Société **Alzheimer** *Society*

"Culture Change in Long Term Care"

An Overview of the Research in Six Long Term Care homes

I. Background

The Alzheimer Society of Canada (ASC) has an obligation to people at every stage of dementia – including helping healthy people stay healthy right through to end of life. One can argue that people living with dementia at the late and end of life stages of the disease are the Alzheimer Society's most vulnerable clients. One can further argue that ASC's obligation to Canadians living with dementia is most urgent when it is to people who are, for the most part, unable to speak for themselves.

Consequently, in 2008, ASC made the decision to embark on a "culture change" initiative that would focus on the needs of people with dementia living in long term care homes and their family members through a person-centred approach. This approach is beneficial for all people with dementia regardless of the stage of the disease or the setting where they live, and is based on the values of dignity and respect, information sharing, participation, and collaboration.

Most people with dementia want to live in their own homes for as long as possible. The reality is, however, that many will move to a long term care home. Fifty-seven percent of seniors living in a residential care home have a diagnosis of Alzheimer's disease and/or other dementia[1], and 70% of all individuals diagnosed with dementia will die in a long term care home[2].

While this initiative focuses on working with others to improve the experiences of people with dementia living in long term care homes, the process and outcomes of this work are intended to inform conversations about quality of life throughout both the disease and health care continuum.

The culmination of the first phase of this initiative was the launch in 2011 of the document, "Guidelines for Care: Person-Centred Care of People with Dementia Living in Care homes" (January 2011). This document summarizes current evidence-based guidelines for care of people with dementia living in long term care, and can be viewed by clicking on the following link.

http://www.alzheimer.ca/~/media/Files/national/Culture-change/culture_change_framework_e.ashx

The content of this document has also served as a platform for phase 2 of this initiative to help formulate our enquiries into how person-centred care can be provided in a long term care home environment.

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[1] Canadian Institute for Health Information, Caring for Seniors with Alzheimer's Disease and Other Forms of Dementia, August 2010.

[2] Mitchell S, Teno J, Miller S, Mor V: *A national study of the location of death for older persons with dementia.* JAGS 2005, 53:299-305.

II. Methodology for the Research in Six Long Term Care homes

A Steering Committee, including representatives from the long term care industry, was formed to help guide this second phase of the initiative. It was led by two co-chairs who have demonstrated expertise in, and commitment to, improving the quality of life of individuals with dementia living in long term care homes. Steering Committee members reflected diverse backgrounds with clinical, academic, organizational and personal expertise.

After discussion and deliberation, the Steering Committee gave the second phase of this initiative the following direction.

1. Ensure that this phase does not duplicate work already being done by others, but rather builds on it. Ensure that it adds value and helps to fill existing gaps in the provision of person-centred care in long term care homes in Canada.

2. Take into account that, while there is already much research that informs what person-centred care is/should be, it is putting these factors into practice which is the greatest challenge for long term care homes.

3. Tease out how it is possible for folks to start and continue on the *culture change journey*.

   What seems to be needed are practical tools and tips to help long term care homes adopt a cultural change which embodies the principles of person-centred care (i.e., translate the theory and research into something useable to long term care administrators, staff and others).

4. The gap that this phase of the initiative should fill, which does not duplicate other efforts, is to provide long term care homes with some tools to help them create culture change by learning how homes who are on the *culture change journey* have made progress.

To enact this direction, a plan was developed and executed to conduct market research in 6 long term care homes situated across Canada, which were selected on the belief that they are providing elements of leading-practice, person-centred care to their residents with dementia.

A group of subject matter experts was recruited to help identify these 6 leading-practice homes using the following selection criteria.

- Objective, third-party information that person-centred care (PCC) is happening in the long term care home (not just information about culture change).
  - Published data or studies.
  - Third party information – e.g., CARF Dementia Care Standards Accreditation, Accreditation Canada, The Planetree Network, etc.
- If objective third-party information is not available, then opinions that can be corroborated that PCC is happening in these homes (not just opinions about culture change).
  - Expert opinions from those who have current, first-hand knowledge of the quality of care provided in these homes to persons with dementia/residents.
- Each home selected will need to have used PCC approaches and processes that are duplicable by most other homes.

- In total, as best as possible, the homes selected will need to:
  - Be fairly typical homes that are credible choices to other homes – other homes will need to be able to see the situation particular to their home reflected in the homes selected.
  - Be geographically representative of the national landscape in which long term care homes operate across Canada.
  - Include the various situations that make up the majority of the long-term care home sector in Canada, regarding things like:
    - Funding
    - For-profit and not-for-profit
    - Personnel in both unionized and non-unionized settings
    - Urban and rural settings
    - Chains and independents
    - Number of beds

The market research in each of these leading-practice homes consisted of two major components.

1. In-depth, one-on-one interviews with a robust and relevant sample of management and staff (i.e., representing a cross-section of long-term care home disciplines). The objectives of these interviews were to accomplish the following.

   - Identify the major person-centred care elements they have implemented in their home for their residents with dementia, and for each element get detailed specifics on:
     - Their objectives/outcomes they were seeking.
     - The approaches they used to implement PCC.
     - What specifically they did and how they did it.
     - How they go about providing PCC on a continuing, sustained basis.
     - Any templates or other materials they used that they can share.

   - Determine how management supports and/or enables staff in providing person-centred care to their residents with dementia.

2. One-on-one interviews with a sample of family caregivers of each home's residents with dementia. The objectives of these interviews were as follows.

   - Identify the major elements of person-centred care that they believe the home provides to their family member, and for each:
     - The approaches the home uses to provide PCC, i.e., what specifically the home does and how it does it.
     - If and how they personally are involved in, and contribute to both the planning for and provision of this element to their family member.
     - The specific benefits this element provides to their family member, AND to themselves.

- Determine in what specific ways this home makes them feel that they too are treated in a *person-centred* way.

It had been hoped to include residents in the interviews with their family members "wherever possible". While many residents were engaged in informal conversations, unfortunately they were not formally interviewed. This was due to two reasons.

In some of the homes, rigorous ethical review processes would have been required which would have taken many months to complete. In others, some family members had agreed to bring their family member to the interview, but decided against it for various reasons when the time came (e.g., the person was not feeling well or having a bad day).

III. Output from the Research in Six Long Term Care homes

The major output of phase 2 of this initiative is 6 detailed reports of findings from the market research, one for each of the homes.

The feedback received from the homes about this market research process was very positive. In fact, many of the homes appreciated the opportunity to pause and reflect on their work and felt that they got as much out of the conversations as they gave. As one staff person said, "It amazed me to walk through the journey and see the results of working together. I really feel (the report on this home) captured some of the passion that I am privileged to work with everyday".

Each of the six homes researched in this study provides person-centred care for their residents with dementia in their own unique way.

While the paths they travelled and specific details of the care they practice may differ, there are common approaches that a number of these homes have used to help them achieve and sustain their success in providing person-centred care. These approaches appear below, captured under similar headings to the ones used in the detailed reports on each home.

IV. Common Approaches Across a Number of the Six homes

A. Management Style

1. The senior administrator and administrative team lead, and are the champions of, person-centred care in the home.
- Creating and sustaining a culture and environment of person-centred care is a core responsibility of the senior administrators of these organizations.
- Accountability for person-centred care is not delegated downward, but radiates throughout the organization from the top.

2. **The senior administrators have ingrained person-centred care into their organizational philosophy and values, often articulating it in their vision and mission statements.**

   - Person-centred care is not seen in these homes as simply another important resident-care initiative or project. Rather, it is recognized by both management and staff as a core value (fundamental belief) and operational principle that informs decision-making and behaviour.

   - As a senior administrator in one home told us, it didn't work when they tried to install person-centred care in their home as a one-off project.

3. **Senior administrators in the home lead by example and "inspect what they expect" of employees and operations.**

   - These administrators:
     - Are visible and accessible to residents, family members and staff, often being on the units rather than isolated in their offices;
     - Have clearly defined and articulated the person-centred care behaviours they expect from staff;
     - Model the person-centred care behaviours expected from staff in their own interactions with residents, staff, and family members of residents; and
     - Have embraced the principle that management involves both communicating expectations to staff and, as importantly, continually following up to ensure these expectations are being met on an ongoing basis.

4. **Senior administrators in the home treat employees the way they want employees to treat the residents and their family members.**

   - The senior administrators of these homes believe that having satisfied and happy staff goes a long way to ensuring resident satisfaction and happiness.

   - To accomplish this, these homes employ both formal and informal processes to do the following.
     - Recognize and value employees.
     - Provide forums for employees to express their opinions and concerns.
     - Give employees a voice in decision-making at the home.
     - Promote personal autonomy and accountability among staff for behaving in a person-centred fashion and "doing the right thing" for residents.
     - Enable employees to use their knowledge, skills and creativity in delivering person-centred care.
     - Solicit staff input and feedback on:
       - The quality of care provided to residents at the home;
       - How they feel they are treated, included, listened to, and empowered; and
       - How responsive they feel management is to their needs and issues.

B. Management Processes

5. The senior administrators have incorporated their philosophy and vision of person-centred care into the formal strategic and operating planning processes of the home.

- These senior administrators:
    - Set strategic and operational goals and outcomes in person-centre care; and
    - Have evolved the traditional clinical outcome measures and metrics to include those for person-centred care.

6. The senior administrators have made their homes "learning" organizations.

- These homes have formal structures and mechanisms, and informal processes, to foster continuous improvement and innovation in person-centred care.
- These senior administrators:
    - Perceive the provision of person-centre care as a journey that never ends;
    - Continually seek and install leading-edge practices and approaches to person-centred care;
    - Educate, train, empower and enable their staff to adopt these leading-edge practices in their everyday care of residents and their family members; and
    - Promote and foster in their home experimentation and innovation in person-centred care that is evidence-based.

7. The homes are striving for greater role flexibility among staff to better meet the needs of residents.

- To help ensure the provision of the best-possible person-centred care to residents, these homes are relaxing restrictive role definitions to encourage all staff – regardless of their specific roles and duties – to be attentive and responsive to the needs of residents.
- These homes are broadening role descriptions and expectations to allow and encourage:
    - Nursing staff to be more involved in the *non-medical* day-to-day lives and activities of residents; and
    - Non-clinical staff (i.e., housekeeping, maintenance and others) to support Care Aides in providing direct care to residents.

8. The homes are building collaborative interdisciplinary teams to meet the needs of residents in a holistic fashion.

- These homes believe person-centred care should focus on all aspects of residents' lives, not just medical care.
- In support of this holistic approach, they are breaking down the professional silos and traditional medical hierarchy by:
    - Including a broader representation of disciplines in resident care conferences and decision-making; and
    - Promoting the value of teamwork and its positive impact on resident care.

C. Initial Intake, Ongoing Care Planning, and Palliative Care

9. **The homes work to ensure that the best in person-centred care is provided to each resident throughout the continuum of their:**
     - **Stay at the home; and**
     - **Dementia.**

   - These homes' initial intake processes are designed to get to know each resident as quickly, thoroughly and holistically as possible to:
     - Ease their transition to their new home; and
     - Provide customized care for them based on their unique needs, desires, and preferences.

   - The ongoing care-planning processes are designed to:
     - Be goal-oriented and inclusive of residents, their family members, and all staff who provide care to the resident;
     - Enrich the lives of the residents throughout their stay at the home;
     - Proactively address the residents' evolving needs, desires, preferences and strengths as they age-in-place at the home; and
     - Be more engaging and valuable for residents, family members, and staff.

   - These homes have designed and implemented end-of-life programs and approaches that:
     - Determine and then provide the necessary care, which the resident and their family want in the later and end-of-life stages of the resident's life; and
     - Treat palliative residents and their family with as much dignity, consideration, respect, and person-centred care as possible through the resident's end of life and death.

D. Recreational Therapy – Programs & Activities

10. **The homes have developed and implemented approaches and tools that provide customized recreational plans for each resident, which deliver specific intervention benefits based on that resident's unique needs and preferences over time.**

   - These homes develop recreational plans for each resident that:
     - Are designed to achieve specific goals and outcomes for that resident;
     - Reflect their choices, preferences and interests;
     - Stimulate them, maintain their level of engagement as best as possible, and help them remain active;
     - Give them experiences that are meaningful to them – that allow them to express themselves, connect with others, feel a sense of freedom and purpose, and have fun;

- Are within their level of capability and range of ability as they age-in-place; and
- Are flexible enough to be adjusted for increasing or diminishing resident capacity.

- These homes have developed tools to:
  - Upon admission, determine each resident's interests, needs, and capabilities as they pertain to recreational activities, and then develop a recreational plan for that resident to meet these interests and needs in a way that keeps the resident happy, active and engaged;
  - Enable ongoing observation, assessment, evaluation, and action planning concerning the resident's participation in each program in their recreational plan; and
  - Evaluate, review and revise each resident's recreational plan as the resident's interests, needs and capabilities change.

E. Environment of the home

11. The homes provide a social and physical environment that is as home-like and "normal" for the residents as possible.

- These initiatives and approaches are born from 3 key philosophies:
  - This is the residents' home, not just an LTC facility;
  - "Normalcy"; and
  - Providing a restraint-free environment.

- The focus of these senior administrators is to de-institutionalize the home – to make a home for residents out of the institution, both physically and in how things get done (i.e., processes). Some examples of what these homes have done include:
  - Designing activities of daily living to bring purpose, joy and a sense of fulfilment to each resident;
  - Managing for day-to-day spontaneity and flexibility in how a resident's day unfolds;
  - Providing medical care in support of the residents' quality of life, rather than medical models and/or concerns having primacy;
  - Where possible, organizing residents into smaller communities of separate neighbourhoods or homes; and
  - Designing a physical environment that is more like a home than a medical institution.

- These homes continually work toward a restraint-free environment. They try to manage the risk of incidents where residents fall and the potentially more dangerous outcomes from employing restraints (e.g., residents tipping over wheelchairs when attempting to stand up with a seatbelt on). Their restraint-free programs have many common components, including the following.
  - Customized physiotherapy plans and therapeutic activities for each resident to maintain and/or improve their physical, mental and emotional status in order to avoid or put off the need for restraint use.
  - Clear procedures and controls regarding the use of restraints.
  - Training and education on these procedures and controls throughout the organization.
  - A fall-prevention program.

- Management and staff try to find and remove the root cause(s) of residents' behaviours to avoid the symptomatic treatment of these behaviours with physical restraints or drugs.
- Putting the "Normalcy" or "Keep it Normal" philosophy into action means:
  - Accommodating residents' habits and preferences as best as possible – based on the belief that if the resident had it at their former home, then they should have it here at their new home; and
  - Keeping everything as familiar as possible for each resident.

F. Staff Scheduling

12. The senior administrators in these homes believe that continuity of care and intimate and trusting relationships between residents and their staff caregivers are important factors in optimizing person-centred care and resident well-being.

- These homes maximize the opportunities for staff members to:
  - Learn about and fully understand the residents in their care, including their personalities, histories and individual needs;
  - Use this knowledge to interpret these residents' behaviours and identify their unmet needs; and
  - Apply this knowledge to provide the best possible person-centred care to each resident.
- These opportunities are provided by doing the following.
  - Care Aides – and where possible, other frontline staff members with daily and direct contact with residents – are dedicated to specific neighbourhoods/units of the home to preserve consistency and continuity of care to residents.
  - Care Aides in many of these homes are also assigned to be the primary caregiver for a specific number of residents in their unit. These primary caregivers will spend the most time and develop the strongest relationships with their residents. Often, they are the primary contact with the family of these residents as well.
    - In some of these homes "primary caregiver" staff members have become informal advocates for each of their residents, making sure their needs are met.

G. Family Engagement

13. The homes use formal processes with family members of residents to accomplish the following.

- **Involve them in what's happening at the home.**
- **Determine, and then work to satisfy their needs, issues and wishes related to their resident and their life at the home.**
- **Educate and engage them in:**
  - **Both the planning for and provision of person-centred care to their resident family member; and**
  - **Decisions about changes in the home.**

- The management in these homes regularly use focus groups, surveys, and/or one-on-one discussions or interviews with family members to actively solicit their input and feedback on things like:
  - Changes, upgrades and improvements to the home (e.g., renovations, processes, programs);
  - How they feel their residents are being treated at the home;
  - Their perceptions of the quality of care at the home;
  - Their experiences at the home; and
  - How responsive they feel staff and management are to their needs, issues, and wishes.
- Management uses the learning from these formal processes to:
  - Determine where and how improvements can be made in the person-centred care of residents and their family members.
  - Identify and satisfy unmet resident and family needs, to the best of their ability.
- These homes also use seminars, in-services, and other educational forums to help educate family members on things like:
  - The philosophies, models and approaches the home uses in the care of residents;
  - Why the staff at the home make certain choices in caring for their resident;
  - The families' own role in both the planning for and provision of their residents' care at the home; and
  - What it's like to have dementia.
- The objectives for dementia education for family members generally focus on things like:
  - Helping family members understand and learn strategies to respond to the changes that dementia brings throughout its continuum; and
  - Giving families the knowledge and tools they need to have a productive visit with their resident.