ABOUT THIS TOOLKIT

This toolkit is for healthcare providers and various stakeholders who support family caregivers. The toolkit contains tools for learning and discussion: summaries, slide presentations, handouts, and suggested resources. The tools are based on the proceedings and products of a conference entitled Supporting Family Caregivers of Seniors: Improving Care and Caregiver Outcomes (hereafter referred to as Caregiver Conference) that was held in April 2014. However, this is not an all-encompassing resource on supporting family caregivers. Rather, we hope this toolkit would be used to initiate discussion and learning. Whether you are a family caregiver, a healthcare professional, a healthcare professional-in-training, a researcher or a policy-maker, our hope is that you use this information in whatever manner may advance the knowledge, understanding, programming and supports in the area of caregiver support.

The toolkit consists of 5 Parts, reflecting the main themes of the Caregiver Conference. Each part contains freestanding sections that could be used to suit your needs. You may reproduce any part of the toolkit provided it is properly referenced. For easy referencing, each section has a suggested citation listed at the end. However, please don’t use the photos apart from the toolkit because these are under copyright licence.

Certain sections recur in the toolkit. Key Learnings summarizes the ideas generated from the discussions. Evidence Summary provides an overview of the published literature. Experts’ Notes show excerpts of slide presentations from conference guest speakers.

This toolkit contains hyperlinks and is best accessed electronically rather than through the print version. It is available online for viewing or download at: https://www.dropbox.com/s/rrxb340fyp91gi/Toolkit.pdf?dl=0

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CONTACT DETAILS

Jasneet Parmar, MBBS, Dip COE
Editor and Project Lead, Discovery Toolkit for Supporting Family Caregivers of Seniors
Associate Professor, Division of Care of the Elderly, Department of Family Medicine, University of Alberta
Medical Director, Network of Excellence in Seniors’ Health and Wellness, Covenant Health
1100 Youville Drive West, DC 405, Edmonton, Alberta T6L 0A3 Canada
Jasneet.Parmar@covenanthealth.ca
www.covenanthealth.ca/innovations/seniors-network-of-excellence

ABBREVIATIONS

AHS Alberta Health Services
CH Covenant Health
CIHR Canadian Institutes of Health Research
NESHW Network of Excellence in Seniors’ Health and Wellness
NWT Northwest Territories
SCN Strategic Clinical Network
UofA University of Alberta
UofC University of Calgary
WHO World Health Organization

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Caregiver Study Group
This group applied for the CIHR Conference Grant and organized the conference Supporting Family Caregivers: Improving Care and Caregiver Outcomes. See back cover for a complete list.

Yvonne Roberts, Program Assistant, NESHW, Covenant Health
Laurie Wear, Administrative Assistant, Edmonton Zone Medical Staff Association
Darlene Blischuk, Assistant

Department of Family Medicine, Univ. of Alberta
Lee Green, MD, MPH, Chair, Department of Family Medicine

Division of Care of the Elderly

Collaborators

Network of Excellence in Seniors’ Health and Wellness (NESHW), Covenant Health
Covenant Health Research Centre
Alberta Health Services – Seniors Health SCN
Alzheimer Society – Alberta and NWT
Alberta Caregiver Association
It has been a 23-year-long road of discovery that has brought me to the point of finally recognizing the value of family caregivers. I believe I know a fair bit now though there is much more for me to learn. What took so long? I often wonder if the culture of our health system with its focus primarily on the patient was the reason. I remember saying many a time to a family caregiver, that “I am sorry but I am not your doctor; she or he is my patient; I am here to address my patient’s needs”. Could it be the policies and regulations that prevent us from engaging family caregivers as true partners-in-care and decision-making? Maybe it was my own cultural bias that expects families to care and provide for the elders. Perhaps the recognition comes from having become a caregiver to my frail older parents and in-laws. Today, I feel at peace at having made this discovery and pledge to dedicate the rest of my career in supporting them and probably volunteering post-retirement. I am very grateful to all the seniors, family caregivers, staff and colleagues that have been on this journey and enabled and empowered me. There is much to do….we will do it together.

The mission of the Alberta Seniors Health Strategic Clinical Network is to enable Alberta’s seniors to optimize their health, well-being, and independence. To achieve this we are engaging with seniors, their family caregivers and other stakeholders to make improvements to health care services and practices. Family caregivers are an integral part of the healthcare system, and as the Canadian population ages their role will become even more important. Family caregivers require support to deal with the physical, emotional, and financial costs of care giving. We are pleased to be working with various stakeholders from across Canada and internationally to advance the research, education, and supports necessary to enable family caregivers to provide care to seniors, while optimizing their own health and quality of life.
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EXECUTIVE SUMMARY

Background

Family caregivers are an integral, yet increasingly overburdened, part of the healthcare system. Their commitment, however, is not without physical, emotional and financial costs. Given the toll of care-giving and the essential role of caregivers as the backbone of the healthcare system, supporting them has become a global public health priority. A recent Canadian study estimates the costs of such unpaid caregiving at $25 billion annually. Many Canadian seniors with complex health conditions are receiving limited hours of home care services and therefore rely on family caregivers. As a result, a large number of family caregivers are stretched beyond their capacity and report high levels of distress. Most eldercare (75%) in Canada is provided by those between 45 and 64 years of age. Twenty-five percent are mainly elderly spouses with their own, often serious, health problems. The growing size of the senior population, and the rapidly increasing number of those in their eighties and older, raises questions as to the continued ability of families to provide the care needed to maintain the seniors’ population in their own homes.

The Caregiver Conference

In 2014, we held a conference entitled Supporting Family Caregivers of Seniors: Improving Care and Caregiver Outcomes. This conference brought together over 120 knowledge users and researchers to Alberta to (1) Discuss evidence and leading practices, (2) Analyze strengths, gaps and barriers to supporting caregivers, and (3) Initiate research plans.

Findings

Our findings highlight the need for centralization of resources for patients, caregivers, and health care providers, as well as support for caregivers to navigate through resources and the healthcare system. Advance care planning and goals of care designation are important, however, there is a need to include planning for care needs not only of the senior, but also of their caregiver. There is no denying that caregiving can be all-consuming impacting individuals’ physical and psychological health as well as their activities of daily living functioning. There needs to be a shift from care providers focusing on the seniors’ needs without any assessment of the caregiver themselves. Education for health care professionals is necessary, with a focus on the development of core competencies regarding both the management of seniors’ needs and provision of support to caregivers. Education for caregivers and future caregivers is also required. Policy change needs to consider the whole care picture instead of having policies tailored only to the senior requiring care.

This Toolkit is a rich compilation of experience, expertise and recommendations of a broad-based collaboration of researchers, clinicians and end-users examining the journey/role/circumstances of caregivers of seniors with a view to understanding the nature of support required in order to sustain this ever-growing group. Focus groups of caregivers, a preliminary environmental scan and examination of the current literature of caregiver support initiatives and a two-day conference were the activities undertaken to provide the valuable content consolidated within this Toolkit. Our intention is that this collection of findings will be useful to researchers, policy-makers, service providers and instructors of future healthcare workers. The production of this Toolkit was made possible by the generosity of the Northern Alberta Association of Family Physicians Grant.

New Initiatives and Collaboration

This project has created new research initiatives in the following areas:

1. iSupport-Canada. A major grant emerging from this conference is an international collaboration with the WHO to develop and evaluate an evidence-informed electronic web portal for caregivers of those with dementia. This portal will be customizable for use in different countries. Proof of concept will be developed within the Canadian context (a developed nation) and then translated for use in India (a developing nation).

2. Support for Caregivers of Seniors at End-of-Life. This research is exploring the significant changes caregivers experience such as a metasynthesis study of transitions experienced by family caregivers of persons at the end of life; and evaluating the multifaceted interventions tailored for caregivers in end-of-life care.

3. Support for Caregivers of Seniors with Complex Needs. This research is evaluating multifaceted support tailored for caregivers of the seniors with complex needs. This focus was included in the CH NESHW Symposium and in the call for proposals for its 2015 Innovation Funding grant.

“What prevents caregivers from advocating? Fear - losing support if you speak up and ask for more.”
1. **KEY LEARNINGS**

**SUPPORTING FAMILY CAREGIVERS OF SENIORS WITH COMPLEX NEEDS**

Jasneet Parmar, MBBS, Network of Excellence in Seniors’ Health and Wellness, Jasneet.Parmar@covenanthealth.ca;
Lesley Charles, MBChB, Family Medicine, University of Alberta

1. **Caregiving involves managing a multitude of tasks, and does not allow for caregivers’ personal needs to be met.**

Informal caregiving begins at the point when an individual needs help tending to any one of the exigencies of life. Caregivers reported that they spend time performing household tasks for the care recipient such as yard work, snow removal, grocery-shopping, driving to appointments, and providing other transportation needs. Managing a household as well as providing care for the other encroaches on time necessary for their self-care, social activities, and household activities. As the demands mount, they lose time for themselves, become more and more isolated, and grow more fatigued. Caregivers state that respite to allow time for self-care would help allay not only the isolation they feel as the scope of their life narrows, but would allow for some renewal physically, mentally, and emotionally.

2. **Changing roles and obligations; the shift away from traditional family structures is having an impact.**

Immigration, inter-racial and same-sex marriage, divorce, and a highly mobile population are some of the factors changing what was once a traditional family structure. As a result, family dynamics, expectations, and language barriers can complicate matters related to caregiving. First generation immigrants may have higher expectations of caregivers in this “instant communication” society demanding immediate responses to care recipients’ concerns. Many adult children carry the dual role of caregiving for both their parents and their children simultaneously. Long-distance caregivers experience somewhat different challenges related to requirements of time, travel, and receiving information second-hand about daily occurrences. Policies (e.g. FOIPP), accountability, and legalities within the system can further frustrate caregiver efforts.

3. **Communication and Information are lacking causing stress and frustration.**

Poor communication and/or lack of coordination were noted between health care professionals – within a facility; between facilities and the community; and between the various services. It was identified that the nature of healthcare and each silo’s concomitant information format and style contributed to a breakdown of communication. This created particular stress and frustration as the care recipient moved through the various parts of the system requiring the caregiver “repeat the story over and over”: complete new forms each time information is requested and do not know what programs and services are available or who to call when they have a question. It was noted that there is not reliable communication between the hospital, home care, and the family doctor. Most information is in English and is not translated.

4. **Knowledge and understanding: What is needed? Where to get it? Who to rely on?**

Knowledge empowers people to make decisions with greater confidence and clarity. Caregivers have identified many areas of knowledge which are often lacking or not provided in any systematic manner. The lack of knowledge on medical condition, the disease progression, and the care plan makes it very difficult to know what to ask, how to advocate, and what to do with conflicting medical information. There is lack of understanding and/or appreciation of the caregiver role/journey and its associated expectations. Many assume the role “because there is no one else” whether in possession of the skills required of him/her as caregiver or not. Ironically, many do not self-identify as caregiver: “if I knew I was one, I might have a better idea what to ask. I don’t know even know what I don’t know”. Distress increases as one wonders “how do I cope if I lack some or all these skill areas?” There is a need to develop an awareness of resources and how they are accessed. Questions arise, because resources are scattered and often diagnosis-specific, about who can help access them, why their healthcare professional isn’t aware of them, and transportation to them.

5. **Challenges with system navigation due to fragmentation and constant change.**

Change is frequently cited as one of the hallmarks of healthcare. There were many references to the fragmentation, constantly changing, and ‘silo-ed’ nature of the system making it stressful to navigate. The reality, and thus the difficulty, is that there isn’t ONE SYSTEM – there are many systems, often in flux, sometimes in conflict and frequently unaware of the others’ services and programs. It is like a series of roads, highways and off ramps all constructed piecemeal to address a particular issue at different times by different people with differing perspectives and outlooks, some of which connect, many of which don’t. And, as most healthcare providers are dealing with issues, no one has time to step back and create an integrated model for caregiving: one that puts caregivers at the centre of their particular journey, assessing their needs, questioning what they would like help with, preparing and supporting caregivers now and in the future through support services, coaching, mentoring, navigation – financial support, valuing caregiver identity and doing caregiver-specific assessments.

6. **Economic impact of caregiving**

As we look at the large number of family caregivers providing informal care to their aging family members, we can only approximate the actual costs of this care. When we begin to analyze the issue we identify two levels of economic impact: one is at the level of the family (caregiver) and the other is at the larger, system level.
a. Individual level impact

As individuals take on the responsibility of caring for family members, they often experience financial repercussions in addition to physical, social and emotional impacts. As time in caregiving increases, it is not uncommon for individuals’ work lives to be disrupted. This can vary from adjusting work schedules, taking increasing amounts of time off work, or even giving up their jobs. This usually occurs during the years of greatest earning potential. Financial challenges mount as costs of living increase, payment for extra staff or supplementing the cost of housing is incurred often with no tax benefit. In addition, different income brackets have differential access to services. Finally, there is the added concern that if healthcare dollars become more competitive, more care responsibilities will fall on families.

b. System level economic issues

Overall, there is a lack of understanding of the costs of caregiving. Service providers and healthcare professionals working in the field are often too busy attending to the growing needs that they are unable to put forward the time to develop a comprehensive strategy that will address all the issues. In addition, it was noted that not only is there a lack of funding and resources for comprehensive services, but when fiscal restraints are made, caregiving resources predominately in the community are the first to be cut. There was strong acknowledgment of numerous competing priorities for the same dollar and a general lack of funding for seniors care. Finally, it was agreed that facility-based care is not sustainable in the long term.

7. Policy Implication

As the demographics of our society change, so too must our support systems adapt to meet the changing demands. Though many individuals, groups and organizations have recognized and attempted to meet the growing needs of this population shift, i.e. the emerging contingent of seniors needing care, what is called for is a realignment of policies and priorities to allow for the creation of a comprehensive suite of services and resources to meet these needs. Changes to physicians’ pay structure would be necessary to allow doctors the time to care for the complex elderly and their caregivers. In the creation of a comprehensive program, one would see the elimination of the duplication of services and the amendment of rules and regulations to support families as caregivers. Streamlined policies and clear protocols would allow for seniors to access the system at various points of intake as well as recognize and address the unique needs of family caregivers.

INTERVENTIONS TO CAREGIVERS

- Case management
- Respite care
- In-home nursing assessments
- Telephone support groups
- Multiple interventions

References


3. EXPERTS’ NOTES

These slides are adapted from the presentation: GLOBAL ADVOCACY AND ACTION

Tarun Dua, MD, MPH, World Health Organization, April 2014

Full Slide Deck: https://www.dropbox.com/s/6evbwnkplophzoc/Dua.pdf?dl=0

duat@who.int

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**Dementia: A Global Epidemic**
- 35.6 million people were estimated to be living with dementia in 2010.
- The number of people with dementia is expected to nearly double every 20 years.
  - 65.7 million in 2030
  - 115.4 million in 2050

**Public understanding of dementia**
- Dementia is often considered a normal part of ageing.
- Associated with stigma which leads to social isolation and delay in seeking diagnosis and help.
- Is sometimes associated with an unhelpful or dismissive attitudes of service providers.

**Health and Social Care Needs**
- Dementia is a major cause of disability in later life.
- No cure for dementia currently available – limited role of drugs but still much can be done.
- Care needs include early diagnosis, symptom management, and long-term support.
- Substantial proportion of care takes place outside formal health sector.

**Dementia Informal Care & Caregivers**
- Most care for people with dementia is provided by informal, unpaid caregivers, including spouses, children, and other family members.
- Dementia is overwhelming for the caregivers – physically, emotionally and economically.
- Support is required from the health, social, financial and legal systems.

**Caregiver Stress and Strain**
- Stress is due to
  - Time spent caring (most spend 4 hours daily)
  - Patient’s behavioral/psychological Symptoms
  - Role strain
  - Social Isolation
- Caregiving Impacts
  - Deterioration in Physical Health
  - Anxiety and Depression in 50-75% of carers
  - Lost Work Productivity

**G8 Dementia Summit Declaration**
- We, the G8 Health Ministers, commit ourselves to call for greater innovation to improve the quality of life for people with dementia and their carers while reducing emotional and financial burden.
- London, 2013
4. EXPERTS’ NOTES

These slides are adapted from the presentation:

FAMILY CAREGIVERS TO OLDER ADULTS WITH COMPLEX NEEDS: DOCUMENTING THE COSTS OF CARING

Norah Keating, PhD, University of Alberta, April 2014
norah.keating@ualberta.ca

Full Slide Deck: https://www.dropbox.com/s/5p65yawmvorsow5/Keating.pdf?dl=0

VOICES OF FAMILY CAREGIVERS: A WINDOW INTO THEIR EXPERIENCES

“Same story, same assessment. Why do I have to keep repeating myself?”
Dear Honourable Minister,

The health services my husband receives has helped us. Thank you very much!

Please allow me to share our story.

Henry arrived in Canada in 1951. He has worked for over 30 years as an architectural technologist for the Federal Government, raising a family of three children and was actively involved in the community. He was in excellent health, with only mild hypertension.

In 2007, he underwent a four-hour elective day surgery just to remove a skin tag, but the parotid gland was also removed. During that time Henry had a stroke that subsequently affected his ability to walk, talk, and void. Over the next several months, he gradually somewhat recovered and was able to use a walker.

In May 7, 2012 he vomited at our Seniors banquet, was admitted, and stayed in the hospital for 10 days. I observed his whole physical body beginning to weaken. When Henry came home, gradually, he became frustrated, confused and agitated. He would constantly call for me, hold and grip the bed railing due to the extreme dizziness. Later that month, we visited our family doctor who noted there was no evidence of seizures. I had not noticed any either. The Doctor mentioned that it is my choice to stop the seizure medication and upon stopping, the confusion and severe dizziness were resolved. During that time, Henry had no bowel movement for 4 days and vomited. We returned back to the hospital where the doctors examined his digestive system and discovered a narrow path in one area of his small intestine which was causing his constipation and vomiting.

All of these unexpected occurrences traumatized Henry’s whole body. He is confined to a bed and wheelchair at home, and requires assistance in eating, bathing, grooming, and most of everything else. Although there is the option of placing him in an assisted facility, I gratefully choose to care for him in our home. I sense this is what he wants. In the last three years, Henry has experienced and been challenged by some complications and sickness, such as different infections and pneumonia. Being in the home, he is able to be cared for, receives a special diet and suitable vitamins, which we believe helps him recover much quicker and also reduces exposure to any other germs and virus. He receives an individual personal touch and loving care in a comfort, restful, quiet, peaceful and familiar environment. Though Henry is not completely back to normal yet, his body is functioning much better and his mind is clearer.

The healthcare system has worked pretty well for Henry. He has a wonderful physician who is responsive to Henry’s needs. The doctor is very collaborative and respects our culture and circumstance. For example, many times, a visit to the emergency department was prevented with just a phone call to the Doctor or by his home visit. In these situations, it eliminates undue stress and anxiety, saves us time and energy for traveling in and out of the hospital, while reducing the expenses on the healthcare system. Of note, as a senior, the visitor chairs in the waiting and patient rooms are very uncomfortable. It is difficult to find quiet places to relax and communicate, and the parking lots are far from the facilities. One becomes exhausted even before seeing the patient, and it is difficult to say goodbye - seeing tears and fears in his eyes, to only to be repeated the next day. Other healthcare providers have also contributed to his great care. Over the years, we’ve developed a functional working relationship with our home-care providers and the healthcare team. They know Henry’s needs and try their best to address all the necessities with the different resources and programs available.

The healthcare service has not always the best, though. A few years back, we had to deal with quite a few challenges: quick turnover of caregivers, inconsistency in care provided; lack of coordination between the caregivers and the specialists, possible misdiagnoses, stress in the emergency department, difficulty in navigating the system; the list goes on. At times, some caregivers or other personnel pursue their own way, methods or ideas in providing care without having an understanding and compassion for his specific needs. Whenever they are uncertain or feel that Henry’s sickness is unmanageable, they insisted that I should call 911. I appreciate that no matter how experienced or qualified professionals are, it is difficult for them to be specialized in my husband’s condition. Having been married for 53 years, I have cared for him since 2007 and 24/7
for last 3 years. In any circumstance, I am able to perceive and recognize my husband’s sensitivities and reactions. Much more than what could be seen physically, I understand his emotions, his preferences, and his spirit.

I’m fortunate to have children who support me. They would search the web for answers and resources. Additionally, I have a daughter who is well-connected to the healthcare system. Frequently, she has called her colleagues and used her network. This is how I got in contact with the excellent work that Dr. Jasneet Parmar and her team are doing on seniors. Most importantly, I thank God and our family for supporting and providing me the courage, strength, knowledge and wisdom with many plans and ideas that give unconditional love for Henry.

Finally, I appreciate and am very grateful each and every day for those who assist and care for Henry. I thank God and bless you all in helping us to make everything possible for creating our loving memories in the remaining years. I hope the system continues to improve and provide the best services. If I may, please allow me to share five wishes:

• First, a phone number that a family member or caregiver could call for a loved one who has a minor problem at home.

• Second, a video camera between home and medical centre to provide healthy aids and diagnostic information for minor injuries or sickness, even just to ensure and comfort the patient and the family to cope with conditions or circumstance.

• Third, doctors who conduct home visits, with the ability to bring in other allied health as needed.

• Fourth, homecare that has its own Health Care Aids to allow for consistency and quality of services.

• And fifth, caregiver classes, such as those given for newly diagnosed diabetes patients, on how to reduce risks in the home, as they do for individuals with low vision.

To conclude, one can have faith and trust in the health care system with freedom of choice including suitable options that minimize the stress on the patient/family and reduce further illnesses. Considerations such as: access to knowledgeable individuals who communicate with simple directions or instructions, how to combat loneliness, isolation and fear - can give hope to sustained independence with good quality of life; and recognizing that the caregiver and family are part of the care team. In all aspects, an individual can maintain their self-worth and dignity in completing one’s plan, purpose, and dreams, enjoying life to its fullness into eternity.

All the best to you!

Sincerely,
Emmy

6. KEY LEARNINGS
VOICES OF FAMILY CAREGIVERS: A WINDOW INTO THEIR EXPERIENCES

Suzette Brémault-Phillips, OT, PhD, University of Alberta
suzette.bremault-philips@ualberta.ca

Family caregivers are the backbone of the healthcare system. In Canada, 3.8 million family caregivers save the healthcare system $25 billion per year. For some, caregiving comes easily, while for others, it is a source of distress. Over time, caregiving can take a significant toll on the caregiver, often leaving them feeling overwhelmed with tasks before them, and with little energy or time to access resources. Their experiences with the healthcare system, healthcare professionals and service agencies can either sustain them through challenging times, or contribute further to their struggles.

Focus Groups
As part of a pre-conference activity to the Supporting Family Caregivers of Seniors conference held in Edmonton on April 14th and 15th, 2014, three 2-hour long focus groups were held with family caregivers. The aim of the focus groups was to hear the voices of family caregivers – their experiences, challenges, struggles, joys and motivation for persevering through hardship, as well as their recommendations regarding education, resources and support them might increase their resilience.

Family caregivers were asked about supports they rely upon, knowledge and skills they require for caregiving, essential resources and how they are accessed, barriers to accessing supports and services, and rewards of caregiving. Focus group discussions were transcribed and a thematic analysis conducted. Below is a summary of the focus group findings.

Caregiving – Many Sources of Stress

Caregivers reported that they feel overwhelmed. They often are stressed due to the demands that caregiving has placed on their life, time, emotions, finances and personal health.

Communication Issues and Inconsistent Access to Resources

Many caregivers indicated that they do not understand the care recipient’s diagnosis or its impact on the person. The use of medical jargon by healthcare professionals makes it difficult for them to understand the medical information provided to them. When caregivers try to be involved in the medical care of the care recipient, they often find their efforts dismissed by healthcare professionals.

Inaccessibility of resources and supports is another challenge for caregivers. Caregivers indicated that they were frequently not informed of valuable resources (e.g. Alzheimer’s Society), learning about them largely through internet-searches or word of mouth. One focus group participant noted: “I learnt from a friend about the Alzheimer’s Society, and when I look back at dealing with the doctors, the professionals, it didn’t really come up.” Caregivers also noted frequently feeling frustrated by having to fight or beg for necessary help, navigate the complexities of the healthcare system alone, communicate with healthcare professionals, make sense of and organize fragmented pieces of information, and integrate the information into their own contexts.

Caregiver Health and Wellness is Impacted

“Caregiving is a 24/7 job,” stated a caregiver. Caregiving was noted to increasingly impact the health and well-being of caregivers. As the care recipient’s health deteriorates, the caregiving role becomes more demanding. The focus often shifts from provision of occasional support (e.g., accompaniment to doctor’s appointments) to assistance with everyday activities (e.g., dressing, bathing, medication). This leaves little, if any time, for caregivers to tend to their own needs.

Costs to Family and Finances

The amount of time and energy that caregiving requires can impinge upon family life and financial security. Relationships, roles, family dynamics and priorities change throughout the caregiving process. Caregivers can find themselves sacrificing time with their own families, missing their own children’s milestones, and compromising family vacations due to caring for another. A caregiver stated, “I have two little kids of my own to chase as well, so you really feel like you sacrifice.”

Caregiving can lead to significant financial burden. Working less, taking time off work or having to give up a job to care for someone can have unintended consequences on the caregiver’s own financial security. Further, the long term costs of medical care, facility living, and private care can be a substantial drain on a caregiver’s finances. As a result, caregivers feel a wide range of emotions such as anger, resentment, confusion and frustration.

The System

Caregivers can experience the system as harsh and rigid. Its policy-driven and at times unresponsive nature does not necessarily accommodate for unique challenges and needs. Caregivers noted feeling that healthcare professionals are not always attuned to the wellbeing of patients. A caregiver stated, “It sometimes feels the system is all about the system and it’s not about the people.” Caregivers frequently feel that they are “fighting” with the system to get the help that they need.
Conclusion

Any combination of the above factors can have a cumulative and overwhelming effect on family caregivers, often placing them in untenable situations that jeopardize their own health, finances, family relationships and overall wellbeing. Left unclear about the diagnosis and its implications and uncertain about the future, family caregivers very frequently feel voiceless and powerless amidst the incredible responsibilities placed on them. Statistics speak to the staggering amount of informal health services caregivers provide. In order to sustain this support, programs and services are needed to explicitly address the needs of this group, and provide them with necessary supports that honour their contribution to care recipients and the system.

Caregivers require access to a wide range of community services and resources, education, training in emergency care specific to the care recipient, and respite supports. They express a need to better understand the implications of diagnoses, prepare for the future, and have a safe space to address concerns.

Caregivers noted that they are more resilient when appropriate supports are provided. Provision of emotional support was noted to result in decreased distress, improved coping and increased caregiver quality of life. Resilience was enhanced when caregivers had an opportunity to cherish moments with the care recipient, had a sense of commitment to the person, and drew on internal spiritual resources. One caregiver stated, “If I can get her to smile, my day is made.” Another commented, “For the first 18 years of my life, my mom took care of me, now it’s payback time.” For others, they hoped to be a role-model to their children so that their children might be inspired to take care of them in their old age.

Recommendations

Focus group participants related a number of recommendations that might result in them feeling better supported in their caregiving journey. Caregivers need advocacy skills and language to effectively interact with healthcare professionals. A caregiver identified the need for, “Assertive communication so that I could better deal with my husband and better advocate for him with healthcare professionals.” Caregivers would like to see more training for healthcare professionals on early dementia recognition and intervention. This training would lead to an earlier diagnosis for patients and access to system and community resources. Caregivers also suggested access to system navigators and professional advocates to help them access resources and advocate on their behalf. Greater awareness of the caregiver experience is foundational to determining interventions to address their needs.

7. EXPERTS’ NOTES
These slides are from the presentation: WHAT DO CAREGIVERS HAVE TO SAY
Anna Mann, Alberta Caregivers Association; Arlene Huhn, Alzheimer Society of Alberta and NWT, April 2014
AMann@albertacaregivers.org  AHuhn@alzheimer.ab.ca
Full Slide Deck: https://www.dropbox.com/s/93ps68owx4cyp03/MannHuhn.pdf?dl=0

Caregiving Impacts Caregivers’ Health and Well-Being
“...desperation, exhaustion total mental, physical, everything, like I just can’t do this anymore but I have to—there’s nobody else.”
- Lack of sleep, stress, physical demands affect health
- No time to look after their needs

Caregivers Experience a Wide Range of Emotions
“...all of a sudden you don’t look so happy anymore....so you really feel like you sacrificed and it starts—sorry, it starts out as a good deed and it turns into a really big burden.”
- Caregivers are often unprepared for the emotional impact of caregiving

Caregivers Don’t Self-Identify
“If somebody talked about care of the caregiver- I saw myself as a helper, that didn’t qualify [me], I’m just helping.”
- Don’t see themselves as caregivers, therefore don’t think to look for or access supports
- Focus is on the patient: friends, family, the system, don’t see them as caregivers either

Work and Finances
“...I was laid off ...I just didn't have the emotional strength to job hunt and my husband was declining.”
- Difficult to balance work and care
- Leave work, reduce hours, take time off

Need Support Services
“...with the support groups you get so much information from other people how things have worked for them and the problems they have had.”

Caregivers seek to have their voices heard, their knowledge & experience valued, recognized and sought as part of the care team.
ONLINE SUPPORT FOR CAREGIVERS OF SENIORS WITH DEMENTIA

“Knowledge empowers people to make decisions, both caregivers and professionals.”
8. KEY LEARNINGS
CAREGIVERS OF SENIORS WITH DEMENTIA: ANALYSIS AND FINDINGS

Jayna M Holroyd-Leduc, MD, FRCPC, University of Calgary
Jayna.Holroyd-Leduc@albertahealthservices.ca

Pre-Conference Literature Review
Given the demands placed on family caregivers of persons with dementia, access to support services from the convenience of home is potentially attractive. Multi-component internet-based caregiver interventions have been shown in several small studies to improve caregiver outcomes. Therefore, the role of on-line support tools for caregivers of persons with dementia was specifically explored during the conference.

Facilitators and Gaps identified at the Conference
Facilitators
Some of the facilitators to on-line caregiver supports identified during the conference included the potential to have questions answered at any time of the day, the possibility of building a virtual community, and validation of individuals who are geographically or socially isolated. On-line supports were also felt to be appropriate for both primary and supporting caregivers.

Barriers
Potential barriers identified during conference discussions included challenges related to accessibility and usability for a variety of potential end-users, and developing a tool that can be easily adapted to changing technology and evidence. The credibility and maintenance of the website was also identified as a potential issue. Caregivers (end-users) need to be involved in developing and testing the on-line tool and privacy issues need to be considered. Both health care professional and caregiver perspectives need to be incorporated and the tool would need to consider what information is needed at all stages of the disease continuum. Additionally, developers would need to consider designing a platform that can be used across different internet browsers. To improve applicability, the tool should align with other health care resources. Finally, the tool should be evaluated by family caregivers before wide-spread distribution.

Next Steps
A team of key stakeholders who attended the conference, including researchers, clinicians, administrators, members from the Alzheimer Society of Alberta & NWT and the World Health Organization, developed a knowledge translation grant proposal to implement and evaluate a multi-component online resource for caregivers of persons with dementia, focusing on improving self-efficacy and self-management. This grant proposal has been successfully funded by the CIHR and results are expected in 2017.

References

Family caregivers are an integral, yet increasingly overburdened, part of the health care system. Informal care costs are estimated to be $252 billion of the $604 billion global societal costs related to dementia. Given the many demands placed on family caregivers of persons with dementia the potential for caregivers to access support services from the convenience of their own home is attractive. In 2012, 83% of Canadians had access to the internet at home, making internet-based caregiver supports a viable option.

Caregiving can come with emotional, physical, social, psychological and financial costs to the caregiver. Multicomponent internet-based caregiver interventions have been shown in several small studies to decrease caregiver perceptions of burden and depressive symptoms and to increase caregiver perception of competence and confidence in decision making, and to delay time to long-term care placement of the care recipient. It has also been shown that outcomes of interventions are often dependent on caregiver characteristics such as gender, age, education and relationship to the care recipient, and on baseline perception of burden, competence and depression. Internet-based caregiver interventions provide an opportunity for interventions which are tailored to the individual and their changing needs. They also provide the convenience of being accessible without any constraints of time or geography. Further research is required to determine the impact of internet-based caregiver interventions on clinical outcomes for both the caregiver and the carer, healthcare resource utilization and costs.

References
2. Canadian Internet Use Survey 2012, Statistics Canada

10. EXPERTS’ NOTES

These slides are from the presentation:
DEVELOPMENT OF INTERNET INTERVENTIONS FOR CAREGIVERS OF PEOPLE WITH DEMENTIA

Professor Dr. Anne Margriet Pot, VU University Amsterdam, April 2014
potam@who.int

Full slide deck: https://www.dropbox.com/s/0d1v74lv2dxsbbx/Pot.pdf?dl=0

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**Online Lessons**
http://www.masteryoverdementia.com

1. Coping with behavioral problems
2. Arranging help from others
3. Taking Time for Yourself
4. Thinking and Feeling
5. Non-helping Thoughts
6. Helping Thoughts
7. Stand up for Yourself: Assertiveness
8. Communicate Problems
9. Booster Lesson: Summary of Techniques

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**Psycho-Education**

**Behaviour Problem**
Mary has Alzheimer’s disease. She asks her husband to help her getting dressed. Her husband sees that she put on her dress inside out. He says to Mary: Let me do it, you put your dress on inside out!

**Solutions**
- No confrontation with mistakes
- Not automatically take over
- Give Mary her dress in a way that she can easily put it on in the right way

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**Changing Non-helping Thoughts into Helping Thoughts**

Relationship between

**Events** -> thinking -> feeling

**Example**

**Event**: The husband of Susan cannot find his keys

**Feeling** of carer Susan: Stressed and miserable

**Her thoughts**: Why do I constantly have to solve these problems? I don’t have time to search.

**Alternative thought**: He cannot help that he forgets. That’s because he has dementia.

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**Non-helping Thoughts**

- I have to do everything alone.
- He/she does not love me anymore.
- I should not bother others with my problems.
- Nobody understands how hard it is.
- It makes no sense to talk with other carers.
- I’m worthless.
- It’s all my fault.
- Nobody can provide the care in the way I do.

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**Helping Thoughts**

Examples of analyzing:

**Events** → Thinking → Feeling

with helping and non-helping thoughts

For example:

**Event**: After day out, very tired

**Thought**: Dementia has ruined our life

**Feeling**: Sad feeling

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**Helping Thoughts**

“My non-helping thought was that we never could have some fun together and that the illness has ruined our lives. This gave me a sad feeling. That’s not the way I want to feel. Therefore, I asked myself if my thought was helping. I realized that my thought was black thinking. What would be helping thoughts? We had a great day together, we both enjoyed it a lot. Probably tomorrow he will be better, he just needs to relax for a day. Now I feel happy and satisfied, because of the beautiful day we had together.”

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11. EXPERTS' NOTES
These slides are from the presentation: GLOBAL CAREGIVING: iSUPPORT FOR DEMENTIA FAMILY CAREGIVERS
Kala Mehta, DSc, MPH, Dolores Gallagher Thompson, PhD, Stanford University School of Medicine, April 2014
Kmehta23@standford.edu
Full slide deck: https://www.dropbox.com/s/v9vo7gwww7c6p2k/Mehta-Thompson.pdf?dl=0

“Family caregivers in end-of-life care undergo multiple concurrent complex transitions.”
12. KEY LEARNINGS
SUPPORTING CAREGIVERS OF SENIORS AT THE END-OF-LIFE

Wendy Duggleby, PhD, RN, AOCN and Jenny Swindle PhD, University of Alberta
wendy.duggleby@ualberta.ca

PRE-CONFERENCE LITERATURE REVIEW
The focus of the Conference was to identify strategies to support family caregivers of persons in the terminal phase of illnesses. A literature review presented to participants identified that interventions to improve outcomes for caregivers of persons in the terminal phase of illness are challenging. For example, there is a limited period associated with advanced disease and while caregivers are helping the dying person, they are also trying to prepare themselves for the eventual death of their family member or friend. Dealing with end-of-life issues adds to the complexity of interventions and their outcomes.

CONFERENCE FINDINGS
Development of provincial frameworks for end-of-life care
Facilitators and Gaps identified at the Conference
Discussion at the meetings identified facilitators that exist for supporting caregivers of persons at the end-of-life. Facilitators include the development of provincial frameworks for end-of-life care and an increase in the research in the area. In Alberta and across Canada provincial health boards have been working on developing provincial frameworks for end-of-life care. These frameworks are consistent with the Canadian Hospice and Palliative Care frameworks that recognize the importance of supporting family caregivers at the end-of-life (Canadian Hospice and Palliative Care, www.chpca.net). They also identified gaps in services supporting family caregivers and the need for research in this area even though there has been an identifiable increase in the research on family caregivers at the end-of-life in the past ten years. Research continues to be needed to identify effective and efficacious ways to support family caregivers.

Caregivers don’t Self-Identify
Many key themes were also identified by participants relating to gaps and barriers to supporting caregivers of persons at the end-of-life. The first involved the definition of caregivers: “who is a caregiver?” Identifying the population is a challenge as caregivers of persons in the terminal phase of illness include those: a) dealing with a variety of advanced diseases, b) who may or may not access palliative care services, and c) who are bereaved. Moreover caregivers may not identify themselves as caregivers; some have not considered their family or friend is going to die; and others do not view death as a natural process making it difficult to discuss end-of-life issues. This results in caregivers not accessing the support services needed to maintain their own health.

Diversity of Caregivers and their Experiences of Caregiving
Caregivers of persons in the terminal phase of illness are diverse. It is important that assessments capture caregivers who are at highest risk and their diverse needs (i.e. goals of care, coping styles, full scope of caregiving journey). There is also diversity in their caregiving experience related to multiple factors such as previous caregiving experiences, the relationship to the person they are caring for, resources available and illness/situation of the family/friend for which they are caring. For example, the caregiving experience may be different when caring for persons with Alzheimer’s disease compared to a person with cancer, or congestive heart failure. When developing interventions to support family/friend caregivers, it is important to be mindful of these differing experiences.

Caregivers Experience Multiple Transitions
Family caregivers of persons in the terminal phase of illness undergo multiple concurrent complex transitions resulting in a diversity of needs and required support. Transitions are significant changes that impact the lives of caregivers. Caregivers of persons at the end-of-life experience multiple significant transitions that impact their physical and mental health. A possible future direction is to complete a synthesis of the current literature identifying transitions and factors influencing them. This knowledge may assist in identifying strategies to support caregivers of persons in the end-of-life along their journey.

Types and Lack of Availability of Resources
Concern was expressed by participants about types and lack of availability of resources offered to caregivers. Current services and resources to support family caregivers of persons in the terminal phase of illness have differing goals. For example, some services reduce the amount of caregiving (respite) while others focus on improving caregiving skills, coping and problem-solving (i.e. services that provide emotional, spiritual and educational support and end-of-life care plans and funerals). Participants described a current focus on providing resources and information to help caregivers provide care, but not enough focus on building relationships and supporting caregivers themselves (i.e. through the process of bereavement, preparing for “the moment”, and providing caregivers with someone to talk to). The participants recommended that resources need to be flexible, practical and simple as caregivers have limited time because of the intensity and limited time of caregiving. As well, resources and support need to focus on the whole illness experience. Currently there is not much support after cancer treatments are done leaving both patients and families feeling abandoned by the system. A definite lack of availability of services for caregivers was noted particularly in rural areas.

Concern on type and availability of resources for caregivers
Bereaved Caregivers

The focus of current resources for caregivers is on the “then and now” with little support during bereavement. Participants identified that there was a lack of support for the caregiver after care recipient dies/post-caregiving support. However, bereavement and saying goodbye is a process that does not stop with death. Also the participants noted that caregiver burnout often occurs after the family member dies. Bereaved caregivers are at high risk for health problems.

Navigation of Services

Responding to the complexity of resources (types and availability), navigation of services was highlighted as an important future direction. Caregivers often do not know what resources are available and advocates are needed within the system to communicate their needs. Healthcare system navigators would be helpful to guide individuals and families through the intricacies of the healthcare system and informal community services. Navigators who are advocates are needed within the formal and informal system to help caregivers access existing resources.

In summary, the participants identified the importance of provincial end-of-life care frameworks having a focus on family caregiving and the need for more research in this area. As well, they described issues of “who is a caregiver”, the diversity of the caregiving experience, and the multiple complex transitions they experience as underscoring the need for flexible, individualized services and resources. The lack of resources particularly in rural areas and for bereaved caregivers was noted. Possible future directions include looking at the literature to determine what is known about the caregiving experience and strategies to deal with the different aspects of their experience. As well, the potential exists for navigators to assist caregivers to access needed resources and services across their experience including bereavement.

13. EVIDENCE SUMMARY
CAREGIVERS OF PATIENTS IN THE TERMINAL PHASE OF ILLNESS

Jacqueline McMillan, MD, University of Alberta
Jacqueline.McMillan@albertahealthservices.ca

Evidence from one systematic review suggests that interventions such as emotional support and advice on coping which directly support the caregiver result in decreased distress and improvement in the ability to cope and the quality of life of the caregiver.1 When the needs of caregivers were assessed, the most frequent informational needs of caregivers included incontinence care, diet, patient comfort, symptom management and medication management.2 Specifically, caregivers reported that a lack of nursing knowledge was particularly anxiety-provoking3 and that two periods in the caregiving experience which are especially tumultuous are the time of discharge from hospital and the short period of time immediately preceding the patient's death.4,5,6

Evidence provided from randomized-controlled trials suggests that caregiver coping skills interventions lead to decreased burden and increased quality of life in the caregiver,7 and that psychosocial interventions result in a more positive caregiving experience.8 Caregiver sleep interventions have resulted in mixed outcomes, including improved sleep quality scores, with no significant change in caregiver quality of life.9 Family therapy has been shown to decrease the negative appraisal of caregiving in the short term, but this outcome was not sustained.10 Creating a scrapbook or audiocassette “legacy” led to decreased stress of caregiving,11 and education on pain management strategies resulted in decreases in caregiver strain.12

There are many potential avenues for proving supportive interventions to family caregivers of patients in the terminal phase of illness. Caregivers request more information and support in the practical aspects of providing nursing care, and acknowledge particular transition points that are particularly stressful. Potential interventions include education around practical aspects of caregiving, pain management, coping strategies, emotional and psycho-educational interventions.

INTERVENTIONS TO SUPPORT CAREGIVERS
• Coping skills interventions
• Psychosocial interventions
• Sleep interventions
• Family therapy
• Scrapbook legacy
• Education

References

14. EXPERTS' NOTES

These slides are adapted from the presentation: NEXT STEPS IN RESEARCH WITH CAREGIVERS OF PERSONS AT THE END OF LIFE

Wendy Duggleby, PhD, RN, AOCN, University of Alberta, April 2014
wendy.duggleby@ualberta.ca

Full slide deck: https://www.dropbox.com/s/4vbsfwydoebeehm/Duggleby.pdf?dl=0


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**Definition of EOL**
- No exact definition of EOL exists
- AHS Draft Palliative and End of Life Care Provincial Framework: “End of Life Care is care provided to patients and their family when they are approaching a period of time closer to death”
- Surprise question: “Would you be surprised if this patient were to die in the next 6-12 months?”

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**Why?**
- Reduce the amount of caregiving?
- Continue caregiving? (i.e. improving caregiving skills, coping and problem solving)
- Improve well-being?
- Enrich their experience?

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**Who**
- Those at highest risk?
  - Primary predictor of caregiver burden is lack of resources, not patient diagnosis or illness severity (Hudson, 2013)
  - Longer hours of informal care and health status of care recipient (CHPCA, 2012)
  - Bereaved caregivers (Most under-researched and under-sourced) (Hudson, 2011)
  - Those with disabilities and rural (CHPCA Fact Sheet, 2012)

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**What: Research Priorities**
- Interventions and Bereavement, Psychosocial (Hudson, 2011)
- Pain and symptom management, psychosocial aspects, effective methods of delivering hospice and palliative care services and programs within the health care system (CHPCA, 2012)

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**What**
- Focus – specific or general (Hudson, 2010)
- Studies with treatment effects targeted specific needs of the caregivers i.e. problem solving skills (McMillan et al, 2006) and Hope (Duggleby et al, 2013)
- Are there ways to design interventions for supporting caregivers that have general application and incorporating individual variation? i.e. Changes Toolkit (Duggleby et al, 2012).

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**Types of Interventions (Harding, 2012)**
- One to one vs group interventions
- Patient/Carer dyads
- Palliative care/hospice interventions
- Respite Interventions
RESEARCH AND RESOURCES
**PART 5  RESEARCH AND RESOURCES**

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### 15. RESEARCH PRIORITIES AND FUTURE DIRECTIONS

Jasneet Parmar, MBBS, UofA; Jayna Holroyd-Leduc, MD, FRCPC, UofC; Norah Keating, PhD, UofA

JasneetParmar@covenanthealth.ca

A main goal of this conference was to identify issues for future study.

**Day 1 discussions centred on caregiver issues such as:**

1. The timing when caregivers seek help
2. Why more research on caregivers and caregiver supports is needed
3. How caregivers identify themselves
4. What interventions have been shown to make a difference for caregivers
5. Reasons as to why support for caregivers is not currently provided

**Day 2 focused on identifying potential research priorities to address the issues identified in Day 1:**

1. Identification of ‘Goals of Care’ for family caregivers
2. Enhanced case management
3. System navigation supports
4. Impactful change and funding models
5. Evaluation of on-line supports that include self-efficacy and self-management modules
6. Knowledge exchange strategies to inform and sensitize current and upcoming generations of the realities of and resources required regarding caregiving

**Discussion**

Our findings highlight the need for centralization of resources for patients, caregivers, and health care providers, as well as support for caregivers in navigating through resources and the healthcare system. Advance care planning and goals of care designation are important, however, there is a need to include planning for care needs not only of the person with complex needs, but also of their caregivers. Education for health care professionals is necessary, with a focus on the development of core competencies regarding both the management of complex needs and provision of support to caregivers. Education for caregivers and future caregivers is also required.

Further research is required regarding case management, support groups, and health education programs. Regarding case management – a process of assessment, planning, facilitation and advocacy for options and services to meet individuals’ holistic needs – more research to determine specific ways in which case management might be helpful to caregivers is warranted. This would contribute to the growing body of research around case management including a systematic review that reported the efficacy of case management in decreasing caregiver burden and increasing caregiver satisfaction.

Telephone support groups, such as those offered through the Alzheimer Society, have shown a significant decrease in burden and depression, together with a significant increase in social support and knowledge among adult child caregivers (but not among spousal caregivers). Health Education Programs – multicomponent group interventions that focus on problem-based coping strategies, education and support for caregivers – is a further area of possible research. A randomized control trial of 105 caregiver-recipient dyads found several positive outcomes for Health Education Program carers: a significant decrease in severe depression, increased perceived caregiver effectiveness, increased knowledge of community resources and how to access them, and increased knowledge about aging and their spouses’ illness. Caregiver burden and perceived stresses also declined. Similarly a one-year randomized control trial of a multicomponent support group for burdened spouses caring for frail elderly veterans resulted in a statistically significant reduction in participants’ subjective burden. Caregivers of frail older adults receiving a multicomponent, interdisciplinary intervention reported overall better health and self-esteem than those in the control group. Research as to whether the introduction of such health education programs with school and college-age students would be beneficial in preparing people for the eventuality of caregiving is also an area of potential research.

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**A 5-Year Research Program with Two Key Priorities**

A longitudinal study of caregivers and their needs, recognizing variable journeys and reciprocity of relationships.

Caregiving changes over time with aging of caregiver and care-receiver, changes in the health of both, changes in the set of family members/ neighbours/friends available to provide care, changes in available services. We need to know about the caregiving journey in order to better understand family caregiver needs and experiences.

An economic cost analysis examining high health care system users versus caregiver costs (from an individual and system level perspective).

From a system level, what can we learn about high users of the health care system—are they predominantly older adults, what are the areas in which most costs are incurred, can we look across acute and chronic care systems to calculate costs? If we could develop profiles of high user groups at the system level and then look at the correspondence between these high costs and those incurred by individual family caregivers we could learn about how these costs are shared and where are the pressure points.

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16. ALBERTA CAREGIVERS ASSOCIATION

About the Alberta Caregivers Association

The Alberta Caregivers Association (ACGA) is the province’s only grassroots organization exclusively dedicated to helping family caregivers maintain their well-being.

The ACGA was founded in 2001 by a group of caregivers who recognized that while there were supports for caregivers, many of them focused on the care recipient; support groups and education programs would discuss the progression of their loved ones illness or what to do if your care recipient fell. The founding members identified a need for supports that would focus on their needs as a caregiver: the difficult emotions, the impact caregiving had on their physical, mental and financial well-being, and the lack of understanding from friends, family and the system.

ACGA Principal Programs

COMPASS for the Caregiver: COMPASS is a 9-module workshop that promotes self-care attitudes and practices among caregivers. The program helps address common stressors- difficult emotions, guilt, grief, resentment, conflicting family relations and social isolation. COMPASS encourages caregivers to take care of themselves by recognizing that they are not alone, that they can accept help and seek respite. One participant rated it the “best thing that has happened to me in years”. The ACGA is currently expanding the delivery of COMPASS across Alberta through partnerships.

Community Caregiver Groups and Caregiver Information Sessions: These drop-in groups provide a place for caregivers to connect with others in similar circumstances over coffee. They are generally established as a follow-up to the COMPASS program and are able to deal with more in-depth understanding of the caregiving journey. The ACGA provides toolkits and support to assist agencies and caregivers set up their own groups.

Caregiver Ambassadors: A program that helps caregivers develop and share their story, with the aim of helping family members, service providers and the general public better understanding of the caregiver experience.

Caregiver Advisor: The Caregiver Advisor is a registered social worker who provides one-on-one support and information for caregivers across the province. The Caregiver Advisor also consults with health professionals and community service agencies to help them identify resources and support their clients.

Caregiver Support Team: The Caregiver Support Team (CST) is an interagency collaboration spearheaded by the ACGA to promote cooperation and information sharing among caregiver-serving organizations. The team has a membership of more than thirty Edmonton-area agencies that meet monthly for education and networking. CST members say they are better able to support their clients as a result of their participation because they have a network of professionals they can consult with and provide referrals to.

Caregiver Navigator: The Caregiver Navigator is a one-day facilitated program that provides training to help professionals and providers support family caregivers. The Navigator project provides broader understanding with regard to the challenges caregivers face and how to effectively support caregivers to develop self-care attitudes. Caregivers are often encouraged to ‘take care of themselves’, but without proper supports they are unlikely to do so until “burnout” is beginning to develop.

More information about the ACGA is available at our website www.albertacaregivers.org or by calling 780-453-5088.

SEVEN TIPS FOR SUPPORTING CAREGIVERS

Anna Mann, Alberta Caregivers Association
AMann@albertacaregivers.org

Caregivers provide assistance to family members and friends with challenges resulting from illness, disability or aging. They provide 80% of the care required by patients living in the community and contribute billions in unpaid labour to our health care system every year.

Though the care they provide is essential, caregivers often go unrecognized and unsupported. This lack of recognition can have a profound impact on the well-being of the caregiver: they have higher rates of depression, stress and are at risk of burnout.

Here are some tips to engage and support the caregivers you meet in your practice:

1. Acknowledge Them
In our patient centred system, it’s easy to focus on the patient. One caregiver described her experience as “My name’s now ‘How’s your mother’”. Asking the caregiver how they are doing tells them that they matter too.

2. Address Their Experience
Guilt, anger, resentment, sadness and frustration are all common emotions for caregivers. Many caregivers are reluctant to admit that they are experiencing these challenging emotions and, as a result, don’t seek help until they are burning out. It is important to normalize those emotions and encourage them to ask for help.

3. Help Them Recognize Stress
Caregivers can become so focused on their care recipient that they don’t recognize that they have high levels of stress. Self-assessments (such as the AMA self-assessment) can help. If you are using a self-assessment, be sure to encourage the caregiver to discuss the results and next steps with you.

4. Look for Signs of Burnout
- Lacks energy
- Life dominated by caregiving, little time for social connections
- Frequently sick
- Difficulty relaxing when help is available
- Always exhausted
- Acts impatient or irritable with their care recipient
- Neglects needs
- Appears overwhelmed, helpless or hopeless

5. Encourage Self-Care
Help caregivers recognize that they may not have to do everything themselves. Ask them what they are doing for themselves and encourage them to access respite and other caregiver supports.

6. Work with Caregivers
Caregivers spend a lot of time with the care recipient and likely know more about their needs than anyone else. Listen to what they have to say and include them in care planning.

7. Provide Referrals
Navigating the system can be hard. Caregivers often don’t know who they should talk to or what resources they should ask for. Don’t assume that they are aware of services; sometimes caregivers are unfamiliar with common programs like home care. You don’t need to know everything that’s available, but help them connect to someone who can help. Here are some key resources to help them connect:

- Alberta Caregivers Association
- Hospital social workers
- HealthLink: Access to home care, respite and case management
- Local information/distress lines (e.g., 211 in Edmonton)
- Local FCSS offices in rural areas
- Disease and disability-specific organizations (for example: the Alzheimer’s Society)
- Seniors outreach workers at local seniors centre

Today in Alberta over 40,000 people have dementia, with 17% of these having been diagnosed under the age of 65. Alzheimer’s disease at this point in time has no known cause or cure. Until a cure is found, the Alzheimer Society is here to help and provide support to those living with a dementia and their care partners.

**Client Services and Programs**

1. **FIRST LINK®** – A direct referral system that connects individuals and families affected by dementia to a coordinated learning and support program from time of diagnosis throughout the progression of the disease. First Link® helps families make informed choices so they can live better with dementia at every stage of the disease.

2. **First Link® Connections** – Individuals with dementia and their care partners join other families in a small group setting. Here they will learn about the Alzheimer Society’s education and support programs, community resources and supports, and planning for the future.

3. **Early Stage Support Groups** – People diagnosed with dementia meet with other people who have a similar diagnosis in a comfortable and welcoming environment where they can share experiences, discuss what works well and what they are successful at.

4. **Care Partner Support Groups** – Care partners meet with other care partners who are experiencing similar situations. A chance to share what does and doesn’t work, and make connections with others.

5. **Seeds of Hope Family Learning Series** – An education program for care partners of persons with dementia at all stages of the disease. Speakers discuss a variety of topics in a small group setting.

6. **Information and Support Services** – People affected by dementia speak directly, privately, and confidentially with staff regarding the many issues and circumstances that arise throughout the journey, information about other community and health care services, including navigating the healthcare system.

7. **MedicAlert® Safely Home** – Personal information and a hotline number are engraved on a MedicAlert® bracelet worn full time by the person with dementia. Should they ever go missing, police can quickly identify them by calling the emergency hotline number.

8. **ASANT Café** – An online gathering place (www.asantcafe.ca) for people with dementia and their care partners, providing 24/7 access to information, education, and support within a virtual community.

9. **Resource Library** – Our resource library has a variety of books, videos, pamphlets, and videos/DVDs on many different topics and issues that may arise throughout the journey.

10. **Public Forums/Webinars** – Designed for large audiences, these education sessions focus on topics relevant to care partners, persons with the disease, and the public.

11. **Presentations** – Staff raise public awareness and understanding of dementia through the delivery of an informative presentation.

For more information, visit our website [www.alzheimer.ab.ca](http://www.alzheimer.ab.ca) or call 780-488-2266.

How are you sleeping at night?
Fine.

How many times do you get up during the night?
Not many.

How many times were you up last night?
Oh, twelve.

It's just another sleepless night for the Alzheimer caregiver!

Providing care for someone with Alzheimer's disease takes a tremendous toll on the physical and emotional health of the primary caregiver, yet many caregivers often don't recognize the warning signs, or deny its effects on their health. Many caregivers tend to set their own needs aside while caring for the person with Alzheimer's disease and hope that if they don't think about it, the stress might just go away.

Dr. Julie Chandler, a physician in Yarmouth, Nova Scotia, says, "Fatigue is one of the major things that I see. People reaching the end of the rope in terms of their patience. Some of this is related to fatigue, because if you're constantly tired from being up all night with the person with Alzheimer's disease, how can you possibly be patient with them even though that's what they need?"

Caregiver stress is a normal part of Alzheimer caregiving. There are steps you can take to reduce it but first, you must recognize it. The 10 warning signs of caregiver stress include denial that the person even has the disease, anger at the person with the disease and others, emotional sensitivity, social withdrawal and depression. Symptoms also include lack of sleep, lack of concentration, exhaustion, anxiety and an increase in health problems.

If you or someone you know is exhibiting signs of caregiver stress, it is important to seek help. The person under stress should go to the doctor for regular check-ups. Ask family members and friends for their help and support. Take advantage of community programs that provide respite and relief from caregiving, practical help with meals or housework and assistance with the care of the person with Alzheimer’s disease. And plan ahead for both the immediate future and the long term. These are just some of the things caregivers can do to make their lives a bit easier.

The Alzheimer Society can help with services such as support groups, counselling, information resources and MedicAlert® Safely Home®, the Society’s wandering registry. The Alzheimer Society also funds research into improved methods of caregiving and service delivery, as well as research into the cause and cure of Alzheimer's disease.
The World Health Organization defines family caregivers as those who provide informal unpaid care. Canada's 3.8 million caregivers are integral to the healthcare system, contributing services valued at $15 billion to seniors with short- or long-term health conditions.

Caregiver stress can be overwhelming, and is greatest among those providing 21+ hours of weekly care, or supporting seniors with depression, cognitive decline, aggressive behaviors, or conditions requiring complex care.

For caregivers, this can result in social isolation, loss of income, family conflict, tension around juggling priorities, and deterioration of both their mental and physical health. What is known to help caregivers is not always available. Greater understanding of ways to foster their resilience is needed.

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The following key ideas surfaced specific to each conference theme:

**CONFERENCE**

- **Caregivers of Seniors with Dementia**
  - (including findings of 11 articles included from 111 unique citations). Multi-component internet-based caregiver interventions have been shown in several small studies to decrease caregiver stress, anxiety, depression and perceptions of burden, and increase self-efficacy and confidence in decision-making. The value of an online tool (iSupport) was explored that would incorporate caregiver self-efficacy and self-management modules recently developed with support of the WHO into web-based resources (provided by the Alzheimer Society of Alberta and the Northwest Territories).

- **Caregivers of Seniors with Complex Needs**
  - (including 10 articles among 46 identified citations). Dealing with end-of-life issues adds to the complexity of interventions and their outcomes. Provision of emotional support and advice on coping that directly assist the caregiver results in decreased distress, improved coping ability and increased caregiver quality of life. Multi-factorial interventions and approaches were explored including the development of provincial frameworks and strategies to provide flexible, simple and practical resources that focus on the whole illness experience.

**PRELIMINARY FINDINGS**

**FOCUS GROUPS**

- For groups with caregivers indicated that they:
  - Don’t necessarily identify themselves as caregivers
  - Often provide support, out of concern or commitment
  - Experience a wide range of emotions
  - Are challenged with interpersonal issues, life & financial stressors
  - Experience impacts to their health, well-being and resilience
  - Most commonly receive support with transportation, house cleaning & maintenance, cooking, and outdoor work.
  - Need support and assistance navigating system complexities
  - Seek to have their knowledge and experience valued, recognized and sought as part of the care team.

**METHODS**

A CIHR grantee planning funded a two-day conference entitled “Supporting Family Caregivers of Seniors: Improving Care and Caregiver Outcomes” was held in Edmonton, AB on April 14-15, 2014.

**PRELIMINARY ENVIRONMENTAL SCAN**

- Preliminary environmental scan, literature review (of Ovid Medline, EMBASE and CINAHL including systematic reviews or randomized controlled trials published in English), and preparation of evidence summaries (by Dr. Jacqueline McMillan).

**PRELIMINARY FINDINGS**

**FOCUS GROUPS**

- For groups with caregivers indicated that they:
  - Don’t necessarily identify themselves as caregivers
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  - Need support and assistance navigating system complexities
  - Seek to have their knowledge and experience valued, recognized and sought as part of the care team.

**DISCUSSION**

**Identified Needs**

1. Development of online tools that support care giver self-efficacy and self-management, and offer web-based resources
2. Centralization and navigation of resources
3. Development of care pathways for caregivers
4. Public education awareness
5. Respite services
6. Advanced Care Planning and goals of care for caregivers
7. Education for healthcare professionals, current & future caregivers
8. Public awareness campaigns

**CONCLUSION**

The 2-day conference aimed at discussing barriers, gaps, facilitators and research priorities related to supporting caregivers of persons with dementia, at end-of-life, and with complex needs successfully drew together key stakeholders provincially, nationally and internationally. Research priorities were developed. Next steps will be Knowledge Exchange activities, formulation of specific teams and preparation of grant proposals.

**REFERENCES**


SUPPORTING FAMILY CAREGIVERS OF SENIORS WITH COMPLEX NEEDS


https://www.dropbox.com/s/vg1k6q2s52lcs46/Complex.pdf?dl=0
SUPPORTING FAMILY CAREGIVERS OF SENIORS: IMPROVING CARE AND CAREGIVER OUTCOMES IN END-OF-LIFE CARE


https://www.dropbox.com/s/0yxayciu6m79czu/End-of-Life.pdf?dl=0

We held a 2-day conference in Edmonton, with pre-conference preparations.

Day 1: Knowledge exchange among 120 attendees – national and international researchers, knowledge users, family caregivers and other stakeholders.

Day 2: Research planning among 76 attendees from Day 1.

The World Health Organization defines family caregivers as those who provide informal, unpaid care.

METHODS

OBJECTIVES

1. To describe the key findings of a CIHR-funded two-day conference entitled Supporting Family Caregivers of Seniors: Improving Care and Caregiver Outcomes.

RESULTS

1. Higher caregiver distress is significantly associated with patient symptom intensity.
2. Higher Caregiver burden is associated with the need for help with daily tasks.
3. Caregivers are interested to increase their nursing skills.
4. Caregiver coping skills interventions lead to decreased burden and increased QOL.
5. Direct emotional support and bereavement care result in positive outcomes for caregivers.

CONCLUSION

Our findings highlight the need for:

1. A synthesis of current literature: caregiver burden, impact on system, best practices and strategies.
2. Designing flexible and practical resources that address the intensity of caregiving.
4. Formulation of care pathways for caregivers.
5. Identification of goals of care for caregivers.
6. Establishment of appropriate, supportive policies that consider the whole picture.

The 2-day conference aimed at discussing barriers, gaps, facilitator and research priorities related to supporting caregivers of seniors successfully drew together key stakeholders provincially, nationally and internationally to focus.

Research priorities were developed. Our next steps will be Knowledge Exchange activities, formulation of specific teams, and preparation of grant proposals.

DISCOVERY TOOLKIT

| 1. Diversity in caregiver experience is related to symptom intensity.
| 2. Family caregivers in end-of-life care report multiple concurrent complex transitions.
| 3. Focus on relationship building and supporting caregivers themselves is needed.
| 4. Advocates/navigators to help caregivers access resources and essential services.
| 5. Goals of services should serve both inside and outside care needs and support of resilience.
|


19. ONLINE RESOURCES

ORGANIZATIONS

Alberta Health Services - Dementia Advice Line
http://www.albertahealthservices.ca/info/facility.aspx?id=1011654&service=1069001
“Albertans can now receive specialized dementia advice by dialing 811.”

Alberta Health Services - Home Care
http://www.albertahealthservices.ca/cc/Page13336.aspx
“Alberta’s Home Care Program supports Albertans of all ages through health promotion, treatments, rehabilitation and home support for you and your family or caregivers.”

Alberta Caregivers Association
www.albertacaregivers.org
“A charity organization that aims to empower caregivers and promote their well-being. We provide one-on-one information, referrals and supportive listening, as well as education and support programs for caregivers.*

Alberta Caregiver College
www.caregivercollege.ca
“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.*

Alzheimer's Disease International
www.alz.co.uk
“ADI is the international federation of Alzheimer associations around the world, in official relations with the World Health Organization.”

Alzheimer Society of Alberta and Northwest Territories
www.alzheimer.ca/ab
“The Alzheimer Society of Alberta and Northwest Territories exists to: heighten awareness about Alzheimer’s disease and related dementia; provide support services; and, support research into the cause and a cure for this disease.”

Alzheimer Society Calgary
www.alzheimercalgary.ca
“We work to ensure that people impacted by dementia have access to high quality education, care and support throughout their journey of impact.

Canadian Caregiver Coalition
www.ccc-ccan.ca/index.php
“The Canadian Caregiver Coalition (CCC) is a virtual alliance of diverse partner organizations that work collectively, and autonomously, to identify and respond to the needs of caregivers in Canada.”

Seniors Association of Greater Edmonton
www.mysage.ca
“The Seniors Association of Greater Edmonton is established to enhance the quality of life of older persons and their families through the work of staff and volunteers, and in collaboration with stakeholders.”
FURTHER READING

Caregiver Consultation 2010: Towards a Provincial Caregiver Strategy (Alberta Caregivers Association, 2010)

“Caregivers are integral providers of care and therefore are equal members of the care team.” (p. 4)

Dementia – A Public Health Priority (World Health Organization, 2012)
http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf?ua=1

Defined by the WHO as “those who provide informal unpaid care”, family caregivers contribute immeasurably to the support of vulnerable seniors. Informal care costs are estimated to be $252 billion of the $604 billion global societal costs related to dementia alone.

Family caregiving: What are the consequences? (Statistics Canada, 2013)

“In 2012, 8 million Canadians, or 28% of the population aged 15 and over, provided care to family members or friends with a long-term health condition, a disability or problems associated with aging.” (p. 1)

Health Care in Canada, 2011: A focus on Seniors and Aging (Canadian Institute for Health Information, 2011)

“Recent data shows that 32% of caregivers who provide more than 21 hours of care per week report distress in their role—four times the proportion of distressed caregivers who provide less than 10 hours of informal care per week” (p. x)

Portrait of caregivers, 2012 (Sinha M, Statistics Canada, 2012)
www.statcan.gc.ca/pub/89-652-x/89-652-x2013001-eng.htm

There is increasing evidence that caregiving is being provided at significant physical, emotional and financial costs to the caregiver. It is estimated that there are over 8 million Canadians providing care to a chronically ill, disabled, or aging family member or friend.

Seniors in need, caregivers in distress: What are the home care priorities for seniors in Canada (Health Council of Canada, 2012)
http://healthcouncilcanada.ca/rpt_det_gen.php?id=348

Family caregivers are the backbone and increasingly overburdened part of the health care system. The Health Council of Canada report on ‘Seniors in need; Caregivers in distress’ outlined the need to support these often vulnerable caregivers and recognized their vital role to the sustainability of the healthcare system.

Study: Caregivers in Canada, 2012 (Statistics Canada)
www.statcan.gc.ca/daily-quotidien/130910/dq130910a-eng.htm

According to a 2012 Canadian survey, most caregivers are between 45 and 64 years of age. More than one-quarter of caregivers are “sandwiched” between caring for parents and raising children. Overall, 28% of caregivers said they would like more assistance, financial or otherwise.

Supporting people who care for older family members (Parmar J, et al., Canadian Medical Association Journal, 2015)
http://www.cmaj.ca/content/186/7/487?cited-by=yes&legid=cmaj;186/7/487

Evidence-based support for family caregivers is not widely available and should be expanded in regional, provincial, national and international efforts to assist family caregivers.

Supporting informal caregivers – the heart of home care (Canadian Institute for Health Information, 2010)
https://secure.cihi.ca/free_products/Caregiver_Distress_AIB_2010_EN.pdf

The burden on and distress among family caregivers is ever increasing. This is particularly evident amongst those who provide >21 hours of care per week, and those who support seniors experiencing depression, moderate to severe cognitive decline, and aggressive behaviours.

Who cares and how much. The imputed economic contribution to the Canadian healthcare system of middle-aged and older unpaid caregivers providing care to the Elderly. (Hollander M, Liu G, Chappell N, Healthcare Quarterly, 2009)

A recent Canadian study estimates the costs of unpaid caregiving at $25 billion.
# CAREGIVER STUDY GROUP

This is a list of participants in the application for the CIHR Planning Grant that funded the conference **Supporting Family Caregivers of Seniors with Complex Needs: Improving Care and Caregiver Outcomes**.

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<tr>
<th>PRINCIPAL APPLICANTS</th>
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<tbody>
<tr>
<td>Jasneet Parmar, MBBS, Dip COE</td>
<td>Medical Director, CH: Network of Excellence for Seniors’ Health and Wellness; Associate Professor, U of A– Family Medicine; Medical Lead, AHS – Edmonton Home Living</td>
</tr>
<tr>
<td>Jayna Holroyd-Leduc, MD, FRCPC</td>
<td>Associate Professor, U of C – Medicine (Geriatrics) and Community Health Sciences; Immediate Past Scientific Director, AHS Seniors’ Health SCN</td>
</tr>
<tr>
<td>Nathalie Jette, MD, MSc, FRCPC</td>
<td>Professor, Departments of Clinical Neurosciences and Community Health Sciences, University of Calgary, Calgary, Alberta</td>
</tr>
<tr>
<td>Suzette Brémault-Phillips, OT, PhD</td>
<td>Assistant Professor, U of A – Rehabilitation Medicine</td>
</tr>
<tr>
<td>Tarun Dua, MD, MPH</td>
<td>Medical Officer, WHO – Programme for Neurological Diseases &amp; Neuroscience; iSupport</td>
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<tr>
<td>Robin Cohen, PhD</td>
<td>Associate Professor, McGill University – Oncology</td>
</tr>
<tr>
<td>Janet Kushner Kow, MD, Med, FRCPC</td>
<td>Clinical Assistant Professor-Geriatric Medicine, Univ. of British Columbia</td>
</tr>
<tr>
<td>Tricia Woo, MD, MSc, FRCP</td>
<td>Associate Professor, McMaster University – Medicine</td>
</tr>
<tr>
<td>Lesley Charles, MBChB, CCfP</td>
<td>Associate Professor, Family Medicine, U of A; Program Director, Care of the Elderly Postgraduate Program, U of A</td>
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<th>CO-APPLICANTS</th>
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<tr>
<td>Ann Syme, RN, PhD</td>
<td>Director, CH – Palliative Institute</td>
</tr>
<tr>
<td>Marjan Abbasi, MD, CCfP</td>
<td>Clinical Assistant Professor, U of A – Family Medicine; Site Leader Geriatric Program, CH – Misericordia Hospital</td>
</tr>
<tr>
<td>Heather Hanson, PhD</td>
<td>Assistant Scientific Director, AHS – Seniors’ Health SCN</td>
</tr>
<tr>
<td>Jamie Davenport, MHS, CHE</td>
<td>Director, AHS – Home Care Development</td>
</tr>
<tr>
<td>Charlene Knudsen, BScN, MEd</td>
<td>Program Manager, AHS – Home Living</td>
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<th>KNOWLEDGE USERS</th>
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<tr>
<td>Glenda Coleman-Miller, MHS</td>
<td>Executive Director , CH – Network of Innovation for Seniors’ Health</td>
</tr>
<tr>
<td>Anna Mann</td>
<td>Executive Director, Alberta Caregivers Association</td>
</tr>
<tr>
<td>Arlene Huhn</td>
<td>Manager, Client Services &amp; Programs, Alzheimer Society of Alberta &amp;NWT</td>
</tr>
<tr>
<td>Heather Jones, BA/BSW, RSW</td>
<td>Social Work Professional Practice Lead, AHS – Home Living</td>
</tr>
<tr>
<td>Heather Luneburg, BASc(Gerontology), RT</td>
<td>Lead, AHS – Home Care Development</td>
</tr>
<tr>
<td>Rachel Bryant</td>
<td>Policy Consultant, Alberta Health–Home Care Policy &amp; Implementation</td>
</tr>
<tr>
<td>Sandy Maclean, BScOT</td>
<td>Manager, AHS – Home Living (Geriatric Consult Team)</td>
</tr>
<tr>
<td>Grace Maier</td>
<td>Director, AHS – Glenrose Rehabilitation Hospital (Specialized Geriatrics)</td>
</tr>
<tr>
<td>Carolyn Cashin, BScK, BSc, OT, DCA</td>
<td>Capacity Assessor, CH – Capacity Assessment Support Service</td>
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<tr>
<td>Gordon Self, DMin</td>
<td>Vice President , CH – Mission, Ethics and Spirituality</td>
</tr>
<tr>
<td>Christene Gordon, BFA, BEd</td>
<td>Director, Client Services &amp; Programs, Alzheimer Society of Alberta and NWT</td>
</tr>
<tr>
<td>Roger Laing</td>
<td>Executive Director, Seniors Association of Greater Edmonton</td>
</tr>
<tr>
<td>Egon Jonsson, PhD</td>
<td>Executive Director and CEO, Institute of Health Economics, Professor-Health Economics (Adjunct, Universities of Alberta and Calgary)</td>
</tr>
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</table>

AHS Alberta Health Services; CH Covenant Health; SCN Strategic Clinical Network; UofA University of Alberta; UofC University of Calgary; WHO World Health Organization

Contact Us
Jasneet Parmar, MBBS, Dip COE
Associate Professor, Department of Family Medicine, University of Alberta
Medical Director, Network of Excellence in Seniors Health and Wellness, Covenant Health
1100 Youville Drive West, DC-405, Edmonton, Alberta T6L 0A3 Canada
Jasneet.Parmar@covenanthealth.ca