Fostering Resilience in Family Caregivers of Seniors in Care

Group Planning Session Summary

August 30, 2017
Covenant’s Network of Excellence in Seniors’ Health and Wellness (the Network) gives voice to seniors through active engagement and makes their priorities, its priorities. By generating ideas in areas of identified need, and disseminating the related knowledge, the Network serves Alberta’s seniors with the ultimate goal of ‘enabling seniors to live to the fullness of their capacity as active and connected members of their communities’.

A strategic focus of the Network is to increase understanding of the vital role family caregivers play in contributing to the health and wellness of seniors. Fostering Resilience in Family Caregivers of Seniors in Care was the Network’s third symposium in a series focused on family caregivers preceded by: Supporting Family Caregivers of Seniors: Improving Care and Caregiver Outcomes (2014); and Supporting Family Caregivers of Seniors within Acute and Continuing Care Systems (2016).

Overview: Fostering Resilience in Family Caregivers of Seniors in Care

Fostering Resilience in Family Caregivers of Seniors in Care was a one-day symposium (August 30, 2017) delivered by the Network that considered ways to: recognize and value the contributions of family caregivers to the healthcare system; raise awareness of the obstacles and challenges family caregivers face in healthcare settings, and their needs for supports; and explore ways to help family caregivers feel supported and valued in their caregiving role.

Attendees included family caregivers, frontline healthcare providers, healthcare managers, seniors’ service organizations, academics, and policy makers who looked for specific recommendations for improving recognition of, and supports to, family caregivers of seniors within acute care, continuing care and home care settings.

Invited speakers presented on first-hand caregiver experiences, best practices for involving caregivers, and related policy development and training implications. In addition to the speaker presentations, a group planning session was held to discuss recommendations based on attendee input from the six conversation circles held in the 2016 symposium. The topics explored in the conversations circles were:

1. Orientation and education of healthcare providers to increase understanding of caregiver needs and how to assist them.
2. Culture change needed within our systems of care to acknowledge, respect and honour family caregivers.
3. Supports needed to engage, empower and foster the resilience of family caregivers.
4. Tools and processes available to help identify and assess caregiver burden.
5. Palliative care and end-of-life supports desired by family caregivers.
6. System change needed from a policy and practice perspective to ensure that family caregiver supports and resources are made available.

The group planning session at our 2017 symposium expanded on the six conversation circle topics by asking attendees to provide specific examples for each topic that would help improve supports to family caregivers. Key input from the group planning session was summarized and the emerging themes are highlighted in the following pages.

**What our Family Caregivers Told Us**

Prior to the group planning session, attendees heard from three family caregivers who shared some of the physical, emotional and financial costs they have experienced during their own personal caregiving journeys. They clearly highlighted the changes that they felt were essential to help them manage their caregiving roles and to care for themselves:

1. Educate healthcare providers to better support family caregivers by:
   a. understanding their challenges
   b. recognizing their value and
   c. fully engaging them in care planning and decision making.

2. Improve communication between healthcare providers and family caregivers by:
   a. welcoming them into the care environment
   b. explaining to them what is happening and updating them regularly
   c. treating them as ‘experts’ regarding the senior in their care and asking for their input and advice.

3. Help family caregivers navigate the healthcare system:
   a. Provide a point of contact where family caregivers can gather information or go to have questions answered.
   b. Know what resources and supports are available to family caregivers and help them access those resources.

4. Create a policy in Alberta that provides adequate financial support for family caregivers and allows them to continue to provide care for the seniors in their care.

*Healthcare providers need to recognize the significant challenges faced by seniors and their family caregivers. They also need to recognize and acknowledge the important role family caregivers play and appreciate their journey.*

- Response from Covenant’s ‘Shape Seniors Care’ Campaign (2015)
Emerging Themes from the Group Planning Session

I. Develop distinct education and training programs for healthcare providers about the needs of family caregivers and the best ways to support them.

Attendees recommended that:

- Family caregivers be included as co-creators of all education or training materials on caregiver needs and supports
- Healthcare organizations develop essential education modules to increase understanding of family caregivers needs and to highlight the value of involving and engaging family caregivers as part of the care team
- Consistent language and key areas of focus are reflected across all curricula developed (degree, diploma and certificate).

Attendees identified several other areas of training that would benefit healthcare providers:

- end of life care and palliative care processes
- multicultural diversity awareness
- communicating with empathy
- a holistic approach to care
- collaborative care where healthcare providers work together with seniors, family caregivers and communities
- increased knowledge of supports and resources that could be made available to family caregivers, and the ability to provide information and make appropriate connections.

It is time for healthcare providers to learn how to connect with family caregivers and how to treat them as an integral part of the care team.

– Attendee of Supporting Family Caregivers of Seniors within Acute and Continuing Care Systems (2016)
II. **Focus on creating opportunities that help healthcare providers better communicate with family caregivers.**

Attendees told us that it was essential for healthcare providers to find ways to improve communication with family caregivers. Examples provided include:

- Advise family caregivers as soon as possible after intake or admission regarding the care taking place and who will be providing the care.
- Develop toolkits, brochures or handbooks to provide general information about operations, contact information and a list of resources available to family caregivers.
- Schedule regular check-ins after each meeting to provide updates and clarification.
- Include family caregivers in meetings or conferences regarding the care plan and provide documentation for future reference. Schedule any required follow-ups as soon as possible after the meeting.

In addition, healthcare providers should centralize information for family caregivers at point of care to communicate:

- who has been assigned to care (names, contact numbers, and shift times)
- information regarding shift transitions and different specialties assigned to care
- the family caregiver’s name, contact information and available times
- information about the senior in care: their likes and dislikes, life story and history, preferred schedule, sensory deficits, and other pertinent information

Other methods suggested to help healthcare providers improve communication include:

- using white boards or bulletin boards inside rooms to share information between healthcare providers and family caregivers
- using a book to document all staff interactions on each shift so family caregivers and staff are aware of what has happened while they were away
- providing written summaries of conversations regarding the care plan to family caregivers for future reference.

---

**Healthcare providers need to include family caregivers to the fullest extent possible, and communication between seniors, family caregivers and healthcare providers needs to improve vastly. We must find a way for everyone involved to work together.**

- Response from Covenant’s ‘Shape Seniors Care’ Campaign (2015)
III. Provide consistent and timely supports to help family caregivers navigate the health system

Attendees suggested that the healthcare system be designed to:

- Provide educational opportunities for family caregivers on end of life care and palliative care processes, the need for personal directives, and respite options.
- Offer caregivers easy access to grief counselling, crisis lines and support groups and increase availability and access to respite options that are convenient for caregivers.
- Recognize stress in family caregivers and guide them where to go to get support. Ensure that facilities are resourced appropriately to provide adequate support and follow-ups as necessary.
- Focus home care services on what works for clients rather than on what works for the system.

Attendees also recommended the creation of a provincial information hub or resource centre with a comprehensive list of resources and supports available to family caregivers, including end of life care and palliative care processes. This could be a component of Health Link (similar to what is currently set up for Dementia Link) that uses an actual person to make the connections. Information would be accessible 24 hours a day, reviewed regularly for accuracy and would also be available web-based and in hard copy.

Within each health care setting there should be a highly trained, single point of contact to guide family caregivers to the appropriate resources and supports based on their current needs.

Healthcare professionals (i.e. physicians, nurse practitioners, social workers, physiotherapists, and occupational therapists) should be accessible to family caregivers in all healthcare settings and available at convenient times for family caregivers (including evening hours and weekend support).

Family caregivers need more than just information – they need resources and supports to help them successfully navigate the complexities of the healthcare system.

- Attendee to Fostering Resilience in Family Caregivers of Seniors in Care (2017)
IV. Support healthcare providers to help them reframe the way they see and interface with seniors and family caregivers.

Attendees told us that the core priority of healthcare providers should be to provide individualized, person-centered care to seniors and their family caregivers.

For family caregivers, this would require:

- ensuring they feel respected and acknowledged and including them in all aspects of care planning and decision making
- treating them as “experts” regarding the senior in their care and actively seek their opinions and advice
- giving them access to the care plan, making sure they understand what is in it, and letting them sign off on it.

For seniors in care, this would require:

- asking for permission to enter rooms and make introductions
- knowing people’s names and using them when communicating
- identifying clients, residents and patients as people first
- providing information and answering questions in a manner that seniors and their family caregivers understand
- ensuring that the life history of each patient is available to all health care providers at point of care and getting to know each patient’s personal stories
- understanding multicultural diversity and respecting choices based on cultural preferences
- respecting choices for care even if it means a person chooses to live with risk
- exploring family goals and expectations and incorporating them when developing the care plan
- asking personal questions such as: “How are you? What matters to you? What is important to you right now? What are your concerns?” and then listening to the answers
- making care less task-oriented and more focused on what the patient wants or needs.

If families and family caregivers truly feel that their loved ones are cared for and cared about, their stress and guilt will be greatly reduced.

– Attendee to Fostering Resilience in Family Caregivers of Seniors in Care (2017)
V. Explore and develop comprehensive policies to ease family caregiver burden.

Key considerations include:

1. Develop a financial benefit program for family caregivers in Alberta.
   - identify and engage all stakeholders (e.g. caregivers, government, health organizations) to provide input
   - use consistent terminology in all policies relating to family caregivers
   - the needs of family caregivers should drive policy, not numbers and data
   - cross-ministerial oversight is required to ensure broad support and avoid duplication.

2. Review current legislation related to privacy to make it easier for family caregivers to get relevant and timely health information for the senior in their care. In addition:
   - honour advance directives that specifically name an agent
   - allow individuals to grant family caregivers access to their personal information
   - consider family caregivers of seniors as partners in care with the ability to access relevant health information
   - develop policy guidelines regarding verbal permissions
   - develop a process to allow release of personal information for persons unable to give consent.

---

*Healthcare providers need to listen to a family caregiver’s concerns, share all pertinent information regarding the care plan, and then allow the senior and family caregiver to consider the choices and assess the risk before making a decision.*

– Response from Covenant’s ‘Shape Seniors Care’ Campaign (2015)
Next Steps

A one-day event titled *Healthcare Workforce Training in Supporting Family Caregivers of Seniors in Care*, scheduled for February 22, 2018 bring together researchers, educators, healthcare providers and managers, seniors and their family caregivers from across Alberta to explore what optimal training for healthcare providers might include and how that training could be implemented and sustained. This meeting will catalyze new partnerships and collaborations and initiate the first step in the development of new education and training materials for healthcare providers that will improve health outcomes of family caregivers of seniors.

Acknowledgements

The Network is grateful to the individuals who contributed their time, knowledge and expertise to the *Fostering Resilience in Family Caregivers of Seniors in Care* symposium:

- **Janice Keefe**, Professor/Chair/Director Nova Scotia Centre on Aging, Lena Isabel Jodrey Chair in Gerontology (Presenter)
- **Brenda Bell**, Family Caregiver (Presenter)
- **Paulette Gelines**, Family Caregiver (Presenter)
- **Lorry Yendall**, Family Caregiver (Presenter)
- **Suzette-Brèmault Phillips**, PhD, Associate Professor, Rehabilitation Medicine, Occupational Therapy, University of Alberta (Presenter)
- **Norah Keating**, PhD, Director, International Association on Gerontology and Geriatrics; Co-Director, Research on Ageing, Policies and Practice, University of Alberta; Professor, Swansea University, UK (Presenter)
- **Jo Ann Molloy**, Senior Director, Operations, Edmonton General Continuing Care (Presenter)
- **Wendy Duggleby**, Associate Dean Research; Nursing Research Chair Aging and Quality of Life; Director Innovations in Seniors Care Research Unit, Faculty of Nursing, University of Alberta (Presenter)
- **Lorelei Sawchuk**, Nurse Practitioner and Education Lead, Covenant Health Palliative Institute (Presenter)
- **Beth Whalley**, Manager, Practice Development Team, South West Home Care, Alberta Health Services (Presenter)

The Network extends special thanks to the attendees of the symposium for their enthusiastic participation and valuable input.