Building a Better System to Support Canadian Family Caregivers

Participate in a National Canadian Conversation: What are the key elements needed to support family caregivers?

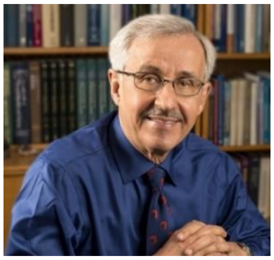
Conversation #1 Recognizing the Family Caregiver Role

September 20, 2022 12:00 – 1:30 MST

Family caregivers have been called the "Invisible Workforce" and the "Backbone of the Healthcare System", yet family caregivers are not recognized in policy nor as partners in care by health and social care providers. The lack of recognition of the family caregiver role was particularly evident during the COVID-19 pandemic, as family caregivers were referred to as 'visitors.'

This conversation aims to answer the question, **"How do we improve recognition of family caregivers and the importance of the family caregiver role?"**

Dr. Richard Schulz, Why Should Healthcare Providers have a Role in Supporting Family Caregivers?



Dr. Richard Schulz, Distinguished Service Professor of Psychiatry, Director of Gerontology, and Associate Director of the Aging Institute of UPMC Senior Services, University of Pittsburgh

American caregiving scholar, Dr. Schulz chaired The National Academies of Sciences, Engineering, and Medicine's landmark study, Families Caring for an Aging America. The report outlined the prevalence and nature of caregiving, the impact on the caregiver's health, employment, and overall wellbeing; the effectiveness of programs and supports aimed at supporting caregivers, and recommended policies to address the needs of family caregivers and minimize barriers.

Andre Picard, Supporting Family Caregivers: What Needs to Change?

Andre Picard is the Globe and Mails Health Columnist. He is also the author of five bestselling books including his latest Neglected No More The Urgent Need to Improve the Lives of Canada's Elders in the Wake of a Pandemic. André is an eight-time nominee for the National Newspaper Awards, Canada's top journalism prize, and past winner of prestigious Michener Award for Meritorious Public Service Journalism. He was named Canada's first "Public Health Hero" by the Canadian Public Health Association, as a "Champion of Mental Health" by the Canadian Alliance on Mental Illness and Mental Health and received the Queen Elizabeth II Diamond Jubilee Medal for his dedication to improving healthcare.

Amy Coupal, Caregiver ID: A Valuable Tool to Engage Caregivers as Partners in Care

Amy Coupal is the CEO of the Ontario Caregiver Organization, a non-profit funded by the Ministry of Health that was formed in 2018 to support Ontario's 4 million caregivers through a range of programs and services for caregivers and professionals who engage them. A family caregiver and visionary leader with 20 years of experience in the not-for-profit sector, Amy is honoured to be leading the Ontario Caregiver Organization through its early days of growth.

Maggie Keresteci, Healthcare Transformation: Family Caregivers' Role

Maggie Keresteci, Executive Director at Canadian Association for Health Services & Policy Research, is a caregiver to her sibling who lives with a life-altering disease. She is passionate about enhancing health for all, while at the same time pursuing system excellence. Whether in a healthcare non-profit, a matrixed corporation, or a politically-charged government agency, Maggie harnesses the power of collaboration and partnerships to drive change through influence. When it comes to developing policies aimed at improving healthcare quality that move seamlessly to practice and programs, Maggie develops roadmaps that articulate value and build trust.

Conversation #2 The Role of Education of Healthcare Providers to Support Family Caregivers: Elements of Effective Education

October 4, 2022 12- 1:30 PM. MST

Family caregivers want empathy, compassion, and respect. Communication and information sharing need to be improved. Family caregivers are looking to be included as partners in care. Assessment of family caregivers' needs, system navigation, and access to resources is needed to help them sustain care and maintain their own wellbeing. Though communication and person-centered care skills are taught in under- and post-graduate health workforce training, family caregivers and other stakeholders emphasize that healthcare providers need person-centered education that recognizes the family caregiver role.

This webinar aims to answer the question, **"How do we educate the health workforce effectively, so family caregivers receive timely and effective support?"**

Speakers:

Dr. Claire Surr - Best Practices in Designing and Evaluating Healthcare Workforce Education to Support Family Caregivers

Dr. Claire Surr, Professor of Dementia Studies and Director of the Centre for Dementia Research at Leeds Beckett University,

Dr. Surr led the national United Kingdom study examining the factors associated with effective health and social care workforce training design, delivery, and implementation. As well as being embedded across the United Kingdom in the design and delivery of health and social care providers' dementia education and training, Dr. Surr's best practices in dementia education findings are being implemented globally. See: Tool to reduce 'variability' in dementia training quality

Dr. Rhoda MacRae—Educating healthcare professionals to support family caregivers: Scotland's National Dementia Champions Programme

Dr. Rhoda MacRae, Reader, Alzheimer Scotland Centre for Policy and Practice at the University of West Scotland

Rhoda, a dementia educator and researcher, is a core member of the Scottish National Dementia Champions faculty where she takes a lead role in the pedagogical design, educational delivery and the evaluation of the programme. She was coordinator of the Palliare Project, a multi-disciplinary project that designed educational solutions to support advanced dementia care practice across Europe. In Canada, Dr. MacRae was a visiting scholar in Faculty of Nursing, University of Saskatchewan and a popular keynote speaker at the Canadian Institutes of Health Research/Covenant Health Network of Excellence in Seniors' Health and Wellness 2019 work to validate the Caregiver Centered Care Competency Framework.

Dr. Jasneet Parmar—Caregiver-Centered Care Education and Practice

Dr. Jasneet Parmar is a Care of the Elderly Physician and Professor, Department of Family Medicine at the University of Alberta has worked for the Specialized Geriatrics Program since 1992. Jasneet spent more than a decade developing the Decision-Making Capacity Assessment Model Toolkit (DMCA) which is endorsed by Alberta Health Services and Covenant Health and is used in hospitals, medical clinics, nursing homes and supportive living communities across Alberta. Dr. Parmar now leads the Caregiver Centered Care Program of Applied Research & Innovation in Health Services Delivery in Family Caregiving, Caregivercare.ca

Donna Thomson—Family Engagement in Research McMaster University's Continuing Education Program.

Donna Thomson facilities two free online courses Caregiving Essentials, for caregivers and The Family Engagement in Research Certificate of Completion Program for researchers (graduate students, research coordinators, investigators, clinician-researchers etc.) and families (parents, siblings, grandparents) who have an interest in child neurodevelopmental research. Both are offered through McMaster University Continuing Education. Donna is the author of The Four Walls of My Freedom and the co-author of The Unexpected Journey of Caring. She consults and speaks on issues relating to research and policy in the area of family caregiving, disability and aging.

Conversation #3 Partnering with Family Caregivers

October 18, 2022 12 to 1:30 MST

Family caregivers want to establish meaningful relationships with all health and social care providers and advocate for the uniqueness of the people they care for. Being consulted about the care-receiver's history, preferences, and care needs, being invited to participate in care, and being provided with regular updates help to develop more positive relationships with health care providers AND better care for the Canadian receiving care. While family caregivers want to be respected as team members, the desired level of involvement depends on the caregiver. It is therefore important for healthcare providers to be able to discuss role expectations.

This webinar aims to answer the question, **"What approaches should we be using to build partnerships between healthcare providers and family caregivers?"**

Dr. Yona Lunsky - Healthcare Providers and Family Caregivers as Partners in Care

Dr. Yona Lunsky Senior Scientist and Director of the Health Care Access Research and Developmental Disabilities (H-CARDD) Program at CAMH- the Centre for Addiction and Mental Health and Professor, Department of Psychiatry, University of Toronto. As the director of the Azrieli Centre for Adult Neurodevelopmental Disabilities and Mental Health, Yona's work focuses on the emotional health of people with developmental disabilities and their families. Most importantly, family caregivers are employed as partners in care in Dr. Lunsky's program.

Barb Maclean "Strengthening Family Partnerships in the Care Team"

Barb Maclean, Executive Director, Family Caregivers of British Columbia is the driving force behind what makes the Family Caregivers of British Columbia a leader in supporting and partnering with family caregivers. She learned first-hand what it's like to juggle work, a young family and caregiving when she supported her family during her own mother's fight with cancer. Strengthening Family Partnerships in the Care Team and Doctors of BC, "Circle of Care: Supporting Family Caregivers in BC" which supports the inclusion of family caregivers in patient and family centred care are two innovative ways in which Family Caregivers of British Columbia is working towards family caregiver and health provider partnerships

Jamie Winkler, Family Caregivers Partnering with Health Providers.

Jamie Winkler is a Research Engagement Strategist, Knowledge Broker, and Community Engagement Facilitator in Family Centered Service. She is Network Coordinator - Cerebral Palsy Alberta Representing Cerebral Palsy of Canada Network, Saskatchewan Cerebral Palsy Association – President, and Saskatchewan Disability Income Support Coalition - Board Member. As mom to neurodiverse twins Bella and Mindy, Jamie's key methodology is an equalitarian, individualized & family centered approach to research and care through knowledge translation and family centered service

Conversation #4 Fostering Family Caregiver Resilience: Moving Beyond Telling Family Caregivers to “Take Care of Yourself”.

October 31, 2022 12:00 – 1:30 MST

Resilience is "the capacity to adapt successfully when faced with adversity." In developing the Caregiver-Centered Care Competency Framework, our stakeholders stressed that “we needed to work together” to build a better system to support family caregivers. Stakeholders stressed that telling the caregiver, “You take care of yourself” was not helpful. A better system, a socio-ecological model of resilience, would support them to access the resources they need to care and maintain their own wellbeing.

This webinar aims to answer the question, **“What should a “better system” to support family caregivers include? Who needs to be involved?”**

Speakers

Nancy Mannix, There is More to Resilience than being told to ”take care of yourself”: The Alberta Family Wellness Resiliency Scale

Nancy Mannix is the Chair and Patron of the Palix Foundation, a private foundation whose philanthropy aims to ultimately support improved health and wellness outcomes for all children and families.

Resilience is a complex life outcome that is commonly misunderstood. The Alberta Family Wellness Initiative (AFWI), a program of the Palix Foundation, has developed the Resilience Scale metaphor for showing how resilience is not simply “pulling yourself up by your bootstraps”rather how to build a better socio-ecological system to support resilience. Use of the Alberta Family Wellness Scale is a tool for health providers to support family caregivers, and families to build resilience by supporting environments rich in serve-and-return interactions and by preventing experiences that may cause toxic stress.

Dr. Kerry Kuluski, Moving Towards a Person-Centred Learning Health System: Family Caregivers Role in the Healthcare System

Kerry Kuluski MSW., PhD is the inaugural Dr. Mathias Gysler Research Chair in Patient & Family Centred Care at the Institute for Better Health at Trillium Health Partners.

Kerry’s research provides insight into [what matters most to patients with complex care needs and their caregivers.]() She works in partnership with patients and caregivers and formed an advisory group to inform her research. With her patient and caregiver partners, she co-designed an intervention which addresses care and communication gaps.

Liv Mendelsohn The Canadian Centre for Caregiving Excellence: A Vision for a Better Canadian System

Liv Mendelsohn, MA, MEd, is the executive director of the Canadian Centre for Caregiving Excellence. Over the course of her career, Liv has founded and helmed several organizations in the disability and caregiving space, including the Wagner Green Centre for Accessibility and Inclusion at the Miles Nadal JCC, which she led for seven years, and the ReelAbilities Toronto Film Festival, where she served as founding artistic director.

Liv serves as the chair of the City of Toronto Accessibility Advisory Committee. In 2019 she was recognized as a recipient of the City of Toronto Equity Award and is a senior fellow at Massey College. Liv was a young carer, has been a lifelong caregiver and has lived experience of disability.

Conversation #5 Supporting Family Caregivers to Navigate Health and Community/Social Care Systems: Three Navigation Models

November 15, 2022. 12:00 – 1:30 MST

Navigating our often-fragmented systems of support and care in Canada can be an arduous task. On their own, many caregivers struggle to find and access services. Family caregivers spend 15 to 50% of their time on the "structural burden of care, trying to access to needed services, and then to coordinate and manage these services over time". Dr. Laura Funk argues that Canadians vastly underestimate the economic and social costs involved – including the stress and frustration generated, and, for caregivers, the time that they spent taking care of themselves and their loved ones, or in paid employment.

While more integrated health and community services grounded in the preferences and needs of both frontline service providers, clients, and family caregivers (reduced silos) would be ideal, progress on integration has been slow.

This webinar aims to answer the question, **"What is needed to help family caregivers navigate our systems of support and care?"**

Three Navigation Models

Dr. Barb Pesut – Nav-CARE: Volunteer navigators making connections-- making a difference.

Dr. Barb Pesut, Professor, University of British Columbia, is a Tier 1 Principal Research Chair in Palliative and End-of-Life Care. She leads Nav-CARE, an intervention in which volunteers, who are trained in navigation, provide services for older persons living at home with chronic illness to improve their quality of life.

Dr. Anthony Levitt and Sugy Kodeeswaran— Family Navigation Project - Navigating the mental health and addiction system for youth and their families.

Dr. Anthony Levitt, MD, FRCP(C), is Chief of the Hurvitz Brain Sciences Centre and the Medical Director of the Family Navigation Project at Sunnybrook Health Sciences Centre.
Sugy Kodeeswaran Executive Director, Family Navigation Project at Sunnybrook The Family Navigation Project (FNP) team of experts helps teens, young adults and/or their families navigate the system more easily to find and gain access to resources, such as service providers and treatment centres.

Sonia Hsiung – Asking "What matters to you?": Person-centred, co-creative navigation through Social Prescribing

Sonia Hsiung is the Director of the Canadian Institute for Social Prescribing (CISP) at Canadian Red Cross. Previously, Sonia managed the successful completion of social prescribing research pilot in Community Health Centres across Ontario, implementing a structured way of connecting clinical care and community-based social supports to address the social determinants of health, with particular focus on loneliness and social isolation. Now at CISP, she is fostering national engagement and partnerships across diverse sectors to learn, grow, share and celebrate social prescribing initiatives.

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Conversation #6 Changing the Culture and Context of Care

November 29, 2022. 12:00 – 1:30 MST

The culture and context of health and community care systems to support family caregivers must be improved. Our consultations and those of other caregiving scholars found ingrained practices, attitudes, policies, and traditions do not support consideration of the family caregiver's own needs, nor do they enable support provision to family caregivers. Culture is deeply embedded in people's values, assumptions, behaviors, and attitudes. Culture develops in the context of everyday practice. As Chief Change Officer in the UK Health System, Helen Bevan said that to transform the culture and context of care, we need to change hearts and minds at scale.

This webinar aims to answer the question**, "What strategies and policies are needed to change the culture and context of care to support family caregivers?"**

Emily Holzhausen, Policies to support family carers in the UK and Advice for Canadians

Emily Holzhausen OBE Director of Policy and Public Affairs Carers UK leads on Carers UK policy, parliamentary, research and media work, encompassing many issues relating to caring including employment. She was responsible for Carers UK's Advice and Information services for 15 years, transforming the service into a wider digital offer. She has worked on two successful Private Members Bills and numerous pieces of legislation which have introduced carer's rights. She leads Carers Week, one of the UK's biggest awareness weeks involving thousands of local events and established Carers Rights Day now in its 19th year. Research and evidence has been at the heart of her work to demonstrate need and how change and practice can benefit carers. She has undertaken over 40 pieces of original research into carers and caring, most recently with her team delivering Caring Behind Closed Doors, (April 2020) – one of the first major pieces of research on carers globally, with Caring behind closed doors: six months on (October 2020).

Dr. Susan C. Reinhard, Policy Work to Support American Family Caregivers and Advice for Canadians.

Susan C. Reinhard, RN, PhD, FAAN is senior vice president and director of the AARP Public Policy Institute and chief strategist for both the Center to Champion Nursing in America (CCNA) and family caregiving initiatives. CCNA, an initiative of AARP Foundation, AARP and the Robert Wood Johnson Foundation, is a national initiative to ensure America has the nurses it needs to provide care in the future.

Susan is a nationally recognized expert in health and long-term care policy, with extensive experience in conducting, directing, and translating research to promote policy change. Previously, she served as professor and co-director of Rutgers Center for State Health Policy, directing several national initiatives with states to help people with disabilities of all ages live in their communities. RAISE Family Caregivers Act Initial Report to Congress and-Social-Workers-Supporting-Family-Caregivers **On September 22, 2021, the Recognize, Assist, Include, Support, and Engage (RAISE) Act Family Caregiving Advisory Council delivered its initial report to Congress.**

Carol Fancott, "Co-designing policy guidance with and for essential care partners: Moving policy into action"

Carol Fancott, PT, PhD, Director, Patient Engagement and Partnerships, Healthcare Excellence Canada (HEC) seeks to build and strengthen relationships, to ensure engagement and partnership are central to her work. Carol has led the co-development and co-delivery of programs and activities that focus on the needs and priorities of patients, caregivers, and communities. A physical therapist by training, Carol also obtained a PhD at the Institute of Health Policy, Management, and Evaluation at the University of Toronto focused on patient engagement and storytelling for organizational learning and improvement. Currently, Carol leads programming related to 'Essential Together' at Healthcare Excellence Canada, a program focused to that supports health and care organizations across Canada to implement policy that values and welcomes essential care partners at all times. As part of this work, HEC hosted policy labs where policy recommendations have been co-developed with those that make policy, implement policy, and are most impacted policy.

James Janeiro, Family Caregivers: The Next Policy Frontier in Canada

James Janeiro **Policy Director from Canadian Centre for Caregiving Excellence** is a public policy and advocacy professional with over a decade of experience in politics, policy and government relations. He began his career in the Ontario public service working on disability legislation. He then transitioned to the political policy space and served two successive Ontario ministers of community and social services as senior policy advisor on social assistance, poverty, and veterans' issues. In 2014, James assumed a new role serving Premier Kathleen Wynne as her social policy advisor.

In this position, he was responsible for a diverse array of policy areas, including poverty reduction, housing, the Basic Income Pilot, disability issues, autism services and municipal affairs. In 2018, James left the public sector for a role in the not-for-profit sector. He was director of community engagement and policy at Community Living Toronto from 2018 to 2022. In this role, James led an ambitious advocacy agenda focused on housing, income security, and service improvement.

Participants: Now it is Your Turn. What do you recommend?

Participate in facilitated breakout sessions after each conversation.

Conversation #1 Recognizing the Family Caregiver Role

September 20, 2022 1:30 -2:00 MST

"How do we improve recognition of family caregivers and the importance of the family caregiver role?"

Breakout Session Questions

1. What are the barriers and facilitators to recognizing family caregivers and the family caregiver role, including in healthcare?
2. What policies are needed to support the recognition of family caregivers and the importance of the family caregiver role?
3. Which stakeholders should be at the table to facilitate the enactment of the needed policy changes?

Conversation #2 The Role of Education of Healthcare Providers to Support Family Caregivers: Elements of Effective Education

October 4, 2022 1:30-2:00 PM. MST

"How do we educate the health workforce effectively, so family caregivers receive timely and effective support?"

Breakout Session Questions

1. What are the challenges to the uptake of healthcare workforce caregiver-centered care education?
2. How do we facilitate the spread and scale of healthcare workforce caregiver-centered care education?
3. What policies may assist with this education?

Conversation #3 Partnering with Family Caregivers

October 18, 2022 1:30- 2:00 MST

"What approaches should we be using to build partnerships between healthcare providers and family caregivers?"

1. What are the barriers to health providers partnering with family caregivers?
2. What strategies facilitate health providers partnering with family caregivers? Think about what health providers and family caregivers may gain from these partnerships.
3. What organizational support is needed to enhance healthcare provider and family caregiver partnerships? Discuss Caregiver Champions, education, research, leadership, policies, and practice.

Conversation #4 Fostering Family Caregiver Resilience: Moving Beyond Telling Family Caregivers to “Take Care of Yourself”.

October 31, 2022 1:30- 2:00 MST

“What should a “better system” to support family caregivers include? Who needs to be involved?”

1. What are the key elements of a shared vision of a “better system to support family caregivers”?
2. Which stakeholders need to be involved in designing and building a better system? Policymakers, Researchers, Healthcare providers, Healthcare leaders, Non-Profits, Educators, Advocacy Organizations Others?

Conversation #5 Supporting Family Caregivers to Navigate Health and Community/Social Care Systems: Three Navigation Models

November 15, 2022. 1:30- 2:00 MST

“What is needed to help family caregivers navigate our systems of support and care?”

1. How do we get the healthcare and social care system to work together to assist family caregivers to navigate the systems of care and access resources?
2. Which stakeholders need to be at the table to improve system integration and navigation for family caregivers?
3. What else is needed? E.g., collaboration between health and social care, policy, funding, Conversation #6 Changing the Culture and Context of Care

Conversation #6 Changing the Culture and Context of Care

November 29, 2022. 1:30- 2:00 MST

“What strategies and policies are needed to change the culture and context of care to support family caregivers?”

1. Is a National Caregiving Strategy part of the needed change in culture? What would be the key elements of this strategy?
2. Who is required to bring about cultural change?
3. What policies are needed to bring about cultural change in healthcare?