



PC P.E.A.R.L.S.[™]

7 key elements of
person-centred care
of people with dementia in
long-term care homes

Alzheimer *Society*

Acknowledgements

This initiative is dedicated to the memory of Karl Samuelson (1957-2012).

A champion of person-centered care in Canada, Mr. Samuelson believed that organizations aspiring to be leading-edge must develop and nurture lasting partnerships with all key stakeholders to ultimately achieve the best outcomes and maximize both quality of life and quality of care.

The Alzheimer Society of Canada is grateful for the guidance and wisdom Mr. Samuelson brought to the Culture Change Initiative.

The Alzheimer Society of Canada thanks Extendicare Canada Inc. and Pfizer Canada Inc. for their unrestricted grants in support of the Culture Change Initiative:





Introduction

PC P.E.A.R.L.S™

7 key elements of person-centred care of people with dementia in long-term care homes

Long-term care homes must work within current regulations and legislation to meet the needs of people with dementia and their families. This is not always easy to do within a person-centred approach. Compliance with regulations and legislation imposes rigorous standards of care, which have historically focused on “tasks” rather than developing relationships. An institutional culture has been the result in many homes.

There is an urgent need to change the culture of care – shifting from an institutional model to a relationship-based approach – and to focus on the needs of people with dementia and their families through a person-centred approach. This approach is beneficial for all people, especially those with dementia, regardless of the stage of the disease or where they live, and is based on the values of dignity and respect, information sharing, participation and collaboration.

Like all individuals, people with dementia are people *first*. Like all of us, they have an inherent dignity, value and personhood which remain with them throughout the whole course of the disease, and this needs to be respected at all times. Many people want to live in their own homes for as long as possible. The reality is, however, that the majority of people with dementia 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 dementia¹, and 70% of all individuals diagnosed with dementia will die in a long-term care home².

Through its culture change initiative, the Alzheimer Society of Canada (ASC) aims to improve the experience of long-term care for people with dementia and their families, and is working with others to provide useful strategies, tools and tips that can help long-term care homes across Canada put the principles of person-centred care into practice.

Background

In 2012, ASC conducted an exploratory qualitative research study in six long-term homes across Canada to understand how person-centred care is put into practice. These homes are not perfect; however they are committed to changing the culture of care in their environment, by providing elements of leading-practice, person-centred care to their residents with dementia in their own unique way. They also reflect the diversity of long-term care homes in Canada, regarding aspects such as: sources of funding, for-profit and not-for-profit, unionized and non-unionized staff, urban and rural settings, chains and independents, and number of beds.

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.



Introduction

PC P.E.A.R.L.S.™

Through this research, ASC learned about seven common key elements to begin and sustain a culture change to provide person-centred care. These elements are outlined and explained in seven information sheets entitled PC P.E.A.R.L.S.™, under the following headings:

- 1 Person and Family Engagement
- 2 Care
- 3 Processes
- 4 Environment
- 5 Activity & Recreation
- 6 Leadership
- 7 Staffing

The approaches adopted and practices implemented by the six homes studied are real-life, credible, effective choices that can be duplicated in most other homes and the lessons learned can be applied in various situations and settings.

ASC encourages long-term care homes to put the PC P.E.A.R.L.S.™ into practice to improve the experience of people with dementia, caregivers and staff. The ultimate goal of ASC is to make person-centred care the norm rather than the exception in Canada, and many long-term care homes already share our vision.

Keep up to date by visiting our website to learn more about ASC's culture change initiative:
www.alzheimer.ca/culturechange.



Person and Family Engagement

PC P.E.A.R.L.S.™

The Alzheimer Society of Canada has identified the following 7 key elements of person-centred care:

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- 3 Processes
- 4 Environment
- 5 Activity & Recreation
- 6 Leadership
- 7 Staffing

There is an information sheet on each of these elements to help long-term care homes begin and sustain a “culture change” to provide a person-centred approach to care.

Families¹ and friends are involved, supported and engaged in the life of the person with dementia. Families, people with dementia and staff are integral members of the team, each one bringing valued and unique expertise to bear. Creating and maintaining meaningful and respectful relationships among care home staff, people with dementia and their families can improve the quality of life for all.

Key principles and some innovative strategies from Canadian long-term care homes

Core principle	Strategies
<p>Know the person with dementia and understand the world from her perspective. Remember that people diagnosed with dementia are people first. Take the time needed to search for the meaning behind their words and actions by learning from the person, their family and friends, and being attentive to non-verbal cues. By inviting family and friends to share their experience of the person’s lifelong values, wishes and personality, creative approaches to improving the person’s day to day life are more likely to happen.</p>	<ul style="list-style-type: none">• Fill out the “Resident’s Day” form. This journal describes a 24-hour day for the resident, written in the first person. It includes their preferences, likes, desires and needs from the time they get up right through to bed time. For example, the journal notes when they like to wake up, what is their preference for breakfast, etc.• Offer choices to residents with dementia. This is part of the “Keep It Normal” philosophy, as it respects their individuality and dignity. The choices presented to each resident are tailored to what staff know about the resident, their history, goals and needs. Offering meaningful choices can be used to encourage and support resident involvement in the home, socialization and activity participation. Instead of posing a simple “yes/no” question, a resident might be asked whether they would like to join the sing-a-long or watch the other residents sing.

¹ The term family includes anyone in the supportive network of people with dementia.



Person and Family Engagement

“We go into their (the residents’) world instead of trying to bring them into our reality.”

– RN

Core principle	Strategies
<p>Be attuned to the needs, stress and grief levels of families. Recognize that they will experience a range of emotions as the disease progresses and will benefit from supportive guidance in making decisions about the resident’s care. Work collaboratively with families and recognize the stress and grief level of families after a long period of caregiving and the move to a long-term care home. Communicate often with them.</p>	<ul style="list-style-type: none"> • Make families and residents feel welcome from the moment the resident moves into the new home. Have a volunteer greet the resident and family at the front door with a baggage cart. The resident and family are taken to their neighbourhood² and are greeted by and introduced to the interdisciplinary staff group. The resident and family are given a tour of the floor and shown to the resident’s room, which has a hooded and monogrammed terry-cloth bathrobe on the bed, a monogrammed bed spread, and small gift bag with a gift certificate to the home’s coffee shop. • Start an Alzheimer Society support group for family members and residents. Encourage the group to meet at the home and provide refreshments and other supports. According to staff, family members who participate in support groups have more satisfying relationships and visits with residents, they cope better with their family members’ dementia, thus reducing stress, increasing comfort and accepting the changes that come with the disease.
<p>Educate families about dementia and person-centred care. This will help them understand the disease process, assist each of them in their role as caregiver/support person, and teach them strategies to respond to the changes dementia brings throughout its progression.</p>	<ul style="list-style-type: none"> • Organize an educational mini-retreat to enable family members to share those experiences that make the day a “good day” for the resident and understand the home’s philosophy of care. Ask families to identify at least one contribution they can make to enhance the person-centred care of the resident. • Hold special education days to involve and engage family members in what’s happening in the home, and educate family members and residents on topics of interest, new directions the home is taking in care, and dementia training.

² A neighbourhood is a small and autonomous living space within a home. It is staffed by a permanent team who is able to get to know the residents and their families, thus meeting their unique needs.



Person and Family Engagement

“They bring in speakers to help educate us about Alzheimer’s... How to live well as we age...For me and to help me understand my Mom”

– Family member

Core principle	Strategies
<p>Educate families about dementia and person-centred care <i>continued</i></p>	<ul style="list-style-type: none"> • Partner with the local Alzheimer Society to provide family education sessions. Ask a trained staff member to conduct a seven-week dementia education course for family members developed by the Alzheimer Society. This course has changed the frequency and improved the quality of visits for participating family members, and in one example, families were better able to assist during mealtimes.
<p>Include family and friends as valued members of the care team. They play an integral role in helping the person with dementia to have a “good day”. They can also help maintain a sense of normalcy and continuity for the person with dementia and familiarize staff with the person’s likes, dislikes and prior ways of being. Listen attentively to feedback from both residents and families. Use this learning to make improvements in person-centred care and to satisfy unmet resident and family needs.</p>	<ul style="list-style-type: none"> • Involve families in care plan development that helps see the resident as a person first, not a patient. For example, redesign the care conferences to begin with resident and family input. Write care plans in a narrative, first-person format, based on a resident’s abilities, rather than deficits. • Adopt a “Fresh Eyes Approach” and invite family members to complete a short survey after their visit to the home in order to identify ways to continually improve the services and person-centred care provided. Feedback is gathered from family members on the quality of care and service they witnessed and experienced during their visit. These snapshots are used as staff coaching tools and to better target the focus of the management team’s education efforts. • Ask family members and residents to present concerns or complaints which have not been satisfied to an independent ombudsperson, who reports only to the CEO and makes recommendations based on family/resident input.



Person and Family Engagement

“It is important to know and interact with residents and their families. The more information I know, the better the care. Residents should have a choice if they’re able to make a choice or you know what their preferences would be.”

– Continuing care assistant

Core principle

Collaborate with families and involve them in the life of the home. Invite, encourage and support families to actively participate in the resident’s activities. Involve them in meaningful ways in decisions about changes in the home and the care of their relative.

Strategies

- Organize a special care luncheon to create a “going out for dinner” experience for residents and their families. Small groups of residents and their families participate in a luncheon outside of their neighbourhood, in the home’s boardroom. The room is set up to look like a restaurant and provides a meaningful, family-centred social outing. This is particularly helpful for residents who are unable or uncomfortable going outside the home to a dinner with their families. The dietary team caters the luncheon and the recreation therapy team helps facilitate social interaction; they also model and coach family members who are uncomfortable on how to interact and relate to residents with dementia.
- Ask families and staff to share ideas and identify needs and gaps in service in recreational programs and activities. Their feedback is used to plan projects such as resident birthday stories, resident video life stories, snapshots of care and a slideshow music therapy program. The slideshow provides residents with music therapy programming in the evening when music therapy staff are not on shift.
- Invite residents, families, staff and local partners to participate in the development of the strategic plan of the home.



Care

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Effective care planning focuses on each resident’s abilities, experimenting with various options to avoid inappropriate use of restraints. It includes routine pain assessment and management to help the person enjoy an improved quality of life. Personalized care begins with a comprehensive and welcoming intake process. It continues with ongoing care planning that is inclusive, goal-oriented and proactively addresses each resident’s evolving needs, desires, preferences and strengths. Residents and their families are treated with dignity, consideration, respect and the best possible person-centred care through the resident’s end of life and death.

Key principles and some innovative strategies from Canadian long-term care homes

Core principle	Strategies
<p>Design initial intake to get to know the resident and their family as quickly, thoroughly and holistically as possible.</p> <p>This will ease the resident’s transition to a new home and help staff to provide customized care based on each resident’s unique needs, desires and preferences.</p>	<ul style="list-style-type: none"> • Give a copy of <i>All About Me</i>¹ to families before admission. This booklet will help them to share critical information about their relative with dementia, so that the interdisciplinary team can get to know the resident. This booklet allows a smooth transition into long-term care, and helps families to feel they are still an integral and continuing partner in the care of the resident. • Involve interdisciplinary team members – preferably including residents and families – to evaluate the existing admission process, recommending improvements so that it is more personal and inviting for each resident and his family. • Post “My Story” boards on residents’ walls to display important aspects of the person’s life, including family relationships and friends, career, hobbies and sports, and other personal information. The boards give staff cues for talking with the resident and family, communicating a sense of caring.

¹ *All About Me*, Alzheimer Society of Canada, 2012. This fillable PDF booklet is available for free download at www.alzheimer.ca/allaboutme.

2 Care

“Care is not the task you are doing, but the conversation you are having with the resident while doing it.”

– Client relations coordinator

Core principle	Strategies
<p>Ensure personalized and effective care planning is in place to avoid inappropriate use of restraints. Staff at all levels need to understand the hazards of using restraints and the process of individualized assessment and care planning to meet each resident’s unique needs. Similarly, families benefit from education about the use of restraints and the potential risks as well as the ethical dilemmas these may represent. Restraints should be used only as a last resort, and every home should have a clearly stated protocol on the use of physical, chemical and environmental restraints.</p>	<ul style="list-style-type: none"> • Try to find and remove the root cause of the resident’s action, possible sources of fear and anxiety. Explore alternative interventions in consultation with the family to avoid the use of drugs. For example, as part of its no restraint policy, a home trained staff in “Hugs, Not Drugs” (a Gentlecare® treatment protocol). They learned how to understand what the resident is trying to communicate through her actions, then identify and satisfy her unmet needs, rather than using drug restraints. • Implement a restraint-free program to balance the risk of falls with the potentially more dangerous outcomes from using physical restraints. For example, a program is designed to eliminate any emotional and physical agitation that may be triggered when residents feel confined or restricted by seatbelts on wheelchairs. The use of wheelchair and bed alarms, alerting staff when a resident tries to climb out, has proven to be safer than physical restraints. The program has resulted in zero restraints without an increase in falls.
<p>Design and implement holistic end of life programs that provide the care in the later and end of life stages. The overall goals of palliative and end of life care are to improve the quality of living and dying for people with dementia and to minimize unnecessary pain and suffering. It is important to discuss palliative and end of life care planning with the person with dementia and their family when the timing is appropriate. Education sessions can be organized to raise awareness about the benefits of receiving end of life care at the home, thus avoiding a stressful transfer to hospital.</p>	<ul style="list-style-type: none"> • Create an innovative end of life program that includes a comfort basket with an array of items to support residents and their families who are in the “actively dying” stage of care. For example, include dignity robes – satiny pink and blue gowns sewn by volunteers – used by staff, instead of a shroud, to prepare the body for final viewing by family before being taken to the funeral home. • Recruit hospice volunteers to provide support to residents and their family members, and keep vigil when needed. • Implement a palliative care program to allow staff more time to spend with the resident. Provide a hotel-like room for family members, if they wish to stay at the home over the palliative period. Palliative information and a comfort cart are supplied, as are customized gowns in flannel or cotton for the palliative residents instead of the standardized “hospital blue.”

2 Care

“He never lost his dignity... They worked hard to help him keep it... They tried hard to always get him to the washroom in time so he didn’t have to use his incontinence product.”

– Family member

Core principle

Design and implement holistic end of life programs that provide the care in the later and end of life stages *continued*

Strategies

- Hire RNs with experience in hospice palliative care to work with residents and their families to determine and provide the necessary care – based on the resident and family wishes – to reduce pain and provide comfort in the later and end of life stages of the disease. When the timing is appropriate, one of the hospice nurses talks with the resident and family to determine the resident’s pain management goals through the later stages of dementia. The RNs are there to support and comfort them on their journey, help families to make informed and compassionate decisions on treatments and interventions, and ensure that the resident’s and family’s desires are identified and respected. They are on call as the need arises for both the residents and their families, and to support staff in the care of residents.



Processes

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Embed person-centred care principles into the strategic plan and operational processes to begin and sustain culture change. Implement processes that support positive relationships among staff, residents and families. Processes will lead to the best outcomes, enhancing the quality of life and the quality of care of people with dementia.

Key principles and some innovative strategies from Canadian long-term care homes

Core principle	Strategies
Build the philosophy and vision of person-centred care into the formal strategic and operating planning processes of the home. Reflect on current policies and practices, set strategic operational goals and outcomes in person-centred care, and ensure processes are consistent with the person-centred care principles.	<ul style="list-style-type: none">• Develop a new strategic plan with the aim of moving the organization towards its vision of becoming a global leader in person-centred care. Members of the leadership team lead or participate in various standing committees and work groups to create and implement action plans related to the strategic plan, and areas identified for improvement.• Establish a person-centred care committee to lead and coordinate improvements in person-centred care, services and support across the organization. Act on opportunities to improve resident and family person-centred care through the continuum of each resident’s stay at the home. Staff regularly give the committee suggestions and ideas. Specific improvements recommended by this committee of rotating staff members have been implemented in the admission process, end of life care, staff education, and projects to enhance resident, family and staff experiences.

3 Processes

“Permission for creativity and innovation comes from the leadership. If it’s for the best interests of the resident and the outcomes are positive, do it.”

– Director of spiritual care

Core principle	Strategies
<p>Create and support the organization as a dynamic learning environment. Recognizing that providing person-centred care is a journey that never ends, seek and implement leading-edge practices and approaches to make culture change happen. Ensure that all staff have the on-going education and training necessary to practice person-centred care and empower, enable, and support them in the adoption of these leading-edge practices in their daily care of residents and their families.</p>	<ul style="list-style-type: none"> • Identify staff champions of person-centred care and train them to become facilitators of retreats focused on person-centred care. Based on the learning from each retreat, groups of 15 to 20 staff from mixed functions and levels are asked both what has been accomplished in person-centred care at the home and what should be improved. The staff’s answers are given to management to review and act upon. • Establish a collaborative partnership with a university to research best-practice approaches in person-centred care. Involving frontline staff, develop care guidelines, policies and practices, drawing on learning from the research project.
<p>Build collaborative interdisciplinary teams that focus on all aspects of residents’ lives, not just medical care – care that nurtures the body, mind and spirit. Include a broader range of disciplines in care conferences and make collaborative decision-making the norm. Promote the value of teamwork and creative collaboration in enhancing daily life for each resident. Interdisciplinary care supports the goal of helping each resident enjoy the best day possible</p>	<ul style="list-style-type: none"> • Plan a meeting between the interdisciplinary care team, the new resident and her family to develop a holistic care plan aimed at improving the quality of life of the new resident. Review this plan monthly to anticipate the needs of the residents and develop appropriate programs. • Encourage and support clinical staff members. For example, a staff member who was completing a Masters of Nursing degree created a successful Collaborative Practice Committee, which was inspired by the kind of collaborative practice she had experienced at school. She worked with the Director of Resident Programs and Services to form a group that explores, tests, refines and implements ways to improve the quality of life of residents. It includes representatives from more than a dozen disciplines and functional areas.

3 Processes

“When you see management involved in resident care, doing the stuff we do, staff notice. It shows we’re all here for the residents. We’re all here to make this place comfortable for them.”

– Resident care attendant

Core principle	Strategies
<p>Strive for greater role flexibility to give residents the best day possible. Broaden role definitions and expectations to encourage all staff to be attentive and responsive to the individual needs, interests, preferences and choices of residents and their families.</p>	<ul style="list-style-type: none">• Plan a meeting between the interdisciplinary care team, the new resident and her family to develop a holistic care plan aimed at improving the quality of life of the new resident. Review this plan monthly to anticipate the needs of the residents and develop appropriate programs.• Encourage and support clinical staff members. For example, a staff member who was completing a Masters of Nursing degree created a successful Collaborative Practice Committee, which was inspired by the kind of collaborative practice she had experienced at school. She worked with the Director of Resident Programs and Services to form a group that explores, tests, refines and implements ways to improve the quality of life of residents. It includes representatives from more than a dozen disciplines and functional areas.• Encourage a nurse to make the residents’ breakfast and serve it to them; this makes them more comfortable with the nurse when it comes time for a medical procedure. If a resident comes into the lounge early in the morning, the nurse will serve her coffee or a muffin.• Encourage interdisciplinary teams with role flexibility to focus on all aspects of residents’ lives, not just medical care. No one is allowed to say, “It’s not my job” or “She’s not my resident”. Giving the resident a good day is everyone’s job and everyone must spend at least 20 minutes talking to residents every day, including the CEO.

4

Environment

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Working within current regulations and legislation, promote a physical and social environment that supports the resident’s abilities, strengths and personal interests and enhances the daily life of people with dementia. A person-centred long-term care home provides a social and physical environment that is as much like a home and as comfortable as possible for the people living there. This requires eliminating institutional features and practices, to make the residence feel like a home both physically and in how things get done.

Key principles and some innovative strategies from Canadian long-term care homes

Core principle	Strategies
<p>Identify and eliminate institutional features and practices. The physical space should be designed like a home rather than a hospital in order to make people feel more comfortable. Medical care and practices should support the person in going about her day, rather than being the centre of the day.</p>	<ul style="list-style-type: none"> • Organize living spaces into smaller, autonomous communities of separate neighbourhoods¹ within a home. The close and consistent contact between residents and staff builds relationships and trust, and makes it possible for staff to get to know the residents and their histories, personalities, needs and preferences. • Consider removing bumpers from hallways and barrier-like counters from nursing stations. Make entrances to residents’ rooms look more like the front door of a home than a hospital room. Paint rooms in softer, warmer and less institutional colours. Update fixtures and bathrooms to look more like hotel rooms, and change lighting to be more natural. • Put mailboxes at the front door of all the neighbourhood houses within a home. The mail carrier can be a resident who comes every morning to deliver the mail.

¹ A neighbourhood is a small and autonomous living space within a home. It is staffed by a permanent team who is able to get to know the residents and their families, thus meeting their unique needs.

4 Environment

“We make things small, like the size of our houses and neighbourhoods, so that people (staff and residents) are well known and important to each other.”

– Leader, resident care services

Core principle	Strategies
<p>Create an accessible environment that promotes residents’ enjoyment of each moment and each day. Make opportunities possible for spontaneity, flexibility and choices in how a resident’s day unfolds. Encourage residents to participate fully in their environment by providing a range of diverse recreational and social activities that meet individual interests and needs. Incorporate familiar sights, routines and rituals that reflect individual habits and preferences.</p>	<ul style="list-style-type: none">• Ensure staff respect personal privacy by knocking on doors before entering residents’ rooms. They respect personal preferences by letting residents sleep in and providing a light breakfast when they are ready. Residents help set the table, make breakfast and wash dishes if they wish.• Encourage families and friends to purchase a meal voucher to dine with the resident in her home. Small groups of residents and their families are invited to participate in a meal organized by recreation staff in a special room in the home so that it feels like a social brunch, luncheon or dinner party.• Offer smaller scale communities within a home, along with consistent staffing, to empower residents to make decisions about how they want their day to unfold. Staff know the residents well enough to help them make choices and be as independent as possible.• Set up a computer room in the home, with devices adapted to residents’ different needs. This makes it possible for them to enjoy games and photography, and maintain relationships with family who live far away. Making computers easily accessible is practical and natural since computers are part of most people’s lives and this helps residents connect with their respective communities.• Make it possible for residents to maintain their familiar individual habits and preferences. For example, a resident used to enjoying a glass of wine at 4 p.m. continues this ritual at her new home.

4 Environment

“This is a pleasant environment to visit. I feel good when I visit Mom. I feel very comfortable with the care. I feel she is in good hands here. Since she came here, I want to visit my Mom, instead of feeling like I have to.”

– Family member

Core principle

Create and commit to a restraint-free environment.

All resident actions are personal expressions and ways of communicating. Invest the time needed to identify what the resident is trying to express and the root causes of her actions. Eliminate the need for restraints by actively listening, understanding the meaning behind the action, and using alternative approaches and responses. Clear procedures and controls should be established for the rare occasion when restraints might be necessary.

Strategies

- Identify the root causes of actions that led to restraint use. Talk with family members of residents to decide the level of “acceptable” risk in implementing alternative approaches. Training programs – such as “Hugs, Not drugs”, Gentlecare®, P.I.E.C.E. S.™ – can teach staff how to do this.
- Customize physiotherapy plans and therapeutic activities for each resident to maintain and/or improve their physical, mental and emotional well-being, thus reducing the likelihood of needing restraint use. Outline clear procedures and controls regarding the use of restraints, and provide related training and education to staff throughout the organization. Put in place fall-prevention programs.
- Create a “least restraint” assessment tool with detailed information about possible contributing factors and alternative interventions. Occupational therapy staff developed a problem-solving tool that rapidly reduced the overall use of physical restraints among agitated residents by half.



Activity & Recreation

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Engage each resident in stimulating and meaningful activities, tailoring recreational plans to the person’s interests, preferences and abilities.

Ensure continuous assessment, review and revision of these plans as the person’s abilities and interests change. A resident’s participation and engagement in group or one-on-one activities can be an important way to support independence, a sense of accomplishment, and a sense of self.

Key principles and some innovative strategies from Canadian long-term care homes

Core principle	Strategies
Make meaningful activities and experiences possible for each resident. Encourage and support residents to participate in a wide range of interests and activities that are personally meaningful, stimulating and enjoyable, and respect their interests, preferences and abilities.	<ul style="list-style-type: none">• Provide a “Breakfast Club” for groups of approximately 7 residents in a special room on each floor once a week, with residents rotating in and out of the club on a 6 to 8 week cycle. This program provides an enjoyable and stimulating social, nutritional and sensory experience for residents who may struggle in other programs. Recreational staff prepare the room for the breakfast to make it as attractive and home-like as possible with flowers, china dishes, fine utensils and soft background music. They serve breakfast to each resident and dine with them, engaging the group in family-type conversation about upcoming outings, their family and current events. Residents participate to the best of their ability in food preparation, setting the table and after breakfast clean-up.• Offer intergenerational programs in which children from two classrooms at the neighbouring elementary school visit weekly to engage in joint activities with residents. The children’s energy and enthusiasm make the day enjoyable and fun for the residents. There are small group activities in which one or two students and a resident work on school assignments involving reading, writing, or working on crafts. Students interview residents, asking a series of questions to create a keepsake memory book. Large group activities include residents and students listening to a teacher reading a story, or participating in seasonal events like Halloween trick or treating, or an end of the school year pizza party.

5 Activity and Recreation

“I do what the residents want to do. For those residents with dementia who have a hard time articulating what they want, I give them choices of things to do, which I know they liked based on past experiences with them.

– Recreation coordinator

Core principle	Strategies
<p>Make meaningful activities and experiences possible for each resident <i>continued</i></p>	<ul style="list-style-type: none"> • Engage residents who have difficulty sitting still for extended periods of time through the “Wandering Artist” program. The art therapist uses a cart with a table easel, canvas, brushes and acrylic paints on it. She follows residents and invites them to paint on the canvas, even if only for a few minutes, and then travels to the next resident and a collective artwork is constructed. • Ask each neighbourhood¹ to be responsible for its own recreational pursuits, in addition to the activities that are offered more widely across the home and in large groups. These smaller resident groupings allow for more flexibility, spontaneity and variety in activity planning. Tailoring activities to individual interests and preferences as residents and staff in the neighbourhood learn from and about each other. This intimate, neighbourhood-driven approach also means that recreational activities happen throughout the week, including after 5 pm on weekdays and on weekends.
<p>Offer customized recreational plans to achieve specific goals and outcomes as determined by the resident. These plans should reflect each resident’s unique and evolving preferences and abilities over time, engaging the person in experiences, opportunities, and/or programs that stimulate them and help them remain engaged. Individualized plans are designed to give residents experiences that encourage them to express themselves, connect with others, feel a sense of freedom and purpose, and have fun.</p>	<ul style="list-style-type: none"> • Develop an extensive resident recreation/activity assessment tool that matches residents’ interests, needs and capabilities with appropriate and effective recreational programs and activities. The tool is incorporated into the initial intake process and used to develop individualized recreational plans. • Complete an initial assessment of each resident’s recreational activity interests and needs 6 to 8 weeks after admission, as part of the overall care plan development. Through discussions with the resident and family, and observing the resident, a customized recreational plan is developed to meet those needs and interests in a way that keeps the resident happy, active and engaged. Review and evaluate, on an ongoing basis, the resident’s participation in the individual activities within the care plan, and provide recommendations and action planning, where appropriate.

¹ A neighbourhood is a small and autonomous living space within a home. It is staffed by a permanent team who is able to get to know the residents and their families, thus meeting their unique needs.



Activity and Recreation

“We have a greenhouse and a full-time master gardener, whose focus is to build relationships with residents by engaging them in his passion for plants and flowers. We also have flower boxes and garden spots available to each resident. They can plant what they want in their own flower box and put their name on it. Often this is an activity that family members participate in as well.”

– CEO

Core principle	Strategies
<p>Evaluate, review and revise each resident’s recreational plan as the resident’s interests, needs and abilities change. Observe and assess the resident’s participation in each aspect of their recreation plan, exploring options to increase their involvement as needed. Recognize that preferences change and what was once meaningful may no longer be so. Lack of initiative is often assumed to be part of the disease; however it can result from activities not being personally meaningful. Over time residents may need more encouragement and support to undertake an activity, which they may not be able to start on their own.</p>	<ul style="list-style-type: none">• Use a therapeutic recreation services annual review tool to assess and provide direction regarding the type of encouragement, cueing or prompting that is helpful in order for the resident to participate in programs and activities. It also evaluates the success or progress of the program in providing benefits and accomplishing specific intervention goals for the resident, and recommends follow-up steps, if required.• Use a tool to track resident engagement levels per day over a 1-month period to assess changes and help match programming to residents’ abilities. This assessment triggers a program meeting discussion that includes trouble-shooting solutions. A resident’s level of engagement will be assessed for all programs in which she participates and the recreational plan and activity mix adjusted as her participation levels and abilities change.



Leadership

PC P.E.A.R.L.S.™

The Alzheimer Society of Canada has identified the following 7 key elements of person-centred care:

- 1 Person and Family Engagement
- 2 Care
- 3 Processes
- 4 Environment
- 5 Activity & Recreation
- 6 Leadership
- 7 Staffing

There is an information sheet on each of these elements to help long-term care homes begin and sustain a “culture change” to provide a person-centred approach to care.

Person-centred care can only happen with strong leaders who are champions of person-centred care, ingrain it in their organizational philosophy and values, and model the actions expected of staff in their own interactions with residents, families and staff. Person-centred leaders understand and embrace the person-centred philosophy, demonstrating a personal and organizational commitment to the principles and practices of person-centred care in the home. They promote culture change, establish strong relationships with families, and empower staff.

Key principles and some innovative strategies from Canadian long-term care homes

Core principle	Strategies
<p>Leadership and administrative teams are the champions of person-centred care in the home. The leadership team recognizes person-centred care as a philosophy that informs decision-making and actions, articulating it in their vision and mission statements, policies and practices.</p>	<ul style="list-style-type: none"> Create a vision and mission document for person-centred care that articulates the organization’s values, beliefs and philosophy, and how it can achieve and sustain that vision. Share the document with staff, residents and families to reinforce and further support culture change. Leaders make the vision live by ensuring that the home implements leading-edge best practices in person-centred care. Make the vision and mission accessible to all, using a visual image, such as a sunflower, to represent all the elements needed for the home’s growth and progress towards enriching the lives of the residents and staff through the delivery of person-centred care. The sunflower mission and vision pictorial is used in the orientation of new staff, interactive staff workshops to assess performance and suggest improvements, and in first-person care plans for residents.

6 Leadership

“We are always out there. We’re accessible. We model the behaviours we expect from our staff. We will always ask, ‘Why is this good for our residents?’ You can’t know the residents here by sitting behind a desk looking at statistics. The stats are important, but you need to be with the staff, residents and families. You need to be visible and seen engaging in the process of care.”

– Director of therapeutic services

Core principle	Strategies
<p>Leadership and administrative teams are the champions of person-centred care in the home <i>continued</i></p>	<ul style="list-style-type: none"> • Articulate a vision of care and make necessary changes in the leadership team to support and achieve the vision to shift a home’s direction towards person-centred care and change an institution-centred culture. Form a new and broader leadership team that is more collaborative, interdisciplinary and representative of each functional area of the home.
<p>The leadership team models the person-centred actions expected from staff in their own interactions with residents, families and staff. The leadership team treats staff the way they want staff to treat residents, families and other staff. They encourage open communication and transparency.</p>	<ul style="list-style-type: none"> • Model person-centred actions by knocking on residents’ doors before entering, greeting residents by name in the hallways, always making eye contact with residents and staff, and demonstrating knowledge about a resident through their conversation. Language is an important tool for reinforcing the cultural values of the organization, so the leadership team is careful that the words they use always show respect and preserve the dignity and humanity of residents, family members and staff. They also continually monitor and correct in a respectful way the use of inappropriate language, labels and terminology among themselves and staff. • Be visible to verbally reinforce the person-centred focus with messages such as “it’s not our workplace as much as it’s the residents’ home.” This also gives the leadership team the opportunity to observe and fine-tune staff actions and approaches with on-the-spot feedback and coaching to help staff explore options to provide better and more individualized care. • Challenge decisions and actions that are contrary to the philosophy and principles of person-centred care and adopt a “root causes approach” to identify the underlying causes of families’, residents’ and staff actions.

6 Leadership

“Our CEO is very involved in the care of each resident. She reads all the 24-hour reports each day. She’s on the floor. She wants our home to be the best, so we need to be the best”

– Resident care associate

Core principle

The leadership team involves staff in decision-making to make culture change happen. Collaborative decision-making is a core element of culture change. Leaders provide staff with opportunities to contribute to decision-making in the home and equip them with the training and education needed to make person-centred care the norm throughout the organization.

Strategies

- Support staff to further their education and upgrade skills. Funds are allocated for staff bursaries across all disciplines to support more training in specific areas, like becoming a restraint-free home. A cheque is given to each recipient during a formal reception and an article with recipients’ pictures is then published in the staff newsletter. The leadership team ensures that staff training in person-centred care is inclusive of all staff, including those who do not have a direct care role such as housekeepers, janitors, cooks, drivers and administrative staff.
- Involve members of the leadership team with nursing backgrounds to conduct in-service and educational seminars for nursing and allied health staff. Leading these sessions provides opportunities to show how person-centredness fits into care delivery, and reinforces to clinical staff the commitment of the organization to person-centred care.
- Motivate staff and make them happy to ensure the satisfaction and happiness of residents. The leadership team accomplishes this by using both formal and informal processes to recognize and value employees. Give employees a voice in decision-making, and provide forums for employees to express their opinions and concerns. Learning circles, for example, give staff the time and space to explore, learn, question, share, discuss ideas and implement actions plans.

6 Leadership

“We manage based on our mission and set of principles. We teach managers and staff how to use them [mission and principles]. That’s how we empower staff. We teach that relationships are more important than tasks.”

– Leader, resident care

Core principle	Strategies
<p>The leadership team encourages staff to be creative and take initiative. They empower staff and recognize their innovative practical approaches to enhancing care, their capacity to reflect on actions and to problem-solve.</p>	<ul style="list-style-type: none"> • Encourage staff to use their knowledge, skills and creativity in delivering person-centred care. Support staff in trying new approaches with residents and being flexible in how and when care is provided. If one member of the team makes a mistake or the approach doesn’t work, the team talks about it, learns from the mistake and tries something else. Manager “Tool Boxes” provide a way for managers to give immediate recognition and reward staff for their accomplishments in delivering person-centred care. These special goodie boxes contain gifts to give out to staff when they go beyond the call of duty. • Encourage staff to come forward with suggestions and recommendations to enhance the quality of residents’ lives. A director of therapeutic services supported the initiative taken by a music therapist in planning a bell choir for residents and wrote a proposal to the volunteer society to get the funding for an extra set of hand chimes.
<p>Create and sustain a culture of person-centred care as a core responsibility on which leaders and managers are evaluated. Leaders communicate expectations to staff about providing person-centred care and continually follow up to ensure these expectations are being met on an ongoing basis.</p>	<ul style="list-style-type: none"> • Conduct performance reviews for all staff, including the leadership team, as these are directly linked to the home’s person-centred philosophy, principles and action expectations. The reviews are designed to assess progress, reinforce and reward person-centred actions, and identify people within the home who may need more support and direction in being person-centred in their approach.



Staffing

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Staff training and support, continuity of care, and the fostering of intimate and trusting relationships between families, residents and staff are key factors in optimizing person-centred care and the well-being of residents. In a person-centred home, staff know who residents are and how to provide care that recognizes the person’s unique needs and preferences, builds on their individual strengths and abilities, and promotes their independence, self-esteem and quality of life.

Key principles and some innovative strategies from Canadian long-term care homes

Core principle	Strategies
<p>Staff understand and adopt a person-centred philosophy of care. Staff focus on people living with dementia first and foremost as individuals, as valued human beings, and strive to understand the experience of dementia and each person’s reality by being present “in the moment”. They are open to culture change and provide individualized, flexible care, recognizing that every person has a unique personality, preferences, history, likes and dislikes, skills and abilities, and a wide range of life</p>	<ul style="list-style-type: none">• Create and use a hiring interview guide to assess the values, attitudes and beliefs of potential employees and see how they match with those needed to deliver person-centred care.• Involve a resident advocate to provide coaching to staff and identify alternative approaches to improve the care and be more person-centred.• Conduct interactive huddles with the staff to brainstorm, share and learn from each other about opportunities to improve the person-centred care of residents.

7 Staffing

“I tell staff that the time they spend learning about the resident, from the resident and their family, is money in the bank. It will help them as much as it will help the resident.”

– Director of therapeutic services

Core principle	Strategies
<p>Make continuity of care the norm so that trusting relationships between staff, residents and their family members are strong and sustainable. This will enable everyone to get to know each other better. Staff use their knowledge and understanding of residents to better meet their unique needs, taking into account their preferences and strengths in ways that promote independence, self-esteem and quality of life.</p>	<ul style="list-style-type: none"> • Assign care aides to be the primary caregiver for a specific number of residents in their neighbourhood¹. They are the primary contact with the families, supporting and encouraging them to be involved and engaged in the life of the person with dementia. Staff become informal advocates for each of their residents, making sure their needs are met. • Ensure consistency of staffing within a neighbourhood to enhance working relationships among staff members and interdisciplinary teamwork. It builds trust and friendships, staff learn about each other’s strengths and weaknesses, and adapt ways to work effectively together. A nurse will help change or weigh residents, in addition to dispensing medications or doing other clinical tasks. Staff pass on to each other what they learn about a resident, leading to better personalized care.
<p>Place a high value on continuing staff education and provide regular training opportunities. Staff are supported to develop, upgrade and use their knowledge, skills and creativity to deliver person-centred care. Quality of care of residents with dementia improves when staff acquire enhanced knowledge and skills.</p>	<ul style="list-style-type: none"> • Provide all newly hired frontline staff with extensive orientation and supervision in the home’s approach to person-centred care, and have a mentor close at hand to provide advice or assistance when needed. • Provide a mandatory two-day Relation-Centred Care Training program to teach clinical staff how to provide care to residents in a person-centred way by focusing on the relationship and not just the task. Clinical staff learn tactics such as maintaining eye contact with residents, using touch to build trust, and reassuring residents by explaining what they are about to do before they do it.

¹ A neighbourhood is a small and autonomous living space within a home. It is staffed by a permanent team who is able to get to know the residents and their families, thus meeting their unique needs.

7 Staffing

“RNs are just as involved as the resident care associates in the day-to-day care of the residents...in time spent with residents. We rely on each other...Very much a team approach...Very close knit...We all help each other out...We all do a little bit of everything”

– Leader, resident care

Core principle	Strategies
<p>Place a high value on continuing staff education and provide regular training opportunities. Staff are supported to develop, upgrade and use their knowledge, skills and creativity to deliver person-centred care <i>continued</i></p>	<ul style="list-style-type: none"> • Organize a “Virtual Dementia Tour” to give staff an opportunity to experience what it is like to live with dementia and thus develop greater empathy for residents. They are outfitted in gear that helps simulate the effects of age and dementia, such as vision-limiting goggles, fingers taped together and a cacophony of noise through headphones, while being asked to complete a series of tasks.
<p>Ensure adequate staffing levels necessary for person-centred care and organize shifts to best respond to resident needs. Allow flexibility in role definitions to encourage all staff – regardless of their responsibilities and duties – to be attentive and responsive to the needs and preferences of residents. Providing person-centred care and support is the responsibility of everyone.</p>	<ul style="list-style-type: none"> • Allow for short-shifts of care aides from 4:30 to 8:30 p.m. to meet the increased needs of residents during “sundowning” periods. • Adjust the schedules of dietary aides assigned to particular neighbourhoods to 12-hour shifts to ensure continuity and consistency of staffing. When one of the two aides assigned to each neighbourhood is not working, the other is on duty as a result of this change. • Broaden role descriptions and expectations to encourage nursing staff to be more involved in the non-medical day-to-day lives and activities of residents. Non-clinical staff (housekeeping, maintenance) are encouraged to support care aides in providing direct care to residents.

7 Staffing

“The Gentle Persuasive Approach (GPA) training involves all staff, regardless of their job. It teaches us how to invite residents to do things and participate. This helps change things for the resident from a ‘have to’ to a ‘choose to/want to’, which makes a huge positive difference.”

– RN

Core principle	Strategies
<p>Recognize and value staff for their contributions and give them a voice in decision-making. Empower staff to do what they believe is right for the resident and to show initiative in providing the best possible person-centred care. When staff enjoy their work, are valued by others and feel close to residents, the care they deliver tends to be more person-centred.</p>	<ul style="list-style-type: none">• Support staff to lead and execute initiatives. A licensed practical nurse (LPN), who was hearing-impaired herself, suspected that some residents’ confusion might be due, in part, to poor functioning of their hearing aids. She volunteered to do an assessment and found that none were using their hearing aids correctly. With support from management, the LPN designed a program that included staff education on checking, inserting, adjusting and cleaning hearing aids to improve the situation.• Gather input to help design a dining room for residents who require assistance in all activities of daily living. Arrange small tables around the room’s perimeter, with spaces between the tables for the residents’ wheelchairs. At mealtimes, caregivers sit facing the residents while helping them eat, which is more satisfying for the residents than being fed from behind or the side, as would be the case at a conventional dinner table.• Give a “Caught Doing Good” award to recognize and reward personal initiative in improving quality of life and demonstrating the values of person-centred care.• Give a “Token of Kindness” for an act big or small that makes a difference in the lives of residents, families and staff. Ask the recipient to enter her story on the website and then pass the token along to other deserving staff members.