

CARP's New Vision for Living in the World of Dementia



A Paradigm Shift for Dementia Care

Dementia is an illness that robs people of their personality, cognitive ability, independence, control, and well-being – essential traits that make a person who they are. As dementia erodes the ability to reason, remember, and to make everyday decisions, constant supervision and intensive care become critical for personal safety and wellbeing. As a result, living in the world of dementia is often frightening, daunting, and unpredictable for the patients as well as for their family and friends providing round-the-clock intensive care.

The larger challenge is that the healthcare system is not well structured to provide patient-centred care to patients with dementia and their caregivers. There is an immediate need for a paradigm shift in how we think about and care for people with dementia and to support the friends and family members who provide care. With the right care in place, people with dementia and their caregivers can maintain a good quality of life. The healthcare systems and governments must enter the world of patients and families living with dementia to better understand and meet their complex needs.

The reach of dementia is widespread and it will continue to grow:

- 750,000 Canadians were living with dementia in 2011ⁱ, and millions more provide informal careⁱⁱ
- Within 20 years, the number of Canadians with dementia is expected to double to 1.4 millionⁱⁱⁱ
- 1-in-10 Canadians say they are the primary caregiver for someone with dementia^{iv} – that means a potential 3.5 million Canadians

The total global societal costs of dementia - direct medical costs, social care, and unpaid caregiving by families and friends, - were estimated to be \$604 billion US in 2010, according to the World Health Organization.^v In Canada alone, the societal costs of dementia have been estimated at \$15 billion in 2010.^{vi}

Research has identified the warning signs, risk factors, symptoms, and behaviours associated with dementia, but there is still no cure, little conclusive evidence of the cause, and very few options for treating symptoms. Several drugs to treat symptoms are available but they have been proven to be minimally effective.^{vii viii} Continued research to find a cure and more effective treatment is important, but patients and caregivers struggling with dementia need help now to deal with their day to day challenges. Often, the families do not know how to care for sufferers, cope with the associated emotional distress, and to manage the financial and time burdens to care for sufferers. Stigma and misunderstanding further exacerbate the challenges, preventing people from discussing their symptoms with their families or seeking medical attention. Meanwhile, there are not enough front line health care workers with the necessary specialized knowledge and the healthcare resources are deployed where and when they are needed most. Consequently, CARP calls for a paradigm shift in dementia care so that patients and their families can better manage their needs and have access to resources to help them live well with dementia.

A Comprehensive New Approach to Dementia Care is needed

People with dementia and their families struggle to live with the condition. Despite the increased public awareness and knowledge of the disease, the necessary care and supports to allow people to live a high quality of life are limited. Research for cures and treatments are essential, but unlike other chronic diseases that may be more manageable, families need help to grapple with the complex care demands of dementia.

Governments and provincial healthcare systems need to understand the world of dementia from the patients' perspective in order to provide effective resources, financial means, and policies that will help them manage the daily realities of dementia. This not only means better access to specialized services but may also require fundamental change in how care is delivered.

CARP is calling for a paradigm shift in how we care for dementia. Canadians need a comprehensive approach that addresses the unique challenges of dementia and invests in supporting those living with it. This can be achieved by investing in:

- 1. Greater caregiver training, support and respite care**
- 2. Mandatory dementia care training for healthcare providers and personal support workers**
- 3. More specialized home care and long-term care with redesigned care protocols and built environment to be dementia-friendly**

CARP recommendations recognize that care for dementia is different from other chronic care, specifically addressing the complex world of dementia. This approach to care is urgently needed not just for patients but also for the families and caregivers who also live in the world of dementia.

Dementia Requires Intensive, Round-the-Clock Care

Dementia is defined by the World Health Organization as a “syndrome, usually of a chronic or progressive nature, caused by a variety of brain illnesses that affect memory, thinking, behaviour and ability to perform everyday activities.”^{ix} Depending on the type of dementia and stage of

the disease's progression, typical behaviour includes wandering and getting lost, memory loss that affects daily function, aggression and delusion, difficulty with language, and performing familiar tasks, and often, loss of executive function.^x

Due to the complex symptoms and behavioural challenges, people with dementia often require round-the-clock supervision and intensive, heavy care, defined as 20 hours of care or more per week^{xi}. As a result, dementia among older persons in high-income countries like Canada is the leading cause of dependency, defined as “the need for frequent human help or care beyond that habitually required by a healthy adult”.^{xii} Intensive caregiving includes assisting with daily activities, such as providing transportation, cooking meals, and grocery shopping, as well as providing functional support, such as assisting with clothing, bathing, feeding, and toileting.^{xiii} Most of this care is provided by informal caregivers, but once caregiving demands increase to heavy, intensive care levels, many turn to home care and long-term care homes for additional support.

Dementia is often compounded with other chronic conditions, such as arthritis, cancer, heart disease, diabetes, and high blood pressure, making it more challenging for the sufferers along with their caregivers. Almost 75% of Canadians aged 65 and older have at least one chronic condition, with a majority of them dealing with multiple conditions.^{xiv}

Managing other conditions can be a greater challenge for those with dementia particularly due to their difficulty with communication and language. As a result, patients who cannot identify their source of their pain may be given antipsychotics for their agitation instead of their pain or discomfort. The Beatitudes Campus, a nursing home in Arizona, understands this challenge and has already made the paradigm shift in caring for dementia. The staff are trained to understand what it is like to have dementia and how to better care for their patients with dementia. As a result, they anticipate and address patients' needs before patients behave negatively.^{xv} The care is not directed by staff routines and procedures but is instead, responsive the patient's comfort levels and preferences.

Caring for the Person, Not the Disease

Dementia does not look the same for all individuals. Often the symptoms and progression of the disease vary with each person and type of dementia. Therefore, care must be individualized, responsive to the person's preferences, behaviour, and specific needs. Care must go beyond the disease, extending to the person as a whole.

CARP advocates for person-centric healthcare in its *One Patient* model.^{xvi} A patient-centred approach takes into consideration the specific health challenges and psychological and emotional needs of each patient.^{xvii} Care should be provided so that it preserves a person's dignity and autonomy and promotes the person's emotional and mental well-being.

Canada's healthcare system has yet to fully adopt person-centric care. Moving into a long-term care home is generally a disruptive process. It is particularly difficult when the patient's emotional and psychological needs are not addressed and health care professionals are unprepared to deal with the challenges of dementia. Most challenging is dealing with the difficult behaviours of dementia patients – wandering, being more active at night,

Hogewey, Dementia Village

A Patient-Centered Care Example

In Holland, a care facility embodied patient-centered care by creating a "Dementia Village", a self-contained alternate reality that allows residents to live independently and safely. The village resembles any other community, complete with shops, living quarters, and even a grocery store and hair salon. It is designed in a homelike setting to allow residents to feel comfortable and live a seemingly normal life, but completely staffed with caregivers trained in dementia care, equipped with 24 hour surveillance, and secured with a locked entrance to the village. Residents are able to wander freely and are encouraged to remain active. As a result, residents are healthier physically and mentally, taking fewer drugs than those in traditional nursing homes.

Source: <http://www.vivium.nl/hogewey>

Starlight Program for Alzheimer's

A Patient-Centered Care Example

In New York, the *Starlight Program* at Riverside Health System provides an evening program for adults with Alzheimer's who experience "sundowning", an associated behaviour common to patients with Alzheimer's who tend to become more active and stimulated in the evening. Instead of the traditional model of day programs, which forces patients to bed in the evening, programs like the Starlight Program provide a stimulating experience for patients throughout the night, which satisfies their needs and provides relief for the caregivers. However, this requires a fundamental shift in how and when care homes are staffed.

Source: www.riversideonline.com

confusion, delusion, aggression - potentially endangering themselves and those around them.

Many long-term care homes use "one size fits all" medical approaches to care that are task-oriented and disease-centric. Too often, physical constraints or drugs are used to control difficult behavioural issues rather than addressing the cause of the disruptive behaviour.

A paradigm shift is needed in how we care for dementia, from a disease-centric to a person-centric approach. Studies have found that people with dementia were less aggressive and agitated with person-centered interventions and care instead of the commonly used drugs. For example, at the Beatitudes Campus nursing home, a resident, a retired dentist, was distressed by the staff requesting a dental exam and refused to cooperate. Rather than using force or drugs, she simply opened her mouth for him to peer inside, an act that was familiar to him and caused him to calm down.^{xviii} Her understanding of the patient and his past as a dentist directed the way she interacted and cared for her patient. Not only did this allow the patient to participate in a meaningful way, but it also encouraged positive patient response. Patient-centered care can improve patient outcomes and well-being while reducing the need or drugs that treat behavioural issues associated with dementia.^{xix xx}

Major Gaps in Care for Dementia

There are serious gaps in care that threaten the quality of life for people living with dementia and for their loved ones. There is a lack of caregiver support for the millions of informal caregivers providing informal intensive care. Secondly, there is a lack of training and expertise in dementia diagnosis and care among health care professionals and personal support workers. Finally, there is a lack of accessible and specialized long-term and home and community care to deal with dementia and the failure of the operational norms to address the actual needs of dementia sufferers.

Lack of Caregiver Support

Caregiving for people with dementia is often overwhelming and frightening for families, who usually become the informal caregivers. Polls have shown that 1-in-10 Canadians say they are the primary caregiver for someone with dementia,^{xxi} representing potentially 3.5 million Canadians, many of whom are providing heavy care.^{xxii} Despite the large numbers, there is a serious lack of formal supports and resources. As a result, caregiving, especially intensive caregiving, can be disruptive financially, mentally, emotionally, and physically.

The round-the-clock care demands of the dementia sufferer often disrupt normal work routines for informal caregivers, requiring them to adjust their working hours, take time off, or even leave the workforce with the attendant loss of income. Workplaces lack caregiver leave programs, job protection for caregivers, and flexible hours or work arrangements.

Governments provide limited financial support for caregivers and insufficient funding for home care and social support programs. In addition, caregivers often bear out-of-pocket expenses, such as transportation, care aids, and professional help to assist with care, all of which creates a significant financial challenge.^{xxiii}

Informal caregivers are unprepared to provide dementia care. Families need formal training and support from the healthcare system to understand the progression of dementia, strategies to deal with challenging behaviours and symptoms, and steps to maintain the safety and health of the person with

dementia. Dementia patients and their families also need to be prepared for the eventual loss of the patient's executive functioning, in which case the families may need to make care decisions on behalf of the patient, including end-of-life care decisions. Patients and their families should be informed of the importance of having conversations about end-of-life decisions, while the patient is able to express their wishes, so that families can be prepared.

Caregivers need respite care and tools to deal with the mental and emotional demands of caregiving, which are their most common challenges.^{xxiv} Caregivers commonly report feeling worried or anxious, tired, overwhelmed, resentful, and lonely, which can also lead to other negative effects on their physical health.^{xxv xxvi}

The levels of emotional and health distress increase with the intensity of care, particularly if it involves behavioural problems or cognitive deficits, such as with dementia.^{xxvii xxviii} High levels of emotional distress and stress are a major concern not only due to the health and safety of the caregivers but also the health and safety of the care recipient.^{xxix}

Lack of Training & Dementia Expertise

Almost half of Canadians with dementia are not being diagnosed early enough^{xxx} due to two main reasons. First, there is a general lack of awareness of dementia and its warning signs among Canadians. As a result, families do not catch warning signs or seek out medical testing early enough. Second, there is a lack of training and expertise in dementia among physicians and healthcare providers.

Most people identify their physicians as the primary source of support when faced with caring for a family member with dementia.^{xxxi} Many family physicians, however, feel uncertain in diagnosing dementia and are reluctant to label patients as having the "disease", according to a Canadian study.^{xxxii} Family physicians have expressed the need for more specialists to help with assessments since identifying dementia is often complex, difficult, and time consuming.

Even when dementia is diagnosed, patients are often inadequately equipped and informed about the kinds of support and resources available to

them. Studies found that family physicians lack awareness of the types of community services and resources that would help patients with dementia.^{xxxiii} More training is needed among physicians but it is also needed for all healthcare providers and personal support workers that care for people with dementia.

Lack of Specialized Homecare & Long Term Care

Dementia patients may at some point require the type of care that can only be offered in a healthcare institution. Due to the strains and limits of informal caregiving, many caregivers eventually seek help from the formal healthcare system either through community resources or institutional care.

In the UK, caregivers identified the most common reasons for admitting their loved one into a long-term care home: the inability to cope with increasing care demands, the care recipient's inability to live independently, the demand for 24 hour care, safety reasons, the advice of health/social care provider, and abusive and aggressive behaviour.^{xxxiv}

Despite the great need, it is a challenge to access community resources and/or institutional care across most of Canada. Wait lists to receive home care or a spot in a long-term care home are long, further straining informal caregivers and threatening the well-being of patients. In Canada, 40% of acute care patients were waiting for residential care in 2012.^{xxxv} More concerning, the people were waiting were more likely to be people with dementia or challenging behaviours due to

LTC Wait Times are Too Long

The Canadian Institute of Health Information's Wait Time Report in 2012 revealed that:

- Ontarians wait an average of 4 months for long-term care
- Nova Scotians wait an average of 5 months for long-term care

their need for specialized services.^{xxxvi}

Additionally, the design of care environments has a direct impact on the experience and care of patients with dementia and the staff's well-being.^{xxxvii}

Dementia-friendly design principles are needed to create spaces that enhance a sense of security, control, and independence, reducing feelings of confusion, failure, and alienation/imprisonment. For example, rooms could be furnished and decorated to give residents a sense of familiarity, reducing confusion and feelings of alienation. Larger facilities could have hallways that loop back to allow safe wandering as well as visual cues to assist with orientation.^{xxxviii}

In Germany, police found that wandering Alzheimer's patients often felt the need to go home, so they look for public transportation. As a result, fake bus stops were built in front of nursing homes for wandering Alzheimer patients, which has helped staff to diffuse the patients' sense of panic and avoid the need for physical restraints.^{xxxix} Such examples show that the built environment also has an important role in how we better care for dementia.

CARP Recommendations

Action is needed immediately to help people with dementia and Alzheimer's disease live quality lives. In fall of 2014, the federal government announced the National Dementia Research and Prevention Plan that outlined various research initiatives and investments to promote healthy living. It was also announced that Dementia Friends program from the UK, which aims to make dementia friendly communities by raising public awareness and reducing stigma around dementia, will be implemented in 2015.

Such research and health promotion is important but people with dementia and their families are still without the needed resources, supports, and care to deal with the realities of dementia today. According to CARP Polls™, three-quarters of members polled are concerned about the onset of dementia, and most CARP members (81%) think Canada is not prepared for the projected growth of dementia cases as the boomers age.^{xl}

CARP advocates for existing healthcare systems and policies to enter into the world of dementia to understand the patients' perspective and shift to a person-centric approach to care. This is particularly important in dementia care as it requires specialized knowledge and a fundamental change in how care is delivered, including when and by whom. CARP's *One Patient* model^{xli} calls on governments to reorganize the healthcare system into one that is integrated and coordinated, allowing patients to navigate the system from one component to another – a system that provides an integrated continuum of care in which care is timely, easy to access, and appropriate. Meeting a patient's full spectrum of health needs is inherently "patient-centred". The next step in the refinement of patient centred care is to specifically address dementia care, including specialized training, the enhanced role of informal caregivers and a fundamental shift in how, when and where care is provided and funded.

In addition to finding a cure and better treatment options for dementia, CARP recommends:

1. Greater Caregiver Support

- Financial supports for all caregivers to relieve the financial burdens of caregiving. The single determinant should be need rather than artificial limitations, such as the Compassionate Care benefit's "terminal illness" requirement, and it must target those who provide heavy care.
- Workplace protection for caregivers who are balancing caregiving and work responsibilities, such as Ontario's Family Caregiver Leave Bill that would provide 8 weeks of job-protected leave for caregiving.^{xlii}
- Respite care options for caregivers to mitigate the high risk of their own physical, mental, and emotional health deterioration. For example, Germany's long-term care insurance allows family caregivers up to 4 weeks of vacation while using their insurance benefits, providing crucial respite care for informal caregivers.^{xliii}
- Formal training, resources, and support on dementia care should be provided for caregivers by the healthcare system.

- Advance guidance and support to help caregivers and dementia patients make care decisions, including end-of-life decisions, which are reflective of the patient's wishes.

2. Training & Expertise in Dementia Diagnosis and Care

- Family physicians to be better trained to use early diagnostic tools and to provide dementia care and support to patients and their families
- Advanced care planning and guidance by health professionals to be available for patients and their families
- Frontline healthcare providers and personal support workers, especially those working in long-term care homes, to be trained to understand dementia, care for dementia, and provide person-centered care.
- Curriculum of medical schools to include geriatric and dementia care, and encourage more students to specialize in geriatrics.

3. More Specialized Home Care and Long-Term Care

- More funding for home care and long-term care to reduce long wait times.
- Redesign protocols and procedures in long-term care homes to better respond to dementia behaviours and needs, such as limiting the use of anti-psychotics and ensuring adequate staffing levels in long-term care homes especially at night
- Built and interior designs of long-term care homes that are mindful of dementia patients' behaviours and needs to facilitate a safer, dementia-friendly environment.

People living in the world of dementia as well as their families cannot just wait for more research to find a cure. As they wait, they urgently need resources and proper care to help them with the daily challenges and hardship they face today. CARP is calling on governments and healthcare systems to step into the world of those living with dementia and shift how we care for those with dementia and their families. Canadians need a comprehensive approach to dementia care so that people with dementia can live high quality lives for as long as possible.

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