy is no longer a visionary document awaiting action. It is a roadmap that now requires:
  - Political will
  - Sustained resources
  - Shared accountability

What I Wish You Knew

It's okay to ask for help.
In fact, it's essential.
And we need to make sure
real help is there for people.

Canada has moved beyond awareness. We are now building the architecture of care – creating the systems, policies and structures that match the depth of care Canadians provide every day.

> "We cannot have the strongest economy in the G7 if we don't get caregiving right." — Leslie Church, MP, Parliamentary Secretary; Liberal Member of Parliament for Toronto–St. Paul's

> "Unpaid work is not considered work in Western societies—and we need to change that." — Leah Gazan, MP, NDP Member of Parliament for Winnipeg Centre

> "We have to care for the people that cared for us. If we don't do that today, we won't have a future tomorrow." — Anna Roberts, MP, Conservative Member of Parliament for King–Vaughan

A Future Built on Care

The Summit emphasized that Canada is ready to move from ideas to action. We are building on our strengths: relationships, research, innovation, community wisdom and the lived experience of millions of caregivers.

We now have a strong foundation for a coordinated national caregiving framework that reflects who we are as a country and the care we aspire to provide.

Next steps identified by delegates include:

- Securing sustained public funding for the National Caregiving Strategy
- Establishing a National Care Council to guide implementation
- Scaling employer-led caregiver support models
- Embedding culturally informed practices throughout care systems

> "The time is now to tell the stories of caregiving! Join the collective voice." — Summit Participant

> "This is a whole-of-government issue that spans multiple levels of government." — The Honourable Stephanie McLean, Secretary of State for Seniors

These actions will ensure a sustainable and equitable future of care for today's caregivers and for the generations who will follow.

Canada stands at a pivotal moment. By acting on what we have learned together and honouring the shared commitment at the heart of the care movement, we can build a country where caregiving is not a struggle carried alone but a collective strength we cultivate together.

The future of care has begun.

> "Care is the architecture of our shared humanity—and our task now is to make that architecture visible, sturdy, and fair." — Dr. Naomi Azrieli, Azrieli Foundation

Introducing the Caregiving Caucus

While in Ottawa, CCCE announced the newest members of the All-Party National Caregiving Caucus, which includes Members of Parliament across the major federal parties represented in the House of Commons.

The Caucus has been assembled to ensure caregivers have a voice in the development of federal policies and regulations.

CCCE will convene the Caucus twice annually.

Members:

Liberal Party of Canada

MP Karim Bardeesy (Tiaiako'n – Parkdale - High Park)

MP Leslie Church (Toronto - St. Paul's)

MP Peter Fragiskatos (London Centre)

MP Anna Gainey (Notre-Dame-de-Grâce - Westmount)

MP Vince Gasparro (Eglinton - Lawrence)

MP Matt Jeneroux (Edmonton Riverbend)

MP Yasir Naqvi (Ottawa Centre)

MP Chi Nguyen (Spadina - Harbourfront)

MP Jean Yip (Scarborough - Agincourt)

Conservative Party of Canada

MP Laila Goodridge (Fort McMurray - Cold Lake)

MP Melissa Lantsman (Thornhill)

MP Anna Roberts (King - Vaughan)

New Democratic Party of Canada

MP Leah Gazan (Winnipeg Centre)

Canadian Caregiving Awards of Excellence

Canadian Caregiving Awards of Excellence

The 2025 Canadian Caregiving Awards of Excellence were presented to the recipients at the Canadian Caregiving Summit Gala, hosted by JUNO-nominated comedian, Courtney Gilmour. The eight recipients offer a powerful snapshot of Canada's caregiving landscape. Their stories reflect remarkable diversity and resilience across communities and contexts.

Congratulations to this year's award recipients for their extraordinary leadership and care.

Vickie Cammack Trailblazer Award: Ron Beleno

Ron is a caregiver, advocate and community leader whose experience caring for his father living with dementia for more than a decade continues to shape his work and inspire others. A passionate voice for dementia awareness, caregiving, aging and technology innovation, Ron brings wisdom and compassion to everything he does. Through Ron's involvement with organizations such as AGE-WELL NCE, Centre for Aging + Brain Health Innovation (CABHI) and CIHR's Towards Healthy Brain Aging initiative, he is always championing approaches that keep dignity, connection and lived experience at the heart of care.

Outstanding Achievement Award: MUSIC CARE by Room 217

Founded by Bev Foster, MUSIC CARE by Room 217 is transforming the way we think about care through the power of music. The organization equips and empowers caregivers with the skills and confidence to bring music into care settings – creating moments of connection, comfort and joy.

Caregiver Advocacy Award: Brenda Lenahan

Brenda is a devoted caregiver to her son and the founder of the BC Complex Kids Society, a family-led, grassroots organization that amplifies the voices of families raising medically complex children. She has built a movement for change that not only connects and supports families but also drives meaningful change to improve systems of care. Her advocacy ensures that families navigating complex care are not just seen and heard, but that their experiences shape the policies that affect their lives.

Young Caregiver Advocate Award: Rebekah Gold

Rebekah is a dedicated young caregiver to her parents and a powerful advocate for young caregivers across Canada. She is the co-founder of the Young Caregiver Council of Canada and serves as a research coordinator with the Young Caregivers Association. As a PhD candidate, Rebekah's research focuses on understanding and strengthening the supports available to young caregivers and their families. Through both her lived experience and her academic work, she is helping to shape a future where young caregivers are recognized, valued and supported to thrive.

Care Provider Leadership Award: Claudiane Coutu Arbour

Claudiane brings deep knowledge, compassion and commitment to her more than 15 years of frontline experience supporting people with disabilities. She represents Francophone and Québec-based care providers in CCCE's DSP Fellowship Program and is pursuing doctoral research focused on the well-being of those who provide care. Her leadership is elevating the voices of care providers and advancing understanding of what sustains them in their vital roles.

Dr. Janet Fast Research Excellence Award: Dr. Janice Keefe

Dr. Keefe is a leading voice in caregiving and aging in Canada. She serves as Chair of the Department of Aging and Family Science at Mount Saint Vincent University and as director of the Nova Scotia Centre on Aging. Her research has informed policies and practices that enhance the lives of older adults across the country. Through her work, Dr. Keefe combines rigorous scholarship with a genuine commitment to improving care and supporting the people who provide it.

Caregiver Community Organization Award: Maskwacis Parents Place and Sawubona Africentric Circle of Support

Maskwacis Parents Place provides culturally appropriate supports and services to Indigenous families living in Maskwacis, Alberta. Services include early intervention supports and assistance with navigating complex health care systems.

After struggling with a lack of support as Black caregivers to a child living with disability, Sherron and Clovis Grant founded the Sawubona Africentric Circle of Support, providing a safe space and community for Black caregivers of individuals with disabilities, helping them access resources and tools in their caregiving journey.

Innovation in Caregiver Programming: Essential Care Partner Support Hub

The Essential Care Partner Support Hub at the Ontario Caregiver Organization provides healthcare organizations across Ontario with the resources, tools and training needed to adopt caregiver-inclusive practices. Since launching in March 2023, the program has connected with over 300 organizations.

What Attendees Told Us

> “This was top to bottom an outstanding networking experience.”

> “A fantastic, well-planned, and deeply inspiring event.”

> “The most organized, layered conference I’ve attended - I honestly can’t see how it could be improved.”

> “One of the best-run conferences or summits I’ve ever experienced.”

> “It made clear that there’s so much work ahead, and that together, we can make real change.”

> “The time is now to tell the stories of caregiving. Join the collective voice.”

> “A remarkably strong political coalition and level of engagement pulled together in such a short time. Congratulations!”

> “The momentum is real. The caregiver movement is gaining speed and strength. When like-minded, motivated people come together, mountains move.
>
> But momentum only matters if we act. We will grow louder, stronger, and more unified.
>
> The bigger and more consistent our collective voice, the harder it is for decision-makers to ignore. Policy makers will listen. Politicians will Act on Care.
>
> This is how change begins and how we will sustain it.”

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Canadian
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Summit 2025