

Meeting the Needs of People Living with Dementia in Alberta's Residential Living Options



Ensuring Person-Centred Care

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INTRODUCTION

Growing numbers of Albertans are living with a form of dementia (Box 1). Alberta's continuing care system provides a range of health, personal care and accommodations services to support the needs of Albertans living with dementia while helping them to maintain choice, independence and quality of life (Alberta Health, 2013). This document has three purposes:

[Part I](#) proposes elements of care to meet the needs of Albertans living with dementia in all residential Living Options, grounded in the philosophy of person-centred dementia care, including appropriate service elements, staffing, supportive leadership and policy, and physical environment.

[Part II](#) describes specialized service delivery in Supportive Living Level 4-D (SL4-D) for the subset of people living with dementia who are unable to integrate into other residential living options.

[Part III](#) presents a quality outcomes framework for dementia care within residential settings, consistent with the Continuing Care Quality Management Framework (Alberta Health Services [AHS], 2014a), is also described and integrated with the Alberta Quality Matrix for Health (Health Quality Council of Alberta [HQCA], 2005).

This paper is not intended to provide clinical guidance for dementia care in residential settings. Instead, it describes evidence-informed understanding of the elements to meet the needs of people living with dementia in any residential living option, as well as the needs of those who require support in a specialized setting, helping to ensure that Albertans living with dementia in these care settings are receiving “the right care in the right place” (Alberta Health Services, 2010b).

Box 1. Dementia in Alberta

Dementia is a progressive, usually irreversible degenerative brain disorder that results in declining cognitive functioning, including thinking, memory, reasoning and judgment, as well as impacting physical functioning and ability. It may have multiple causes in older people, including Alzheimer's disease (AD) (nearly 70% of cases) and vascular dementia (about 20%). Other types in older adults may include frontotemporal and Lewy Body dementia (Alzheimer Society of Canada [ASC] 2011, 2010; Alzheimer's Disease International [ADI], 2013; World Health Organization [WHO], 2012). Recent analyses suggest about one in five (20%) Canadian seniors who receive continuing care services (including home care) have dementia, as do a majority (57%) of those living in a residential care setting (supportive living or long-term care) (Canadian Institute for Health Information [CIHI], 2010). Similarly, recent analysis of Alberta administrative data shows that slightly less than one-third of residents of SL3 environments (30.9%), slightly less than half (46.6%) of SL4 residents, nearly all SL4-D residents (94.4%) and 59.7% of LTC residents have a diagnosis of dementia (Poss, 2014, p. 24). Further, in line with the anticipated increase in the overall proportion of seniors in Alberta, the proportion of Albertans living with dementia is also expected to nearly double by 2038 (to over 100,000 from 40,000 in 2008) (Smetanin et al., 2011).

PART I. UNDERSTANDING THE NEEDS OF PEOPLE LIVING WITH DEMENTIA IN RESIDENTIAL CARE LIVING OPTIONS

Understanding the needs of people living with Alzheimer's disease and other forms of dementia in residential living options has been the focus of considerable attention, as there is well established evidence that the needs of these residents are often unmet in these settings, resulting in reduced quality of life (QoL) and increased behaviours that may be disruptive for the self and others (among other negative outcomes that will be explored in greater detail in the following sections) (ADI, 2013; Cadieux, Garcia & Patrick, 2013).

The literature largely does not distinguish between the needs of people living with dementia in assisted/supportive living (SL) or long-term/nursing home (LTC) (Cadieux, Garcia & Patrick, 2013). Accordingly, the literature examined in this section is focused on needs of people living with dementia in residential care settings generally (which refers to any congregate living facility and may include both AL or LTC type facilities (ADI, 2013; Stonebridge, 2013)

Moving into a residential care facility is usually undertaken to ensure that particular health needs of the person living with dementia that have grown too complex or costly to meet in the home can be appropriately addressed (ADI, 2013; Hancock, Woods, Challis & Orrell, 2005), including responsive behaviours (such as wandering) (Canadian Institute for Health Information, 2010). However, there is well-established

evidence that the ongoing needs of people living with dementia and ongoing global needs of people living with dementia in residential care are much broader than specific health or clinical care issues.

Understanding the ongoing needs of people living with dementia in residential care settings has been the subject of extensive research in recent years, and a range of critical needs in addition to those specific health or functional issues that may have initially motivated the move into a congregate living setting have been identified. A recent systematic review by Cadieux and colleagues (2013) identified 19 core needs of people living in residential care settings emerging from 68 studies published between 2000 and 2010, including two studies that examined subjective (i.e., self-described) needs (Table 2.1). The identified needs span social, psychological (emotional and intellectual), and environmental, in addition to functional support (i.e., with instrumental activities of daily living [IADLs] and activities of daily living [ADLs]), and health and medical care needs. Needs are presented in order of the number studies mentioning the need.

Table 1. Needs of people living with dementia in residential care identified in the literature

Need	Definition
Management of behavioural problems	Need to receive support from staff in decreasing behavioural symptoms (general) and be provided with appropriate care measures (e.g., redirection) when exhibiting disruptive behaviors
Need for daily individualized activities/care	Need to engage in meaningful daily activities (inside or outside the facility) tailored to the resident's interest and abilities. Activities are not limited to the individual per se; activities may be offered in a group setting. Includes the need to receive individualized care (e.g., medication prescribed to meet individual symptom)
Social needs	Need for social interactions that allow the resident to connect with others on an interpersonal level; meaningful interactions and communication opportunities with staff, family members, and residents

Need	Definition
Emotional needs/personhood	Need to retain a good emotional balance (increase positive feelings such as pleasure and decrease negative feelings such as sadness). Development of a sense of personal identity (expression of self). Feelings such as reassurance, affection, acceptance, and appreciation are of great emotional importance)
Activities of Daily Living (ADLs)	Receiving support for or assistance with activities of daily living (ADLs). These include activities we normally perform for ourselves (eg, hair care, eating/drinking, getting in and out of bed, and toileting)
Need for independence/choice	Need to preserve a sense of agency by means of continued opportunities for decision-making and personal control (ie, right to refuse medications and choice of activities). In the event of inability to make own decisions, residents' next of kin, speaking as the resident and involved in decisions related to the care.
Cognitive needs	Need for assistance with the interpretation of messages and surroundings
Need to be safe/secure	Need to feel safe and be protected from self-injury as well as doing or receiving harm from other residents.
General overall physical health	Need to retain good physical health by means of medical oversight and care, exercise, and nutrition.
Need to be in a homelike comforting environment	Need to reside in a "homelike" environment which induces a sense of familiarity
Need to receive proper pain management	Need to diminish the discomfort caused by physical pain

Need	Definition
Sensory needs	Need for optimal environmental features to engage and optimize understanding of the environment without under- or over- sensory stimulation (e.g., proper lighting—visual stimulation). Relates to the resident’s 5 senses.
Need for daily structured care	Need for continuous, routine, predictable care
Functional needs—Instrumental Activities of Daily Living (IADLs)	Receiving assistance in performing IADLs
Need for knowledgeable staff	Need for staff trained and experienced in dementia specific care.
Sexual needs	Need for the opportunity to continue intimate relationships
Need for privacy	Need for the opportunity to have a secluded personal environment, if privacy is desired
Money—financial issues	Need to have financial stability
Spiritual needs	Need for spiritual support and comfort and opportunities to exercise religious preferences

Adapted from Cadieux, Garcia & Patrick (2013, pp. 5-6).

The authors highlight that the following list of needs is not necessarily exhaustive and validation with residents, family and front-line staff should be undertaken to identify whether the ordering of the needs reflects their perceptions of the relative importance of the needs.

The Person-Centred Philosophy of Dementia Care

Historically, residential care services for seniors and others living with chronic conditions requiring ongoing care were grounded in the institutional and illness-centered model, emphasizing task-centred care for health and medical needs and care focused on treatment for individual symptoms or illnesses. Responding to the broader social, psychological and environmental needs of the individual, in addition to physical care needs,

was often less understood and therefore neglected (ADI, 2013; Alzheimer’s Association [AA], 2009a; ASC, 2011, 2010; Fazio, 2009; Kitwood, 1997; Nazarko, 2009).

Increasingly there has been a shift in emphasis towards the philosophy of person-centred care for dementia, grounded in the concept of personhood pioneered by Tom Kitwood (1997; Kitwood & Bredin, 1992) and others. This approach acknowledges that persons living with dementia continue to be full persons in spite of the cognitive changes they experience. These people maintain strengths and abilities throughout the progression of the illness to both communicate preferences and emotions, to engage with others and to participate in activities they enjoy. They experience optimal quality of life in an environment that is appropriately adapted to support those strengths and abilities and responds as holistically as possible to the unique social, psychological, physical and environmental needs of the individual (AA, 2009a; ADI, 2013; ASC, 2011; Fazio, 2009; Nazarko, 2009).

Table 2 shows an example of this shift in emphasis from an understanding of people living with dementia only focused on loss and decline in functioning, towards considering the strengths and abilities that may be retained and contribute to ongoing quality of life and well-being and the possibility of living well with dementia in residential care settings (Fazio, 2009).

Personhood *is a standing or status that is bestowed upon one human being by others in the context of relationship and social being. It implies recognition, respect and trust.*

-Tom Kitwood, 1997

Table 2. Alternative Perspective of the Stages of Dementia – Selected Retained Strengths and Abilities

Early	Middle	Late
<p>A person continues to be able to:</p> <ul style="list-style-type: none"> • Talk about the past in great detail • Perform basic arithmetic • Perform noncomplex tasks or more complex tasks with assistance • Have memory of personal history with reminders or cues • Engage in social and mentally challenging situations when included appropriately or in a simplified manner 	<p>At this stage, individuals can:</p> <ul style="list-style-type: none"> • Convey feelings • Be in and enjoy the moment • Perform simple mental arithmetic • Select clothing with limited choices • Have knowledge about themselves and recognize family faces and individuals • Enjoy an afternoon nap or early morning sunrise • Use bathroom with cues and support/assistance • Use toilet and be successful with reminders • Perform or assist with tasks that are repetitive in nature • Move around and take walks with supervision 	<p>At this stage, individuals can:</p> <ul style="list-style-type: none"> • Use or understand simple words or phrases, and are often able to respond nonverbally or with groans • Eat with assistance and use the bathroom with assistance • Walk with help and sit with support • Recognize and enjoy the tastes of favorite food

Abridged and adapted from Fazio, 2009, pp. 53-56

Alongside changes in dementia care philosophy, there has been growing adoption of this person-centred approach among providers of residential care across North America and internationally (WHO, 2012). The Alzheimer Society of Canada (ASC) has joined advocacy groups such as the US-based Pioneer Network (n.d.) to develop a “culture change” initiative focused on providing guidance for service providers around navigating the shift from a traditional medical orientation to the implementation of a person-centred approach to care. The initiative includes the release of *Guidelines for care: Person-centred care of people with dementia living in care homes* (2011), in-depth case studies of six facilities across Canada working to implement person-centred care (2013), and *PC P.E.A.R.L.S.™*, a toolkit grounded in seven key elements of person-centred dementia care. Box 3.1 outlines the core values of person-centred dementia care defined by the Alzheimer Society of Canada (2011).

Box 2. Alzheimer Society of Canada's core values of person-centred dementia care

Dignity and Respect: Like all individuals, people diagnosed with dementia are people first. Care staff listen to them and honour their perspectives and choices. They have an inherent dignity, value and personhood which remains with them throughout the whole course of the disease and should be respected at all times. The values, beliefs, cultural and spiritual backgrounds of people with dementia and their families are incorporated into the planning and delivery of care.

Information Sharing: Care home staff communicate and share complete and unbiased information with people with dementia and their families in ways that are affirming and useful. People with dementia and their families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.

Participation: People with dementia and families are encouraged and supported in participating in care and decision-making at the level they choose. This therapeutic relationship is based on the participation of the person with dementia, regardless of their level of cognitive or physical impairment. The goal is to focus the relationship on the person, without excluding family members.

Collaboration: People with dementia and families are also included on an organization-wide basis. Care home managers collaborate with people with dementia and families in policy and program development, implementation, and evaluation; in health care home design; and in professional education, as well as in care planning.

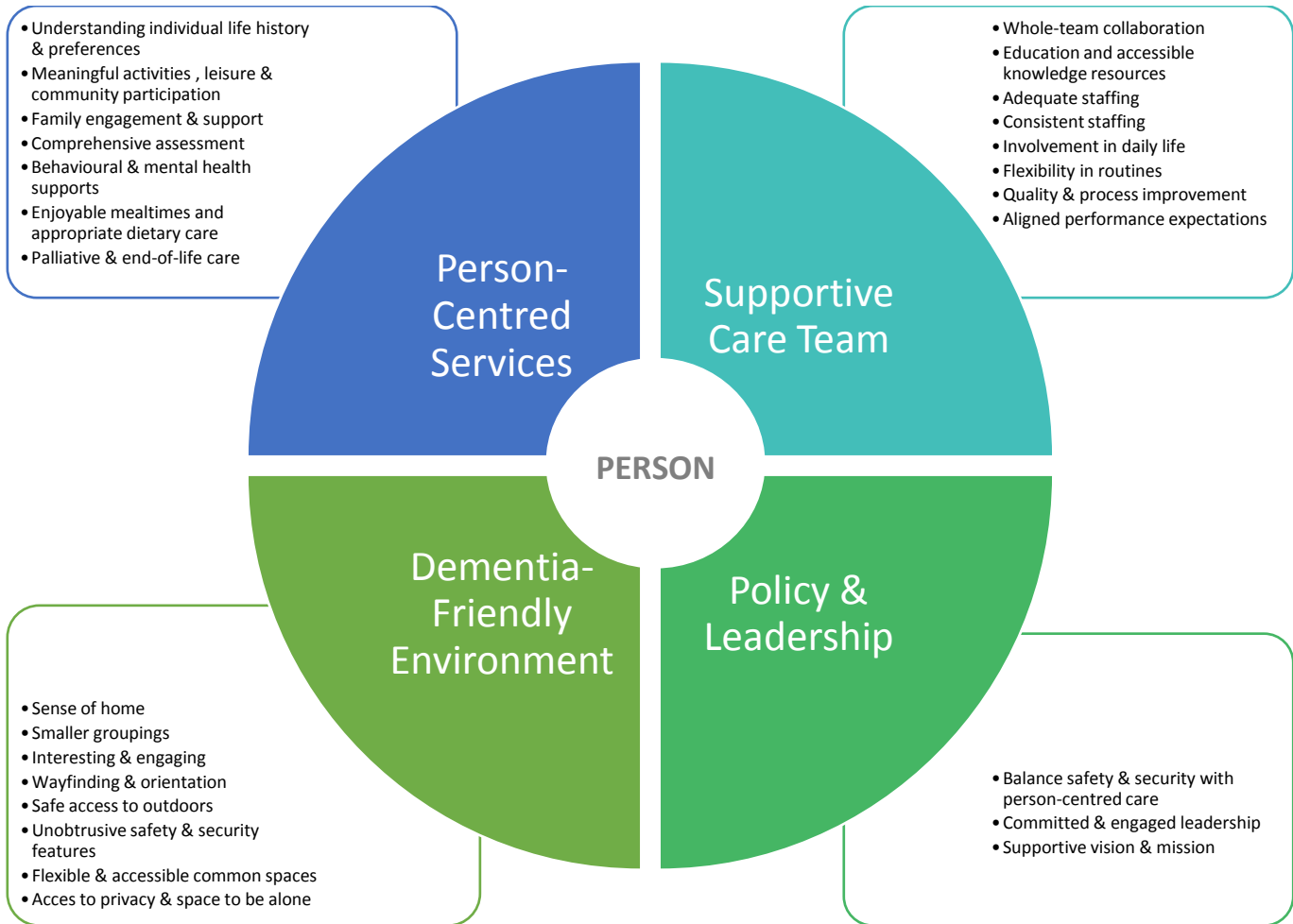
From Alzheimer Society of Canada, 2011, p. 11

Ultimately, a person-centred approach to residential care strives to value the whole person while addressing the full range of social, psychological, environmental and physical care needs as described in the previous section (ADI, 2013). In other words, institutions are being transformed into homes for the people living there (Alzheimer Association-Illinois Chapter). Numerous models and approaches to care have been developed that are in line with the culture change movement towards a person-centred approach, including the Eden Alternative, the Green House® Project and the Planetree Model (Fazio, 2009). *Supportive Pathways* (Carewest, 2013), an Alberta-developed program, is an approach to dementia care grounded in the person-centred philosophy. This program has been identified by Accreditation Canada as a Leading Practice in long-term care service delivery (Accreditation Canada, 2013). Numerous Alberta-based providers of residential continuing care services are working ensure the provision of person-centred dementia care. Some have adopted models such as the Eden Alternative, Supportive Pathways, or the Best Friends Approach (Bell & Troxel, 2001) utilized by the Alzheimer Society of Calgary, that are consistent with this philosophy of care.

ELEMENTS OF PERSON-CENTRED DEMENTIA CARE IN RESIDENTIAL LIVING OPTIONS

This section describes foundational elements for providing person-centred dementia care in all residential living options, including person-centred program elements, a supportive care team, dementia-friendly environment, and policy and leadership (summarized in Figure 1). The elements are drawn primarily from evidence-informed guidelines for dementia care in residential care settings, especially those from the Alzheimer Society of Canada (2011, 2014) the US Alzheimer’s Association (2009a, b), and Alzheimer’s Australia (2007) as well as guidelines related to dementia care services generally (National Institute for Health and Clinical Excellence, 2010) and mental health services for seniors (Wilson, MacCourt and Tourigny-Rivard, 2011).

Figure 1. Elements of Person-Centred Dementia Care in Residential Settings



Person-Centred Services

The following section outlines the components of service delivery required to support holistic, person-centred dementia care in residential settings. In providing residential supportive living and long-term care services for people living with dementia there is need for collaboration and sharing of responsibility across many players. It is valuable to the principle of seamless health service delivery that responsibilities and

accountabilities of all service providers be clearly understood and agreed upon, and mechanisms supporting ongoing communication and collaboration established.

Understanding of individual life history and preferences

Oft times, understanding the person and the person's response to their current situation lies in an understanding of who the person is, and was throughout their lifetime. Therefore, a critical element of person-centred dementia care is to ensure that all direct care providers who regularly interact and support the person living with dementia develop an understanding of the person—learn to know them. The mechanism assisting this “knowing” is an in-depth review of life history inclusive of “individual interests, customs, beliefs, as well as cultural, spiritual and ethnic backgrounds” (ASC, 2011, p. 13; ADI, 2013; AA, 2009a). Such knowledge is developed through building relationships over time, and requires the contribution of the person, family, friends, and all staff interacting with the person (ASC, 2014). Such a history can be shared in creative ways such as life history boards, albums, and focused documentation. The information must be easily accessible to all direct care staff using innovative approaches to documentation and sharing as described above. It may be helpful for the staff person most directly responsible for the person's care to coordinate the process of gathering and presenting this information. All team members involved in care should contribute where possible. It is critical to engage with families as a primary source of information and understanding about their family member.

Meaningful activities, leisure and community participation

Opportunities to engage in meaningful activities, both scheduled and spontaneous, unscheduled leisure and interactions throughout the day has been highlighted in the literature as a critical element of quality of life for people living with dementia in residential settings, and has proven to impact “mortality, depression, physical function and behavioural symptoms” (Alzheimer Association in ADI, 2013, p. 52). In a 2011 study, this need is reflected in the perceptions of residents and families in an Alberta research review of congregate living settings (Strain, et al., 2011). Residents and family respondents identified access to social and recreational activities as an important area requiring increased attention. Nearly half of DSL residents (47%) and over half of LTC residents were found to spend little or no time on activities when awake and not receiving personal or ADL care. Nearly one in five (18%) of DAL residents and one-third (34%) of LTC residents had low to no social engagement, comprising “ease of interacting with others, pursuit of involvement in the life of the facility, participation in social activities of long-standing interests, and visits or other interaction with a long-standing

social relation or family members. Nearly one-third (30%) of DSL residents and four in ten (38%) of LTC residents reported or indicated that they felt lonely (p. iii).

People living with dementia may require support in initiating and engaging in activities; however, when tailored to individual preferences and strengths, having access to a broad range of appropriate opportunities for social interaction, physical activity and pursuing individual interests and priorities like reading, listening to or playing music or other visual arts and crafts can support meaningful experiences for people living with dementia in residential settings, providing opportunities “to express themselves, to connect with others, to feel a sense of freedom and purpose and to have fun” (ASC, 2011, p. 28). Residents should be supported in regularly engaging in normal and familiar activities they enjoy and are appropriate for their individual strengths and abilities throughout the day. For example, meal times can also provide enjoyable social activity for many residents, and in some facilities where involvement in meal preparation is possible, can also provide important opportunities for meaningful activity and engagement. Other examples include individual, one-on-one and group activities. Even very brief interactions, such as paying a complement, sharing photos, supporting a resident in choosing their clothing for the day, sharing a favorite snack, listening to music, playing with a facility pet, or simply sitting quietly together can enhance meaning, reduce loneliness and support enjoyment and relationship-building for both residents and staff. Availability of opportunities for interaction and engagement as well as activities and recreation can also often play a crucial role in mitigation of responsive behaviours associated with dementia (e.g., Cohen-Mansfield, 2004; Kowlanowski, Faick, Frazer & Penrod, 2010; Kverno, Black, Nolan and Rabins, 2009).

Opportunities for physical movement and exercise are also an important part of activities and recreation, as well as overall engagement, for people living with dementia in residential settings. Inactivity is associated with overall negative health and well-being. Even encouraging simple movement through the course of the day (i.e., not necessarily part of a formal exercise program), such as standing up, can help to improve or maintain mobility (Slaughter & Estabrooks, 2013). While the evidence regarding the impact of physical activity programs on responsive behaviours is inconclusive, it can improve cognitive functioning and ability to perform daily activities (Forbes, et al, 2013). Activities can support building sense of community engagement both within the facility and with the community outside the facility (AA, 2009a; ASC, 2013, 2011).

Connection with community can be fostered through engagement of volunteers and programs supporting connections and interaction with community members who might share in activities that may be meaningful for residents and enrich the social milieu (e.g., intergenerational programs and school groups,

artists, musicians, pet therapy programs). Some approaches to culture change, such as the Eden Alternative, advocate for establishing children and people of all ages, as well as animals and plants, as normal, ongoing parts of daily life, rather than as isolated programs. For example, Eden Alternative facilities will often establish on-site daycare programs for children of staff and others in the community, adopt numerous pets of different kinds, and include many indoor plants and outdoor gardens (Thomas, 1996).

Family engagement and support

Family engagement and support is imperative across continuing care settings. Given the progressive trajectory of dementia, it is especially critical to support and engage with the families of persons living with dementia in residential care settings as full partners in care. Families play an essential role in supporting staff in developing a care plan that reflects an in-depth knowledge of the person and “their likes and dislikes and prior ways of being” (ASC, 2011, p. 4; ASC, 2014). Ensuring person-centred care also requires families are supported in meaningfully engaging in the daily life of their family member to whatever extent they wish to engage. Further, dementia care is extended to the families to support their feelings of grief and loss they will experience as the illness progresses, and to education and training around the disease course and their potential family partner/caregiver role. Information, service navigation, education and skills training should be available for family caregivers. Independent family councils or an ombudsperson should be available to respond to family concerns and to make recommendations to facility management (ASC, 2014).

Family caregivers are at risk for experiencing adverse impacts to their own psychological health and well-being (Pinquart & Sorensen, 2003) and so should also have access to ongoing psychosocial needs assessment and referral for counseling and appropriate mental health supports when required (ASC, 2011; National Institute for Health and Clinical Excellence [NICE], 2010; Wilson, MacCourt and Tourigny-Rivard, 2011).

Comprehensive assessment

Assessment should address the following areas to support staff in responding appropriately to the individual strengths and needs of each resident (AA, 2009a; ASC, 2011).

- Cognitive health
- Physical health
- Physical functioning
- Pain
- Behavioral status
- Mood

- Sensory capabilities
- Communication abilities

These areas are addressed through the interRAI Resident Assessment Instrument-Home Care (RAI-HC) assessment conducted annually for all Supportive Living clients by AHS Case Managers, and the RAI 2.0 assessment (full assessment conducted on admission, annually and with a significant change and partial conducted quarterly) in LTC by site staff. However, for the information gathered in these assessments to contribute to care and support planning, it is crucial that the information is accessible to all staff involved in care, including direct care staff. Areas for which people living with dementia in residential care are at greater risk include inadequate pain management (due to greater difficulties in communicating when suffering from pain), depression, falls and use of restraints (AA, 2009a; ASC, 2011). Risk for choking is another important consideration.

Behavioural and mental health supports

Providing appropriate supports for responsive behaviours associated with dementia and other causes of cognitive impairment such as delirium, as well as mental health challenges common in residential care settings (particularly mood problems such as depression and anxiety), is also a critical service component to ensure that the needs of persons living with dementia are appropriately met. Both depression and responsive behaviours have been linked to overall self- and proxy-rated quality of life for people living with dementia in long-term care settings (Beerens et al., 2013). Recent analysis of Alberta administrative data shows that 16.0% of SL3 residents, 20.6% of SL4 residents and 26.6% of SL4-D residents showed signs of depression, compared with 42.7% of LTC residents. Further, data from the interRAI assessment indicates 15.3% of SL3 residents, 21.6% of SL4 residents and 46.4% of SL4-D residents and 51.8% of LTC residents experienced one or more of four measured aggressive behaviours within the previous three days of assessment, as did (Poss, 2014, p. 24). A person-centred approach, recognizes that these behaviours, and mood disorders as well, often represent communication of unmet social, psychological, physical or environmental needs and aims to identify and respond appropriately to those needs (AA, 2009a; ASC, 2011).

Appropriate education and training for staff related to supporting residents experiencing responsive behaviours and mood changes, including the assessment of social, psychological, physical and environmental needs and the use of appropriate nonpharmacological interventions is described in a later section that outlines considerations for the care team.

Box 3. Toolkit for the Appropriate Use of Antipsychotic Medications in Long-term Care

The Seniors Health SCN's *Toolkit for the Appropriate Use of Antipsychotic (AUA) Medications in Long-term Care* provides resources related to approaches to individualized assessment of social, psychological, physical and environmental needs, and provides resources supporting first-line use of nonpharmacological interventions to support responsive behaviours related to dementia and other causes of cognitive impairment. The *AUA Toolkit* also provides links to numerous evidence-informed resources related to best practices in person-centred dementia care for front-line staff, including communication approaches and supporting meaningful activities and engagement. The *AUA Toolkit* is available on the **Alberta Health Services** website at <http://www.albertahealthservices.ca/auatoolkit.asp>.

Specialized behavioural and mental health consultation services

Access to specialized behavioural and mental health support services as a consultative referral resource is required to support residents, staff and families with (a) complex and persistent responsive behaviours that are unresponsive to strategies and approaches and (b) severe and persistent mental health problems. A review of Ontario and British Columbia planning documents showed that these teams typically support staff through the provision of assessment, recommendations, and both direct (time-limited) and indirect (i.e., consultation to other providers) treatment, as well as recommendations and strategies related to social and environmental modification strategies. Teams specialized in addressing mental health needs, including mood disorders, should be competent to provide evidence-based psychotherapeutic interventions such as cognitive behavioural therapy (CBT) when appropriate (NICE, 2010). Other services should include education and training for staff and families to support capacity building (Wilson, MacCourt and Tourigny-Rivard, 2011).

Comprised of health care professionals with additional training and expertise in dementia care and responsive behaviours, these teams can provide consultation and support related to complex and persistent behavioural challenges. The teams may include representation from a range of disciplines including nursing, occupational therapy, psychology, speech language pathology and social work. Such teams should also provide specialized geriatric psychiatry consultation and leadership whenever possible (Wilson et al., 2011). In rural and remote communities, these services should be accessible through telehealth or other appropriate means when providing services on site is not possible.

Crisis response

Residential care staff should be supported with appropriate education and team collaboration processes to enable prevention, early intervention, and de-escalation of negative responsive behaviours that may pose risk to the safety of the self, other residents and staff. Education and approaches to supporting such behaviours must be presented so staff will explore the meaning of such behaviours from the unique perspective of the person. Appropriate education for staff, as well as mechanisms to support team collaboration and communication, are discussed further in a later section. Considerations for relevant policy (e.g., Least Restraint) is also described later in the document.

In cases where staff determine that additional support is required, crisis response services should be available to provide immediate consultation or intervention as needed. While specialized geriatric behavioural and mental health outreach and consulting teams do not usually respond to crises, they should be available to provide consultation and education to the crisis response teams, such as an Adult Mental Health Crisis response team (Wilson et al., 2011). As above, these services should be accessible via telephone or other means as necessary in rural and remote areas. Crisis team models and protocols should be examined that link to or include security services and/or first responders (e.g., Emergency Medical Services [EMS], Police Services) to support responses to incidents that may pose an immediate threat to the safety of the resident or others.

Behavioural treatment and stabilization units

If persistent complex behavioural or mental health challenges emerge, particularly aggressive behaviours that may pose a risk of harm to self or other residents and staff, access to longer-term behavioural support or stabilization units should be available that can provide appropriate treatment and support to meet the needs of these residents and to assure resident and staff safety. These units usually serve as a transitional service and provide flexible lengths of stay. They also often provide direct admission arrangements to avoid unnecessary transfers to emergency or acute care. Further, staff in these units should have strong collaborative working relationships with the staff of specialized behavioural and mental health consulting teams and/or facility staff, to support development of an appropriate care plan upon return to the residents' home facility (Dr. M. Tourigny-Rivard, personal communication, February 21, 2014).

Ideally, these services are available in a local or regional facility, as close as possible to the patient's own home or community, so that family and friends may continue to be engaged in the resident's care (Wilson,

et al., 2011). For residents living in rural or remote areas, transferring out of their home communities is often a last resort and support by consultation teams (described previously) is a preferred first option.

Enjoyable mealtimes and appropriate dietary care

Dining and mealtimes can provide an important opportunity for meaningful activity and enjoyment, as well as for exercising personal choice about where, when and what one eats to the extent possible. Allowing for flexibility in meal times and ensuring that snacks are available throughout the day can help support individual preferences and dietary needs. Choices for meal options should be provided where possible (AA, 2009a; ASC, 2013; ASC, 2014).

Further, people living with dementia in residential care settings are at risk for declining overall health and wellbeing due to inadequate food and fluid consumption (AA, 2009a). Food and drink should be adjusted for resident preferences and health needs (e.g., appropriate textures as assessed by a registered dietician must be available).

Palliative and end-of-life care services

Consistent with the *Alberta Provincial Palliative and End of Life Care Framework* (AHS, 2014) palliative care services should be available to on site to all residents of any Living Option, and should also adopt a person-centred approach to understanding the needs and preferences of the individual and her or his family through the end of life (AA, 2009a; ASC, 2011). As for any person, the focus of palliative and end of life care for people living with dementia should be on supporting comfort, minimizing physical symptoms and responding to emotional and spiritual needs of the person and their family (Alzheimer's Association-Greater Illinois Chapter, 2010). A transfer to hospital, hospice, or a higher level of care should not be required except in exceptional circumstances.

Supportive Care Team

Numerous factors related to the composition and structure of the care team appear to interact to support person-centred care and quality of life for residents living with dementia. Further, the literature on person-centred care does not describe a single optimal staffing model or mix. Factors that appear to influence quality of care and quality of life for people living with dementia include staffing models and organizational structures that support whole-team collaboration and empowerment (especially for unregulated direct care staff who provide the majority of care); access to appropriate education for person-centred dementia care as

well as to ongoing coaching, support and knowledge resources; and adequate numbers of direct care providers.¹ Other approaches important to supporting person-centred care include consistent staffing, involvement in the daily life of the resident, flexibility in routines, continuous quality and process improvement activities, and aligned performance expectations for staff. Specific considerations for staff roles and responsibilities in SL4-D settings are examined in Part II.

A foundational tenet of person-centred care is that **all** staff, including support staff (e.g., clerical, housekeeping, maintenance) must play a role in supporting residents in engaging in meaningful social activities, interactions and relationships to create a supportive social milieu. Leadership must support expanded roles, responsibilities and expectations that “encourage all staff to be attentive and responsive to the individual needs, interests, preferences and choices of residents and their families” (ASC, 2014, p. 10).

Whole-Team Collaboration Approaches

A range of approaches to challenging traditional institutionalized staffing models have been developed as part of culture change initiatives in an effort to increase whole-team collaboration, and particularly to ensure inclusion and empowerment of direct care staff to ensure improved individualized care needs. Empowering staff, particularly direct care staff, is associated with improvements in the delivery of individualized care (Caspar & O’Rourke, 2008; Caspar, et al., 2013; Caspar, et al., 2008). Such empowerment requires involved leadership and whole team support, as well as open communication strategies between staff members. Examples of mechanisms developed across Canada to support whole-team collaboration and improvement are described in Box 4 below.

The ideas for improvement have really been coming from our front-line staff. We’ve really learned that we need to tap into their wisdom and their knowledge.

*Dana Penner Dyck, Director of Care Services,
Bethany Care Society, Calgary*

(TREC, 2014.)

¹ For the purposes of this document, the term ‘direct care staff’ is used to encompass unregulated front-line workers in residential settings, including Health Care Aide (HCAs). Where different terms for these workers are used in specific program examples are used, the term used in the name of that program or initiative is used (e.g., the Ontario term Personal Support Worker [PSW]).

Box 4. Mechanisms to Support Whole-Team Collaboration and Empowerment

Care Team Communication Strategies. Numerous approaches have been developed to facilitate open and inclusive communication and information sharing among all care team members.

Interdisciplinary Care Team meetings and care conferences that include all staff involved in the care, including direct care staff.

Unit huddles including all front-line staff, including direct care providers, LPNs and RNs.

Staff Focus Groups are held twice per year to check in with staff about their overall sense of how things are going in the facility, with representation from all staff (ASC, 2014b).

Direct care staff-only meetings to provide a forum for sharing among direct care staff and leadership.

Leadership Opportunities. In spite of their foundational role in the delivery of care, direct care staff are often excluded from leadership opportunities within the Care Team (Wilhelm et al., 2013). The following are examples of mechanisms developed to empower direct care providers to collaborate in and lead improvements in quality of care through the creation of leadership opportunities accessible to direct care providers.

Supportive Pathways Change Champions, Carewest. Change Champions support overall development within the Care Team of a person-centred approach to dementia care, in line with the Supportive Pathways approach. They help to coordinate team-based QI initiatives, such as team huddles. The Site Champion may be a Health Care Aid or someone from any other discipline within the care team (M. Collins, personal communication, February 27, 2014).

PSW Champion Program, Behavioural Supports Ontario (BSO). As part of the BSO initiative, the Champlain Local Health Integration Network of Ontario established a Personal Support Worker (PSW) Champion program. A PSW in each home is selected and linked directly to the local geriatric mental health (GMH) outreach team to receive education in behavioural support and person-centred care approaches, which the PSW then shares with fellow PSWs in the site. The Champion can also connect fellow PSWs directly with consultation and support through the GMH team. An online community of practice was also created to enable Champions from different homes to connect with one another (Dr. M. Tourigny-Rivard, personal communication, February 21, 2014).

Box 4, continued

Collaborative Quality Improvement Initiatives.

SCOPE (Safer Care for Older Persons [in Residential] Environments) Project, Alberta and British Columbia. A project of the Transforming Research in Elder Care (TREC) initiative, the SCOPE project is piloted an opportunity for direct care staff to lead QI initiatives in collaboration with senior management and clinical experts with skills in quality improvement, in one of three areas (pain, behavior and skin integrity). The teams' initiatives were successful and demonstrated the ability for direct care staff to lead QI initiatives. Ongoing and active leadership support was critical in sustaining improvements (TREC, 2014).

Organizational Structure

Culture change models have attempted to challenge traditional residential care facility hierarchies to improve the ability of direct care staff to utilize their knowledge of each resident to improve individualized care by increasing the responsibility of direct care staff over their work, improving communication channels and exchange of information with other team members. The Green House[®] home model presents one example of a to reducing the hierarchy and increasing direct care staffing numbers without increasing overall staffing (The Green House Project, 2014a; Figure 1). Direct care staff form self-managed teams of universal workers and report directly to a Guide, usually the site administrator, who is trained as a coach. Nursing and allied health staff form a Clinical Support team that providing consultation and support for the direct care staff.

Education

Empowering all staff with appropriate education regarding dementia, communication and meaningful engagement with residents, as well as providing professional staff with the skills and knowledge to assess potential causes of responsive behaviours and to identify appropriate interventions and supports, is essential to providing person-centred, evidence-based dementia care.

Baseline education in person-centred dementia care should be required for **all** staff, including direct care staff, professionals, and support/ancillary staff. *Supportive Pathways*, developed by Carewest, provides a

foundation in person-centred dementia care, including collaboration with families, creating normal living environments and providing meaningful activities. The program also addresses supporting responsive or altered behaviours, and sexuality and intimacy as a part of a normalized life experience, while ensuring safety and security for the person, other residents and staff (Carewest, 2013). The Alzheimer Society of Calgary also provides its [Best Friends Approach™](#) training for staff in Calgary and area (Alzheimer Society of Calgary, 2014). The [Gentle Persuasive Approach](#) and [U-First!](#) (based on the P.I.E.C.E.S. described below) programs also offer this baseline education regarding dementia, responsive behaviours and appropriate communication approaches in a format appropriate for direct care staff (AGE Inc., 2014; U-First!, 2014). The opportunity for all staff to participate together in learning opportunities can also support team building and open communication (ASC, 2014).

The [P.I.E.C.E.S.](#) program (representing Physical, Intellectual and Emotional health, maximizing the Capabilities of the individual, Environment and Social needs) provides professional staff working and consulting in the care of older adults living with complex physical, cognitive and mental health needs and associated behaviours with a common systematic approach for assessment and identification of appropriate supportive care strategies (P.I.E.C.E.S., n.d.).

[Non-violent crisis response and response to inappropriate sexual behaviour.](#) Specific educational programming related to responding to behaviours that pose a risk to the safety of the self, other resident and staff, as well as responding to incidents related to inappropriate sexual behavior, should also be available to all members of the care team. Opportunities to develop appropriate education based on existing baseline education programs (i.e., Supportive Pathways, Gentle Persuasive Approaches) should be further explored to ensure that these issues are addressed in the context of a person-centred approach to care. The training must address non-violent de-escalation approaches that are appropriate for frail older people and consistent with the principles of least restraint or restraint-free approaches.

All staff should also receive opportunities for ongoing learning through refresher courses or inservices on specific topics of interest. The Rosehaven Provincial Program provides province-wide access to several relevant education modules related to dementia care and behavior support (The Bethany Group, 2014).

Knowledge Resources

All staff should also have ready onsite access to evidence-informed knowledge resources to support decision-making. Tools should be audience-appropriate, up-to-date and based on best evidence, and available

within the immediate environment of the staff. A pilot study of eight knowledge translation approaches available to support direct care staff in maintaining a mobility intervention found that direct care staff (i.e., HCAs) and managers ranked paper reminder systems, health care aide discussion groups, flowsheet feedback and informal walkabouts/discussions as most effective (Slaughter and Estabrooks, 2013). Further, the *AUA Toolkit* described in Box 3 provides a source of resources for professional staff related to person-centred dementia care and non-pharmacological interventions that is available online for providers province-wide.

Adequate Staffing

While recommendations regarding optimal staffing ratios for people living with dementia in residential care settings, particularly for direct care and activity staff, were not identified in the literature or guidelines, it is acknowledged that generally a lower ratio of residents per direct care staff is required to support adequate engagement of residents and to prevent and support responsive behaviours (Gnaedinger, 2000). Lower resident to staff ratios have been associated with higher quality care generally (Castle, 2007). Specific considerations for direct care staffing ratios in SL4-D settings are described in Part II.

Environmental factors such as the physical layout of the facility or access to supplies may influence ideal staffing numbers. For example, facilities with long hallways may require a larger number of staff in order to keep residents in sight (Gnaedinger, 2000). Ratios may also vary if a multi-skilled worker model (described further in Part II) is adopted for direct care staff roles.

Supporting process improvement initiatives related to time management can also improve efficiency in utilization of staffing resources and overall job satisfaction (Mallidou et al., 2013). For example, staff participants in an Alberta study of two LTC facilities and an SL facility made suggestions for specific opportunities to streamline tasks and increase opportunities to spend uninterrupted time with residents, including minimizing documentation and charting occurring in multiple locations, and reducing medication administration from four times daily to two times through adopting the use of slow-release or longer acting medications (Wilhelm et al., 2013).

Consistent Staffing

Staff consistency allows staff to truly learn to know and build relationships with the residents they support. Enabling direct care to build relationships with residents results can improve trust, understanding and empathy (McGilton & Boscart, 2007). It is recommended that staff be dedicated to particular neighborhoods or units, or assigned to become the “primary caregiver” of small groups of residents (ASC, 2013, 2011). Staff teams should also be consistent to ensure cross shift and shift to shift communication and opportunity to observe for small nuances in resident responses that would otherwise go unnoticed by staff unfamiliar with each unique resident.

Evidence suggests that direct care staff experience increased job satisfaction when their role allows them to work consistently with the same residents (Bishop et al., 2009).

Multi-skilled or universal worker roles. Some organizations have helped to achieve this consistency and reduced the number of individuals within the residents’ environment by creating *multi-skilled* or *universal worker* roles, combining direct care staff responsibilities for supporting personal care with responsibilities for one or more of meal planning and preparation; activities, recreation and leisure; and housekeeping. Combining responsibilities can increase opportunities for building relationships and being involved in residents’ daily lives, discussed further below. Implications for staffing ratios are considered further in Part II.

Involvement in daily life

Staff in Alberta care facilities want the opportunity to spend more time with residents (Wilhelm et al., 2013). As noted, all staff (including support staff such as housekeeping and maintenance), and especially direct care staff, must engage with residents, and use their own daily work activities to be involved in enhancing the daily life of the resident (AA, 2009a; ASC, 2014). Such an approach requires every person in the building to be empowered to engage with residents, and involve residents in their activities. As described above, staff also need to be supported in finding time in their daily work to spend informal, unscheduled time with residents, rather than an emphasis on “a culture of ‘time and task’” (Mallidou, et al., 2013).

After 5 pm, the recreation staff go home and we get creative. We think about things we can do with our residents. I know the one of the orderlies does karaoke in the evenings with him. When he’s in a good mood, happy and laughing, I know who’s been working with him.

-Family member, Union Villa Care Facility,
Unionville, Ontario

(ASC, 2014c, p. 13)

Flexibility in routines

Allowing staff the opportunity to be flexible in times for waking and sleeping, bathing, meal times and availability of activities and opportunities for interaction, socializing, or time alone, helps to create a supportive, individualized milieu (ASC, 2013).

Quality and process improvement initiatives

All staff, and particularly direct care staff most involved in the care of the resident, should be engaged in care quality and process improvement activities. As described previously, huddles, all-staff collaborative person-centred care committees, and site champions can be established, and also serve as empowerment mechanisms (ASC, 2014). Opportunities for HCAs to act as site champions can be particularly valuable for empowering HCAs to share their knowledge of resident preferences to influence improved person-centred care. Purposeful conversations focused on what staff have learned about the resident in the course of their shift must be fostered and the information communicated in such a manner that care can be continually changed to further resident comfort and engagement with their environment.

Performance expectations

Senior leadership and management must set and reinforce expectations for staff performance that are consistent with the overall philosophy of person-centred care as described above. Examples include:

- Supporting staff in being flexible, allowing residents to set the direction of the work day, rather than enforcing expectations associated with task completion;
- Supporting the expectation that all staff are responsible for engaging residents in creative ways through the day;
- Supporting creativity and engagement in quality and process improvement initiatives among all staff; and
- Continuously reinforcing language and approach that is consistent with person-centred care.

Dementia-Friendly Environment

The design of the environment of the facility is critical in influencing the development of an overall supportive milieu (State Government of Victoria, Australia, Department of Health, 2011). Optimal evidence-informed environmental design modifications are those that provide:

- A sense of home, with a quiet and calm atmosphere;
- Creation of smaller groupings or neighborhoods;
- Features supporting way-finding and orientation;
- Features throughout the facility (e.g., plants, animals, multimedia centres, unique and varied textures, pictures, etc.) that residents find interesting and engaging;
- Safe access to outdoors;
- Unobtrusive safety and security features;
- Flexible and accessible common spaces to accommodate activities and leisure; and
- Private bedrooms with private bathrooms where possible.

Optimizing Safety and Security while Supporting Person-Centred Care

Facilities should have least restraint/restraint free policies (pharmaceutical, mechanical, environmental and physical) and falls prevention programs given the increased risk of people living with dementia in these areas (AA, 2009a, ASC, 2013). A policy on sexuality and intimacy should also be in place, supporting a balance between protection of safety and security of the person and others with a sensitivity toward supporting sexuality and intimacy as part of personhood and a normalized life experience (Carewest, 2010). Clear procedures should be in place to support staff in responding to incidents where the safety residents is compromised.

Balancing Safety and Security with the Right to Experience Normal Life Risks. At the same time, supporting person-centred care and quality of life in residential settings requires support for individuals to make personal choices regarding their daily lives, even if those choices may present risks to personal safety. Risk is a normal part of life and an over-emphasis on safety and risk-avoidance can restrict opportunities for meaningful engagement, growth and enjoyment (The Eden Alternative, 2012). Conversations should be supported between staff and residents or designated decision makers and family members regarding the potential considerations regarding risks associated with personal choices in daily activities (Mitty & Flores, 2008).

The Role of Supportive Leadership in Developing, Reinforcing and Championing Person-Centred Culture

The results of the ASC's (2013) case studies of six Canadian care facilities reveal the critical role of leadership in the successful implementation of a person-centred philosophy of dementia care. Facility management and administration play an essential role in championing person-centred care and creating a supportive and respectful culture for both residents and staff through all levels of the organization and grounded in the vision and mission (ASC, 2014). Development of education and mentorship opportunities to support leaders in implementing person-centred care should be further examined.

I will ask a staff member, "Help me understand how this [behavior or decision] fits with our values."

-CEO, Sherbrooke Community Centre,
Saskatoon

(ASC, 2014d, p. 5)

PART II. MEETING THE NEEDS OF PEOPLE LIVING WITH DEMENTIA AND SPECIALIZED BEHAVIOURAL NEEDS IN THE SL4-D LIVING OPTION

The AHS and partner SL4-D Task Group agreed that there is a subset of people living with dementia and/or other forms of cognitive impairment in a residential care setting who require a specialized living option due to particular behaviours, such as:

- wandering with a high risk of and intention for elopement;
- frequent night movement disruptive to others;
- shadowing others;
- lack of insight regarding personal space resulting in disruption to others;
- socially inappropriate behaviours that are disturbing to others;
- need for constant cuing and redirection, or resistance to care; and
- Inappropriate elimination.

The current AHS Living Option Guidelines outline the following descriptors of individuals who would best be served in a SL4-D environment:

- Those individuals who display physically aggressive or sexually inappropriate behavior may benefit from an SL4-D setting; however, these behaviours should be predictable and respond to a therapeutic approach and environment.

- May have complex but stable medical care needs that can be appropriately met through the 24-hour on site scheduled and unscheduled health services provided by an Licensed Practical Nurse (LPN) and Health Care Aides (HCA), with the support of additional professional health services including Registered Nurse (RN) or Registered Psychiatric Nurse (RPN) carrying out the case management functions and 24-hour on-call availability of a Registered Nurse (RN), provided through AHS.
- Those individuals demonstrating unpredictable physically aggressive or sexually inappropriate behaviour which creates a high risk of harm for the self or others in their environment may not have their needs appropriately met in the SL4-D setting and may require a specialized behavioural support care option with onsite access to 24/7 registered nursing assessment and care.

Features of Care in SL4-D Settings

To best support this population, there are several considerations in relation to the elements described above that for care in SL4-D settings. While the above elements apply, the following aspects were identified by the Task Group as requiring a specialized approach to ensure high-quality care. Specific considerations for the care team, including staff roles and responsibilities, are also described.

Person-Centred Service Elements

Meaningful and purposeful activities, recreation and leisure

In SL4-D settings, opportunities for normal daily tasks/activities, recreation and leisure that align with individual strengths and preferences must be available in the resident's immediate living environment (e.g., her or his own unit or even private room) as going to different locations may prove overwhelming. Further, small group and one-to-one to one activities should be available in addition to larger group activities, for those who find large group activities overwhelming. Availability of familiar physical activity (including, where applicable, activity related to past work, such as farming or carpentry) may be particularly helpful for mitigating agitation and anxiety for some individuals who may otherwise be at risk for physically aggressive behavior.

Comprehensive assessment

Comprehensive assessment coordinated by Case Managers will likely require additional time with residents to get to know their strengths and preferences, and to collaborate with families, direct care staff and other members of the interdisciplinary care team, including medical care providers. This may be particularly

important related to determining potential underlying causes for responsive behaviours (in keeping with the *Toolkit for Appropriate Use of Antipsychotics in Long-term Care*, which utilizes the P.I.E.C.E.S. framework to guide assessment).

Crisis Response

Staff must grow to develop relationships with each individual resident and understand their unique response to events or sensory stimulation. In cases where it is important for each resident's escalating behaviour to be described, including those antecedents that can be identified, the behaviours anticipated to occur and successful mitigation and de-escalation strategies. When a crisis occurs where immediate risk to safety is posed for the resident, other residents or staff, direct care staff and the LPN will liaise with available consultant resources including the Case Manager, 24 hour on-call RN, and available crisis response resources.

The SL4-D Care Team

The collaborative care team in SL4-D settings will address the same elements for a supportive care team described in Part I (e.g., mechanisms for whole-team collaboration, consistent staffing, involvement in daily life, flexibility, etc.). Considerations for sharing responsibility between the SL4-D site staff, the AHS Case Manager, and AHS Health Services staff, are described in Appendix B.

Roles and Responsibilities

The following section describes considerations for roles and responsibilities of members of the interdisciplinary care team in SL4-D settings.

Direct Care Providers

As described earlier in the document, as the care providers with the most direct daily contact with residents, direct care providers play a foundational role in the delivery of person-centred dementia care in specialized SL4-D settings. As discussed in Part I, the roles and responsibilities of direct care staff may vary depending on the staffing model and whether a multi-skilled or universal worker model is utilized.

Regardless of the specific responsibilities of the direct care providers, a common characteristic of the role is the critical importance of engaging the resident in meaningful interaction through the course of supporting daily care and activities familiar to the person (e.g., supporting the resident in choosing clothing for

the day). This requires gentle communication approaches and response to individual behaviours recognizing their own contribution to the individual's environment as care providers (ASC, 2013).

In SL4-D settings, coaching and formal supervision for direct care providers regarding clinical care issues is provided by site administration, the Case Manager, on-call RN, and/or an on-site clinical leader. These resources also provide expertise in areas of clinical care of people living with dementia where there is greater risk for challenges, particularly pain management and falls prevention.

At the same time, leadership and professional staff provide valuable consultation, support and coaching for family, direct care providers and other support staff related to aspects of behavioural support, engagement and overall approach to person-centred dementia care and creation of a supportive culture and environment. Formalized opportunities for whole-team communication (e.g., interdisciplinary care team meetings) as described in Part I can help to foster this kind of collaborative practice among the whole team.

Recreation Therapists and/or Assistants

Recreation therapy will coordinate the development of individualized social and recreational activity plans. They offer consultation services, supporting site staff in responding to challenges with engaging particular residents in meaningful recreation, activity or interaction. Plans may be carried out by direct care providers or recreation assistants based on personal strengths and preferences, supporting access to individual, one-on-one and group-based activities, as well as community-based activities. Plans are continually revised and updated to reflect changes in resident preferences, strengths and needs (ASC, 2013, 2011). As previously described, in SL4-D settings, recreation, activities and interaction must be accessible within the residents' living area, and offer more opportunities for 1:1 or small group activities. Learning to understand individual resident strengths and preferences equires time and engagement between the resident and staff.

Case Manager

AHS continuing care has adopted a collaborative, strengths-based case management approach as the health service delivery model for case management to facilitate integration of continuing care services and support linkages to the broader continuum of health and related services. In SL4-D, case management is provided by AHS health professionals, usually an RN or Registered Psychiatric Nurse (RPN). In these settings, the case manager will require more time to assess and coordinate care for residents who have difficulty communicating for themselves, and supporting direct care staff and LPNs in assessing behavioural challenges. They need to liaise more frequently with consultative behavioural and mental health resources, as well as

other members of the allied health care team (e.g., occupational therapy, speech language pathology, social work). Case Managers working in these settings are required to have P.I.E.C.E.S. training to support the care team in assessing root causes of behaviours. They provide decision support for LPNs and HCA staff, particularly regarding assessment of behaviours and identification of appropriate strategies to support them.

Licensed Practical Nurse (LPN)

In SL4-D settings, the LPN provides direct team leadership for direct care staff regarding personal care and daily clinical issues. The LPN collaborates with the direct care staff, Case Managers, and other members of the care team to ensure high-quality clinical care. As the professional nursing team member on-site 24-hours, the LPN requires P.I.E.C.E.S. training in order to be able to collaborate with direct care staff and the on-call RN in supporting responsive behaviours, especially during evenings, nights and weekends.

Registered Nurse (RN)

SL4-D requires on-call access to a Registered Nurse 24/7. This nurse provides consultation and support or as-needed nursing services for site staff. The nurse will place a crucial role in supporting site staff with clinical issues as well as responsive behaviours, especially during evenings, nights and weekends.

Rehabilitation Therapy

Consultation and treatment from rehabilitation therapy professionals, including occupational therapy (OT), speech-language pathology (SLP), physical therapy (PT) and respiratory therapy (RT), will be accessible to all SL4-D clients. OTs offer critical expertise in environmental modification, problem-solving strategies and adaptive aids that can support residents with dementia in engaging in activities, interactions and other aspects of their daily lives (National Collaborating Centre for Mental Health, 2007). Similarly, SLPs can offer strategies to address cognitive communication issues that may interfere with resident engagement in their daily lives (American Speech-Language-Hearing Association, 2014).

Dietitian

The Alberta Accommodation Standards and Health Services Standards for DSL require a Dietitian consult to ensure the site's food services menu is in keeping with the daily required nutrition for the population. Where individuals require food texture changes or a special diet, the Dietitian must be involved in these clinical decisions. All diet and texture types must be available in SL4-D settings.

Social Work

Social workers act as advocates for residents and families, supporting residents and families with the social and emotional impacts of dementia and other forms of cognitive impairment from a strengths-based approach. They may assist with guardianship, trusteeship, cognitive capacity assessment, determining personal directives, and agent responsibilities. As an expert in family communications and relationship capacity, the social worker can support the person and their personal support system with the transition to congregate living, helping families redefine their role and relationship. They may provide families with referrals to community-based resources such as family caregivers support groups, education and informal resources provided by the Alzheimer Society. They may provide guidance for families and site staff related to person-centred, holistic approaches to care. They may also help to mediate disagreements or conflicts between residents, families and staff, particularly regarding resident decision-making capacity, supporting resident autonomy and the right to take risks in the course of daily life. Finally, they can support residents and families with grief and bereavement counselling during the final stages of life (Canadian Association of Social Workers, 2014).

Pharmacist

Pharmacists working with residents living with dementia need to understand and contribute to team-based decision-making related to both pharmacological and nonpharmacological interventions related to memory loss and behaviours. They need to be available to liaise with members of the care team and to provide information and support for families (Kaldy, 2010). They work collaboratively with other members of the care team to ensure that care is provided with best practice guidelines, such as the Seniors Health SCN's (2013) *Guidelines for the Appropriate Use of Antipsychotic Medications in Long-term Care*. As noted in Part I, they may also be able to support initiatives improving efficiency in medication delivery by staff by examining opportunities to use slow- or timed-release medications, helping to free staff time for interaction with residents.

Medical Services

Medical care needs of all SL residents, including SL4-D residents, are provided for by independent primary care physicians, or in some cases, by primary care or care of the elderly nurse practitioners. The medical care of clients living with dementia who have specialized behavioural needs as defined previously requires particular attention by medical care providers, in close collaboration with other members of the care

team, to investigation of possible medical causes for responsive behaviours and mood problems. Medical care providers ensure that any medical intervention is appropriate and in line with best practice guidelines, such as the Seniors Health SCN's (2013) *Guidelines for the Appropriate Use of Antipsychotic Medications in Long-term Care*. The medical care provider works in close collaboration with the person living with dementia, family caregiver, case manager, pharmacist and other team members as needed to ensure appropriate medical care and treatment. Where behavioural and mental health outreach teams are involved with a particular client, the medical care provider reviews recommendations from the team and makes orders related to treatment as appropriate. The medical care provider, in consultation with other members of the care team, may also make referrals to these teams or other specialized resources as needed. To meet the needs of SL4-D clients, medical care is best provided on site to optimize team collaboration and reduce resident anxiety related to leaving a familiar environment.

Staffing ratios

Staffing ratios must be adequate to accommodate preventing and supporting responsive behaviours, especially during personal care by allowing time for staff to build relationships with residents and take time during care. Staffing must also be able to accommodate small group and one-to-one engagement and interaction. A small number of managers and operators of SL4-D programs spoken to suggest ideal ratios may vary between 1:6 and 1:8. However, as discussed in Part I, ideal staffing ratios may be influenced by numerous factors including physical layout and whether a multi-skilled worker model is utilized.

Staff education

In keeping with educational requirements described in Part I, SL4-D staff will have access to education as follows:

- All SL4-D staff (direct care and support staff) will have baseline education in person-centred dementia care described in Part I.
- All SL4-D staff (direct care and support staff) will have baseline education in dementia, communication and engagement approaches, and avoiding or de-escalating critical situations.
- All front-line care staff complete education on non-violent crisis response and responding to inappropriate sexual behavior.
- Professional nursing staff including LPN, case manager and consulting RN must have P.I.E.C.E.S. training.

- Refreshers and opportunities for ongoing learning will be available for all staff.

Specialized Features of the Environment

In addition to features of the environment described in Part I, in SL4-D settings it is especially critical that the physical environment supports dignity and the right to autonomous movement while ensuring that residents do not leave the facility in unsafe circumstances. While some of these approaches may also be adopted in other dementia care settings, SL4-D settings must provide:

- Interesting and stimulating environments that distract from exit points;
- Ensure ready and safe access to outdoor and indoor areas for walking, including enclosed circuits;
- Creatively disguised exits and fences;
- Direct lines of site to common areas from staff areas;
- Fences high enough to discourage climbing and continuous to the ground. Good design can also ensure that views of surrounding country-side, neighborhood or garden are available (State Government of Victoria, 2011).
- Lines of site from inside the building to outside areas;
- Technologies to prevent disturbances, especially at night time (e.g., pressure mat sensor by the bed that can activate an alarm);
- Additionally, private bedrooms and bathrooms must be provided in these environments.

PART III. QUALITY OUTCOMES FOR DEMENTIA CARE IN RESIDENTIAL SETTINGS

Implementation of the structures and processes outlined in the service model above is expected to influence the following outcomes associated with high-quality person-centred care and quality of life in dementia. The indicators are organized across the Alberta Health Quality Matrix Dimensions of Quality.

Table 3. Quality Outcomes for Dementia Care in Residential Settings

Quality Dimensions	Indicators	Measures
Acceptable	Quality of life	InterRAI Quality of Life Survey
	Person-centred care	Person-Centred Assessment Tool

Quality Dimensions	Indicators	Measures
	Client/family satisfaction	TBD
Appropriate	Overall context of care (culture, leadership, and evaluation/feedback)	Alberta Context Tool (ACT)
	Use of appropriate practice guidelines	TBD
Accessible	Decreased ALC days	TBD
	Reduction in the use of ER or Acute care admissions for behaviours associated with dementia	TBD
	Wait times/access to services within program based on assessed need	TBD
	Assistance when needed	TBD
	Engagement in recreation and meaningful activity throughout the day	RAI-HC Section F
Effective	Decreased responsive behaviours	RAI-HC Section E3&4
	Decreased inappropriate use of antipsychotic medications	RAI-HC Section Q2a
	Decreased mood problems (depression and anxiety)	RAI-HC Section E1&2
	Decreased skin problems	RAI-HC PURS Scale
Efficient	Decreased acute care and emergency admission	TBD
	Decreased staff turnover	TBD
	Increased staff satisfaction	TBD
Safe	Decreased restraint use (physical)	RAI-HC Section K9e
	Decreased falls injury	TBD
	Decreased aggressive behavior	RAI-HC Section E3 – occurred, easily altered; occurred, not easily altered
	Decreased delirium	RAI-HC Section B3 – sudden or new onset/change in mental function over last 7 days, in last 90 days; Delirium CAP
	Decreased staff injury	TBD

APPENDIX A

Alberta Health Services **Designated Living Option Guidelines: AHS Case Manager Clinical Decision Support Tool (Sept 24, 2010)**

Supportive Living Level 3 Assisted Living (SL3)	Supportive Living Level 4 Enhanced Assisted Living (SL4)	Supportive Living Level 4 Dementia Enhanced Assisted Living (SL4-D)	Long-term Care Facility
<ul style="list-style-type: none"> Health Care Aide - 24 hour on-site Registered Nurse - 24 hour on-call availability <p>Medical Conditions:</p> <ul style="list-style-type: none"> Medical condition is stable and appropriately managed without a 24-hour on-site RN or LPN PRN medication assistance available if client capable of making request <p>Cognitive Status:</p> <ul style="list-style-type: none"> May have mild dementia but behaviourally stable May require unscheduled reassurance No known risk of elopement but may wander – is easily redirected Social behaviour does not induce fear and anxiety in other residents No known risk of self-harm or harm to others <p>Note: site may have a secured environment</p> <p>Functional Status:</p> <ul style="list-style-type: none"> Mobilizes independently or with one-person transfer Requires unscheduled personal care (assistance with management of incontinence, cueing and/or assistance with meals, transportation to meals, direction and/or cueing for initiation and completion of activities, assistance with pre-packaged scheduled medications) Able to call for help using a call system <p>Exclusion Considerations:</p> <ul style="list-style-type: none"> Complete meal assistance if dietitian support / consultation is not available Mechanical lift transfers Two-person transfers Chronic unmanaged incontinence <p>RA-HC Outcome Scales Expected Range: Cognitive Performance Scale: 0 - 3 ADL Hierarchy: 0 - 3 IADL Difficulty: 4 - 6 CHES Scale: 0 - 3 MAPLE Scale: Mod, High or Very High</p>	<ul style="list-style-type: none"> Licensed Practical Nurse and Health Care Aide - 24 hour on-site Registered Nurse - 24 hour on-call availability <p>Medical Conditions:</p> <ul style="list-style-type: none"> May be complex but is stable and appropriately managed safely through an interdisciplinary client centred plan of care Unscheduled professional assessments may be required to adjust the plan of care which may include medication management <p>Cognitive Status:</p> <ul style="list-style-type: none"> May have varying levels of dementia but are behaviourally stable May require unscheduled reassurance Minimal risk for elopement but may wander – is easily redirected Social behaviour does not induce fear and anxiety in other residents Minimal risk of self-harm or harm to others <p>Functional Status:</p> <ul style="list-style-type: none"> Will have complex physical care needs that cannot be met at home or in a lower level of supportive living May require the following types of assistance with ADLs: <ul style="list-style-type: none"> Complete meal assistance including tube feeding Mechanical lift transfers Two-person transfers Total assistance to mobilize including portering Medication assistance or administration <ul style="list-style-type: none"> Chronic unmanaged incontinence <p>Exclusion Considerations:</p> <ul style="list-style-type: none"> Unpredictable behaviour placing self and others at risk (may not be an exclusion consideration in some settings) Requires 24-hour on-site RN professional services Requires intensive and/or extensive rehabilitation services that cannot be easily accessed <p>RA-HC Outcome Scales Expected Range: Cognitive Performance Scale: 2 - 4 ADL Hierarchy: 2 - 4 IADL Difficulty: 5 - 6 CHES Scale: 0 - 3 MAPLE Scale: Mod, High or Very High</p>	<ul style="list-style-type: none"> Enhanced Assisted Living (SL4-D) <p>Medical Conditions:</p> <ul style="list-style-type: none"> Will have moderate dementia that may progress to later stages or other forms of cognitive impairment (CPS 3 or greater) Lacks awareness of personal space of others Will have unpredictable behaviours which may include risk for elopement May have unpredictable behaviours placing self and others at risk but manageable in this environment. <p>Cognitive Status:</p> <ul style="list-style-type: none"> May have complex physical care needs that cannot be met at home or in a supportive living environment May require the following types of assistance with ADLs: <ul style="list-style-type: none"> Complete meal assistance including tube feeding Mechanical lift transfers Two-person transfers Medication assistance or administration Chronic unmanaged incontinence <p>Exclusion Considerations:</p> <ul style="list-style-type: none"> Clients with unstable acute medical or psychiatric conditions who require acute care hospitalization <p>RA-HC Outcome Scales Expected Range: Cognitive Performance Scale: 3 - 5 ADL Hierarchy: 1 - 3 IADL Difficulty: 5 - 6 CHES Scale: 0 - 3 MAPLE Scale: High or Very High</p>	<ul style="list-style-type: none"> Registered Nurse, Licensed Practical Nurse and Health Care Aide - 24 hour on-site <p>Medical Conditions:</p> <ul style="list-style-type: none"> Will have complex unpredictable needs but is clinically stable and can be managed safely with 24-hour on-site RN and regularly scheduled and unscheduled on-site physician support for complex end of life care needs, complex medication management, or complex nursing interventions Unscheduled assessments are often required to address changing resident care issues <p>Cognitive Status:</p> <ul style="list-style-type: none"> May have any stage of dementia May have unpredictable behaviours placing self and others at risk <p>Note: facility may have a secured dementia care unit</p> <p>Functional Status:</p> <ul style="list-style-type: none"> Will have complex physical needs with care requirements that cannot be met at home or in a supportive living environment May require the following types of assistance with ADLs: <ul style="list-style-type: none"> Complex nutritional intake requirements Intensive and extensive rehabilitation requirements Complex elimination requirements Complex family dynamics requiring on-site RN interventions <p>Exclusion Considerations:</p> <ul style="list-style-type: none"> Clients with unstable acute medical or psychiatric conditions who require acute care hospitalization <p>RA-HC Outcome Scales Expected Range: Cognitive Performance Scale: 2 - 4 ADL Hierarchy: 2 - 5 IADL Difficulty: 5 - 6 CHES Scale: 2 - 4 MAPLE Scale: High or Very High</p>

APPENDIX B

Responsibilities and Accountabilities for AHS Continuing Care – Client/Family, AHS Continuing Care-Case Manager, SL4-D Site Staff and AHS Health Professionals

Understanding of Individual Life History and Preferences			
Client and Family	AHS CC-CM	SL4-D Site Staff	AHS Health Professionals (Consulting and Referral)
<ul style="list-style-type: none"> Share life history, preferences, hobbies, activities and leisure activities with DSL Site staff and AHS CC-CM during pre-admission conference and other opportunities for duration of residence 	<ul style="list-style-type: none"> Participate in sharing and learning about resident life history and preference during pre-admission conference and at other opportunities for duration of residence 	<ul style="list-style-type: none"> Coordinate gathering of information regarding life history, preferences, hobbies, interests of resident during pre-admission conference and through ongoing consultation mechanisms such as family conferences and interdisciplinary care team conferences 	<ul style="list-style-type: none"> Relevant AHS staff participate as needed to improving understanding of resident life history, preferences and interests (e.g., Registered Nurse [RN], Recreation Therapy [Rec. T.], Social Work [SW], Occupational Therapy [OT], Speech Language Pathologist [SLP])

Comprehensive Assessment (modified from Alberta Health Services, 2014b)

Client and Family	AHS CC-CM	SL4-D Site Staff	AHS Health Professionals
<ul style="list-style-type: none"> • Participate in assessment process • Confirm assessment accurately reflects status and care needs 	<ul style="list-style-type: none"> • Determine assessment observation period • Set RAI-HC assessment reference date and communicate to the DSL site • Complete RAI-HC according to AHS assessment expectations and CIHI coding guidelines utilizing all sources of information within one month of admission • Identify when additional secondary or specialized assessments are required and complete or arrange for these to be completed • Confirm assessment captures the client's perspective of their health status and care needs • Review RAI-HC outcome measures and communicate relevant information with DSL site 	<ul style="list-style-type: none"> • Agree to RAI-HC assessment reference date • Complete RAI-HC Tracking Tool in collaboration with the CM within assessment observation period • Review RAI-HC outcome measures and communicate relevant information with AHS-CM 	<ul style="list-style-type: none"> • Participate as needed in providing information for assessment

Meaningful Activities, Recreation and Leisure			
Client and Family	AHS CC-CM	DSL Site Staff	AHS Health Professionals
<ul style="list-style-type: none"> Client and family participate and engage in activities, recreation and leisure to the extent that they wish to and in line with personal preferences 	<ul style="list-style-type: none"> Shares any information that may support engagement and participation in meaningful activities Refers to AHS Health Professionals when there is a need for support with health challenges that may challenge ability to engage in preferred activities or leisure (e.g., Rec. T., OT, PT, SW, mental health [MH], dietician). Notifies physician or nurse practitioner [NP]. 	<ul style="list-style-type: none"> Provide access to structured and unstructured activities and recreation in line with individual client preferences, during days, evenings and weekends All DSL site staff and administration are responsible for interacting and engaging with residents, even for brief interactions, during days, evenings and weekends Provide opportunities for community participation and engagement (e.g., volunteer programs, intergenerational programs) SL4-D Settings: Ensure recreation and leisure activities are available within client living area (i.e., client is not required to leave unit or site to participate in activities) 	<ul style="list-style-type: none"> Provide clinical support and development of plan to support clients in engaging with recreation and activities (especially Rec. T.) Provide site staff with coaching and education as needed SL4-D Settings: Plan activities and recreation opportunities that are appropriate to client behavioural needs (e.g., smaller group or individual activities, physical activity)

Family Support and Engagement			
Client/Family	AHS CC-CM	DSL Site Staff	AHS Health Professionals
<ul style="list-style-type: none"> Participate in engagement opportunities (e.g., family conferences, councils) and share ongoing feedback on care with DSL Site Staff 	<ul style="list-style-type: none"> Refer to AHS Health Professionals as needed (e.g., SW, MH) Refer to community-based support programs as appropriate (e.g., Alzheimer Society education, information and support) 	<ul style="list-style-type: none"> Provide ongoing and regular opportunities for family engagement opportunities (e.g., family conferences, councils) Be available to receive ongoing input and feedback from families regarding care 	<ul style="list-style-type: none"> Provide support to families as needed with grieving, loss, or mental health issues that may be associated with transition to a residential setting (e.g., SW, MH)
Dining and Dietary			
Client/Family	AHS CC-CM	DSL Site Staff	AHS Health Professionals
<ul style="list-style-type: none"> Share information regarding client's personal preferences (e.g., favourite or disliked foods, dietary requirements, preferred times of day to eat) Share ongoing feedback on food and dining experiences with DSL site staff Family members may wish to participate in everyday meals and special events 	<ul style="list-style-type: none"> Coordinate Dietitian assessment as needed 	<ul style="list-style-type: none"> Provide access to choice in meals and snacks Provide flexible meal times and make snacks available throughout the day When possible, create opportunities for client engagement in meal preparation, or opportunities for families to participate in everyday meals and special occasions Implement any dietary needs indicated in care plan by 	<ul style="list-style-type: none"> Dietitians and other health professionals (e.g., medicine, OT) will provide support with dining and dietary needs care plan development as needed and assess for any risks (e.g., choking risk)

		Dietitian, physician or nurse practitioner	
Behavioural and Mental Health Supports			
Client/Family	AHS CC-CM	DSL Site Staff	AHS Health Professionals
<ul style="list-style-type: none"> Participate in assessment and development of strategies and approaches to supporting responsive behaviours and mental health issues, based on knowledge of client and personal preferences Provide ongoing feedback and input regarding services 	<ul style="list-style-type: none"> Working with site staff, refer to behavioural and mental health consulting supports in cases of complex, severe and persistent behavioural or mental health issues (e.g., those that fail to respond to approaches identified by site staff, severe and persistent mental illness, behaviours that may pose a risk to safety of self or others) 	<ul style="list-style-type: none"> Follow AUA Guideline and Toolkit recommendations regarding support of responsive behaviours related to dementia and other causes, using non-pharmacological approaches as a first-line approach In severe and complex cases (e.g., those which fail to respond site-based attempts to manage, severe and persistent mental illness, behaviours that may pose a risk to the safety of self or others), work with AHS CC-CM to refer to appropriate AHS resources (e.g., behavioural or geriatric mental health consulting) 	<ul style="list-style-type: none"> Behavioural and geriatric mental health consulting teams provide consultation, recommendations, education and capacity building for client, family and site staff If required, support temporary stay with a behavioural support/stabilization/transition unit

		<ul style="list-style-type: none"> In crisis situations (e.g., client poses immediate risk of harm to self or others), link to appropriate available emergency or crisis supports 	
Palliative and End-of-Life Care Services			
Client/Family	AHS CC-CM	DSL Site Staff	AHS Health Professionals
<ul style="list-style-type: none"> Provide input and feedback on care as comfortable 	<ul style="list-style-type: none"> Refer to AHS palliative and end-of-life care staff 	<ul style="list-style-type: none"> Work closely with AHS palliative and end-of-life care staff to implement care plan 	<ul style="list-style-type: none"> Palliative and end of life care staff work with client, family and site staff to develop care plan

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