



Ministry of Health Policy Instrument

Type:	Supporting Policy Directive
Policy Name	Dementia Care

Version	1.0
Effective Date:	
Division/Branch:	Specialized Services Division
Ministry Contact:	Director Palliative and Dementia Care
Document Number:	
Date:	July 11, 2017

Deputy Minister
Ministry of Health



DEMENTIA CARE

POLICY OBJECTIVE

This policy outlines expectations for Regional Health Authorities specific to the delivery of dementia care across the continuum of care and aims to enable people to live well with dementia from diagnosis to end-of-life.

Expected Impact on Health Outcomes and Service

1. *Acceptability*: Individuals, family caregivers, and health care providers have high levels of satisfaction with service delivery. Care is respectful of and responsive to preferences and needs of individuals and their family caregivers.
2. *Appropriateness*: Services meet the unique medical and psychosocial needs of the individual receiving service, and associated family caregiver needs. Services are provided in a culturally safe manner.
3. *Accessibility*: Timely access to appropriate care in all care settings is provided as close to home and community as possible. Access to service is coordinated on behalf of and in collaboration with individuals and their family caregivers.
4. *Efficiency*: Health care resources meet the needs of individuals, family caregivers, and health care providers while supporting a sustainable health care system. Individuals receive most of their care in the community, utilizing facility-based care options as needed and appropriate.
5. *Effectiveness*: Care improves quality of life and is based upon evidence-informed assessment and delivery of health care and service needs.

DEFINITIONS

Advance Care Planning is a process by which a capable adult communicates their beliefs, values and wishes for future health care with their family/friend(s) and health care providers¹.

Cultural Humility is a process of self-reflection to understand personal and systemic biases and to develop and maintain respectful processes and relationships based on mutual trust. Cultural humility involves humbly acknowledging oneself as a learner when it comes to understanding another's experience.²

¹ Adapted from *My Voice Advance Care Planning Guide*

<http://www.health.gov.bc.ca/library/publications/year/2013/MyVoice-AdvanceCarePlanningGuide.pdf>

² <http://www.fnha.ca/wellness/cultural-humility>

Cultural Safety is an outcome based on respectful engagement that recognizes and strives to address power imbalances inherent in the healthcare system. It results in an environment free of racism and discrimination, where people feel safe when receiving health care.³

Dementia refers to a set of symptoms associated with progressive deterioration of cognitive function affecting daily activities. Symptoms of dementia can include memory loss, judgement and reasoning problems; and, changes in behaviour, mood and communication ability. Dementia is caused by various brain diseases and injuries. Alzheimer's disease is the most common cause of dementia. Vascular dementia, frontotemporal dementia, and Lewy body dementia constitute other common types.⁴

Interdisciplinary team refers to a group of health care providers who work together in a coordinated and integrated manner with patients to achieve health care goals. Effective interdisciplinary teams display collective competency, shared leadership, and active participation of each team member involved in patient care.

Responsive Behaviours refer to a set of expressions (actions, words, or gestures) that may arise from an unmet need or environmental stress. People living with dementia may exhibit responsive behaviours as a means of communicating personal, social, or physical needs.^{5,6}

Trauma Informed Approaches are policies and practices that recognize the connections between violence, trauma, negative health outcomes and behaviours. These approaches increase safety, control and resilience for people who are seeking services.⁷

SCOPE

This policy covers Health Authority delivered dementia care in home, community and hospital settings.

POLICY DIRECTION

To enable high quality dementia care in all regional health authorities, in all settings where health authority services are provided, dementia care will include the following attributes:

1. **Person and Family-Centred Approach:** People living with dementia are empowered and supported to make informed decisions about their care and day-to-day life to the fullest extent they are capable. Authentic and ongoing engagement put the values and preferences, including respect and dignity, of the person with dementia at the centre of

³ <http://www.fnha.ca/wellness/cultural-humility>

⁴ Adapted from Public Health Agency of Canada. Dementia [Internet]. Ottawa (ON): Public Health Agency of Canada; [2016 Aug 5; cited 2017 May 2].

⁵ Adapted from (Dupuis, Wiersma, & Loiselle, 2012).

⁶ Adapted from http://www.behaviouralsupportsontario.ca/Content/Pledge/BSO_Person-Centred_Language_Initiative_Report%20October_2018.pdf

⁷ <https://www.canada.ca/en/public-health/services/publications/health-risks-safety/trauma-violence-informed-approaches-policy-practice.html#s1>

decision-making and recognizes family caregivers/substitute decision-makers as partners in care.

2. **Modifiable Risk and Protective Factors:** Information is made available to the public about modifiable risk and protective factors. People can reduce their risk of dementia by getting regular exercise, not smoking, avoiding harmful use of alcohol, controlling their weight, eating a healthy diet, and maintaining healthy blood pressure, cholesterol and blood sugar levels, according to guidelines issued by the World Health Organization.⁸
3. **Early Diagnosis, Information and Community Supports:** Early diagnosis enables people with dementia to plan ahead and has been shown to improve quality of life.⁹ Health care professionals are supported to identify and diagnose cognitive changes in the early stages of the disease. People with dementia and their family and friend caregivers are provided information about dementia care and community services early after diagnosis and as required to support living well with dementia (e.g. referral to First Link®).
4. **Advance Care Planning:** Serious illness conversations are integrated early after diagnosis and continue as a routine part of the care process. Conversations include information about the trajectory of a person's condition, goals of care, and legal requirements related to future health care including the role of substitute decision makers.
5. **Responsive Behaviours:** A person-centred and trauma-informed approach to care addresses the person with dementia's underlying care needs that may contribute to the expression of responsive behaviors. All individuals working and volunteering in the care environment receive training relevant to their role, enabling a team-based approach to anticipate and prevent responsive behaviours where appropriate; and, to recognize, understand and manage responsive behaviors in a person-centred manner.
6. **Care Environment:** Dementia-friendly design is incorporated into care environments. Dementia-friendly design includes adaptations of the physical, social and emotional environment to achieve person and family-centred care and services.
7. **Coordination and Continuity of Care:** Information, services and support for people living with dementia is coordinated and enables continuity of care. People living with dementia have access to integrated and coordinated care by an interdisciplinary team.
8. **Clinical Standards, Guidelines and Processes:** Health authorities promote consistent and equitable access to high-quality dementia care. Up-to-date clinical standards, guidelines and processes inform care provided. This includes clinical guidelines for appropriate prescribing of anti-psychotic medications.
9. **Education and Coaching:** Education and training, including coaching and mentoring, is provided for all individuals working and volunteering in dementia care environments (relevant to role) to ensure comprehensive, high quality, and culturally appropriate person-centred dementia care.

⁸ <https://apps.who.int/iris/bitstream/handle/10665/312180/9789241550543-eng.pdf?ua=1>

⁹ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6080387/>

10. **Indigenous Peoples (First Nations, Metis and Inuit):** Health Authorities work collaboratively with First Nations, Metis and Inuit peoples to provide culturally safe and trauma-informed dementia care regardless of setting. Protocols for communication, referral, and intra/inter professional support and advice are in place to care for people living with dementia and their family and friend caregivers, including within Indigenous communities.
11. **Underserved Populations:** Health authorities proactively identify populations that may be underserved by dementia care services, including but not limited to: ethnic and cultural minority communities, Official language minority communities, rural and remote communities, the LGBTQ2¹⁰ community; and, individuals with young onset dementia¹¹ or intellectual disability. Mechanisms are established to enable all people with dementia care needs access to high quality, culturally appropriate person and family-centred dementia care (e.g. translation of print materials, use of interpreters as necessary).
12. **Respite and Caregiver Support:** Caregivers are offered meaningful, appropriate and flexible respite and support services. Respite enables caregivers to balance a quality of life outside of providing care, affording time to rest and recuperate. Caregiver support provides both emotional support and education/training on practical skills for caregiving.

VIRTUAL CARE

Virtual care will be used to leverage expertise in dementia care, supporting evidence-informed and patient/family centred care as well as support for health care providers.

DATA ANALYTICS AND REPORTING

Collection, submission and reporting of data in support of this policy is under development and will ultimately enable understanding of dementia care service characteristics and population needs.

PERFORMANCE INDICATORS

Indicators to evaluate the performance of this supportive policy directive are under development.

REVIEW & QUALITY IMPROVEMENT

The policy will be refreshed as needed and reviewed on a three year cycle; or, when deemed appropriate through consultation between Ministry and external stakeholders.

LINKAGES

General Policy Direction – Integrated System of Care

Supportive Policy Directions:

- Patient Medical Home
- Complex Medical and Frail Adults SCSP
- Mental Health and Substance Use SCSP

¹⁰ Lesbian, gay, bisexual, transgender/transsexual, queer/questioning, two-spirited

¹¹ Young Onset Dementia is the term used when symptoms of dementia start before the age of 65. The terms “Young Onset” and “Early Onset” are used interchangeably.

DRAFT FOR CONSULTATION

- Continuity of Care
- Interdisciplinary Team Based Care

Supporting Policy Directions:

- Respite Care Policy
- Palliative Care Policy

DRAFT



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Type:	Supporting Policy Direction
Policy Name	Palliative Care

Version	4.3
Effective Date:	
Division/Branch:	Health Services Division
Ministry Contact:	Executive Director, Seniors' Services
Document Number:	
Date:	June 17, 2020

Deputy Minister
Ministry of Health

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PALLIATIVE CARE

POLICY OBJECTIVE

This policy outlines expectations for regional health authorities specific to the delivery of palliative care, across the continuum of care, in order to improve the quality of life of people living with life-threatening and/or advancing life-limiting illnesses and their family caregivers¹.

Expected Impact on Health Outcomes and Service

1. *Acceptability*: Individuals, family caregivers, and health care providers have high levels of satisfaction with service delivery. Care is respectful of and responsive to preferences and needs of individuals and their family caregivers.
2. *Appropriateness*: Services meet the unique medical and psychosocial needs of the individual receiving service, and associated family caregiver needs. Services are provided in a culturally safe manner.
3. *Accessibility*: Timely access to appropriate palliative care services in all care settings is provided as close to home and community as possible. Access to service is coordinated on behalf of and in collaboration with individuals and their family caregivers.
4. *Efficiency*: Health care resources meet the needs of individuals, family caregivers, and health care providers while supporting a sustainable health care system. Individuals receive most of their care in the community, utilizing facility-based care options as needed and appropriate.
5. *Effectiveness*: Care improves quality of life and is based upon evidence-informed assessment and delivery of health care and service needs.

DEFINITIONS

*Palliative Approach to Care*²: Care that focuses on meeting an individual's and family caregiver's needs – physical, psychosocial and spiritual – at all stages of a life-limiting or life-

¹ Family caregiver refers to non-paid caregivers the individual receiving service chooses to have support them and does not necessarily denote a formal familial relationship.

² Adapted from [The Way Forward National Framework; A Roadmap for an Integrated Palliative Approach to Care \(2015\)](#), p57.

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threatening condition. It reinforces the individual's autonomy and right to be actively involved in their own care and strives to give individuals and family caregivers a greater sense of control. It sees palliative care as less of a discrete service offered to dying persons when treatment is no longer effective, and more of an approach to care that can enhance their quality of life throughout the course of their illness. It provides key aspects of palliative care at appropriate times, focusing particularly on open and sensitive communication about prognosis and illness, advance care planning, psychosocial and spiritual support, and pain/symptom management. As the illness progresses, it includes regular opportunities to review the individual's goals and plan of care.

Palliative Care: Care provided in accordance with a palliative approach to care (defined above), including the early identification and assessment and treatment of pain and other problems - physical, psychosocial and spiritual³. Palliative care may be combined with other active treatments aimed at reducing or curing illness; or, it may be the focus of care when curative treatments are no longer sought.⁴

General Palliative Care: Routine aspects of palliative care that can reasonably be expected to fall within the core skill set of any health care provider, appropriate to their scope of practice. Examples include profession appropriate management of pain, nausea, depression, anxiety, and discussions about goals of care and treatment. General palliative care is provided by a wide range of health care providers including, but not limited to, general practice physicians, specialist physicians (other than specialists in palliative care), nurse practitioners, nurses, pharmacists, social workers, paramedics and spiritual care providers.

Specialized Palliative Care: Complex aspects of palliative care that can reasonably be expected to require additional education, training and/or experience beyond the core skill set of health care providers providing general palliative care, for example, management of intractable physical symptoms; complex depression, anxiety and/or grief; and, conflict resolution regarding goals or methods of treatment.

³ Excerpt adapted from World Health Organization, <http://www.who.int/cancer/palliative/definition/en/>, extracted May 29, 2018.

⁴ Excerpt adapted from [End-of- Life Care Action Plan](#) (2013). BC Ministry of Health. p.2.

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*Life-Limiting Condition*⁵: Conditions that can be reasonably expected to cause death. Some life-limiting conditions progress quickly while others may cause a slow deterioration over many years.

*Advancing Life-Limiting Condition*⁶: Life-limiting conditions that are progressing and can be reasonably expected to cause death within the foreseeable future.

Life-threatening Condition: Conditions that may cause death but are still potentially treatable or curable.

Cultural Safety: Cultural safety is an outcome based on respectful engagement that recognizes and strives to address power imbalances inherent in the healthcare system. It results in an environment free of racism and discrimination, where people feel safe when receiving health care.⁷

SCOPE

This policy covers health authority delivered palliative care services in home, community and hospital settings including, but not limited to, palliative care for adults with life-limiting, life-threatening or advancing life-limiting conditions. A palliative approach to care is appropriate at any age and stage of a life-limiting or life-threatening illness and can be provided together with any beneficial treatment. While this policy contains information that could apply to people under 19 years of age, the scope of this policy is adults 19 years of age or older.

POLICY DIRECTION

To enable high quality palliative care in all regional health authorities, in all settings where health authority services are provided, palliative care services will include the following attributes:

⁵ Adapted from [End-of- Life Care Action Plan](#) (2013). BC Ministry of Health, p.2.

⁶ Adapted from [The Way Forward National Framework; A Roadmap for an Integrated Palliative Approach to Care \(2015\)](#), p.56.

⁷ First Nations Health Authority, <http://www.fnha.ca/wellness/cultural-humility>, extracted May 29, 2018

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1. ***Palliative Approach to Care:*** Early systematic identification of individuals who can benefit from a palliative approach to care is embedded into care delivery processes in all settings. Palliative care principles are embedded into care processes appropriate to the setting and linked with timely access to conversations about goals of care and a proactive approach to the prevention of unnecessary suffering.
2. ***Home and Community Settings:*** A comprehensive and coordinated system of care prioritizes the provision of palliative care at home and in community settings, including hospice, assisted living, long-term care, and ambulatory care. In-hospital care is available for individuals whose care needs cannot be appropriately supported at home or in a community setting. People with palliative care needs that are manageable outside of a hospital or hospice facility receive timely and appropriate services that enable them to remain in their home or home-like setting (i.e., assisted living, long-term care) and contingency plans are identified to prepare for care needs that might reasonably be expected to occur.
3. ***Generalist Model of Palliative Care:*** General palliative care is provided by a range of care providers as part of their routine care of individuals with life-limiting/life-threatening illness. General practice physicians, a wide range of specialist physicians, nurse practitioners, nurses, and other members of the health care team provide general palliative care appropriate to their scope of practice.
4. ***Specialized Palliative Care:*** Specialized palliative care is provided by health care professionals with advanced knowledge and skills in palliative care and whose activity/practice focuses on palliative care. Specialized palliative care advice is available 24/7 to health care providers who provide general palliative care, with consultation and problem-solving support provided in person, by phone or use of virtual technology. Professionals providing specialized palliative care are available to assume care of individuals with complex palliative care needs, or share care with generalist providers, as needed and appropriate.
5. ***Psychosocial Support and Respite Care:*** Individuals and their family caregivers are connected to psychological, spiritual, bereavement and respite support as appropriate.
6. ***Integration of care provided by community organizations:*** Formal linkages between health authorities and community-based organizations, including hospice societies, support and promote a comprehensive system of palliative care including availability of bereavement and other support services. Health authorities enable people to access community-based palliative care services and support work to raise public awareness of palliative care and the importance of advance care planning.

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7. **Rural and remote settings:** People requiring palliative care who live in rural and remote settings are supported with local services where available. Health authorities work with individuals and their family caregivers to establish a person-centred plan of care based on the individual's anticipated care needs, their preferences, and available resources. Contingency plans are identified to prepare for care needs that might reasonably be expected to occur.
8. **Indigenous Peoples (First Nations, Metis and Inuit):** Health authorities work collaboratively with Indigenous individuals and health system partners to provide culturally safe, appropriate and trauma-informed palliative care regardless of setting. Protocols for communication, referral, and intra/inter-professional support and advice are in place to care for people with palliative care needs and to support systems of care for Indigenous peoples.
9. **Underserved Populations:** Health authorities proactively identify populations that may be underserved by palliative care services (i.e., ethnic populations, cultural groups, people living in poverty or people who are unstably housed) and establish culturally safe mechanisms enabling all individuals with palliative care needs to access high quality person-centred palliative care.
10. **Clinical Standards, Guidelines and Processes:** Health authorities have standardized processes for palliative care services that promote consistent and equitable access to high quality palliative care. Up-to-date and peer-reviewed screening, assessment and symptom management guidelines inform care provided and standardized processes, forms, assessment documents and care plans are in place across the continuum of care.
11. **Advance care planning:** Advance care planning conversations are routinely integrated into the care process, promoting person-centred serious illness conversations, identification of goals of care, identification of substitute decision makers, and development of care plans and treatment decisions. Health authority policy directs consistent management and storage of advance care plans and supports translation of advance care plans into individualized plans of care.
12. **Education and coaching:** Education and training, including coaching and mentoring, is provided for health care providers and volunteers to ensure comprehensive, high quality, and culturally safe palliative care.
13. **Benchmarking:** quality indicators, workload measures, minimum data sets and case load standards are developed provincially based on national standards and implemented in each health authority.

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Virtual Care

To improve access to person-centred palliative care, virtual care will be embedded into day to day operations where appropriate to meet care needs.

Virtual care extends the reach of generalist and specialist palliative care providers, enabling evidence-informed and person-centred care as well as education and training of health care providers.

DATA ANALYTICS AND REPORTING

Collection, submission and reporting of data in support of this policy enable understanding of palliative care service characteristics and population needs.

PERFORMANCE INDICATORS

Collection, submission and reporting of data enable assessment of palliative care performance with respect to attributes outlined in this policy directive.