



# 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:

- 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.

**Families<sup>1</sup> 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><b>Know the person with dementia and understand the world from her perspective.</b> 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"><li>• 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.</li><li>• 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.</li></ul> |

<sup>1</sup> The term family includes anyone in the supportive network of people with dementia.



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

– RN

| Core principle   | Strategies   |
|--|--|
| <p><b>Be attuned to the needs, stress and grief levels of families.</b> 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"> <li>• 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 neighbourhood<sup>2</sup> 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.</li> <li>• 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.</li> </ul> |
| <p><b>Educate families about dementia and person-centred care.</b> 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"> <li>• 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.</li> <li>• 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.</li> </ul>   |

<sup>2</sup> 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.



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**“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><b>Educate families about dementia and person-centred care</b> <i>continued</i></p>  | <ul style="list-style-type: none"> <li>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.</li> </ul>   |
| <p><b>Include family and friends as valued members of the care team.</b> 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"> <li>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.</li> <li>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.</li> <li>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.</li> </ul> |



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**“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  | Strategies  |
|---|---|
| <p><b>Collaborate with families and involve them in the life of the home.</b> 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.</p> | <ul style="list-style-type: none"><li>• 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.</li><li>• 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.</li><li>• Invite residents, families, staff and local partners to participate in the development of the strategic plan of the home.</li></ul> |