

Select Standing Committee on Health

***Improving End-of-Life Care
for British Columbians***



MAY 2016



May 10, 2016

To the Honourable
Legislative Assembly of the
Province of British Columbia

Honourable Members:

I have the honour to present herewith the First Report of the Select Standing Committee on Health for the Fifth Session of the 40th Parliament.

The Report covers the work of the Committee regarding best practices to improve end-of-life care for British Columbians and was unanimously approved by the Committee.

Respectfully submitted on behalf of the Committee,

Linda Larson, MLA
Chair

Table of Contents

Composition of the Committee	i
Terms of Reference.....	iv
Glossary.....	vii
Executive Summary	viii
Introduction	1
Consultation Process	4
Meetings Schedule.....	6
Committee Findings.....	7
Palliative Model of Care	7
Supports and Services	13
Training, Recruitment and Retention.....	18
Advance Care Planning	21
Families and Caregivers	24
Alzheimer’s Disease and Dementia	27
Summary of Recommendations	31
Appendix A: List of Written Submissions and Presentations on End-of-Life Care	35
Appendix B: Selected Readings	38

Composition of the Committee

Members

2nd Session

Linda Larson, MLA	Chair	Boundary-Similkameen
Judy Darcy, MLA	Deputy Chair	New Westminster
Donna Barnett, MLA		Cariboo-Chilcotin
Dr. Doug Bing, MLA		Maple Ridge-Pitt Meadows
Katrine Conroy, MLA		Kootenay West
Sue Hammell, MLA		Surrey-Green Timbers
Richard T. Lee, MLA		Burnaby North
Hon. Norm Letnick, MLA <i>(to April 30, 2014)</i>		Kelowna-Lake Country
Jane Jae Kyung Shin, MLA		Burnaby-Lougheed
Hon. Michelle Stilwell, MLA		Parksville-Qualicum
Dr. Moira Stilwell, MLA <i>(from April 30, 2014)</i>		Vancouver-Langara

3rd Session

Linda Larson, MLA	Chair	Boundary-Similkameen
Judy Darcy, MLA	Deputy Chair	New Westminster
Donna Barnett, MLA		Cariboo-Chilcotin
Dr. Doug Bing, MLA		Maple Ridge-Pitt Meadows
Sue Hammell, MLA		Surrey-Green Timbers
Richard T. Lee, MLA		Burnaby North
Jennifer Rice, MLA		North Coast
Bill Routley, MLA		Cowichan Valley
Hon. Michelle Stilwell, MLA		Parksville-Qualicum
Dr. Moira Stilwell, MLA		Vancouver-Langara

4th Session

Linda Larson, MLA	Chair	Boundary-Similkameen
Judy Darcy, MLA	Deputy Chair	New Westminster
Donna Barnett, MLA		Cariboo-Chilcotin
Dr. Doug Bing, MLA		Maple Ridge-Pitt Meadows
Marc Dalton, MLA <i>(from October 20, 2015)</i>		Maple Ridge-Mission
Sue Hammell, MLA		Surrey-Green Timbers
Richard T. Lee, MLA <i>(to October 20, 2015)</i>		Burnaby North
Dr. Darryl Plecas, MLA		Abbotsford South
Jennifer Rice, MLA <i>(to September 8, 2015)</i>		North Coast
Bill Routley, MLA		Cowichan Valley
Jane Jae Kyung Shin, MLA <i>(from September 8, 2015)</i>		Burnaby-Lougheed
Dr. Moira Stilwell, MLA		Vancouver-Langara

5th Session

Linda Larson, MLA	Chair	Boundary-Similkameen
Judy Darcy, MLA	Deputy Chair	New Westminster
Donna Barnett, MLA		Cariboo-Chilcotin
Dr. Doug Bing, MLA		Maple Ridge-Pitt Meadows
Marc Dalton, MLA		Maple Ridge-Mission
Sue Hammell, MLA		Surrey-Green Timbers
Dr. Darryl Plecas, MLA		Abbotsford South
Selina Robinson, MLA		Coquitlam-Maillardville
Jane Jae Kyung Shin, MLA		Burnaby-Lougheed
Sam Sullivan, MLA		Vancouver-False Creek

Committee Staff

Susan Sourial, Clerk Assistant, Committees and Interparliamentary Relations

Lisa Hill, Committee Research Analyst

Aaron Ellingsen, Committee Researcher

Terms of Reference

2nd Session Terms of Reference

On February 25, 2014, the Legislative Assembly agreed that the Select Standing Committee on Health be empowered to:

1. Consider the conclusions contained in the Interim Report, October 2012, of the Select Standing Committee on Health of the 39th Parliament; as such, the Interim Report of the Select Standing Committee on Health, and any submissions and evidence received during the 39th Parliament, are referred to the Committee;
2. Outline potential alternative strategies to mitigate the impact of the significant cost drivers identified in the Report on the sustainability and improvement of the provincial health care system; and
3. Identify current public levels of acceptance toward the potential alternative strategies.

In addition to the powers previously conferred upon the Select Standing Committee on Health, the Committee shall be empowered:

- a. to appoint of their number, one or more subcommittees and to refer to such subcommittees any of the matters referred to the Committee;
- b. to sit during a period in which the House is adjourned, during the recess after prorogation until the next following Session and during any sitting of the House;
- c. to conduct consultations by any means the committee considers appropriate;
- d. to adjourn from place to place as may be convenient; and
- e. to retain such personnel as required to assist the Committee;

and shall report to the House as soon as possible, or following any adjournment or at the next following Session, as the case may be; to deposit the original of its reports with the Clerk of the Legislative Assembly during a period of adjournment and upon resumption of the sittings of the House, the Chair shall present all reports to the Legislative Assembly.

3rd and 4th Session Terms of Reference

On October 9, 2014 and February 25, 2015, the Legislative Assembly agreed that the Select Standing Committee on Health be empowered to:

1. Consider the conclusions contained in the Interim Report, October 2012, of the Select Standing Committee on Health of the 39th Parliament; as such, the Interim Report of the Select Standing Committee on Health, and any submissions and evidence received during the 39th Parliament, are referred to the Committee;

2. Outline potential alternative strategies to mitigate the impact of the significant cost drivers identified in the Report on the sustainability and improvement of the provincial health care system; and
3. Identify current public levels of acceptance toward the potential alternative strategies; and,
4. Consider health capital funding options.

In addition to the powers previously conferred upon the Select Standing Committee on Health, the Committee shall be empowered:

- a. to appoint of their number, one or more subcommittees and to refer to such subcommittees any of the matters referred to the Committee;
- b. to sit during a period in which the House is adjourned, during the recess after prorogation until the next following Session and during any sitting of the House;
- c. to conduct consultations by any means the committee considers appropriate;
- d. to adjourn from place to place as may be convenient; and
- e. to retain such personnel as required to assist the Committee;

and shall report to the House as soon as possible, or following any adjournment or at the next following Session, as the case may be; to deposit the original of its reports with the Clerk of the Legislative Assembly during a period of adjournment and upon resumption of the sittings of the House, the Chair shall present all reports to the Legislative Assembly.

5th Session Terms of Reference

On March 1, 2016, The Legislative Assembly agreed that the Select Standing Committee on Health be empowered to:

1. Identify potential strategies to maintain a sustainable health care system for British Columbians; and
2. Consider health capital funding options.

In addition to the powers previously conferred upon the Select Standing Committee on Health, the committee shall be empowered:

- a. to appoint of their number one or more subcommittees and to refer to such subcommittees any of the matters referred to the committee and to delegate to the subcommittee all or any of its powers except the power to report directly to the House;
- b. to sit during a period in which the House is adjourned, during the recess after prorogation until the next following Session and during any sitting of the House;
- c. to conduct consultations by any means the committee considers appropriate;
- d. to adjourn from place to place as may be convenient; and
- e. to retain such personnel as required to assist the committee;

and shall report to the House as soon as possible, or following any adjournment or at the next following Session, as the case may be; to deposit the original of its reports with the Clerk of the Legislative Assembly during a period of adjournment and upon resumption of the sittings of the House, the Chair shall present all reports to the Legislative Assembly.

Glossary

Alzheimer's disease¹ — the most common form of dementia, Alzheimer's disease is irreversible and destroys brain cells, causing thinking ability and memory to deteriorate. Alzheimer's disease is not a normal part of aging.

Dementia² — a chronic, progressive disease of the brain that affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, judgment, and executive function.

End-of-life care³ — end-of-life care is associated with advanced, life-limiting illnesses, and focuses on comfort, quality of life, respect for personal health care treatment decisions, support for the family, psychological and spiritual concerns.

Life-limiting illness³ — life-limiting illness is used to describe illnesses that can be reasonably expected to cause the death of the individual within a foreseeable future. This definition is inclusive of both malignant and non-malignant illnesses that are expected to shorten an individual's life.

Palliative care³ — palliative care is specialized medical care for people with serious illness. It focuses on providing patients with relief from the symptoms, pain, and stress of a serious illness – whatever the diagnosis. The goal is to improve quality of life for both the patient and the family and is provided in a variety of locations, including people's homes and community settings, hospices, residential care settings and hospitals. Palliative care is provided by a team of doctors, nurses and other specialists who work with a patient's other doctors to provide an extra layer of support. Palliative care is appropriate at any age and at any stage in a serious illness and can be provided together with any beneficial treatment.

Person/patient-centred approach² — an approach to the management of a health condition that incorporates biological, psychological, sociological, and functional perspectives. This approach recognizes that these perspectives all interact to determine an individual's experience of the condition.

Population needs-based approach to palliative care³ — a population needs-based approach recognizes that individuals facing a serious illness have different needs, based on their unique health conditions, stage of disease and complexity of symptoms. Health care services and supports should therefore vary in type and intensity to most effectively meet the needs of the individual.

¹ Alzheimer Society Canada website, available at: <http://www.alzheimer.ca/en>

² The Provincial Dementia Action Plan for British Columbia (Ministry of Health, November 2012)

³ The Provincial End-of-Life Action Plan for British Columbia (Ministry of Health, March 2013)

Executive Summary

On July 23, 2013, the Legislative Assembly of B.C. tasked the Select Standing Committee on Health (the Committee) to identify strategies for maintaining the sustainability and quality of our province's health care system. The Committee issued a call for written submissions in June, 2014, including a series of four questions designed to focus the consultation process. By the end of December, 2014, the Committee had received 374 submissions, 111 of which were in response to the Committee's question about best practices that could be implemented to improve end-of-life care. As 231 of the submissions received addressed physician-assisted dying, the Committee issued an Interim Report in October, 2015 with recommendations specific to this topic. The Committee also invited organizations who had made written submissions to present in person and Committee Members heard from 24 organizations during these public meetings between April and September, 2015. This report provides a summary of key themes identified through the consultation process and makes 42 recommendations to improve end-of-life care for British Columbians. The Committee will continue its public consultation in 2016 to identify strategies for maintaining the sustainability and quality of B.C.'s health care system.

Palliative Model of Care

Definitions around palliative care have changed to include a focus on those living with serious life-threatening illnesses, as opposed to only those who may succumb to their illness in the near future. This new definition is not constrained by a patient's age or where palliative services may be delivered, whether it be in the home, the community or a hospital setting. Research findings indicate that the sooner a patient is able to access palliative care, the better the outcomes; thus the focus shifts to helping those with serious illnesses live well. The need for palliative care services applies to communities across the province, including those in rural, remote and isolated areas. The Committee supports moving toward a more integrated palliative model of care and recommends that: timely information regarding available social services and advance care planning be provided to patients with chronic life-limiting illnesses; patients be referred to palliative care earlier in the course of their illness; the expansion of in-home services for the frail elderly be supported, based on successful models already in place; the provision of services for palliative and end-of-life care in rural, remote and isolated communities is fairly distributed to meet the needs of those communities; an integrated and interdisciplinary palliative model of care be applied across the health service continuum to reflect a patient-centred approach to cultural practices and sensitivities regarding end-of-life care; initiatives to implement pro-active home visits be supported; and a patient-centered approach be focussed on the optimization of quality of life and include an emphasis on comfort and function.

Supports and Services

Families and caregivers need to feel supported in delivering care to those with life-limiting illnesses, whether it be in the home or another setting, and they want to easily find information online to help inform planning and decision-making. Key aspects of supports and services for patients, families and caregivers, such as facilities, home care, services, health data and technology could be improved. Therefore, the Committee recommends that: more dedicated palliative care beds be created in hospitals and community settings; equal access to hospice care be provided through the development of new palliative care sites across the province and that these beds be located in facilities that offer comfortable, home-like settings; a centralized, tiered, community-based palliative care service model be expanded, particularly in rural areas; investment be provided for a more robust in-home care support system with 24/7 availability across the existing continuum of care, including palliative care; the expansion of day care options within senior's centres be considered to ensure access to a variety of centralized services and programs for seniors within their communities; a mechanism be created to regularly collect information and feedback from patients, families and caregivers to ensure ongoing assessment and improvement to end-of-life care, services and resources; a frail seniors health registry be established to allow seniors to stipulate their wishes to receive acute care support services, in conjunction with their advance care directive; information about programs, resources and services be provided in a centralized and accessible online format; a system or repository where advance care directives can be centrally housed and retrieved by emergency medical teams be created; and in order to increase the use of telemedicine, web consultations and other virtual technologies be supported to enable patients to remain in their homes and communities.

Training, Recruitment and Retention

The need for increased investment in the training, recruitment and retention of physicians, nurses and other health care professionals was highlighted, especially in remote, rural and isolated communities. The Committee recognizes the value of providing continued investment in our province's health care providers and recommends that: stable funding be provided to ensure increased investment in the training, recruitment and retention of health professionals, including those who specialize in palliative care in remote, rural and isolated communities; the number of dedicated residency spaces in palliative care be increased and adjusted according to population trends and demand; an optional alternate fee structure be offered physicians who face the challenge of travelling long distances to meet the needs of patients in rural, remote and isolated communities; and training be provided to ensure that health care professionals know how to implement and follow advance care directives and to assist health care professionals to communicate effectively and sensitively with patients, families and caregivers.

Advance Care Planning

Patients, families and caregivers want to be able to plan ahead regarding care and to know that the patient's wishes will be respected when end of life is imminent. Committee Members heard about the need for an increased focus on advance care planning, a central repository to house these documents, and more education, tools and improved enforceability. Committee Members recognize the benefits of advance care planning, want to see improvements in this area and support this by recommending that: advance care planning become part of the required standard of care for patients with chronic or complex illnesses; advance care plans/directives include input from the entire care team to ensure they are developed with a patient-centric focus; a centralized and secure repository for advance care plans/directives be created to allow retrieval by emergency health teams, patients, families and caregivers; health care workers be trained to assist patients, families and caregivers to develop health care plans that are easy to draft, understand, update and follow; the *Adult Guardianship Act* and the *Representation Agreement Act* be amended to clarify and improve enforceability of end-of-life care directives and to specify the inclusion of personal care in both Acts; and any applicable provincial legislation be amended to align with anticipated federal legislation related to physician-assisted dying.

Families and Caregivers

Committee Members acknowledged the key role that families and caregivers play in providing assistance, care and comfort to those in the final stages of life and expressed appreciation for this selfless and often unrecognized work. Improving supports, education and respite care for families and caregivers is a cornerstone to improving end-of-life care for British Columbians and in recognition of this, the Committee recommends that: improvements be made to communications and educational materials for patients, families and caregivers to aid in the development of end-of-life care plans; education and information about organ and tissue donation be included in end-of-life plans and palliative care programs; increased access to respite care, training and other supports be provided for caregivers, including those living in remote, rural and isolated communities; holistic strategies be developed to ensure that mental health, cultural and spiritual considerations are reflected in end-of-life planning and care; and the concept of "end-of-life care" be added to B.C.'s online public portal for instruction on how to complete advance care plans/directives.

Alzheimer's Disease and Dementia

Committee Members recognize the challenges faced by the significant number of British Columbians diagnosed with Alzheimer's disease or dementia and their families. Palliative and end-of-life care supports and services must be tailored to patients, families and caregivers who live with Alzheimer's disease or dementia and to help facilitate this, Committee Members recommend that: a patient-centred palliative model of care be developed in residential care facilities that is responsive to the unique needs of those with Alzheimer's disease or dementia; community organizations partner with

health care providers to promote consistent and responsive dementia training; training programs and screening protocols be implemented to enhance competence and confidence in assessing frailty, dementia and Alzheimer's disease; support be provided for an advance care planning process that includes an assessment for frailty, dementia or Alzheimer's disease and outlines the risks or benefits of various treatments early in the process; support and dedicated funding be provided for initiatives that provide assistance to those with Alzheimer's disease or dementia and their families; increased access to in-home respite care support for family members and caregivers be provided; and the availability and use of assistive technology be increased for those living with Alzheimer's disease or dementia.

Introduction

Maintaining the sustainability and quality of British Columbia's health care system

Many British Columbians enjoy a good quality of life, including one of the longest life expectancies in Canada⁴ and the lowest rates of obesity, smoking, and infant mortality in the country.

Maintaining a strong and responsive health care system to meet the needs of citizens is a topic of interest to all British Columbians. Access to high quality health care for British Columbians, regardless of where they live, is an important focus of B.C.'s health care system. The provision of health care in rural, remote and isolated communities can present significant challenges, including the recruitment and retention of health care professionals to work in these specific communities.

B.C.'s health care system has changed dramatically in recent decades to meet the demands of citizens and respond to the changing health care environment and demographics. The advancement of innovative treatments, therapies, drugs, and diagnostic technologies has led to significant improvements in the health and longevity of British Columbians. Our health care system has also had to evolve to meet changing requirements, notably a greater emphasis on treating long-term chronic conditions, and addressing the pressures of a growing and aging population. Of the province's total population, 16.9 percent is aged 65 or older – a number that is expected to double within the next 25 years.⁵ While not all of those who are aging will experience dementia or Alzheimer's disease, it is estimated that currently between 60,000 and 70,000 British Columbians have dementia.⁶

Health care is the single largest area of provincial spending, accounting for almost 40 percent of total government spending.⁷ The budget for the Ministry of Health in the 2016/17 fiscal year is estimated at almost \$18 billion, and forecast to increase to nearly \$19 billion by 2018/19.⁸ Submissions and presentations from individuals and organizations indicate that one of their priorities is for government to maintain the quality and sustainability of the province's health care system, including palliative and end-of-life care.

Both palliative and end-of-life care provide comfort and are part of the overall continuum of care. Palliative care can begin at diagnosis, be provided at the same time as treatment, and typically refers to specialized medical care for people with a serious illness. The focus of palliative care is to provide patients with relief from the symptoms, pain, and stress of being ill. End-of-life care begins after treatment of the disease is stopped and when it is clear that the patient is not going to survive the

⁴ Life Expectancy Tables, Vital Statistics Agency, BC Ministry of Health (2012)

⁵ Population projections, BC Stats, Ministry of Labour, Citizens' Services and Open Government (2012)

⁶ Provincial Dementia Action Plan for British Columbia (2012)

⁷ BC Budget and Fiscal Plan (2016)

⁸ BC Ministry of Health 2016/17 – 2018/19 Service Plan

illness. End-of-life care is usually offered only when the person is expected to live six months or less and focuses on comfort, quality of life, respect for personal health care treatment decisions, support for the family, and psychological and spiritual concerns.

Palliative and end-of-life care are both situated on the continuum of care model that spans the course of a person's life, from birth to death. The continuum of care model is commonly defined as the array of health services that span the course of a person's life, from primary care (including prevention and health promotion), through institutionally based secondary and tertiary care, to community and home-based services that promote health maintenance, rehabilitation, and palliation at the end of life.

End-of-life care for British Columbians

In 2008, the Canadian Institute for Health Information (CIHI) conducted a study of the usage patterns of health care services in the two years prior to death for nearly 30,000 British Columbians of all ages who died between April 2003 and March 2004. The report findings indicate that despite the fact the majority of deaths were from diseases that are known to be life-limiting, only about 15 percent of the study group had received palliative care. Identification and receipt of palliative care services tended to be most closely linked to cancer patients, rather than those who died from other diseases such as congestive heart failure, kidney disease or dementia.⁹

Our health care system needs to provide effective end-of-life care with comfort, dignity, and quality of life for British Columbians. This includes the range of services delivered by a variety of health professionals who provide pain and symptom management, community nursing and rehabilitation services, home support, respite services, and residential hospice care.

There are a number of plans and resources already in place that address end-of-life and dementia care in B.C., including the *Provincial End-of-Life Care Action Plan for British Columbians*, the *Provincial Dementia Care Action Plan for British Columbia* and *My Voice* (B.C.'s advance care planning guide, available online through the Ministry of Health website). The Ministry of Health has promised to provide "additional funding to support hospice and palliative services for children and adults as part of our work toward doubling the number of beds by 2020 and supporting end-of-life care."¹⁰

British Columbians and their families and caregivers indicated in their submissions to the Committee that end-of-life care is an important part of the continuum of care provided through a sustainable, efficient health care system. As end-of-life care was the topic that received the most interest in response to the Committee's call for submissions, Committee Members decided to begin their

⁹ The Provincial End-of-Life Care Action Plan for British Columbia (2013)

¹⁰ Strong Economy Supporting British Columbians: Balanced Budget 2015 Highlights

inquiry into the quality and sustainability of British Columbia's health care system with a review of the submissions received on end-of-life care. What follows in this report is a summary of findings based on submissions received by the Committee and recommendations related to improving end-of-life care for British Columbians.

Consultation Process

On July 23, 2013, the Legislative Assembly of British Columbia tasked the all-party Select Standing Committee on Health to identify strategies for maintaining the sustainability and quality of B.C.'s health care system. To fulfill their mandate, in June 2014, the Committee invited British Columbians (including patients, families and caregivers) to share their ideas on how we can continue to ensure the sustainability of, and make improvements to, our health care system. In order to focus the consultation, the Committee sought submissions addressing any or all of the following questions:

- How can we improve health and health care services in rural British Columbia? In particular, what long-term solutions can address the challenges of recruitment and retention of health care professionals in rural British Columbia?
- How can we create a cost-effective system of primary and community care built around interdisciplinary teams?
- What best practices can be implemented to improve end-of-life care?
- How can we enhance the effectiveness of addiction recovery programs?

Approximately 340 stakeholder organizations and individuals were invited to make a submission and a background document and general call for submissions were provided to all Members of the Legislative Assembly for distribution through their constituency offices. In addition, information about the consultation was posted on the Committee's website and distributed through social media.

Written Submissions

A total of 374 submissions were received from individuals, health sector advocacy groups, service providers, and professional associations across British Columbia by the December 31, 2014 deadline, 111 of which addressed best practices to improve end-of-life care (one of the four topics proposed in the Committee's call for submissions).

Submissions received on end-of-life care addressed a wide range of topics, including: pain management; palliative care; access to palliative care across the province and across the continuum of care; improved training for health professionals; resources for families and caregivers; and better integration of advance care planning into current health care models.

Although not part of the Committee's call for submissions, 231 of the 374 submissions received addressed the specific topic of physician-assisted dying. Due to the number of submissions received on this topic, in March 2015, the Select Standing Committee on Health struck a subcommittee to review the submissions received. The Committee heard presentations on the topic of physician-

assisted dying at public hearings on two dates in April and July, 2015 and released their interim report in October 2015.

Presentations

In addition to the call for written submissions, Committee Members invited stakeholder groups who had made written submissions to present before the Committee in order to provide additional information on priorities for improving end-of-life care. Between April 15 and September 14, 2015, the Committee heard from 24 different organizations during these public meetings, including public bodies, non-profit agencies, health care researchers, and other stakeholders. A full list of end-of-life care presentations is available in Appendix A.

Presentations and written submissions received by the Committee on health care sustainability in British Columbia are available for viewing or download on the Committee's website:
<https://www.leg.bc.ca/cmt/health>

The Committee will continue its public consultation in 2016 as part of its work to continue to identify strategies for maintaining the sustainability and quality of B.C.'s health care system.

Meetings Schedule

2nd Session

<i>Date</i>	<i>Type</i>	<i>Location</i>
March 26, 2014	Organizational Meeting, Briefings	Victoria
April 9, 2014	Business Planning	Victoria
May 27, 2014	Organizational Meeting	Victoria
September 11, 2014	Business Planning	Vancouver

3rd Session

October 9, 2014	Organizational Meeting	Victoria
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4th Session

March 5, 2015	Organizational Meeting	Victoria
March 26, 2015	Business Planning	Victoria
April 15, 2015	Presentations	Victoria
April 22, 2015	Business Planning	Victoria
April 29, 2015	Presentations	Victoria
May 13, 2015	Briefing; Presentations	Victoria
May 15, 2015	Presentations	Vancouver
July 15, 2015	Presentations	Victoria
September 14, 2015	Presentations	Vancouver
October 15, 2015	Sub-Committee Meeting	Vancouver
October 21, 2015	Deliberations Adoption of Interim Report	Victoria
October 28, 2015	Deliberations	Victoria
December 15, 2015	Deliberations	Vancouver

5th Session

March 31, 2016	Organizational Meeting Deliberations	Vancouver
May 2, 2016	Deliberations Adoption of Report	Victoria

Committee Findings

Palliative Model of Care

Palliative care is a relatively new area in medicine, and one that is still finding its place within British Columbia's health care system. While palliative care programs and services in the province are strongly connected to cancer care in the minds of many, evidence received through presentations and written submissions on end-of-life care emphasized the importance of developing a broader understanding of the relevance and applicability for palliative treatment and services, which is referred to as a palliative model of care. As the University of British Columbia (UBC) Division of Palliative Care expressed succinctly in their written submission, "Palliative care has changed in the last ten years to being applicable to patients with serious life-threatening (not life-limiting) illness. Modern palliative care helps patients to live life as well as possible — not just to die well. You do not have to be imminently dying to benefit from palliative care; in fact, the earlier in the course of illness you receive palliative care, the better the outcomes."

Committee Members felt that it is important to appreciate the full implications of terms like "chronic, life-limiting illnesses." As groups including the UBC Division of Palliative Care, the BC Cancer Agency, the Alzheimer Society of B.C., the UBC Department of Family Practice, Community Geriatrics, and others explained, a fundamental building block of an effective palliative model of care involves developing a comprehensive understanding of conditions comprising life-limiting illnesses. For example, Alzheimer's disease and frailty fall outside many health providers' current understanding of conditions that may benefit from palliative care, despite widely-acknowledged patient health trajectories associated with each condition, inevitably concluding with death. Committee Members heard that a broadened understanding by health care providers of life-limiting conditions can support early diagnosis, timely patient education, improved patient decision-making, and more satisfactory outcomes for better-informed patients.

Dr. Jay Slater and Dr. John Sloan, from the UBC Department of Family Practice, Community Geriatrics, specialize in treating frail elderly patients. They described the benefits of a team approach to palliative care for the frail elderly population: "[Frail seniors] prefer and somehow instinctively understand that they benefit from being provided with care that assures their comfort and care that maintains their function. There's only one way to get that to them, and that is through a team approach." Their team-based practice provides expanded services and 24/7 care for frail elderly patients through home visits. This helps prevent repeated visits to hospital emergency departments and allows their patients to remain comfortably in their homes for a longer period. This introduces two predominant end-of-life care priorities: the importance of timely access to care, regardless of a

patient's location in the system; and the crucial supporting role that a team-based and patient-centred approach to integrated palliative care plays in ensuring timely access to resources and services.

Rural Palliative Care Services

Inequities in the provision of health care services across the province – and in particular, those related to palliative and end-of-life care – were highlighted by numerous organizations and individuals who appeared before the Committee and sent written submissions. Committee Members heard that uneven distribution of palliative care funding through health authorities in B.C. can have a significant impact on the provision of end-of-life care services in remote, rural and isolated communities. In their written submission, Squamish-Lillooet Regional District drew attention to these irregularities: “Unofficial two tier medical services are in effect in B.C. and pose serious challenges to the continued provision of high-quality public health care as it promotes deleterious competition between public and private services.”

Funding shortfalls for hospice services within health authorities in B.C. was another area of concern as this limits the support and services that hospice societies are able to provide in their communities. The Desert Valley Hospice Society told the Committee: “Funding for rural hospice societies tends to be quite unequal. Some health authorities fund hospice societies, and some don't. There's no equality in that process. The rural societies are attempting to fill many of the gaps in care, which we don't have because we're not big enough to get the services that an urban centre has. As a result, much of our time and energy is spent on fundraising. We feel that maybe a formula could be developed for rural hospice societies that could take into account the fact that funding is essential for us to deliver our programs and to enable us to expand contracts to provide certain services for the health authorities.”

On behalf of the Association of Registered Nurses of B.C., Andrea Burton highlighted the gaps in service in the north: “... in British Columbia palliative services really vary across the province. What you can access in Fort St. John may be very different than what you can access in Burnaby. That's very challenging both for health care providers and for people in the community. We really need to start to pull together and figure out what the palliative services in B.C. really are so we can start to address gaps.”

Committee Members recognize that further discussion is needed to understand the significant scope of issues surrounding the provision of health care services in remote, rural and isolated communities and will continue to explore this, along with the need to develop long-term solutions to address the recruitment and retention of health care professionals in these areas, through their continued consultation in 2016.

Integration

The delivery of health care often depends on interdisciplinary teams of health care professionals – physicians, nurses, pharmacists, social workers, counselors, psychiatrists, physiotherapists, midwives, and others – who work together to provide patients with different aspects of care. The coordinated provision of health care by interdisciplinary teams contributes to the provision of high-quality, integrated, and efficient health care services.

Committee Members heard repeatedly that priority should be placed on providing access to integrated palliative services for patients throughout the province, and across the health care system — whether at home in their communities; in acute, home or primary care; or in a residential care setting. With respect to timely access, the Canadian Cancer Society, the Canadian Association of Occupational Therapists – BC Chapter, and the Shuswap North Okanagan Division of Family Practice provided submissions that indicate that referring patients with chronic life-limiting illnesses and cancer to palliative care earlier in the course of their disease is preferable so that palliative care teams can provide early assessment and relief of symptoms. This includes the provision of appropriate social services to lessen distress for patients and families, to discuss advance care planning, and to improve quality of life.

iPANEL (Initiative for a Palliative Approach in Nursing: Evidence and Leadership), during their presentation to the Committee, spoke about the importance of an integrated palliative approach across the health service continuum, and about the need to extend and expand chronic disease management and primary care strategies to include an integrated palliative approach to care. Several additional health sector service providers reiterated this view, specifically the integration and inclusion of health practitioners including: primary care physicians (including those with specific training in palliative care), occupational therapists, practitioners of Traditional Chinese Medicine and acupuncture, allied health professionals (including paramedics and social workers), nurses, nurse practitioners, spiritual advisors, pharmacists, care aides, as well as patients, families and caregivers. In addition, the inclusion of cultural competencies, diversity and inclusion awareness to ensure a more inclusive approach to palliative care to better reflect the diversity of British Columbians should not be overlooked. As noted by Charles Brasfield in his written submission to the Committee, “The care needs to be specific enough to help the identified patient, but also flexible enough to accommodate cultural practices of the individual.” For example, the level of involvement of family members in caring or interacting with the patient can vary, depending on culture.

Pro-active Home Visits

The challenge of providing health care and support for an aging population is one faced by many countries. In their presentation to the Committee, the Council of Senior Citizens’ Organizations

highlighted the “preventive or pro-active home visits” program in place in Denmark to support that country’s aging population. In 1996, the Danish government introduced legislation to ensure that every citizen aged 75 and older would receive the offer of two pro-active home visits every year. In 2010, the *Consolidation Act on Social Services* was revised to offer one pro-active home visit per year. The aims of the home visit program is to provide support for an overall improved quality of life for seniors, maintain or improve functional ability and increase seniors’ feelings of independence and interconnectivity with their communities. Individual municipalities in Denmark have jurisdiction over how they implement the home visits so that they can be customized for regional requirements.

The health care worker assigned to the home visit will perform their assessment based on a number of aspects, including: frailty, functional ability, mental acuity, housing conditions, and financial stability. The worker will also evaluate potential requirements for assistive living devices and home care support services. Local authorities are able to offer a range of integrated services and supports to seniors through these visits. In their 2006 report *Older people and preventive home visits*, AgeForum – an independent council set up by the Danish Ministry of Social Affairs to monitor and assess the conditions of older people in Denmark – noted that “It appears that good cooperation between home care services, preventive offers and local GPs is the key to achieving the best results.” AgeForum also reports that women appear to benefit more from pro-active home visits than men and that 80-year olds benefit more than 75-year olds. The report also states that the pro-active home visit program was implemented at no additional cost to taxpayers by reallocating funding from other sources.

While not all seniors accept the offer of a pro-active home visit, according to AgeForum, those that do appear to have more positive outcomes such as the ability to stay in their homes longer, to live healthier lives in old age, and an increase in functional ability for some participants. In a 2014 presentation to a think tank on planning for the future of seniors’ and dementia care hosted by the College of Licensed Practical Nurses of Alberta, Eva Pederson, Director of Policy, Aging Division with the Danish Ministry of Social Affairs, noted that 75 percent of seniors aged 80 to 84 and 30 percent of those aged 90 years or older still reside in their own homes.¹¹ The Danish government has not constructed any new nursing homes since 1987 and has moved towards a more integrated system of care for seniors and persons with disabilities.

Comfort Care

A number of presenters and several written submissions addressed the importance of increasing the focus in end-of-life care on “comfort care” – that is, to consider quality of life as well as quantity of life remaining when making treatment decisions for patients. Proponents of comfort care note that the focus should be on patient-centred care based on personal comfort and function, rather than

¹¹ Government of Denmark: *Caring for the Elderly the Danish Way*: Eva Pederson, Director of Policy, Aging Division, Ministry of Social Affairs (2014)

curing or over-medicalizing those with life-limiting illnesses. It is worth noting that the overlap between considerations of comfort care for those approaching end of life and the even more widely raised issue of advance care planning is key to timely and informed comfort care decision-making. This is especially important for the information and education available to health professionals, patients and their families.

Comfort care is an important component of moving towards a more patient-centred and holistic approach to end-of-life care supported by an interdisciplinary team of health care professionals, as well as an important element for consideration in development of a population needs-based approach to palliative care as defined in the *Provincial End-of-Life Care Action Plan for British Columbia*.

In their written submission to the Committee, the Cranbrook Kimberley Hospice Society explained that at some point in the life of an individual, "...the focus of care should shift from being one of prolonging life to supporting the individual in making the final transition from life to death." Likewise, the Shuswap North Okanagan Division of Family Practice summarized patient-centred palliative/end-of-life care and comfort care: "The degree to which all people, regardless of their social setting or location, can achieve the goals of privacy, dignity, and comfort at the time of their death could be one of the measures of the success of our society." On the topic of comfort care, the Committee heard that end-of-life care needs to be patient-centred and that optimization of the patient's quality of life always needs to be a consideration when different interventions, services and medications are being offered. As expressed by Dr. Lindsay Pritchett in his written submission to the Committee: "...terminally ill patients are given futile treatments for prolonged periods of time. This extends their dying process unnecessarily. This is unkind to them, and expensive to the medical plan."

Conclusions

The number of presentations and written submissions that the Committee received that relate to palliative and end-of-life care indicate that this is an area of importance for many British Columbians and key stakeholder organizations. The current definition around palliative care is shifting towards a focus on those living with life-threatening illnesses, rather than only those who may succumb to a serious illness in the near future. This new definition recognizes that a patient may be receiving care at home, or in a community or hospital setting. Committee Members learned that patients who are referred to palliative care earlier in the course of their illness have better outcomes and want to ensure that this option is made available to those with chronic, life-limiting illnesses. Committee Members want to ensure that supports and services are in place to help ensure a person's dignity and autonomy when they are dealing with a life-limiting illness. Through their deliberations, the Committee discussed an integrated and interdisciplinary model of palliative care applied across the health service continuum to encompass the various options available to patients and hope to see the realization of this model. This applies particularly to those who live in remote, rural and isolated communities

where these supports and services can be less widely available. Committee Members expressed support for the team-based services and 24/7 care for the frail elderly through home visits that Drs. Sloan and Slater talked about in their presentation to the Committee and wondered if this model could be expanded.

The preventive or pro-active home visits program that has been implemented in Denmark has allowed seniors in that country to remain in their homes longer and Committee Members would like to see a similar initiative implemented in British Columbia. The concept of “comfort care” was one of the areas that the Committee thought could be developed to ensure that quality of life is a primary consideration when options for treatment are presented to patients, families and caregivers.

Recommendations

The Committee therefore recommends to the Legislative Assembly that the provincial government:

Palliative Model of Care

1. Offer timely information regarding available social services and advance care planning to patients with chronic life-limiting illnesses.
2. Refer patients with chronic life-limiting illnesses to palliative care earlier in the course of their illness.
3. Develop a team approach to palliative care and provide support for the expansion of in-home primary care services and supports for the frail elderly, based on successful models already in place.
4. Ensure that the provision of services for palliative and end-of-life care in rural, remote and isolated communities meets the needs of those communities.
5. Ensure that an integrated palliative model of care is applied across the health service continuum, including primary care, home care, residential care and acute care that includes a patient-centred approach to cultural practices and sensitivities respecting end-of-life care and recognizes the differences between rural and urban access.
6. Implement an interdisciplinary team-based approach for integrated palliative care across the health service continuum including: primary care physicians, nurses, nurse practitioners, spiritual advisors, allied health professionals, care aides, as well as patients, families and caregivers.
7. Support initiatives to implement pro-active home visits for seniors, based on the Danish model.
8. Ensure that a patient-centred approach focuses on the optimization of quality of life and includes a focus on comfort and function as considerations when options for treatment regarding end-of-life care are presented to patients, families and caregivers, including the time-to-benefit ratio of prescribed interventions, services and medications.

Supports and Services

Facilities

Palliative care patients have specific requirements in both acute care and residential settings, and several organizations expressed the need for expanded and improved facilities to provide palliative care across the province. The Desert Valley Hospice Society presented testimony to the Committee regarding care challenges resulting from swing beds — which are beds that can be shared between palliative and other patients on an as-needed basis. They stressed the importance of facilities having dedicated palliative care beds available in hospitals or other care facilities to try to ensure that beds for end-of-life care would be available when needed. Various submissions received by the Committee expressed the need for more facilities, more palliative care or end-of-life care beds, and general hospice space expansion, with a focus on increasing the number of palliative care sites and settings throughout B.C. Numerous submissions suggested that designing palliative care spaces to be more comfortable, home-like settings – rather than clinical or sterile environments – could have a more positive effect on patients, families and caregivers. As stated by Heather Peterson in her written submission to the Committee, “I believe palliative care should be separate from a hospital setting. Surroundings should be home like and comfortable. Emphasis on medical procedures should be minimized as much as possible.” Another written submission noted that facilities should be designed specifically for individuals with dementia so that they can sustain as much quality of life as possible for their specific end-of-life care requirements.

Home Care

Presentations and written submissions by key provincial stakeholder groups, ranging from current health service providers, sector advocacy organizations and health sector professional associations, noted that the need to provide expanded services through more facilities to a greater patient group will require additional provincial investment in palliative and end-of-life care. In her written submission to the Committee, Sheila Campbell shared her experience in taking care of her husband who passed away from cancer in 2013: “I found caring for him at home to be overwhelming and at times we both suffered from the lack of assistance.”

It was noted that palliative patients tend to appreciate supports and services (including palliative care, home support visits or nursing and home hospice) that enable them to stay in their homes and in their communities, as these can promote better quality of life. Further, increased supports for home and community care offer potential cost savings and cost avoidance, as support services enable patients to avoid the cost-intensive acute care system while at the same time ensuring that acute care beds are available for those most in need. The BC Centre for Palliative Care cited Vancouver Coastal Health Authority statistics that strongly support home care as an effective tool for avoiding acute care: “They looked at the last six months of life. What they found is if you were attached to home

care, you spent an average of 20 days in acute care. If you were not attached to home care, you spent an average of 100 days.”

In their presentation to the Committee, the UBC Department of Family Practice, Community Geriatrics, stated that around-the-clock care is crucial to the success of efforts to keep patients at home and in their communities. To that end, several submissions highlighted expanded roles for current health providers, including nurse practitioners and paramedics. In their written submission to the Committee, the Association of Registered Nurses of B.C. proposed exploring opportunities for an increased role for paramedics – for example, in emergency rooms, in home and community care, or in residential care settings – to capitalize on the existing expertise of these health care professionals in broadened settings.

Other presenters and submissions noted that there should be increased resources allocated toward support for transitions within the health care system. The First Nations Health Authority (FNHA) pointed out during their presentation that First Nations patients leaving isolated communities for treatment often expect they will not be able to return home. The same is true for many residents of rural, remote and isolated communities. Possible options for services to facilitate patients staying in their community include: enlisting telemedicine, web consultations and other technological opportunities to support home care; creation of supports to ensure smooth and safe transitions for patients moving from acute care back into homes; increased supports to allow patients to die at home, should they so desire; and the creation of in-between places, familiar enough and comfortable enough that patients don't feel like they're in an acute care setting. According to the BC Cancer Agency, minimally-invasive palliative procedures, such as comfort care measures, often help patients avoid long stays in acute care. Committee Members discussed the idea of expanding the utilization of seniors' centres to include programs and medical services to support home care, which could also provide seniors with increased opportunities for socialization.

The Committee heard from the Cranbrook Kimberley Hospice Society that increased investment in hospice societies could support patients' abilities to remain in their own communities and close to home, which would provide some of the medical and social supports that allow people to die where they prefer. The Shuswap North Okanagan Division of Family Practice presented their “palliative campus of care” concept to the Committee, which is the organization's recommended model for a centre of excellence for the provision of rural, community-based and generalist-driven palliative and end-of-life care. Campus of care models typically relate to tiered senior living accommodations that have independent housing, assisted living and residential care provided within one complex so that seniors can move to different levels of support as needed without moving to a new facility.

Health Data and Technology

Several organizations that presented to the Committee emphasized the need for improvements to how health data is collected, shared and accessed. In particular, the need for better centralization of health data related to end-of-life and palliative care. Committee Members heard that while relevant data was being collected, it was not always made available to patients, families and caregivers in an accessible and comprehensive fashion. Presenters spoke about the sense of empowerment that comes with the access to information about end-of-life care for patients, families and caregivers and how improvements to how data is collected, accessed and shared could positively impact those needing relevant information at a particularly difficult time in their lives and the lives of their families.

In his presentation to the Committee, Richard Jock from the First Nations Health Authority stressed the importance of ensuring that resources and information are available to patients, families and caregivers in centralized, online formats that can be accessed anywhere and at any time. The Committee also heard that how patient and caregiver experiences are evaluated and analyzed over time needs to be enhanced to ensure that a continuous cycle of assessment and improvement, including performance measures, is built into any health data collection measures implemented provincially. In their joint written submission to the Committee, the First Nations Health Authority and First Nations Health Council suggested that work could be done to “develop a culturally safe ‘report card’ for performance measures; include appropriate measures at the patient, service, and system levels.”

The UBC Department of Family Practice, Community Geriatrics, described how a centralized collection of information, including data relevant to the frail elderly and those who have Alzheimer’s disease or dementia, could help empower patients and families to make informed choices when the need for palliative care arises. The creation of a frail elders health registry is another potential solution to address the fragmentation of information currently available. Representatives from the Federation of Oceanside Residents’ Associations described technological resources and virtual options to facilitate connectivity for patients, families, caregivers and doctors or other health professionals when an in-person visit or consultation may not be feasible, such as the creation of a centralized accessible information portal which would include telemedicine or telehealth options. The Federation of Oceanside Residents’ Associations highlighted a trial that had been conducted that connected patients virtually with a nurse practitioner who could assess the patient’s health concerns to see if follow-up action was required, rather than the patient being required to visit the emergency room or doctor’s office to be assessed in person.

The Committee also heard from the Desert Valley Hospice Society regarding the need for a registry of advance care directives available to medical personnel and to patients to ensure that those requiring end-of-life care can have early access to personalize their decisions. Other issues that are specific to

rural, remote and isolated communities were highlighted, including the need for 24/7 availability of palliative services.

Conclusions

Supports and services are crucial to ensuring that appropriate palliative and end-of-life care can be provided to British Columbians, their families and caregivers during the final stages of life. The delivery of supports and services to British Columbians who live in remote, rural and isolated communities is a particular area of concern for the Committee and is repeatedly highlighted within this report as a priority. This includes different facets of support, whether it is medical care provided within a hospital, or home care support that allows patients to remain in a familiar and comforting environment. Committee Members would like to see more dedicated palliative care beds and improvements in the delivery of palliative care throughout the province. The Committee expressed support for the recommendation made by the Select Standing Committee on Finance and Government Services in their *Report on the Budget 2016 Consultations*: “Expand support and funding for a broad range of hospice care and bereavement programs to ensure that these services are available to British Columbians and their families.” (Recommendation #22)

Through the personal stories that were shared during the consultation process, Committee Members understand the value of home care and the supports that allow patients to remain comfortably in their homes during their final weeks and months. The need to ensure quality of life informed their discussions and underpins their recommendations in this area. Advancements in technology provide many opportunities to deliver supports, services and information to patients, families and caregivers where and when they need it. Collecting and sharing information online in a way that empowers patients, families and caregivers is an important facet that Committee Members would like to see highlighted for the delivery of end-of-life care.

Recommendations

The Committee therefore recommends to the Legislative Assembly that the provincial government:

Supports and Services

9. Provide dedicated palliative care beds in hospitals and community settings.
10. Provide equal access to hospice care through the development of new palliative care sites across the province, and ensure that these sites are designed to be comfortable, home-like settings.
11. Consider the expansion of a “palliative campus of care” model to enable centres of excellence for the provision of rural, community-based and generalist-driven palliative and end-of-life care.

12. Provide investment for a more robust in-home care support system with 24/7 availability across the existing continuum of health care, including palliative care.
13. Expand day care options within seniors' centres to ensure that seniors living in their homes within all regions of the province have access to a variety of centralized services and programs in their communities, including medical care and opportunities for socialization.
14. Create a mechanism to collect information and feedback from patients, families and caregivers on a regular basis to ensure a continuous cycle of assessment and improvement for all end-of-life care, services and resources provided through all health care providers.
15. Establish a frail seniors health registry with flexible screening protocols to allow seniors to stipulate their wishes to receive acute care support services when a health crisis occurs, in conjunction with their advance care directive.
16. Create a database, website or other centralized accessible information portal where patients, families and caregivers can access information about available programs, resources and services for palliative and end-of-life care.
17. Create a system or repository where advance care directives can be centrally housed and retrieved by emergency medical teams, including paramedics, doctors and nurses.
18. Support the use of telemedicine, web consultations and other virtual technologies to provide home care services to enable patients to remain in their homes and communities.

Training, Recruitment and Retention

The need for stable funding to ensure an increased investment in the training, recruitment and retention of physicians, nurses and other health care professionals was highlighted by a number of presenters and many of those who provided written submissions to the Committee. A number of submissions focussed on the need for improvements in training, recruitment and retention strategies for rural, remote and isolated areas where there can be unique challenges in retaining long-term health care professionals. Medical professionals in rural, remote and isolated communities can often face the additional challenge of travelling long distances to facilitate patient care and an alternate fee structure might help alleviate this perceived imbalance in the current fee structure and provide fair compensation for travel time.

In their written submission to the Committee, Save our Northern Seniors explained that recruitment and retention of health care workers are critical issues for those in the northern region of the province. The high cost of living and lack of affordable accommodation often deters health care professionals from coming to work in their area and they recommended that Northern Health be provided with additional resources to encourage recruitment and retention of staff through incentives. A written submission by the BC Association of Speech/Language Pathologists and Audiologists suggested that a centralized database of all available health care jobs be created as a solution to help increase knowledge of available opportunities (including those in rural and remote regions) which could be promoted through health associations and universities.

Many submissions also identified the need for increased training in end-of-life care for all health care professionals. As iPANEL stated: “We’ve kind of lost this idea that actually people die everywhere in our health care system. Everybody needs to know how to do this...they all need to have a general ability to provide good quality palliative care.”

Organizations such as the Association of Registered Nurses of B.C. and the BC Cancer Agency, among others, specifically identified the need for increased training to ensure that physicians and other health care professionals have the resources they need to communicate effectively and sensitively with patients, families and caregivers about end-of-life care. As noted by the Association of Registered Nurses of B.C., “...health providers need to have a better understanding of how to have those [end-of-life] conversations, and they’re telling us constantly that they don’t feel like they have the education and the knowledge to do that well.” The Committee also heard that health care professionals might benefit from additional training on how to implement and follow advance care directives or *My Voice*.

In their presentation to the Committee, representatives from First Nations Health Authority suggested that an opportunity exists for FNHA to work more closely with health authorities in B.C. to help ensure that physicians and other health care professionals have the opportunity to develop

cultural competencies. The importance of developing holistic and culturally-sensitive strategies that encompass spiritual elements as well as the environmental, social, physical and emotional needs of patients, families and caregivers was another important aspect of end-of-life care that was highlighted during the presentation. Representatives from FNHA also suggested that a review of resource materials, with the goal of ensuring they are appropriate from a culturally competent perspective and are sensitive to the needs of vulnerable populations and marginalized communities, would be beneficial to confirm that materials address language barriers, socio-economic factors, as well as accessibility and diversity perspectives, to help make them inclusive for everyone in our communities.

The UBC Division of Palliative Care noted that only 15-20 percent of the people that die of expected deaths with chronic illnesses see a palliative specialist. The remaining patients continue to be cared for by other physicians and health care professionals. Despite this, palliative care is not incorporated into many of the residency programs, and family practice in B.C. does not have a mandatory palliative care rotation. They stressed the need for education of physicians so that they are “at a level where they understand the issues, they have the skills and they have the competence to be able to deliver the symptom management, coordinate the advanced-care planning discussions.” The UBC Division of Palliative Care suggested that a minimum of six dedicated residency spaces should be allotted to palliative care per year over the next 10 years to help address this issue.

Conclusions

Pressures on British Columbia’s health care system are expected to increase in the coming years, particularly in relation to an aging population. The need for more trained health care professionals will also continue to increase; and in particular, for those who specialize in palliative and end-of-life care. Rural, remote and isolated communities face the greatest challenge in recruiting and retaining physicians and other health care providers. Committee Members would like to see a dedicated emphasis on training, recruitment and retention efforts, supported by stable increased funding. In relation to this, the number of residency spaces in palliative care should be increased and adjusted based on population trends and demand.

The Committee understands the challenges faced by physicians providing care in rural, remote and isolated areas and an optional alternate fee structure should be offered to compensate them fairly for travel time. The development of cultural competencies for health care professionals could help ensure that they have the skill set necessary to communicate effectively and sensitively with patients, families and caregivers who represent the diverse communities of B.C.

Recommendations

The Committee therefore recommends to the Legislative Assembly that the provincial government:

Training, Recruitment and Retention

19. Provide stable funding to ensure increased investment in the training, recruitment and retention of health professionals, including physicians, nurse practitioners, nurses and care aides specializing in palliative care.
20. Ensure that training, recruitment and retention initiatives meet the needs of rural, remote and isolated communities.
21. Work to increase the number of dedicated residency spaces in palliative care and adjust this number according to population trends and demand for health care in the years to come.
22. Offer an optional alternate fee structure for medical professionals, including physicians and nurse practitioners, who must travel long distances to meet the needs of their patients in rural, remote and isolated communities.
23. Provide training and resources to assist health care professionals communicate effectively and sensitively with patients, families and caregivers facing end-of-life care decisions or choices.
24. Ensure that all health care professionals receive training on how to implement and follow advance care plans/directives or *My Voice*.

Advance Care Planning

Committee Members heard from a range of presenters and received a number of written submissions regarding the need for an increased focus on end-of-life care planning, also referred to as advance care planning, to help implement an improved palliative approach to care for British Columbians with life-limiting chronic illnesses and for those nearing end of life.

Advance care planning is a critical aspect of a patient-centred palliative approach to care. Organizations such as iPANEL described the integral relationship such planning can play in improving end-of-life care: “The first things that we are doing in a palliative care unit is talking to the family and the patient about what their goals of care are and how they want to see the end of their life unfold.”

The BC Centre for Palliative Care cited benefits for patients as well as caregivers and family members: “With advance care planning... about 92 percent of people choose less aggressive options and experience increased quality of life, increased use of hospice, and there’s better long-term outcomes for family members. There’s less PTSD. There’s less depression, less anxiety. There’s this knowledge: We did what Mom wanted, and we did the best we could to align choices with that.” The BC Cancer Agency recommended support for an advanced care planning process that takes into account frailty or dementia assessment, and the risks and benefits of treatment.

Doctors of BC outlined the importance of looking at best practices for end-of-life care, including the integration of the palliative care approach into management of life-limiting chronic disease; advance care planning forming part of the required standard of care for patients with chronic or complex illness; support for physicians to assist families develop advance care plans/directives; integration of advance care plans within patient records; and consideration of the time-to-benefit ratio of prescribed interventions and medications for patients approaching end-of-life.

Public Awareness and Registry

A prominent theme throughout submissions to the Committee related to ensuring availability and education around tools for advance care planning, both for patients and health care service providers throughout the province, and the development of a registry to ensure emergency medical care providers have timely access to directives. As the Alzheimer Society of B.C. observed: “It’s really great that we’ve got tools like representation agreements and powers of attorney for people to put their wishes in place in advance, but people really need to know about them...” The BC Cancer Agency pointed out that while tools for advance care planning exist, a provincial mechanism to provide access to these tools is needed. Pointedly, “If someone’s got an advance care directive, and they’ve got it in a safety deposit box in TD Bank, it’s no use to them when they drop dead on the sidewalk outside the bank. Nobody knows where it is, and they can’t read it, so [that person] ends up in ICU. We need to

have some kind of a system whereby the advance directives are retrievable provincially by the emergency medical teams.”

The BC Centre for Palliative Care described its provincial initiatives and seed grants to support advance care planning workshops and education, which build on existing workshops in regions like the Comox Valley. A number of written submissions received by the Committee stressed the importance of the development of health care plans that are easy to create, update, understand and follow. Health care workers could provide assistance to patients, families and caregivers to develop these straightforward advance care plans/directives. Nidus Personal Planning Resource Centre and Registry, the BC Cancer Agency, the Desert Valley Hospice Society and a range of written submissions recommended the creation of an advance care planning registry, with the topic addressed tangentially in various other stakeholder presentations.

Enforceability

Stakeholder organizations including Nidus and the BC Centre for Palliative Care recommended increased legal enforceability of advance care plans/directives. Dr. Doris Barwich, who presented on behalf of the BC Centre for Palliative Care, referenced her recent research experience: “When we asked patients what they wanted around end-of-life care choices and preferences, we documented that, and then we looked at their chart to see what the orders were. Can you guess what the agreement was between what they told us they wanted and what the orders were? So 36 percent of the time there was an agreement. We talk a lot about patient-centred care. Here is a way we can actually get there.”

In the context of the 2014 BC Supreme Court case *Bentley vs. Maplewood Seniors Care Society*, in which the judge suggested that spoon feeding would not fall under health care consent, but rather might be considered personal care, Nidus recommended amendments to the *Adult Guardianship Act* and the *Representation Agreement Act* to clarify and improve enforceability of end-of-life care directives and to specify the inclusion of personal care. As Joanne Taylor of Nidus stated: “...ensure that we have clarity in education about the legislation, about representation agreements so that people can use it to do their planning. Perhaps the representation agreement doesn't have to be used, because people will be able to make their decisions right up to the point of death. But our experience is that there are often times when people are going to need that assistance.”

The federal government introduced legislation on April 14, 2016 in the House of Commons to provide a framework for physician-assisted death in response to the Supreme Court of Canada decision in *Carter v. Canada* (Attorney General), 2015 SCC 5. *Bill C-14, An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)*, is designed to address the Court's ruling that sections of the *Criminal Code* were invalid insofar as they infringed the right of an individual under the *Canadian Charter of Rights and Freedoms* to seek medical assistance in

dying. The Court set a deadline June 6, 2016 for a legislated response to the ruling. Provincial health legislation may need to be amended in order to give effect to the Court's decision and to align with legislation adopted by the Parliament of Canada.

Conclusions

The Committee appreciates the value of advance care planning and how important it is for patients, families and caregivers to know that the patient's wishes will be respected and plans followed when end of life is imminent. There is a need for more awareness, training and support to help promote advance care planning and to ensure that patients, families and caregivers receive guidance and assistance in how to create, update and access their plans. A centralized repository should be created to house advance care plans/directives so that they can be accessed by emergency medical personnel and other health care professionals should a health crisis arise.

Enforceability of advance care plans/directives is another area that Committee Members focused on in their deliberations. The *Adult Guardianship Act* and *Representation Agreement Act* were two examples of legislation that could be reviewed regarding enforceability of directives and to specify the inclusion of personal care. The Committee also discussed the possibility that other provincial legislation may require updating should the Parliament of Canada adopt *Bill C-14, An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)*.

Recommendations

The Committee therefore recommends to the Legislative Assembly that the provincial government:

Advance Care Planning

25. Implement advance care planning as part of the required standard of care for patients with chronic or complex illnesses.
26. Work with patients, families and caregivers to ensure that end-of-life care plans are developed with a patient-centric focus.
27. Create a centralized and secure repository or registry for advance care plans/directives so they can be easily retrieved by emergency medical teams, patients, families and caregivers.
28. Enable health care workers to assist patients, families and caregivers to develop health care plans that are easy to draft, update and follow, and that include input from the entire care team.
29. Amend the *Adult Guardianship Act* and the *Representation Agreement Act* to clarify and improve enforceability of end-of-life care directives and to specify the inclusion of personal care.
30. Amend any other applicable provincial legislation as required to align with anticipated federal legislation related to physician-assisted dying.

Families and Caregivers

An unavoidable implication of an aging population living with more complex health problems is increased demands and burdens on family caregivers, who do not always have the capacity and resources to meet their family member's needs. Key health sector advocacy groups and professional associations including the Association of Registered Nurses of B.C., the Alzheimer Society of B.C., and the Denominational Health Association highlighted the need for improved supports for families and non-professional or informal caregivers, who provide a majority of care for family members outside of long-term care facilities. Committee Members acknowledged the key role that caregivers and family members play in providing care and assistance to those at the final stage of their lives, and expressed appreciation for this often unrecognized and selfless work.

In their presentation, the Shuswap North Okanagan Division of Family Practice told Committee Members the story of an RCMP officer facing a terminal illness with complex care needs, who was able to die peacefully at home with the support of a family physician and caregivers, despite the absence of many critical support services for residents in rural areas of B.C. In her analysis of this case, presenter Dr. Joan Bratty commented: "It is clear that our current model of rural palliative care does rely fairly heavily on the goodwill and capacity of care providers. In this example, one of the family members was an experienced nurse. But most individuals are not so lucky, and the choice to die at home can be fraught with risk and the potential for suffering on the part of both the patient and family members. It is actually very difficult to quantify the degree of the suffering. There are studies looking at that. But from personal experience, we do know that caregiver burnout is enormous, and there is a high social cost to that. There's fallout in terms of psychologic illness in family members who witness a difficult or traumatic death. That's well known to us who work in this field."

Dr. Neena Chappell of the Centre on Aging at the University of Victoria provided additional insight into the role caregivers play in end-of-life care: "Caregivers provide between 75 and 85 percent of care to older adults, and despite what you may hear in the media, care from informal caregivers is not declining. Family members are not looking to shun their older members. It is true, however, that their older members are living longer, and they're living longer with more complex health problems. So the demands and the burdens on family caregivers are increasing, and they're not always ones that they are able to meet, despite their best efforts."

In terms of outcomes, Dr. Chappell added that, "There are now several studies that have come out of Europe that show that when governments expand community services and home care for older adults, family caregivers do not shirk their responsibilities. They do not stop providing care. Older adults remain longer in the community and outside of institutional care when there is comprehensive community care provided, and informal caregivers often play a key role in enabling that."

Education and Respite

The Committee heard from a number of presenters and submitters that there is a need to improve communications, education materials, and physical, emotional and financial support for patients, families and caregivers to provide informed support for decision-making and the development of end-of-life care plans. A component on education and information about organ and tissue donation options available provincially, such as BC Transplant, should be included in end-of-life care plans. As noted by Canadian Blood Services in their written submission to the Committee, “The ability to help others through organ and tissue donation often comforts and provides solace to families and patients whose death is inevitable.” The Committee also heard that there may be an opportunity to include more information on end-of-life care as part of online resources that provide assistance to complete advance care plans/directives, such as *My Voice*.

In their presentation to the Committee, the Canadian Cancer Society talked about outcomes related to a generalized lack of support for palliative or end-of-life care: “We know that there’s insufficient funding and supports for palliative care programs, and it has a huge impact on the caregivers. They shoulder a huge burden without enough support, particularly in the community...” Limited funding for palliative care and programs in rural British Columbia has particularly significant impacts on caregivers. Committee Members learned about the Caregiver Program which is available in Burnaby through the Burnaby Seniors Outreach Services Society. On behalf of the Society, Alfred Woo outlined the services provided for caregivers through their program, including resources, information sessions, peer counselling, and one-on-one and group support. In his written submission to the Committee, Don Morris provided a description of an initiative he is involved in where he hosts end-of-life conversation cafes in a casual setting in the community. Refreshments are served while individuals discuss death and the process of advance care planning, including *My Voice*, while presentations are also made by expert speakers or panelists.

The provision of additional resources to ensure that appropriate respite care and training is made available to caregivers would enable patients to remain in their homes and communities. This is especially relevant for those living in remote, rural or isolated communities where respite care might be less readily available. In his written submission to the Committee, Neil Buchan highlighted the opportunity for caregivers to remain connected with their communities through the provision of regular respite care to help alleviate the sense of isolation that caregivers often face. Karla Wagner suggested that periodic “recommended” respite care could be prescribed for caregivers or spouses [by their physicians] so that they can be relieved of their duties on a regular basis to help prevent burnout and alleviate some of the stress factors associated with around-the-clock caregiving.

Conclusions

The need for improved supports for families and caregivers, who provide the majority of care for family members outside of long-term care facilities, is a critical aspect of end-of-life care. Families and caregivers play an important role in providing care to those in the final stage of their lives and Committee Members want to ensure the appropriate supports and services are in place to provide assistance. Patients, families and caregivers require better information, educational materials and support to make informed decisions and to develop end-of-life care plans. As an example, more information about organ and tissue donation could be included in end-of-life care planning. Committee Members would like to see holistic strategies that take into account mental, spiritual and cultural considerations reflected in end-of-life care planning.

Gaps currently exist in the availability of respite care and Committee Members feel strongly that these gaps should be addressed, with a focus on those who live in remote, rural and isolated communities where this service is often less available.

Recommendations

The Committee therefore recommends to the Legislative Assembly that the provincial government:

Families and Caregivers

31. Improve communications, educational materials, and physical, emotional and financial support for patients, families and caregivers to aid them in the development of end-of-life care plans and decision-making.
32. Ensure that education and information about organ and tissue donation is included in end-of-life and palliative care programs.
33. Increase access to respite care, training and other supports for caregivers, including those living in rural, remote and isolated communities.
34. Develop holistic strategies to ensure that mental health, cultural and spiritual considerations are reflected in end-of-life planning and care.
35. Add the concept of “end-of-life care” to B.C.’s online public portal for instruction on how to complete advance care plans/directives or *My Voice*.

Alzheimer's Disease and Dementia

Committee Members heard a range of presentations on the challenges faced by British Columbians living with Alzheimer's disease or dementia, and their families and caregivers. There are between 60,000 and 70,000¹² diagnosed dementia patients in the province currently, and this number is expected to more than double to 177,000 by 2030.¹³ Considering that dementia is a progressive, terminal disease with no remission rates or survival statistics, the Committee Members heard from various submitters and presenters that this was a particular area of concern to be addressed in relation to end-of-life care. According to British Columbia's Seniors Advocate Isobel Mackenzie, 61 percent of residential care residents have a diagnosis of dementia, and it was further noted that 34 percent of senior home care patients have the same diagnosis. Committee Members recognized a need for improved end-of-life care for dementia patients, including introduction of a palliative model of care designed to support people to "live as well as possible for as long as possible and to have a meaningful end of life and a dignified end of life," as was noted by the Alzheimer Society of B.C. The Committee noted the importance of providing palliative care that is organized around the patient's needs and comfort in residential care facilities.

Diagnosis and Symptom Management

To ensure that patients and caregivers have every available opportunity to participate in treatment planning, accurate and early diagnosis and clear communication around prognosis are important elements of care for those with Alzheimer's disease or dementia. As noted by Dr. Margaret McGregor, on behalf of the Vancouver Division of Family Practice, "Even when significant frailty or dementia is evident, it is not uncommon for frail people to come and go to acute care in the last six months of their life and have many procedures that do more harm than good. This often occurs without any clear communication to the resident or the family that the end of their natural life is near, and without any review of goals of care, given that reality. So it's really an uninformed consent."

If provision of accurate information for patients is important, priority must also be placed on training for all health care professionals with a role to play as members of an interdisciplinary care team — physicians, nurses, allied health professionals, and care aides. Dr. McGregor cited research on diagnosis and treatment of patients entering their last six months of life. With respect to cancer care, physicians tend to be successful at diagnosing the approach of death. However, "...in the case of dementia, even though 76 percent of [dementia patients] had died by the end of six months, only 4 percent of those people had been identified [by physicians] as being close to death." Dr. McGregor noted that, in contrast to cancer patients, "These patients were far more likely to have feeding tubes put in, to have do-not-resuscitate orders, and more importantly, very few of them had their symptoms managed. So they were much more likely to have shortness of breath, to have pain, to have

¹² Provincial Dementia Action Plan for British Columbia (2012)

¹³ Alzheimer Society of B.C. presentation, May 15, 2015

all the things that occur toward the end of life that, if they're not really concentrated on and treated, can be very distressing, again, for both the patient and the family.”

Supports

Committee Members recognize that there are a number of supports currently in place for those with Alzheimer's disease or dementia. In November 2012, the Ministry of Health released *The Provincial Dementia Action Plan for British Columbia: Priorities and Actions for Health System and Service Redesign*, which outlines the province's priorities to address the needs of British Columbians with dementia, including a shift towards more integrated primary and community care that focusses on a more person-centred approach to dementia care. The plan also outlines priorities and recommended actions for dementia care including: support for prevention and early intervention, provision of quality person-centred dementia care and working to strengthen system capacity and accountability. The Committee Members expressed support for the plan and hope to see the province work to implement the improvements outlined within the plan to provide better support for those with dementia and Alzheimer's disease in B.C.

Caring for a family member with dementia or Alzheimer's disease is a 24/7 endeavor, as quite often these family members cannot be left alone at any time and they often require assistance with regular daily activities. The Committee heard that families and caregivers who provide daily support for those living with dementia or Alzheimer's disease need to have respite care made available to them on a regular basis as the stress and constant responsibility of looking after a family member with dementia or Alzheimer's disease can begin to adversely affect the health of the care provider. Increased access to respite care for caregivers should be provided and respite care in the home should be considered a priority. Respite care provided in a familiar environment, such as the home, can often be less unsettling for those with dementia or Alzheimer's disease who can become stressed or agitated by introduction to unfamiliar environments.

The Committee heard about supports in place for those with Alzheimer's disease or dementia, such as the province's Alzheimer registry, which tracks anyone with dementia over the age of 45 for whom a physician has made a billing related to dementia two times in a year. The Alzheimer Society of B.C. also cited the value of the Alzheimer disease therapeutic initiative (ADTI), which allows people with dementia to access medications that were not previously on the provincial formulary. Additionally, the Alzheimer Society of B.C. provides support through programs including the First Link Program, an “early intervention service designed to connect individuals and families affected by Alzheimer's disease or another dementia with services and support as soon as possible after diagnosis.” First Link is accessible on referral from a physician, although individuals and families may also self-refer. Various initiatives currently underway, such as the Alzheimer Society of B.C.'s *Dementia-Friendly Communities* initiative have the goal to build inviting and supportive communities where people who are living with dementia can feel comfortable participating in everyday activities. The Committee also

heard about the benefits of the Alzheimer Society of B.C.'s *Finding Your Way* program, which works to help reduce risks for dementia patients related to wandering, as well as the organization's *First Link Dementia Helpline* to enable the organization to continue to provide province-wide support and information services for anyone with questions about dementia and Alzheimer's disease. Committee Members also expressed interest in the expanded use and availability of assistive technologies to help improve the daily lives of those living with dementia or Alzheimer's disease and their families or caregivers.

Opportunities for Improvement

Improvements to end-of-life care and advance care planning are critical for those with dementia or Alzheimer's disease. Education related to palliative care currently plays a minor role in the education programs for physicians, nurses, and allied health professionals, and there is an urgent need for such training for the care aides who provide a great deal of support for patients in residential care facilities. The Alzheimer Society of B.C. emphasized the need to expand training and incorporate current notions of end-of-life care to include people with dementia. It was recommended that an assessment for frailty, dementia or Alzheimer's disease be included in advance care planning processes. Initiatives such as this could help facilitate an earlier diagnosis and prognosis, and allow for more timely participation of patients, families and caregivers in treatment or advance care planning processes.

Improved training programs and screening protocols would help increase competencies for health care professionals to confidently assess frailty, dementia and Alzheimer's disease in their patients. Community organizations could partner with health care providers, including care aides, to offer supports for more consistent and responsive dementia training.

Nidus spoke to the significance of advance care directives and representation agreements for those with Alzheimer's disease and dementia. Dr. David Robertson, from Dying With Dignity Canada, described the case of Margot Bentley, a former dementia care nurse whose advance planning regarding treatment choices has been overruled in British Columbia's courts. "[Dementia patients] must be able to leave instructions that cannot be overridden. At Dying With Dignity Canada we believe that Margot Bentley's legacy should be that no one else need endure as she is enduring. We believe that the laws should state that the last advanced-care directive written before a person became incapable of consenting on their own behalf should endure... Right now individuals can complete a do-not-resuscitate order. But what if someone wants to refuse treatment other than resuscitation? We need to have broader options for refusal of treatment, and our health care providers need to be educated more about respecting them."

Conclusions

With an aging population, the number of British Columbians who will be affected by Alzheimer's disease or dementia is projected to increase. Committee Members want to ensure that the appropriate

supports and services related to end-of-life care are in place to respond to the significant challenges faced by those who live with Alzheimer's disease or dementia, their families and caregivers. When palliative care is provided in residential care facilities, it needs to be organized around the patient's needs and comfort. Health care professionals should feel competent and confident in assessing frailty, Alzheimer's disease or dementia and should be provided with the appropriate resources and training to accomplish this. Committee Members suggest that community organizations could partner with health care providers to promote consistent and responsive dementia training. This also applies to discussions regarding advance care planning and the availability of various treatment options that may be outlined for patients, families and caregivers.

Increased access to in-home respite care support for family members and caregivers should be provided to help minimize stress on those whose loved ones are suffering from the final stages of Alzheimer's disease or dementia. Committee Members expressed appreciation for the many programs and services that are already in place in communities across B.C. to provide assistance to those diagnosed with Alzheimer's disease or dementia and their families, and want to see the provision of dedicated, stable funding for these programs and services.

Recommendations

The Committee therefore recommends to the Legislative Assembly that the provincial government:

Alzheimer's Disease and Dementia

36. Support a patient-centred palliative model of care in residential care facilities that is responsive to the unique needs of people living with dementia or Alzheimer's disease.
37. Create opportunities for community organizations to partner with health care providers to promote consistent and responsive dementia training.
38. Implement training programs and screening protocols that enhance competence and confidence in assessing frailty, dementia and Alzheimer's disease for health care professionals.
39. Support an advance care planning process that takes into account an assessment for frailty, dementia or Alzheimer's disease and outlines the risks or benefits of various treatments as early as possible in the process.
40. Provide increased access to in-home respite care support for caregivers.
41. Explore options to increase the availability and use of assistive technology for those living with dementia or Alzheimer's disease.
42. Provide support for initiatives such as those implemented by the Alzheimer Society of B.C.'s Dementia-Friendly Communities' initiative and provide dedicated, stable funding for programs that assist those first diagnosed with Alzheimer's disease, like First Link.

Summary of Recommendations

The Select Standing Committee on Health recommends to the Legislative Assembly of British Columbia that the provincial government:

Palliative Model of Care

1. Offer timely information regarding available social services and advance care planning to patients with chronic life-limiting illnesses.
2. Refer patients with chronic life-limiting illnesses to palliative care earlier in the course of their illness.
3. Develop a team approach to palliative care and provide support for the expansion of in-home primary care services and supports for the frail elderly, based on successful models already in place.
4. Ensure that the provision of services for palliative and end-of-life care in rural, remote and isolated communities meets the needs of those communities.
5. Ensure that an integrated palliative model of care is applied across the health service continuum, including primary care, home care, residential care and acute care that includes a patient-centred approach to cultural practices and sensitivities respecting end-of-life care and recognizes the differences between rural and urban access.
6. Implement an interdisciplinary team-based approach for integrated palliative care across the health service continuum including: primary care physicians, nurses, nurse practitioners, spiritual advisors, allied health professionals, care aides, as well as patients, families and caregivers.
7. Support initiatives to implement pro-active home visits for seniors, based on the Danish model.
8. Ensure that a patient-centred approach focuses on the optimization of quality of life and includes a focus on comfort and function as considerations when options for treatment regarding end-of-life care are presented to patients, families and caregivers, including the time-to-benefit ratio of prescribed interventions, services and medications.

Supports and Services

9. Provide dedicated palliative care beds in hospitals and community settings.
10. Provide equal access to hospice care through the development of new palliative care sites across the province, and ensure that these sites are designed to be comfortable, home-like settings.
11. Consider the expansion of a “palliative campus of care” model to enable centres of excellence for the provision of rural, community-based and generalist-driven palliative and end-of-life care.

12. Provide investment for a more robust in-home care support system with 24/7 availability across the existing continuum of health care, including palliative care.
13. Expand day care options within seniors' centres to ensure that seniors living in their homes within all regions of the province have access to a variety of centralized services and programs in their communities, including medical care and opportunities for socialization.
14. Create a mechanism to collect information and feedback from patients, families and caregivers on a regular basis to ensure a continuous cycle of assessment and improvement for all end-of-life care, services and resources provided through all health care providers.
15. Establish a frail seniors health registry with flexible screening protocols to allow seniors to stipulate their wishes to receive acute care support services when a health crisis occurs, in conjunction with their advance care directive.
16. Create a database, website or other centralized accessible information portal where patients, families and caregivers can access information about available programs, resources and services for palliative and end-of-life care.
17. Create a system or repository where advance care directives can be centrally housed and retrieved by emergency medical teams, including paramedics, doctors and nurses.
18. Support the use of telemedicine, web consultations and other virtual technologies to provide home care services to enable patients to remain in their homes and communities.

Training, Recruitment and Retention

19. Provide stable funding to ensure increased investment in the training, recruitment and retention of health professionals, including physicians, nurse practitioners, nurses and care aides specializing in palliative care.
20. Ensure that training, recruitment and retention initiatives meet the needs of rural, remote and isolated communities.
21. Work to increase the number of dedicated residency spaces in palliative care and adjust this number according to population trends and demand for health care in the years to come.
22. Offer an optional alternate fee structure for medical professionals, including physicians and nurse practitioners, who must travel long distances to meet the needs of their patients in rural, remote and isolated communities.
23. Provide training and resources to assist health care professionals communicate effectively and sensitively with patients, families and caregivers facing end-of-life care decisions or choices.
24. Ensure that all health care professionals receive training on how to implement and follow advance care plans/directives or *My Voice*.

Advance Care Planning

25. Implement advance care planning as part of the required standard of care for patients with chronic or complex illnesses.
26. Work with patients, families and caregivers to ensure that end-of-life care plans are developed with a patient-centric focus.
27. Create a centralized and secure repository or registry for advance care plans/directives so they can be easily retrieved by emergency medical teams, patients, families and caregivers.
28. Enable health care workers to assist patients, families and caregivers to develop health care plans that are easy to draft, update and follow, and that include input from the entire care team.
29. Amend the *Adult Guardianship Act* and the *Representation Agreement Act* to clarify and improve enforceability of end-of-life care directives and to specify the inclusion of personal care.
30. Amend any other applicable provincial legislation as required to align with anticipated federal legislation related to physician-assisted dying.

Families and Caregivers

31. Improve communications, educational materials, and physical, emotional and financial support for patients, families and caregivers to aid them in the development of end-of-life care plans and decision-making.
32. Ensure that education and information about organ and tissue donation is included in end-of-life and palliative care programs.
33. Increase access to respite care, training and other supports for caregivers, including those living in rural, remote and isolated communities.
34. Develop holistic strategies to ensure that mental health, cultural and spiritual considerations are reflected in end-of-life planning and care.
35. Add the concept of “end-of-life care” to B.C.’s online public portal for instruction on how to complete the advance care plan directives or *My Voice*.

Alzheimer’s Disease and Dementia

36. Support a patient-centred palliative model of care in residential care facilities that is responsive to the unique needs of people living with dementia or Alzheimer’s disease.
37. Create opportunities for community organizations to partner with health care providers to promote consistent and responsive dementia training.
38. Implement training programs and screening protocols that enhance competence and confidence in assessing frailty, dementia and Alzheimer’s disease for health care professionals.

39. Support an advance care planning process that takes into account an assessment for frailty, dementia or Alzheimer's disease and outlines the risks or benefits of various treatments as early as possible in the process.
40. Provide increased access to in-home respite care support for caregivers.
41. Explore options to increase the availability and use of assistive technology for those living with dementia or Alzheimer's disease.
42. Provide support for initiatives such as those implemented by the Alzheimer Society of B.C.'s Dementia-Friendly Communities' initiative and provide dedicated, stable funding for programs that assist those first diagnosed with Alzheimer's disease, like First Link.

Appendix A: List of Written Submissions and Presentations on End-of-Life Care

Written Submissions:

Alzheimer Society of B.C., Rebecca Morris
Dr. Karen Andres
Heather Armstrong
Association for Reformed Political Action (ARPA)
Canada, Mark Penninga
Association of Registered Nurses of B.C. (ARNBC),
Julie Fraser, Joy Peacock
Karen Back
Phil Barker
BC Association of Speech/Language Pathologists and
Audiologists, Julia Hodder
BC Association of Traditional Chinese Medicine and
Acupuncture Practitioners, Joseph Ranallo
BC Cancer Agency, Pain and Symptom
Management/Palliative Care Program, Dr. Gillian
Fyles, Dr. Pippa Hawley, Dr. Michael McKenzie
BC Centre for Palliative Care, Dr. Doris Barwich
BC Health Coalition, Edith MacHattie, Rick Turner
BC Naturopathic Association, Dr. Victor Chan
BC Nurses' Union, Gayle Duteil
Alex Berland
Chris Bibby
Charles Brasfield
Jesse Bredenhof
British Columbia Dental Association, Ina Hunt
British Columbia Federation of Community Health
Centres, Scott Wolfe
Neil Buchan
Eric Burkle
Burnaby Seniors Outreach Services Society (BSOSS),
Danelle Laidlaw
Sheila Campbell
Canadian Association of Occupational Therapists,
BC Chapter, Giovanna Boniface
Canadian Blood Services, Dr. Graham D. Sher
Canadian Cancer Society, British Columbia and
Yukon Division, Kathryn Seely
Select Standing Committee on Health
Report May, 2016
Centre for Clinical Epidemiology and Evaluation,
Dr. Margaret McGregor
Community Resources Society, Ashcroft & District
Health Care Auxiliary and Thompson View
Manor Society, Barbara Pesut, Ed Staples, Nienke
Klaver
Council of Senior Citizens' Organizations of British
Columbia, Art Kube
Cranbrook Kimberley Hospice Society, Donald L.
Davidson
Denominational Health Association, Susan House
Desert Valley Hospice Society, Dr. David Shaw, Lois
Brummet
Doctors of BC, Dr. Bill Cavers
Irmgard I. Dommel
Kathryn M. Drew
Dorothy Drubek
Dying With Dignity Canada, Wanda Morris
Susan Evans
Federation of Oceanside Residents' Associations,
James Dimmick
First Nations Health Authority and First Nations
Health Council, Avril Ullett
Judy Gaylord
June Halter
Bernice Halvorson
Pam Harte
Claire Hawrys
Marijke Henkemans
Patricia Hibbitts
Marcia Hogan
Hospice Society of the Columbia Valley, Maxine
Jones
Barbara Hourston
Dr. Sue Hughson

Initiative for a Palliative Approach in Nursing:
Evidence and Leadership (iPanel), Kelli Stajduhar,
Carolyn Tayler
Patri Janyk
Lois Jarvis
Christine and Melville Johnston
Heather Keith
Ronald Kirstein
Jim Knight
Nicholas Lamm
Logan Lake Health Care Advisory Committee,
Elaine Pennoyer
Joan Lyons
DeAnna MacArthur
Warren H. Maidens
Nancy Martens
Cecilia Mavrow
Dr. Margaret McGregor, Dr. Sue Turgeon, Dr. Jay
Slater
Dianne McKay
Rozlyne L. Mitchell
Don Morris, M.Ed
Judy Moscovitz
Shelley Myatovic
Neil Naiman
Carol and Rob Nelson
Nidus Personal Planning Resource Centre and
Registry, Joanne Taylor
Jim Norris
Penelope M. Pattison
Penticton & District Hospice Society, Kelly Phipps
Heather Peterson
Dr. Lindsay Pritchett
Professional Association of Residents of British
Columbia, Kate Milne
Richmond Poverty Response Committee, Lynda
Brummitt, De Whalen, Lara Miramontes, Colin
Dring

Ridge Meadows Seniors Society, Sheila Pratt, Bob
Foster
Dr. W. David Robertson
Ron Peterson and Penny Tilby
Herman J. Ruitenbeek
Sharon Sadler
Salt Spring Health Advancement Coalition, Barb
Aust
Save Our Northern Seniors, Jean Leahy, Jim Collins,
Margaret Little
Ina Shah
Cindy Shipley
Shuswap North Okanagan Division of Family
Practice, Dr. Richard Sherwin
Judith Sim
Margaret Slade
Anne Spencer
Squamish-Lillooet Regional District, Jack Crompton
Carol Stanley
Glen Stedham
Carol Stein
Support Our Health Care (SOHC) Society of
Princeton, Edward Staples
Lori Swanson
Patricia Thomson
Christina C. Thorsell
UBC Division of Palliative Care, Dr. Pippa Hawley
Union of British Columbia Municipalities, Marylyn
Chiang
Vancouver Division of Family Practice, Cheryl Hogg
Karla Wagner
Dr. Norman Wale
Barbara Westerman
Danielle Wittal
Ruth Zenger

Presentations:

Alzheimer Society of B.C., Barbara Lindsay, Rebecca Morris (May 15, 2015, Vancouver)

Association of Registered Nurses of B.C. (ARNBC), Andrea Burton, Joy Peacock, Alexandra Arndt (May 15, 2015, Vancouver)

BC Association of Traditional Chinese Medicine and Acupuncture, Joseph Ranallo (May 13, 2015, Victoria)

BC Cancer Agency, Pain and Symptom Management/Palliative Care Program, Dr. Pippa Hawley (May 15, 2015, Vancouver)

BC Centre for Palliative Care, Dr. Doris Barwich (September 14, 2015, Vancouver)

BC Civil Liberties Association, Josh Paterson (July 15, 2015, Victoria)

British Columbia Seniors Advocate, Isobel Mackenzie (April 29, 2015, Victoria)

Burnaby Seniors Outreach Services Society (BSOSS), Alfred Woo (May 15, 2015, Vancouver)

Canadian Cancer Society, British Columbia and Yukon Division, Barbara Kaminsky (May 15, 2015, Vancouver)

Canadian Centre for Policy Alternatives, Marcy Cohen, Iglia Ivanova (September 14, 2015, Vancouver)

Centre on Aging, University of Victoria, Dr. Neena Chappell, Dr. Marcus Hollander (September 14, 2015, Vancouver)

Council of Senior Citizens' Organizations of British Columbia, Art Kube, Kathleen Jamieson, Mohinder Grewal (May 15, 2015, Vancouver)

Cranbrook Kimberley Hospice Society, Donald L. Davidson (September 14, 2015, Vancouver)

Desert Valley Hospice Society, Dr. David Shaw (September 14, 2015, Vancouver)

Doctors of BC, Dr. Bill Cavers (May 13, 2015, Victoria)

Dying With Dignity Canada, Wanda Morris, Dr. David Robertson (April 29, 2015, Victoria)

Federation of Oceanside Residents' Associations, Dr. James Dimmick, Tom Davies (April 29, 2015, Victoria)

First Nations Health Authority, Richard Jock (May 13, 2015, Victoria)

Initiative for a Palliative Approach in Nursing: Evidence and Leadership (iPANEL), Dr. Kelli Stajduhar, Dr. Patricia Coward (April 15, 2015, Victoria)

Nidus Personal Planning Resource Centre and Registry, Joanne Taylor, Christine Gordon, Hassan El Masri (May 15, 2015, Vancouver)

Shuswap North Okanagan Division of Family Practice, Dr. Joan Bratty (September 14, 2015, Vancouver)

UBC Department of Family Practice, Community Geriatrics, Dr. Jay Slater, Dr. John Sloan (May 15, 2015, Vancouver)

UBC Division of Palliative Care, Dr. Pippa Hawley (May 15, 2015, Vancouver)

Vancouver Division of Family Practice, Dr. Margaret McGregor, Dr. Sue Turgeon (September 14, 2015, Vancouver)

Appendix B: Selected Readings

Below is a list of selected readings that Committee Members referenced in their deliberations:

“A Bitter Pill: How the Medical System is Failing the Elderly” (Dr. John Sloan, 2009) available through various booksellers and online.

“B.C. Health System Strategy Implementation: A Collaborative and Focused Approach” (B.C. Ministry of Health, 2014) available at: http://www.cchl-ccls.ca/document/1088/BC_Health_System_Strategy_Implementation.pdf

“Being Mortal” (Atul Gawande, 2014) available at: <http://atulgawande.com/book/being-mortal/>

“Best Practices in Home Care for Seniors: Synthesis Report from the 2014 International Forum” (B.C. Ministry of Health and Michael Smith Foundation for Health Research, 2014) available at: http://www2.gov.bc.ca/assets/gov/people/seniors/about-seniorsbc/pdf/best_practices_in_home_care_for_seniors.pdf

“Caregivers in Distress: More Respite Needed” (Office of the Seniors Advocate BC, 2015) available at: <https://www.seniorsadvocatebc.ca/osa-reports/caregivers-in-distress-more-respite-needed/>

“Improving Care for B.C. Seniors: An Action Plan” (B.C. Ministry of Health, 2012) available at: <http://www2.gov.bc.ca/assets/gov/people/seniors/about-seniorsbc/pdf/seniorsactionplan.pdf>

“My Voice: Expressing My Wishes for Future Health Care Treatment” Advance Care Planning Guide (B.C. Ministry of Health, 2013) available at: <http://www.health.gov.bc.ca/library/publications/year/2013/MyVoice-AdvanceCarePlanningGuide.pdf>

“Not to be Forgotten: Care of Vulnerable Canadians” (Canadian Federal Parliamentary Committee on Palliative and Compassionate Care, 2011) available at: https://www.mcgill.ca/palliativecare/files/palliativecare/parliamentary_report_eng_dec_2011.pdf

“Placement, Drugs and Therapy... We Can Do Better” (Office of the Seniors Advocate BC, 2015) available at: <https://www.seniorsadvocatebc.ca/osa-reports/placement-drugs-and-therapy-we-can-do-better/>

“Raising the Bar: A Roadmap for the Future of Palliative Care in Canada” (Senate of Canada, 2010) available at: http://www.chpca.net/media/7859/Raising_the_Bar_June_2010.pdf

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