
Designated Care Partner Project

A joint initiative by

Dementia Network Calgary

Health Coalition of Alberta

Caregivers Alberta

The Canadian Red Cross

Alzheimer Society of Calgary

Lifestyle Options Retirement Communities

Two Long Term Care Operators based in Calgary (to be announced)

University of Calgary

to

Facilitate safe and responsible access of essential family caregivers to continuing care environments during the COVID-19 public health pandemic

A National Conversation about Seniors Care

The onset of the COVID-19 public health pandemic has sparked a national dialogue about seniors care in Canada. The conversation has become increasingly focused on the importance and value of family caregivers to, not only their family members living with dementia, but also the Canadian healthcare system. Family caregivers are a national healthcare resource and are a critical factor in the provision of care for people living with dementia. Even before COVID-19, there were 8.1 million family caregivers in Canada and they contributed \$25 billion annually in unpaid care.

The physical distancing and infection control requirements of COVID-19 have disproportionality impacted older adults, particularly those residing in long-term care. Canadians over the age of 60 account for 36% of the cases but 95% of the deaths, with 82% of the total deaths being linked to long-term care and seniors' homes. Of those residing in long-term care homes, 69% have a formal diagnosis of dementia. As older adults living with dementia confront COVID-19, family caregivers fulfill an ever-expanding role in helping curb the spread of the disease as well as supporting their family member to cope with the stress and anxiety of this unprecedented situation. Unfortunately, as policy-makers and other key stakeholders have worked to accommodate the restrictions to promote safety, older adults have faced the unintended consequences and have suffered from being isolated from essential services.

Specific and early restrictions on access to people living with dementia - in institutional residential facilities and in home-care environments, have been prolonged resulting in deterioration of care levels for these persons and subsequent reduction in their quality of life.

In most Canadian jurisdictions, essential family caregivers have been denied access to loved ones, despite these individuals not being visitors but critical participants in the care of the person living in continuing care. Pre-COVID-19, these individuals attended to the daily needs of loved ones, providing such services as feeding, toileting, dressing, personal hygiene and companionship.

It is widely recognized that family caregivers provide essential care that results in therapeutic benefits including staving off social isolation. For people living with dementia, social isolation can have devastating effects including an increase of responsive behaviours as well as a progression of cognitive impairment. The current COVID-19 pandemic is particularly difficult for people with dementia as they are often incapable of understanding why a caregiver has suddenly become absent. For people living with dementia, these caregivers are often the only people they recognize and trust.

A recent qualitative study from the University of Calgary in collaboration with the Seniors Health SCN indicates that some family caregivers reported an accelerated cognitive decline in their loved one which was attributed to the effects of social distancing and suggested

advocating for the resumption of respite services. Nationally recognized gerontologists are also expressing concern around the impacts of Confinement disease. Confinement disease is defined as the deleterious effects of reduced care and minimal interactions for continuing care residents that result in declining physical and mental health and, in the one study, increased mortality rates.

The national conversation about seniors' care widely recognizes the need for caregiver access policy to evolve in time for the next wave of COVID-19, which is expected as early as the fall of 2020. It also recognizes the complexities of balancing the care for people living with dementia, and in continuing care facilities, against the threat of COVID-19. In a current pilot study with researchers from the University of Calgary, family caregivers are expressing great concern for the family member residing in continuing care facilities. As one family caregiver shared: *"Biggest worry - it started out being that they might get Covid. Now, it's that they will go nuts - my Mom's isolation has been severe as she is also on a dementia ward - 2, three week Covid isolations and the a few GI isolations due to her roommate and then, just the isolation from my Dad (he is on a different floor, same building) and then his hospitalization... my biggest fear now is that this is how their last few years of life will be - like this. Absolutely awful. **They fear isolation more than Covid.**"*

The current public order in Alberta allows for essential family caregivers, but access is determined solely by operators and their concerns around contagion risk are preventing caregivers access to their facilities to provide critically needed care services to persons living with dementia. Proactive solutions that meet the needs of seniors, caregivers and continuing care operators can be achieved by designating family caregivers as Designated Care Partners; essential service providers for people living with dementia.

Designated Care Partners

A Designated Care Partner (DCP) is any person that the resident and/or substitute decision-maker (SDM) identifies. The resident and DCP work with the health care team to define how they will be involved in care, care planning, and decision-making. DCPs fill a care-needs role similar to that of healthcare aides (bathing, dressing, toileting, and eating). A DCP is ***not an alternative to or synonymous with a patient visitor***, therefore they are not intended or designed to be in lieu of patient visitor policy or processes.

A DCP has formal training in the proper use of personal protective equipment (PPE) as well as infection control and prevention (IP&C) and is subject to the same COVID-19 pre-screening protocols as their fellow healthcare workers.

Other provinces in Canada have incorporated Designated Care Partners into continuing care operations, including Saskatchewan, Ontario and Quebec. Designated Care Partners and the processes to train them address many concerns raised by facility operators including, but not limited to:

1. PPE training and certification;
2. COVID-19 pre-screening protocols;
3. adherence to current Public Health Orders; and
4. verifiable designation to ensure consistency of care as pandemic protocols adjust to the ebb and flow of public infection rates.

The designation of Designated Care Partners would contribute to confidence in the government's public health measures during COVID-19. This could be accomplished by:

1. Identifying Designated Care Partners for people living in continuing care facilities as distinct from familial or social visitors;
2. serving a specific purpose in care provision;
3. assisting the healthcare team in decision making; and
4. following established infection prevention protocols.

It is imperative to implement this type of designation now as people living with dementia are at risk for escalating and continued adverse health outcomes.

Proposal

Goals

- Develop a rigorous set of training and evaluation protocols, in partnership with continuing care operators, to mitigate concerns associated with the potential for in-facility COVID-19 outbreaks, and to allow for ease of implementation.
- Develop and assess policy-oriented solutions to mitigate the deleterious impacts of isolation and lack-of-access to family caregivers for people living in continuing care environments.
- Demonstrate the commitment of civil society to assist the Government of Alberta and continuing care operators in developing safe and responsible policies to permit access of essential caregivers during the COVID-19 public health pandemic, and in advance of an increase in public infection rates.

Overview

Partner organizations will form a steering committee to develop and standardize a DCP program, which will recruit potential candidates who meet the definition of an essential caregiver as defined by Alberta's Chief Medical Officer of Health Public Health Order 14-2020.

DCP candidates will undergo an in-depth and rigorous training program focused on the correct use of PPE, hygiene protocols, and safety standards supporting public health pandemic guidelines. Safety protocols, developed in conjunction with a continuing care operator partner organization will guide the training.

PPE and safety protocol training and certification by a national charitable organization will be issued in the context of the pilot project, to ensure trainees and operators share a mutual understanding of expectations and in-facility protocols. Trainees and operators will be supplied with the appropriate PPE by stakeholder partners as required.

DCPs will be granted access to the continuing care facility, as per the stipulations of the operator and critical care services will be provided in alignment with the training that has been provided.

Our academic research partners will measure and evaluate the outcomes of DCP access to residents in continuing care facilities. These outcomes will include: 1) COVID-19 infection rates; 2) physical and mental health outcomes of the residents, caregivers, and facility staff; and 3) workplace health and safety compliance.

The study will be complete by September 2020, and will inform a series of recommendations to assist in the broader development of visitation policy by the Chief Medical Officer of Health and the Government of Alberta.

If the pilot study shows effectiveness of the DCP program, the project will be further developed and disseminated for a national roll-out and include a yearly certification requirement similar to those offered for CPR and First Aid.

Project Partners

Partner	Role
Dementia Network Calgary	<ul style="list-style-type: none">● Project lead● DCP recruitment
Caregivers Alberta	<ul style="list-style-type: none">● Project support● DCP recruitment
Canadian Red Cross	<ul style="list-style-type: none">● Provide PPE and IP&C training● Certify DCPs who complete the training
Health Coalition of Alberta	<ul style="list-style-type: none">● Knowledge Transfer● DCP recruitment
Alzheimer Society of Calgary	<ul style="list-style-type: none">● Communication training for DCPs● Research funding
United Way	<ul style="list-style-type: none">● Funding for PPE and IP&C training
Care Facility Operators	<ul style="list-style-type: none">● Provide site-specific training● Host the pilot project at its facilities● Facilitate research activities● PPE Provision (via Alberta Health)
Dr. Gwen McGhan RN, PhD, GNC(c), Assistant Professor, Faculty of Nursing, University of Calgary	<ul style="list-style-type: none">● Research lead● Measure the outcomes of the project
Dr. Deirdre McCaughey, PhD MBA, LSSGB, Associate Professor in the Cumming School of Medicine, Department of Community Health Sciences at the University of Calgary, O'Brien Institute for Public Health W21C Research and Innovation Centre	<ul style="list-style-type: none">● Research lead● Measure the outcomes of the project

Supporters

These individuals and organizations publicly support the creation of a DCP designation in Alberta and all advocacy efforts to reduce restrictions on caregiver access to people living with dementia. The care provision actions of essential caregivers are critically needed to protect the health and wellness of Albertans.

- Barb Ferguson, Alzheimer Society of Calgary
- Kristi Puchbauer, Alberta Hospice Palliative Care Association
- Donna Durrand, Alberta Council on Aging
- Lisa Poole and MaryBeth Wighton, Dementia Advocacy Canada
- Annastasia Stevens, Calgary Seniors Resource Society
- Judy Birdsell, IMAGINE Citizens Collaborating for Health
- Mollie Cole, Past-President, Canadian Gerontological Nursing Association

Role for Government of Alberta

Partner organizations invite the Government of Alberta to help develop a “Made in Alberta” solution to the national challenge of caregiver access to continuing care facilities during the COVID-19 public health pandemic, by:

- Joining the pilot project steering committee;
- validating the research effort; and
- committing to consider the research outcomes and policy recommendations to follow.

Current Project Leads

Dementia Network Calgary

The Dementia Network Calgary is a multi-stakeholder organization with representation from families impacted by dementia and members from academic, private, non-profit, and public sectors. We work to improve the quality of life for people living with dementia.

Since the onset of the COVID-19 public health pandemic, our organization has collaborated with several stakeholders in the continuing care space - including Caregivers Alberta and the Health Coalition of Alberta, to urge relaxation of COVID-19 restrictions on public home-care respite workers for people living with dementia, and for family caregivers to people living in continuing care facilities.

We have focused our advocacy efforts on offering positive solutions to government that harnesses the power of civil society.

The caregiver organizations we represent share concerns that any easing of restrictions must balance the benefit to vulnerable seniors against the risk of exposure to infection of COVID-19, especially in shared living facilities.

Health Coalition of Alberta

We are a Coalition of voluntary sector groups advocating with a united voice for better access to optimal health care for all Albertans. Our mandate is to advocate for people-centered health care in Alberta. Through the strength of our membership, we will be consulted with, and listened to, when decisions are made that impact the health of Albertans.

We are an alliance of patient and consumer individuals, groups, health charities, non-profits and other coalitions. We have come together to strengthen our voice in advocating for and supporting a health care system that provides the best care and treatment options to every Albertan. We are a united voice advocating for better access to optimal health care for all Albertans.

Caregivers Alberta

Caregivers Alberta is a not-for-profit association that works to raise the profile of and public support for caregivers, their issues and Caregivers Alberta. We provide programs that meet the information, education, support, networking, and advocacy needs of individual caregivers and work to influence and affect systems change at all levels to recognize caregivers and address their needs. We support communities and their caregivers throughout Alberta and aim to ensure the growth, sustainability, relevancy, and effectiveness of Caregivers Alberta.

The Canadian Red Cross

The Canadian Red Cross works to improve the lives of vulnerable people by mobilizing the power of humanity in Canada and around the world. The Canadian Red Cross Society is part of the largest humanitarian network in the world, the International Red Cross and Red Crescent Movement. This network includes the International Committee of the Red Cross (ICRC), the International Federation of Red Cross and Red Crescent Societies (Federation) and 190 National Red Cross and Red Crescent Societies dedicated to improving the situation of the most vulnerable throughout the world.

Lifestyle Options Retirement Communities

Lifestyle Options Retirement Communities are locally owned and its mandate is to operate quality, affordable seniors' retirement buildings. We endeavor to create and sustain affordable, supportive retirement communities that foster healthy aging by focusing on the strengths and capabilities of each individual in meaningful life experiences through active living.