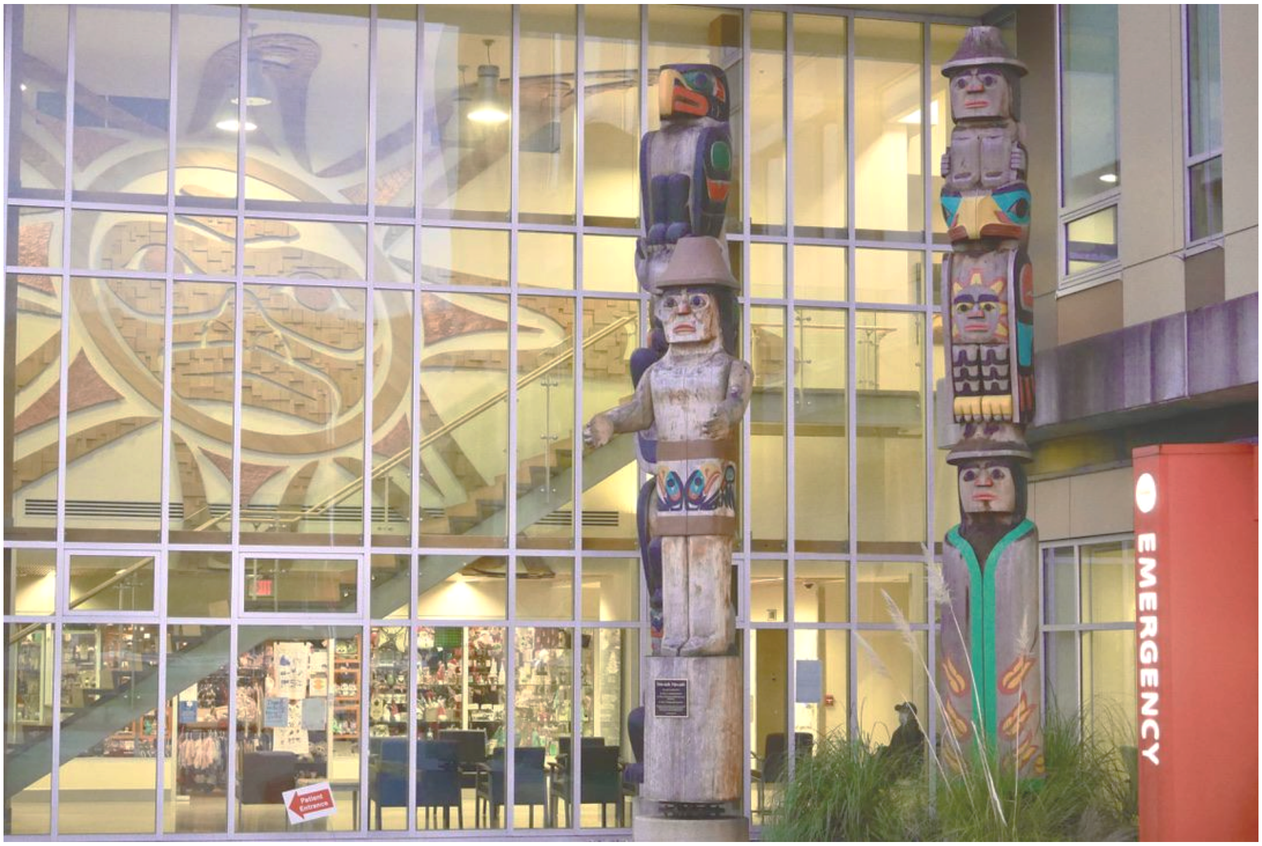
# PALLIATIVE AND END-OF-LIFE CARE ON THE SUNSHINE COAST

## A scan of current and future needs

DECEMBER 2021



by Pat Feindel, PhD

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and

Sunshine Coast Division of Family Practice - Shared Care Palliative Care Working Group

# ACKNOWLEDGEMENTS

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*This report is informed by input from many individuals who took the time to share their thoughts and experiences regarding palliative and end-of-life care. We are grateful for their valuable contributions.*

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www.coasthospice.com

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# Executive Summary

While the population of Canada is aging, the Lower Sunshine Coast is facing an intensification of this trend. One third of the Sunshine Coast population is now 65 or older, a much higher proportion of seniors than in BC overall. By 2035, seniors will make up almost 38% of the Sunshine Coast population, compared to the almost 25% projected for BC, and they will be older than the present senior population.

This shift in age demographics will have a significant impact on health care on the Lower Sunshine Coast, particularly on palliative and end-of-life care. This study, undertaken on behalf of the Palliative Care Working Group of the Sunshine Coast Division of Family Practice and the Sunshine Coast Hospice Society, examines the current capacity of palliative and hospice care on the Coast and explores how capacity will need to be enhanced to address both the current and projected needs of an aging population.

The Lower Sunshine Coast already has a strong and collaborative palliative care network, developed through community-based leadership and initiatives. It includes physicians, palliative care nurses, licensed practical nurses, care aides, and staff and volunteers of community organizations. While there is no palliative care unit in the local hospital, the Palliative Care Working Group, funded by Shared Care, has supported collaboration among health care personnel, identification of gaps and opportunities, and training to enhance skills. The Sunshine Coast Hospice Society has, for over three decades, advocated for hospice care, providing support to patients and families and raising awareness about end-of-life choices.

Current palliative care practices developed on the Coast are consistent with integrated palliative care and population needs-based care best practices reflected in federal and provincial policy, based on the principle that:

> *Hospice palliative and end-of-life care must be an integral part of health care, and available in all settings of care, including hospital, long-term/continuing care, residential hospices, shelters and individual homes … and must be part of the treatment repertoire of any health care professional, supported by consultation or referral to a specialist palliative care team. (Canadian Hospice Palliative Care Association (CHPCA) 2015)*

Moving away from hospitalization to community-based care reduces health care costs and responds to growing consumer demand for quality and choice in end-of-life care (Canadian Institute for Health Information (CIHI) 2018).

**Current challenges in palliative and end-of-life care identified by study informants include:**

- shortage of health care staff – physicians, nurses, practical nurses, care aides – exacerbated by a housing shortage and high housing costs (whether rental or ownership)
- local hospital operating beyond capacity
- shortage of long-term care beds for current need, with projected greater shortage in future, despite new build (Silverstone) adding 20 beds
- hospice capacity (two suites) has not kept pace with population growth, and the plan to double capacity to four beds will not meet current or projected needs
- palliative respite care needs are unmet
- misconceptions and stigma create barriers to palliative and hospice care
- insufficient support for family caregivers, especially considering aging demographic
- psychosocial support services for patients and caregivers offered by Sunshine Coast Hospice Society could be more effectively integrated into palliative care
- Competence in addressing cultural diversity and cultural safety is underdeveloped

**Key areas for enhancing palliative and end-of-life care include:**

- strengthen health care staff recruitment and retention, especially in home care nursing and long-term care
- provide ongoing training for health care staff (nurses, physicians) in palliative and end-of-life best practices to maintain quality and patient access to care
- increase public awareness of palliative and end-of-life services and their benefits
- increase training and support for family and other informal caregivers
- increase palliative home care services
- increase long-term care capacity to address projected increase in older population
- reduce unnecessary hospitalizations through enhanced community supports
- increase capacity of residential hospice to 6-8 suites
- integrate community-based support services with palliative and hospice health care
- support cultural safety and diversity training, and improved communications and co-planning with shíshálh Nation

There is an opportunity for the Primary Care Network to support palliative and end-of-life care in its planning.

Given that the Sunshine Coast is struggling to meet current needs and is poised to face a much greater demand for palliative and hospice services, efforts to enhance these services cannot come too soon. Some informants felt developing a site with an interdisciplinary focus on palliative and hospice care would be timely. It could support and build on the collaborative relationship that exists on the Sunshine Coast among palliative care professionals and community-based organizations and volunteers, while fostering information exchange, training, resource sharing, and greater integration of palliative and hospice services.

# Table of Contents

# I. Introduction

It has been widely recognized that the population of Canada overall is aging – that is, we are seeing a steady increase in the senior population relative to younger age groups. The Sunshine Coast is experiencing this age shift to a greater degree than most other BC communities. Provincial statistical calculations estimate that one third (32.8%) of the current population of the Lower Sunshine Coast is aged 65 and over[1], far exceeding the overall provincial rate of one fifth (19.7%) and making the Sunshine Coast a "natural retirement community." By 2035, the percentage of Sunshine Coast residents aged 65 and over is projected to increase to 37.8%. Not only does this have numerous social and economic ramifications for the Coast, it will have a dramatic impact on the health care system.

As people age, they develop more chronic conditions and life-limiting illness, increasing demands on health services, including palliative and hospice care. Furthermore, an overall increase in population of all ages will add a growing demand for palliative and hospice care among younger age groups with life-limiting illnesses.

With the Sunshine Coast facing such a significant growth of the senior population and related health care challenges, an assessment of palliative and end-of-life care resources is timely.

## Sponsors of this scan of palliative and end-of-life care

This scan has been undertaken on behalf of the Sunshine Coast Hospice Society (SCHS) and the Palliative Care Working Group of the Sunshine Coast Division of Family Practice (SCDoFP) to explore the current state of palliative and end-of-life care on the Lower Sunshine Coast – including assets, gaps, and challenges – and to identify future needs and opportunities for service enhancement. Its findings will contribute to the planning of each organization's future direction.

The SCHS initiated the first hospice services on the Coast and has been active for over three decades. In addition to contributing financial support for the hospice suites located at Shorncliffe Intermediate Care Facility, the Society provides services such as volunteer companions and vigil for the dying, programming and support for the bereaved, advance care planning, public education programs to raise awareness about end-of-life issues, and advocacy for improved palliative services. Recently the Society spearheaded the Green Sleeve advance care planning initiative in collaboration with health care providers and first responders. The SCHS has committed to raising funds to increase local hospice residential capacity and services.

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[1] In a total population estimated at 31,802. If those aged 50 and over are added to that percentage, the "senior" population of the Lower Sunshine Coast is 56.6% compared to 40.6% for BC overall. In 2016, the average age on the Sunshine Coast was 54.7 years, compared to 42.5 years across BC (*LHAP 2018/19,* p 5).

The SCDoFP works to improve local primary health care, provide professional support for physicians, and increase local physicians' influence on health care delivery and policy. The Division has coordinated a Palliative Care Working Group (funded through Shared Care), which provides support to health care professionals in the form of palliative care training and information. Current funding for the Working Group comes to an end in December 2021, and the Division aims to continue support for palliative care through other avenues, including Primary Care Network planning.

## Methodology

This scan was conducted between July and October 2021. The report is based on four main sources of information:

1. interviews with health care workers involved in palliative and hospice care, including physicians, nurses, home care nurses, licensed practical nurses and care aides, hospice staff and volunteers, and health care administrators
2. interviews with family members of palliative and hospice patients
3. reports, studies and policy papers related to palliative and hospice care
4. statistical records

A total of 28 individuals were interviewed, with follow-up questions sent by email in some cases. (See Appendix C for documents reviewed.)

## Definitions

Palliative care emerged as a field of health care over four decades ago, primarily in response to the needs of terminally ill cancer patients. Initially it focused on providing symptom management and comfort in the final weeks and days of life for patients whose curative treatment options were exhausted. Since then, improved medical treatments have brought changes in the nature of illness and dying. There are fewer sudden deaths, and people live longer but more often with life-limiting illness or chronic conditions. Many such conditions now progress more slowly, prolonging life as well as the process of dying. Furthermore, a more informed and assertive population of health consumers has demanded greater choice and self-determination about end-of-life care.

As a result, practices in palliative and hospice care have expanded from an emphasis on short-term end-of-life care in hospitals to providing care over a longer period in a variety of community settings.

Palliative care is specialized medical care for people with life-limiting 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 to provide care 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 health care professionals, who work with a patient's other doctors and community-based service providers 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 curative treatment.[2]

This model of palliative and end-of-life care is called an integrated approach, or a community needs-based approach. Its features include:

- early identification of palliative needs
- early introduction of palliative care concurrently with other health care interventions
- focus on patient comfort and quality of life
- community-based palliative care in a range of settings that address patient needs and wishes (e.g. home, assisted living/long-term care, and hospice)
- emphasis on physical, emotional and spiritual needs of the patient, and well-being of family and caregivers.

Additional definitions of terms that reflect current best practices and philosophy of palliative care can be found in Appendix A.

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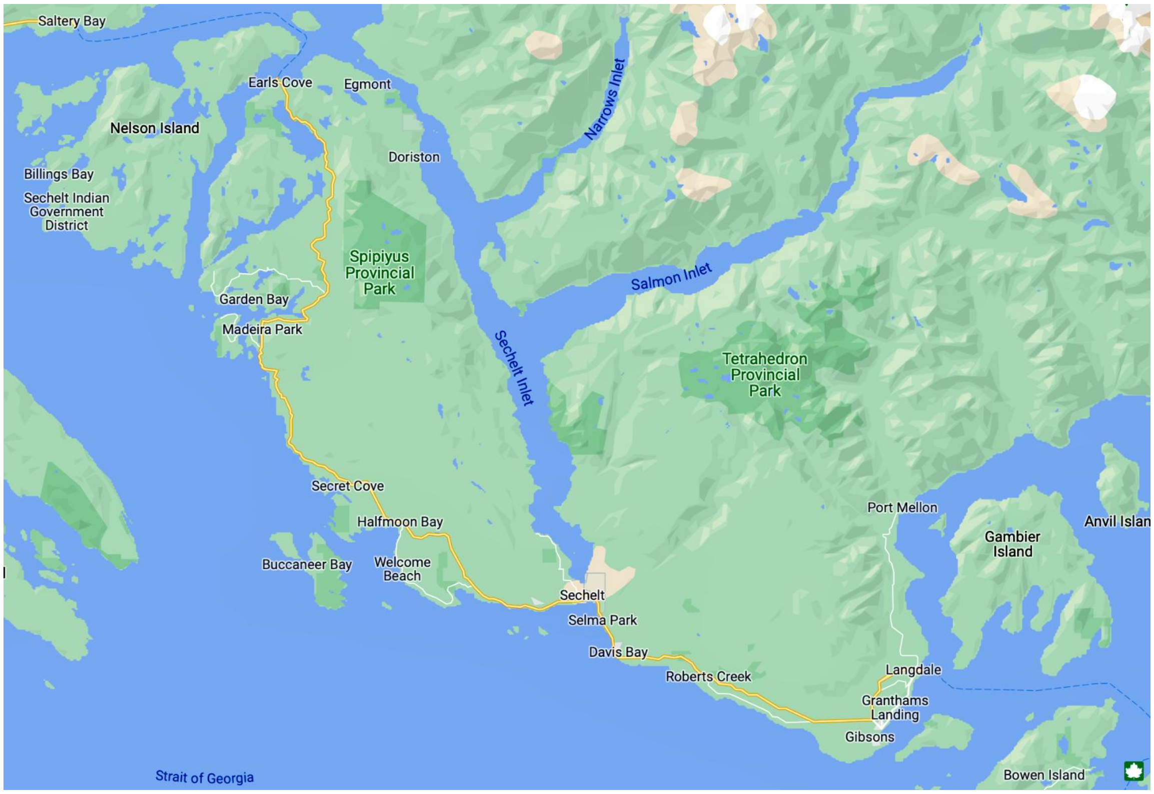
[2] Adapted from *Provincial End-of-Life Care Action Plan for British Columbia* (2013).

# II. Broad factors affecting the Lower Sunshine Coast



## An aging population

As noted in the introduction, BC, like the rest of Canada, is facing a steady increase in the proportion of the population that is aging, as indicated in a rise in the median life expectancy from 71.5 years in 1975 to 80.8 years in 2020 (BC Stats). In BC, the percentage of seniors aged 80+ is projected to grow from 4.7% of the population in 2021 to almost 8% by 2035 (BC Stats).

The Lower Sunshine Coast (see map for included area) has a significantly higher proportion of residents aged 65 and older than the BC average. The largest segment of the Sunshine Coast population is currently between 65 and 69 years, followed by the 60-64 and 70-74 age groups. By 2035 the percentage of residents aged 65 and over is projected to increase to 37.8%,[3] and their average age will go up: the largest population age group will be 75-79, followed by those aged 80-84. In addition, the number of people aged 85 and older will more than double. This trend is projected to continue well into the future (see Chart below – highest numbers highlighted in red).

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[3] Of a projected total population of 34,289. Government of British Columbia, BC Stats – Population Projections, https://bcstats.shinyapps.io/popProjApp/

|  | **Total** | **Age** |  |  |  |  |  | |
|---|---|---|---|---|---|---|---|---|
|  | **Population** | **50-64** | **65-69** | **70-74** | **75-79** | **80-84** | **85-90+** | **% of Pop 65+** |
| **2021** | 31,802 | 7567 | 3247 | 3079 | 1954 | 1074 | 1083 | 32.82% |
| **2035** | 34,289 | 5757 | 2223 | 2682 | 2809 | 2510 | 2738 | 37.8% |
| **2041** | 34,775 | 6065 | 1946 | 2094 | 2408 | 2403 | 3722 | 36.16% |

### Health care implications

A large aging population has significant implications for local health service use and end-of-life care. According to the *Local Health Area Profile* (LHAP) for 2018/19 (October 2020), well over half of all Sunshine Coast residents above the age of 60 are living with illness or chronic conditions. The second highest demand on primary care (measured in number of family physician visits/year) is for illness and chronic conditions, generated primarily by seniors (*LHAP 2018/19*, p. 26). For the top five categories of illness or chronic condition,[4] the Sunshine Coast has higher rates than BC, and higher even than the rest of the Vancouver Coastal Health region (*LHAP 2018/19*, p. 8). A small proportion of Sunshine Coast seniors are at the end-of-life stage (p. 7), but this is likely to increase in coming years.

BC's *End-of-Life Care Action Plan* states that with "BC's growing and aging population, it is projected that the prevalence of chronic conditions may increase by 58% over the next 25 years" (*End-of-Life Care Action Plan BC*, p. 2). "The need to care for more seniors along a continuum of care in BC will inevitably change the dynamics of the health care system in the future, particularly for home care and long-term care services" (*LHAP 2018/19*, p. 6).

With an aging population, it has become more widely recognized that palliative and hospice care provide valuable forms of support that benefit patients and their families at a particularly challenging time, while helping to reduce acute care hospital costs. With an increase in population, this type of care will also be more in demand by younger age groups experiencing life-limiting illness. "Palliative care can help to improve quality of life for people of all ages with life-limiting illnesses by relieving symptoms, enabling a peaceful and dignified death, and providing support to family through the dying and bereavement process" (CIHI 2018, p. 6).

## Federal and provincial policy context

Both federal and provincial health policy makers have recognized the implications of an aging population for health care and aging supports, and for over a decade have worked to develop national and provincial policy on palliative care to ensure Canadians have equitable access to quality services.[5] (See Appendix B for details of federal and provincial policy and strategies.)

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[4] Hypertension, osteoarthritis, asthma, episodic mood and anxiety disorders, ischemic heart disease (p. 9).

[5] See for example: Health Canada, *Action Plan on Palliative Care* (2019) and *Framework on Palliative Care in Canada* (2018); Canadian Institute for Health Information, *Access to Palliative Care in Canada* (2018); Canadian Hospice Palliative Care Association (CHPCA), *The Way Forward National Framework: A Roadmap for an Integrated Palliative Approach to Care* (2015); Provincial Hospice Working Group, *Hospice Care in BC – The Path Forward* (August 2020);

These policy frameworks support an integrated approach to palliative care, meaning palliative care offered by a collaborative team of professionals and community services in a range of settings determined by the patient's level of need, choices and preferences. However, equitable access to this range of services has not yet been achieved either in terms of quality control or geographic access (see D. May, 2021).

The increased attention to palliative and hospice care is also driven by a changing public culture regarding end-of-life decision-making – a public that is more informed and assertive about health care; more willing to discuss aging, death and dying, and end-of-life wishes; more likely to prefer to die at home; and more inclined to use the tools now available for formally documenting one's wishes. Shifts in public awareness and values are also evident in the passage of legislation regarding medical assistance in dying (MAiD), and public outcry about conditions in long-term care facilities. All of these factors add pressure to health care providers and policy makers to address growing demands for choice and quality in aging and end-of-life care.

**Given the focus on improving palliative and hospice care at both federal and provincial levels, there is a unique opportunity to frame local palliative care and hospice initiatives in terms of their contribution to achieving quality and equitable access goals.**

## Position of hospice societies in the palliative care system

Despite broad federal and provincial support for palliative and end-of-life care, hospice services occupy a somewhat unique position in health care planning and budgeting. While all other services that fall under palliative/hospice care are funded by the BC Ministry of Health (through health authorities and other channels), hospice care is publicly funded only in part. Health authorities provide operating funds for hospice beds and sometimes provide the premises, while not-for-profit hospice societies raise funds to maintain non-medical features of the premises, and often acquire properties to house them. In addition, hospice societies deliver a range of complementary volunteer-based services for which they receive no operational government funding.

As the Provincial Hospice Working Group (PHWG)[6] reported in 2020, this results in inequitable and variable funding across the province, which impacts hospice work, innovative strategies, and long-term planning. The funding structure creates challenges in the capacity to network and collaborate across sectors, and to exchange best practices and up-to-date training materials (PHWG 2020).

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BC Ministry of Health, *Provincial End-of-Life Care Action Plan for British Columbia*: *Priorities and Actions for Health System and Service Redesign* (2013) preceded by *Provincial Framework for End-of-Life Care* (2006).

[6] The Provincial Hospice Working Group is an advocacy coalition of hospice societies that aims to improve communication, funding and access to hospice services in BC.

Not-for-profit hospice societies are often unequal partners in the planning and delivery of services and have inconsistent communication channels with the provincial government. For example, “hospice organizations are not represented on provincial boards charged with overseeing palliative and end-of-life care” (PHWG 2020).

The move to a more integrated approach to palliative and end-of-life care may increase opportunities for hospice societies to work collaboratively with other health care and community partners to coordinate services and provide more equitable access to a range of services.

# III. Present Capacity

Palliative and end-of-life care on the Lower Sunshine Coast are currently provided to patients in a variety of settings. As noted above, palliative care is appropriate at any age and at any stage in a serious life-limiting illness to improve quality of life, and can be provided concurrently with other therapeutic treatments. Patients move through various settings while receiving palliative care, as their needs change – from home to long-term care to hospital or to hospice.

This reflects the *integrated approach* promoted by the national framework, as well as the *population needs-based approach* adopted by the province of BC – that is, early identification and provision of palliative care in a range of settings throughout the community, with support from a specialized palliative care team and community-based caregivers.

## Current palliative and end-of-life services

### Family physicians

Patients are generally identified as palliative by their family physician after a diagnosis of a life-limiting illness and provided with or referred to various palliative care resources. The family physician provides palliative care in conjunction with the palliative home and community nursing team.

Physicians and nurses on the Coast have been offered additional training in palliative care (the Pallium LEAP [Learning Essential Approaches to Palliative Care] Mini Course funded by the BC College of Family Physicians) and encouraged to introduce appropriate palliative services early in a patient's journey. There is one physician who provides specialist palliative care support to family physicians and takes referrals of palliative care patients with complex needs and/or patients closer to end of life who move to the Sunshine Coast and need a family physician.

The north end of the Lower Sunshine Coast is served by the Pender Harbour Health Centre which provides integrated health care service for its largely rural population. This includes a part-time family physician and palliative home care nursing team.

In addition, Vancouver Coastal Health (VCH) funds a Palliative On-Call team – a group of four physicians (one internal medicine physician and three family physicians) who provide after-hours support for palliative patients and palliative homecare nurses. BC's Medical Services Plan has introduced a fee structure for palliative care and specialist consultation.

### Informal/family caregivers

Those who are able to live at home with a palliative condition under their family physician's care are likely to have family members or close friends who provide some care. Family members (or other caregivers) caring for a palliative patient can receive respite hours and bereavement support from the SCHS. This might mean that a SCHS volunteer comes to the home to spend time with a patient, or that the patient might attend a wellness program at SCHS.

(It should be noted that residential respite is not readily available for palliative patients. Though long-term-care facilities provide some beds for general respite care, these are booked well in advance, and there is virtually no local capacity, other than hospitalization, to respond to urgent needs for palliative respite care.)

Patients may also be eligible for palliative home care nursing and personal care through VCH. Home care nurses provide training and support to family caregivers. This might include training family caregivers to give subcutaneous medications, provide wound treatment, catheter management and provide other levels of personal care. Family caregivers can also access caregiver support groups (through the Sunshine Coast Resource Centre) or counselling (through Mental Health), or private home nursing care if it is available and if they can afford it.

### Palliative home care nursing

Home care nursing and personal care is coordinated by Home and Community Care Services (within the Vancouver Coastal Health Authority (VCH)). A supervising palliative care nurse monitors the patient, supervises medication, provides information and support to family caregivers, and supports health care assistants (aides) performing personal care. Home care nurses have access to consultation with the palliative nursing coordinators during business hours, and to a provincial palliative care consultant by phone after hours (instituted in recent years). They also have access to the local Palliative On-Call Team.

Providing home care can be challenging if palliative patients do not have secure or accessible housing. Such patients may be housed in shelters or discharged from hospital to temporary housing contracted by VCH.

Some families may choose to supplement VCH home care with private home care nursing if they can afford it and if services are available. There are several private home care companies on the Coast and they report that there is more demand for their services than they can fill. Through Home and Community Care Services, VCH also contracts out to available private home care nursing companies to meet current demands.

### Hospital

Patients can be identified as palliative while in hospital or admitted as palliative in need of acute care or reassessment. If palliative patients receiving home care experience a health crisis, they are admitted to hospital through Emergency (ER). This is more likely if the patient is without an advance care plan or has not discussed end-of-life wishes with family and caregivers. Family physicians can admit a patient directly to a medical ward (avoiding ER); however this is typically avoided if the patient will need any ER services (fast access to imaging, labs, pain meds, etc).

As the Sechelt Hospital does not have a designated palliative care unit, palliative patients are integrated into general medical wards. Some palliative hospital patients may be designated as ALC (Alternate Level of Care) meaning they are waiting for discharge to a suitable alternative setting. Some informants indicated that there is an informal "long-term care" ward where ALC patients are placed while they wait for long-term care beds, though the hospital does not provide typical long-term care.

## Long-term care

Three facilities on the Lower Sunshine Coast – Shorncliffe, Totem Lodge, and Christenson Village – provide care to those who need daily support or cannot live independently (due to chronic conditions or disability).  The total number of long-term care beds among these three facilities is 188 (including 30 for dementia care).

Patients in long-term care are designated as palliative if their health declines significantly.  Staff sometimes initiate conversations with family members and request the designation from the family doctor.  Palliative care is often the focus for a majority of patients in long-term care, with an emphasis on quality of life.  Many residents indicate their wish to receive all their care for reversible conditions in the long-term care facility rather than be transferred to hospital.  Family physicians provide most of the palliative care in this setting, though palliative care specialists may be consulted for complex needs or if the resident requests MAiD.  Goals of care are discussed regularly with the family physician, especially with any health changes, or at the annual care conference  which includes a multidisciplinary team (dietician, resident coordinator, rehab assistant/physiotherapist, occupational therapist, recreation therapist, pharmacist, family physician/medical director and substitute decision makers).

Long-term care staff are offered a one-week training course in palliative care at Victoria Hospice.

## Residential hospice services

A two-suite hospice facility at Shorncliffe provides a tranquil setting for those nearing the end of life when care needs have exceeded what can be provided at home.  Each private room includes an ensuite bathroom, while a furnished common area accommodates the needs of family members and caregivers, with computer, kitchenette and bathroom amenities and access to a garden.  There are rollaway cots and a comfortable recliner that can also serve as a bed for loved ones who want to stay with their family member.

Referral to the hospice residence is through the VCH Palliative Care Team at Home and Community Care Services.  Average length of stay is about 30 days.  Palliative Care Coordinators report that there are typically 1–4 patients waiting for hospice at any given time.  SCHS volunteers provide companionship and vigil if requested, and also maintain the gardens and non-medical amenities.

## Sunshine Coast Hospice Society services

From its offices in Davis Bay, the SCHS offers free, volunteer-based services to palliative patients and their caregivers and loved ones that supplement medical palliative care.  These include palliative wellness programs, volunteer-led advance care planning support, bereavement support, end-of-life companionship and bedside vigil.  The Society offers public workshops, presentations, resources and events focussed on raising awareness of palliative and end-of-life care issues, and advocates for increased palliative and hospice services on the coast.

### shíshálh Nation

The Nation's Health Department is not a primary care provider, but offers supplementary care, including home care nursing for those with chronic conditions. Home care policy has been revised in the last few months and care aides will be available for members soon. Meanwhile, home care is provided primarily by VCH. There has been very little demand for palliative home care on reserve, or for MAiD. Many families do not have the capacity to care for someone at home.

The shíshálh Nation Health Department has worked to increase cultural safety at Sechelt Hospital, an ongoing task due to the high turnover of staff. The hospital currently has a joint working group with the shíshálh Nation to address this issue.

### Advance care planning

Physicians and home care nurses are encouraged to fill out MOST (Medical Orders for Scope of Treatment, replacing the provincial No CPR order forms) with patients who are palliative or living with chronic conditions to determine the level of medical intervention they wish. The Green Sleeve advance care planning initiative also provides a way for people to make their wishes known to family and health care practitioners should they be unable to express them. This helps to prevent unnecessary medical interventions or hospitalization when the patient does not want them.

The Green Sleeve initiative is coordinated by SCHS in collaboration with the SC Division of Family Practice and the Shared Care Palliative Working Group, the shíshálh Nation, and BC Emergency Health Services (BCEHS). SCHS conducts advance care planning (ACP) workshops and has specially trained volunteers who can provide additional support and information to residents working on their advance care plans. They offer additional ACP resources online at https://coasthospice.com/acp/

### Medical Assistance in Dying (MAiD)

With the passing of legislation regarding medical assistance in dying in 2016, physicians are now required to provide patients with access to information and the choice of this option should they request it, though physicians may choose not to provide MAiD themselves.

Patients on the Lower Sunshine Coast who request MAiD must be assessed by two independent practitioners. Typically the family physician does an initial assessment and the second assessment is performed by one of the three-person MAiD team (a palliative care family physician, an internist, and a nurse practitioner). There are also three local nurses who are available to assist and provide support for all involved in the procedure. If local practitioners are unavailable, the VCH MAiD Coordinating Service helps to bring needed staff from Vancouver.

# IV. Assets and strengths of current practice

Almost without exception, those interviewed for this scan commented on the exceptional quality of health care personnel who provide palliative and hospice care on the Lower Sunshine Coast, from physicians to palliative care nurses, licensed practical nurses, health care assistants, and community volunteers. They are perceived as knowledgeable, compassionate, available for support and consultation, dedicated to patient care, and invested in their community. Palliative care nurses and specialist physicians have provided strong leadership in this field.

The Palliative Care Working Group has raised the awareness and competency level of health care professionals in palliative care by offering training and clarifying consultation pathways.

It was noted that the Sunshine Coast has a reasonably high rate of palliative patients dying at home – a goal of health care providers and the most desirable outcome for many patients. CIHI has reported that although a majority of Canadians indicate in surveys that they would prefer to die at home, in 2015 only 15% of Canadians did so, with the majority of deaths (61%) occurring in hospitals (CIHI 2018 *Access to Palliative Care in Canada,* p. 10). However, of 332 deaths on the Lower Sunshine Coast in 2020, 100 were designated as palliative care and of those, 58 were home deaths, 31 occurred in hospital, 10 in hospice, and 1 was sent off Coast (causes unknown for the other 232 deaths). (See discussion under Challenges – Access to Residential Hospice Care.)

Other features of palliative and hospice care that received positive comment included:

- Benefits of new after-hours provincial palliative consultation phone line for home care nurses
- The palliative care kit provided to family caregivers that includes medication supplies and information on end-of-life care, including a VCH pamphlet on what to expect
- The quality of residential hospice care – family members praised attentive, compassionate staff who supported not just the patient but also offered consistent and caring support to family members and caregivers
- Sunshine Coast Hospice Society support for palliative patients and families in the form of vigil support at end of life, grief groups and individual counselling, the recently introduced "Circle" day program for palliative patients, and advance care planning support to complete the newly introduced Green Sleeve
- Provincial government palliative care benefits for patients at home, as well as standardized fees for family physicians and specialists providing palliative care
- Mental health support received by family caregivers – from home care nurses and from VCH mental health services
- Caregivers' Support Group (through Sunshine Coast Resource Centre) also helpful

- Sunshine Coast long-term care facilities successfully avoided COVID-19 outbreaks

In addition, several physicians have increased their knowledge and skills with respect to Medical Assistance in Dying (MAiD), making this an available option for those who choose it. This contrasts with some other regions of BC where it is less accessible to patients.

# V. Challenges and gaps in capacity

## Staffing shortages

Staffing shortages throughout the health care system were raised repeatedly by most informants in this study as an ongoing challenge to providing robust and quality palliative and end-of-life care. A major reason is housing shortages and costs on the Sunshine Coast: between 2016 and 2019 (even prior to a COVID-19 related real estate boom), the average price of a detached home increased by over 50%, while the median income increased by only 11%; meanwhile rental charges have nearly doubled and rental stock is low (see *Sunshine Coast Housing Needs Report* 2020). Additional factors affecting recruitment and retention include the cost of living in general and deficits in infrastructure that would support families moving here, such as child care and public transportation (see *Strategic Framework for Action on Poverty Reduction* 2021, and *Sunshine Coast Child Care Action Plan* 2020).

The impact of staff shortages is manifested in long work hours, curtailment of time spent with individual patients, fatigue, burnout, increased time off work, increased injuries, and ethical conflict or low morale for personnel who are unable to provide the quality and level of care they wish to, due to workload. All of these pressures, of course, have been intensified by the COVID-19 pandemic.

An additional outcome of staff shortages is that work is often contracted out on a temporary or limited term basis to health care professionals from off the Coast. As a result, there is a high turnover of staff, lower community attachment, and a range of competence levels in palliative and end-of-life care. While some training has been provided, this needs to be ongoing to maintain quality and consistency of care.

Below is a more detailed discussion of staff shortages in different areas of health care impacting palliative and hospice care.

### Primary care

The LHA Profile for 2018/19 indicates that the Sunshine Coast is doing slightly better than the provincial average in terms of family physicians per capita (14.7 per 10,000 pop, vs 12.6 for BC). Even when adjusted to include only those who are community-based providers (active caseload above 50 patients making 3+ visits/year), the Sunshine Coast is still better off than BC overall (10.4 per 10,000 vs 7.8 per 10,000 for BC) (*LHAP 2018/19*, p. 20).

However, recruitment is a challenge, and new family physicians sometimes contract for relatively short periods, increasing the turnover rate and reducing community attachment and long-term continuity for patients.

Most GPs have a full caseload, rarely take new patients, and are concentrated in Sechelt or Gibsons. Northern Sunshine Coast residents depend on one integrated health resource, the Pender Harbour Health Centre, with one family physician, home care nursing, ambulatory care, some lab services, and a private transport bus for medical appointments on the lower Coast.

Many family physicians provide on-call services at Sechelt Hospital, and most offer on-call home visits to palliative patients. Sechelt Hospital Emergency is the primary provider of after-hours care.

There is one physician providing on-call and home visits to homebound frail elderly patients. This population is currently underserved on the Coast and has been identified by the Division of Family Practice as an emergent health care need warranting further exploration, given that it is likely to increase as the senior population ages.

### Nursing

Both the hospital and community health services face a chronic shortage of nursing staff. VCH has resorted to contracting with off-Coast agencies to supplement nursing staff. On a random check of nursing positions posted for VCH on the Lower Sunshine Coast (Sechelt & Gibsons) in early October 2021, there were 40 nursing postings (Registered Nurse and Registered Psychiatric Nurse, for hospital, long-term care and community positions) and 10 postings for Licensed Practical Nurses.[7]

There have been changes in entrance requirements for nursing specialty programs that affect retention. A requirement to have practical experience on medical/surgical hospital wards to qualify for specialty training has been removed, enabling nursing graduates to go directly into specialty training, sometimes working concurrently in other areas of nursing. As one hospital nurse commented: “My department now has four nurses training in specialties. So, while we are okay for staff right now, in four months they will all be leaving for jobs in their specialty.”

### Community health care assistants

Several informants reported an urgent shortage of health care assistants (care aides) especially with respect to home care and long-term care. Home and Community Care Services frequently contract with private home care nurses, LPNs, and care aides to fill gaps in staffing levels. Informants could only speculate on the reasons for the shortage: lack of housing, a gap between expectations and reality regarding the tasks of the job among newly trained employees (due perhaps to inadequate practicum experience during training), rigid job parameters, as well as wage levels and a prevalence of part-time postings. However, in a random check of home care aide job postings in October 2021, most were full-time positions, in contrast to about a half and half split between full- and part-time nursing positions.

There is a slight differential in care aide wages between home care and long-term care, which may contribute to some attrition of home care aides or migration from home care to positions in long-term care. Community health assistants in home care earn $23.27 – $25.45 an hour, while long-term care assistants earn a starting wage of $25.83.

To address this shortage, in 2020 the Sechelt Hospital Foundation piloted a subsidy program for health care assistant training, in the form of paid tuition at Capilano University in exchange for a year’s work commitment. However, of 11 subsidized graduates who completed this program in 2021, only two remained in care aide positions a few months after

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[7] RN/RPNs: 18 full-time, 17 part-time, and 5 casual positions. LPNs: 2 full-time, 6 part-time, and 2 casual – 6 of those were hospital positions and 4 long-term care (the latter all part-time or casual).

completion. The others chose to repay their tuition subsidy rather than fulfill their work commitment.  The provincial government has initiated a similar program with some strategic adjustments to better orient students and align their expectations with job activities.

Long-term care conditions and staffing shortages have been the subject of intense public scrutiny, particularly since the onset of the COVID-19 pandemic.  A recent report from the BC Seniors Advocate (October 2021) recommended increased staffing, a higher nursing to care aide staff ratio, and more paid sick days for staff, to address vulnerabilities that led to increased COVID-19 outbreaks in long-term care provincially.

Even though they fared well in terms of COVID-19 outbreaks, local long-term care facilities face chronic staff shortages and are rarely able to achieve ideal staff/resident ratios.  This has resulted in some long-term beds being kept vacant at local facilities, for example Christenson Village, which further limits the ability to transfer ALC patients out of acute care beds at Sechelt Hospital.

**The shortage of staff is an ongoing stress factor that will need to be taken into consideration in future planning.  Increased efforts to provide palliative care at home, in long-term care, or in hospice will create greater demands on those services.  Without enhancing service capacity and strengthening recruitment and retention of staff, patients will be underserved, and palliative caregiving will fall to informal/family caregivers who will not always have the resources to meet this demand. If family/informal caregivers are unable to provide care at home, patients will need to be admitted to the hospital for care.**

## Informal/family caregiving

The integrated model of palliative care emphasizes caring for people at home and in the community for as long as possible, to reduce hospital admissions and unplanned hospital deaths.  Where families or informal caregivers have the resources to carry this out, the palliative journey can be a positive one.  However, the model relies on family and home conditions that are not available to all.  This presents some challenges, particularly with respect to the population of the Lower Sunshine Coast:

- As several informants in this study pointed out, “You can’t die at home if you have no family or friends.” Many senior residents on the Sunshine Coast (particularly those who have moved here to retire) do not have family living nearby.  If they do have family, it may well be a spouse with health challenges of their own.  If there are adult children nearby, they may be working or raising a family and unable to provide intensive care.
- Some palliative care patients live alone or without a strong support network and require an alternative to informal/family care.
- Informal/family caregivers may be reluctant or unable to change their relationship to a primarily caregiving one.
- Providing palliative nursing care to a family member can take away from the caregiver’s quality time with their loved one.

- Even if informal/family care is available, being a caregiver takes time and money (which is often not accounted for when comparing home care and hospital care costs). Some family members lack the resources to provide ongoing care.
- Primary family caregivers are often unable to work when they are caring for their ill family member, creating further financial hardship.
- Informal caregivers are at risk of deteriorating health if they are unsupported and unable to take time for self care (see Cohen et al. 2015)

Palliative care coordinators and hospital social workers are frequently challenged to find appropriate settings for palliative home care patients if the patient has no secure home or whose home has become unsuitable or inaccessible, and has insufficient income to cover the cost of alternative housing and other expenses. Those with economic and housing challenges are the most at risk of "falling through the cracks."

## Community awareness of palliative and hospice care options

Health care practitioners have identified public misconceptions and stigma about palliative care as a barrier to accessing care. An excellent brochure developed by the Palliative Care Working Group is likely to assist physicians and their patients in overcoming some of these barriers. The SCHS's public education activities and work on the Green Sleeve advance care planning initiative also help raise awareness and reduce stigma.

However, community awareness of palliative and end-of-life services is limited. Several informants mentioned the difficulties faced by patients and caregivers seeking information about and access to services. And while some health care practitioners and family caregivers are well aware of services, several are unfamiliar with the work of the SCHS or have unclear ideas about what services it provides or who funds them.

## Hospital capacity

Sechelt Hospital, serving the entire Lower Sunshine Coast, has over 50 beds[8] but is known to have been operating above its optimum capacity well before the COVID-19 pandemic (with figures of 130% for 2017-18 and 120% for 2018/19 cited – *Coast Reporter*, Jan 8, 2020). Sechelt Hospital provides a higher than average rate of outpatient care (scheduled day procedures) without hospitalization (*Local Health Area Profile* (LHAP) *2018/19*, p. 40), a measure that mitigates demand for hospital beds.

The *Local Health Area Profile 2018/19* for the Sunshine Coast indicates there are three main categories of avoidable hospital use:

a. **Readmissions** within a month of discharge – Lower Sunshine Coast rates of readmission are slightly higher than provincial averages for all age groups (4.2 per 100 hospitalizations, vs. 3.4/100 for BC). Among those over 60, readmission rates are

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[8] Number of beds at Sechelt Hospital was difficult to pin down. Figures cited ranged from 38 (VCH website), to 40 (*LHAP 2018/19*) to 62 (Sechelt Hospital Foundation). Some variation may occur due to a number of "unfunded beds" (VCH) or the allotment of some beds for ALC patients, which are sometimes not included in bed count.

slightly higher than the provincial average. Readmissions may not always be avoidable but could be reduced by greater capacity in community-based support.

b. **Ambulatory Care Sensitive Conditions** (ACSC) – admission rate for patients with chronic conditions was higher for the Sunshine Coast than the rest of BC in 2018: 623 per 100,000 pop, vs 513 for BC ( 2018/19). This would be reduced by enhanced ambulatory care in the community.

c. **Alternate Level of Care** (ALC) – this refers to patients who occupy a hospital bed but do not require acute hospital care and are waiting for suitable care elsewhere. In most cases, ALC patients are awaiting beds in long-term care or assisted living, but some are waiting for hospice care. (See Access to residential hospice care, below.) Prolonged stay in hospital may expose patients to infection or functional decline, while it reduces hospital capacity to respond to acute care needs.

Though ALC rates tend to be higher in small and medium sized community hospitals, the Sunshine Coast rate of ALC was lower in 2018 than the BC average (*LHAP 2018/19*, p. 43). Just over 2% of hospital stays include one or more days of ALC care, well below the BC rate of 4.6%. However, 13% of hospital inpatient days were dedicated to ALC (only slightly lower than the BC rate of 13.5%). Reducing this rate by increasing the capacity of hospice care, long-term care, and assisted or supported living would free up hospital beds for acute care.

Not having a palliative care unit in Sechelt Hospital means that palliative care patients are integrated into acute care wards, where conditions are unlikely to be ideal. Hospitals can be busy, noisy, impersonal and limited in their capacity to accommodate family needs. In contrast, hospice care provides a tranquil environment where the focus is on the needs of patients nearing the end of life – including emotional and spiritual needs – and accommodating family well-being. Palliative and hospice care in community settings can further reduce unnecessary hospitalizations and increase patient satisfaction.

## Long-term care capacity

Demand for long-term care on the Lower Sunshine Coast far exceeds current capacity. There are 188 long-term beds (including 30 for dementia) in three facilities, Shorncliffe, Totem Lodge and Christensen Village. Waiting lists for long-term care are long (though numbers were not available, some informants spoke of wait times in terms of years rather than months or weeks). When openings do occur, priority tends to be given to ALC hospital patients waiting for long-term care.

Shorncliffe and Totem Lodge are slated to be removed from long-term care services (total of 108 beds), leaving Christensen Village (80 beds) and a new private facility, Silverstone, planned for 2022/23, which will provide 132 beds (with four designated for hospice care). With the opening of Silverstone, the overall net increase in long-term care beds will be 20. Long-term care staff indicated this would be inadequate to meet even current needs.

Furthermore, a repeating theme among long-term care workers is the chronic shortage of staff, making it difficult to achieve optimum staff/resident ratios. In some cases this has led to keeping some beds vacant due to insufficient staffing.

Given population projections for the Sunshine Coast, demand for long-term care is likely to increase significantly. The impact of a shortage over time will mean that long-term care candidates will increasingly resort to hospitalization, home care nursing, and family caregivers – placing extra demands on all these resources.

## Access to residential hospice care

Two hospice beds were established on the Sunshine Coast in 2001 and capacity has not been increased in 20 years to keep up with population growth and the increasing proportion of senior residents. Current demand for hospice beds consistently exceeds availability.

Home and palliative care coordinators indicated that in any given month, there are 1-4 patients waiting for a hospice bed. Patients who cannot be accommodated in the hospice residence may be hospitalized or die in unplanned and unsuitable circumstances. In some cases, if the patient wishes, they may be sent to hospice care off the Coast to be closer to family and support.

Statistics gathered by Palliative Care Coordinators indicate that of 183 palliative care deaths in the 20 months from January 2020 to August 2021, at least 15 individuals who died in hospital could have been supported in hospice had there been capacity, while another five could have died at home with support. Four patients were sent off Coast to other hospice facilities, while 35 were on the waitlist for hospice at some point during that period.

An anecdotal indication of unmet need is that during this study, informants mentioned three separate plans to provide single-bed private hospice care units on private property. Two of these were initiatives by home care nurses (active and retired) who saw an urgent need; the third was by a business owner whose family member had needed hospice care.

The average hospice stay is 30 days. Several informants indicated that more flexibility in length of hospice stay is needed, as the trajectory of a patient's end-of-life journey is often unpredictable. Among the small number of family members interviewed for this scan, two had family members whose hospice stay was over two months. Both indicated that home care was not an option for their family member, and both had deep appreciation for the time and care provided in hospice rather than in hospital.

A need that was repeatedly reported by family caregivers and health care workers was for palliative respite care to allow family caregivers a restorative break. Research has shown that without palliative respite support, family caregivers can experience significant health risks (Cohen et al, 2016). In addition, there is a need for short-term supervision of palliative patients to reassess medications or symptom management. Both of these needs are currently met by hospitalization, though they could be addressed by hospice care if an adequate number of beds and staffing were available.

There are additional challenges to providing palliative or hospice care for those who have complex needs beyond palliative care, such as addiction, homelessness, or mental health issues. Current options of emergency shelters or motel rooms are inadequate.

**Every informant who was asked about hospice capacity for this study responded that two hospice beds are inadequate to meet the needs of the aging population on the Lower Sunshine Coast. Increasing capacity to four beds will not address needs for palliative respite care or reassessment. Most informants indicated that at least six beds, with the capacity to expand to eight without additional capital expenditures, would be preferable, as it would address anticipated need and allow for palliative respite care and reassessment.**

## Cultural diversity and cultural safety

As indicated earlier, the shíshálh Nation Health Department has worked to increase cultural safety at Sechelt Hospital, where Indigenous patients have experienced some barriers to care and to family or community involvement in their care. Due to high turnover of staff, this is an ongoing task, though there is now a joint working group with hospital and shíshálh representatives addressing this issue.

This issue is likely to gain more attention provincially as a result of the 2020 report commissioned by the BC Ministry of Health, *In Plain Sight: Addressing Indigenous-specific Racism and Discrimination in B.C. Health Care*, by the Hon. Dr. Mary Ellen Turpel-Lafond.

While several informants from a range of palliative and end-of-life care services indicated openness to training in cultural diversity and safety, none reported being offered such a training opportunity.

## Access to MAiD

MAiD has been gradually integrated on the Lower Sunshine Coast as an end-of-life option for those who wish it.

In 2020, there were 27 patients on the Lower Sunshine Coast who opted for MAiD. Of those, 20 died at home, 3 in the hospice suites at Shorncliffe, and 4 died in hospital. This is a significant increase from previous years, when a total of 29 palliative patients chose MAiD in a three-year period between 2016 and 2018.

These MAiD deaths represent 8.13% of total deaths in 2020 on the Lower Sunshine Coast, significantly higher than the national average of 2.5% of total deaths in the same time period[9]. The provincial average in 2020 was 4% of total deaths, the highest provincial rate in Canada.

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[9] Government of Canada. *Second Annual Report on Medical Assistance in Dying in Canada 2020.*

Between 2019 and 2020, uptake of MAiD in BC overall increased by 22%. Across Canada, it increased by 34.2%.[10] In 2020 BC had the third highest number of MAiD deaths among Canadian provinces and territories (after Quebec and Ontario) ), with an average patient in BC age of 76.8 years..

In the past year especially, the increase in demand for MAiD on the Lower Sunshine Coast has added to the workload of the team providing MAiD.

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[10] 7,595 reported cases in 2020, 5,660 reported cases in 2019. In 2020, 1,572 of those cases occurred in BC, the third highest number of cases after Ontario and Quebec.

# VI. Key areas for enhancing palliative and hospice care

With the dramatic increase in elderly seniors projected for the Lower Sunshine Coast over the next two decades, it is clear that the need for palliative, hospice and end-of-life care will be growing. Health care providers and community supports need to prepare for this. Areas of enhancement fall into one of two large categories – building health care capacity to accommodate the anticipated higher numbers of patients and enhancing the quality of integrated care through training and collaboration.

## Staffing recruitment and retention

Increased primary care needs of a growing senior population with increasing levels of illness and chronic conditions will place additional demands on all aspects of palliative and hospice care and necessitate increased staffing of primary care, palliative home care nursing, long-term care and hospice staff.

Developing incentives to improve recruitment and retention of home care and long-term nursing staff is crucial to strengthening palliative and end-of-life care services.

Remedial strategies could include:

- developing job incentives/enhancements
- participating in advocacy and strategizing for new workforce housing, affordable housing and other infrastructure supports such as child care.

## Professional training and public awareness

As palliative care practice moves to a more integrated community-based model, there will be an ongoing need for training in palliative and end-of-life best practices throughout the health care system to maintain consistency and quality of service. This is especially important if ongoing staff shortages necessitate continuing the practice of hiring agency and short-term workers with different levels of palliative care skills and experience.

To reiterate, best practice surveys conducted at federal and provincial levels have concluded that integrated palliative care is the most effective use of health care resources and provides patients and families with the best range of options.[11] Its main principles include:

- early identification of palliative needs by family physician
- early introduction of appropriate levels of palliative care
- provision of palliative care concurrently with other treatments
- support to family physicians by palliative care specialists and team
- emphasis on supporting patient quality of life, comfort and pain management

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[11] See federal and provincial policy documents for palliative hospice care, outlined in Appendix C.

- provision of palliative care in a variety of settings based on patient needs and wishes
- attending to family/informal caregiver well-being
- ensuring consistent quality care and equitable access to services

Though the Lower Sunshine Coast does not have a palliative care hospital unit, it does have a multidisciplinary team of practitioners who take leadership roles in the palliative and hospice field and support a collaborative approach to care. They have already initiated training and implemented many of the principles of integrated palliative and end-of-life care on the Lower Sunshine Coast. It became apparent during this scan that some health care practitioners were unaware of complementary support services offered by the SCHS, and this information should be included in training.

Palliative and end-of-life care services are not well understood by the public, and misconceptions hinder access to care. Developing support for and public access to integrated palliative care will require ongoing efforts to increase public awareness of available services and their benefits.

## Informal/family caregiver training and support

Informal and family caregivers face numerous challenges in providing care to a loved one – financial, physical, emotional, health, etc. With increased emphasis on palliative home care, support for informal caregivers will need to be strengthened. Enhanced caregiver supports could include:

- training regarding how to provide personal care, administer medication, do patient transfers, and manage a health crisis, etc. This would free up some of the time spent by palliative care nurses on training and supporting family caregivers.
- information on self care
- greater access to palliative respite care through residential hospice and SCHS services
- caregiver peer support and counselling
- anticipatory bereavement and grief support
- assistance accessing services and financial benefits or supports (e.g. caregiving benefits and tax credits, informal support funds)

## Palliative home care nursing

With the increased emphasis on supporting those with life-limiting conditions to live at home, the demand for palliative home care nursing will increase significantly. Supplementing the existing team of palliative home care providers – already stretched to the limit – is essential. This includes expansion of the coordinating role for palliative home care.

Improving communication between SCHS and home care nurses to ensure they are aware of services available from SCHS would also increase access to those complementary services. For example, more detailed information about SCHS services should be included in home care kits provided to family caregivers.

## Long-term care capacity

Though the Silverstone long-term care facility will come online in 2022 or 2023, the net increase of capacity will be inadequate to meet present or projected needs. The current ratio of long-term care beds to senior population (about 10,450) is 1:55, which is already insufficient. The planned complement of 208 beds will, by 2035, achieve a ratio of 1:62 (1 bed for every 62 residents) – a reduction in overall capacity.

If the Sunshine Coast were to aim for a ratio of 1:40 long-term care beds to senior residents by 2035, it will need a total of 324 long-term care beds, requiring creation of 116 new beds. In addition, as some seniors have expressed a wish not to receive care in a long-term care facility, exploring creative alternatives would be a useful strategy. For example, some communities have created small-scale care homes, such as those developed by the Abbeyfield Houses Society (see https://abbeyfield.ca/british-columbia/).

## Hospital capacity

Already operating above optimum capacity, Sechelt Hospital will face significantly greater demands as an aging population increases with a concomitant increase in illness and chronic conditions. Research has shown that, while comparative costs are difficult to measure precisely, the costs of palliative and end-of-life care in hospital are far greater than community-based alternatives (see Luta et al., 2021, and QELCCC, 2013~). Enhancing community-based palliative and hospice care can reduce unnecessary hospitalization and diagnostic procedures and interventions, while offering more choice and self-determination to those approaching end of life.

## Residential hospice care

The existing two residential hospice beds are clearly inadequate to meet current needs. Most informants held the view that two additional beds would barely catch up with current demand and would not accommodate the increased demand that is sure to come with an aging population. Furthermore, it would not address palliative respite and reassessment needs. Some informants felt the Sunshine Coast should have as many as 12 hospice suites, though most fell somewhere in between, suggesting six to meet immediate need, with a built-in capacity to expand to eight or more without additional capital expenditure. A dedicated facility with its own entrance was considered more inviting to patients and families than suites located inside a long-term care facility, though proximity to a health care facility was seen as beneficial.

Enhancing hospice capacity to an eight-bed facility would provide several benefits:

- reduce waiting list for hospice
- address current and projected needs arising from changing demographics
- accommodate unmet need for palliative respite care and reassessment
- address the needs of patients without family to care for them (likely to increase)
- reduce use of acute care hospital for palliative and end-of-life care

- offer more people the choice of a tranquil end-of-life setting where pain and symptom management can be provided
- reduce unplanned or inappropriate palliative and end-of-life hospitalizations
- allow more flexibility in length of hospice stays, and earlier access to hospice for greater comfort, care and support
- enable hospice to meet more complex medical needs of patients due to increased staffing
- accommodate different cultural practices regarding end of life and dying, including Indigenous practices

## Diversity, inclusion and cultural safety

Expanding training in cultural diversity, inclusion and safety among all who provide palliative and end-of-life services would be beneficial to the Lower Sunshine Coast community that is growing increasingly diverse and that is situated in traditional shíshálh and Sḵwx̱wú7mesh territories. This training would ideally involve gaining understanding of cultural practices related to illness and dying, but also historical background regarding the impact of discriminatory and colonial practices on health and access to care. The BC Ministry of Health report, *In Plain Sight*, provides valuable background information and recommendations on this issue.

Demand for palliative care within the shíshálh Nation has been limited, while home care for chronic conditions is more common. Communication between the Nation and palliative care services under VCH – including long-term care, hospice care, and hospital care – requires ongoing attention to ensure cultural practices are honoured. shíshálh health service providers also indicated a strong interest in being involved in hospice and palliative care planning.

## MAiD training

As mentioned in previous sections, there has been a significant increase in demand for medical assistance in dying on the Lower Sunshine Coast in the last year. Increasing the local capacity to manage this demand with sensitivity, through additional training and staffing, would be preferable to seeking supplementary expertise off the Coast.

## Community collaboration

Given that the Lower Sunshine Coast is poised to face a much greater demand for palliative and hospice services, having a central location for an interdisciplinary focus on palliative and hospice care would be timely. It could support and build on the relationships that exist on the Sunshine Coast among palliative care professionals, community-based volunteers, and the shíshálh Nation, while fostering information exchange, training, resource sharing, and greater integration of palliative and hospice services. Collaboration can expand access to the community-based volunteer services that address the emotional, psychosocial and spiritual needs of palliative patients and their families that are provided by organizations such as the SCHS and Caregiver Support Network.

This would also enable expansion of SCHS services that supplement medical palliative care, such as support groups for palliative patients and caregivers, respite and companionship hours, advance care planning education and support, grief and bereavement support, and support to hospice staff. A palliative care centre would also enable additional therapeutic services for home-based palliative patients, such as massage, healing touch, and music therapy.

Specific recommendations emerged regarding SCHS communications – including increased communication with health care workers about SCHS services (for example, in the palliative home care kit), and greater public clarity about services provided and their funding sources.

## Other palliative and hospice care recommendations

Other palliative and hospice care enhancements suggested by informants included:

- A navigator/guide for health related services – Navigating the health care system is challenging, and people with a new diagnosis may be particularly overwhelmed or distressed and need assistance identifying and locating the support they need, whether related to accessing health care, financial support, help with daily tasks, emotional support, etc. Ideally a navigator would provide this assistance to both patients and informal/family caregivers.
- An additional suggestion was an online resource to assist people with a serious illness or life-limiting condition to navigate access to health care and other supports. (Note: The SCHS is in the process of developing such online resources for Lower Sunshine Coast residents, in addition to producing a three-part information video series for patients and families living with life-limiting illness.)
- Addition of a geriatric psychiatrist to the palliative care team.
- Flexibility of nursing job duties – Under VCH home care protocols, job duties for nurses, LPNs and care aides are strictly defined, limiting flexibility in tasks performed. Private home care nurses and LPNs are able to offer "all inclusive" care – from personal care and shopping, to palliative and end-of-life care, without strict limitations on what work they can perform, providing a more seamless experience of support for clients and more consistency in personnel. (This is noted in recognition that job task protocols are a valid strategy by health care unions to protect workers' rights. However, they can also have an impact on patients' experience of care.)
- Address wage differential between home care, long-term care and hospital care aide positions.

# VII. Conclusion

This report outlines the current status of palliative and hospice care services on the Lower Sunshine Coast and outlines anticipated needs based on projected growth in the population, particularly the senior population.

The SCHS and Sunshine Coast health care professionals have already shown leadership in establishing community-based hospice care and developing an integrated model of palliative care that emphasizes care at home and in the community to minimize unnecessary or unplanned hospitalization.

This environmental scan highlights the strengths of current practice and points to current and future challenges. Its aim is to enable planners to build on the existing foundation, enhance a collaborative network of professionals and volunteers, and create options that respond to the expressed wishes of those managing life-limiting conditions or approaching the end of life.

# Appendices

## Appendix A – Definitions

The *Provincial End-of-Life Care Action Plan for British Columbia* (2013) provides the following definitions of palliative care terms, reflecting current best practices:

**Palliative Care** – 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 to provide care 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 curative treatment.

**End-of-Life Care** – 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, and attention to psychosocial and spiritual concerns.

**Life-Limiting Illness** – 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.

The provincial document cited above omits hospice care, though it would align with "end-of-life care." There are variations in definitions of hospice care, ranging from philosophical to descriptions of services included.

**Hospice Care** – Hospice facilities provide end-of-life care in a peaceful, compassionate environment for those who cannot be at home, where the focus is on the comfort of the patient, responding to their wishes and choices, addressing emotional and spiritual needs as well as physical care, and supporting the well-being of caregivers and family members. Hospice societies provide a range of other services for patients and their family members and caregivers, such as bereavement support, respite, day programs, and assistance with advance care planning. Hospice care encompasses "a whole-person approach that aims to improve the quality of life of individuals living with a progressive, life-limiting illness, as well as ensure the well-being of caregivers, family members, and friends impacted by the person's illness or death." (Provincial Hospice Working Group, 2020, p 4).

The Canadian Hospice Palliative Care Association uses the term "hospice palliative care" to refer to the approach to care described in both palliative and hospice care above.

## Appendix B – Federal and provincial policy on palliative and end-of-life care

Health care policy makers have recognized that providing a comprehensive system of palliative and hospice care in a variety of community settings can alleviate demands on acute care hospitals as well as provide a valuable and more appropriate form of care that benefits patients and their families at a particularly challenging time. Research has overwhelmingly shown that those who receive palliative care early in their health care journey have an improved quality of life and are more likely to die in circumstances they have chosen – at home or in community care, rather than in hospital after an unplanned admission (CIHI 2018).

This has led to efforts to shift palliative care practices across the country, to emphasize early identification of palliative needs – regardless of diagnosis – and provision of palliative care alongside beneficial treatments in a variety of community settings.

To that end, both federal and provincial health care authorities have developed policy frameworks and action plans regarding palliative care:

### Federal

- 2012-15 – a federally funded project, The Way Forward, researched current practices, costs, best practices and evaluation tools, etc, regarding integrated palliative care across Canada and elsewhere. Published several reports on specific topics, as well as *The Way Forward National Framework: A Roadmap for an Integrated Palliative Approach to Care* (2015).
- 2017 – all provinces and territories agreed to a Common Statement of Principles on Shared Health Priorities that highlighted the need to improve access to home and community-based services, including palliative home care and residential hospices (CIHI 2018, p. 10)
- 2017 – Canadian government passed legislation mandating the development of a framework on palliative care in Canada to improve access to palliative care
- 2018–CIHI published the report, *Access to Palliative Care in Canada*
- 2018–Health Canada released *Framework on Palliative Care in Canada*

The Way Forward project emphasized an integrated palliative care approach, which supports palliative care delivered concurrently with other forms of treatment, in a variety of settings:

> Canada must work towards a system of community-integrated palliative care. When someone is diagnosed with chronic, life-limiting illness, involving palliative care providers early can improve quality of life and reduce suffering. This means that high quality hospice palliative and end-of-life care must be an integral part of health care, and available in all settings of care, including hospital, long-term/continuing care, residential hospices, shelters and individual homes. It also means that the palliative approach to care must be part of the treatment repertoire of any health care professional, supported by consultation or referral to a specialist palliative care team when necessary (The Way Forward, About Us, http://www.hpcintegration.ca/about-us/about-the-initiative.aspx).

The goals of an integrated approach are that:

1. people discuss their wishes with health care provider early and often – advance care planning evolves as disease progresses and/or as person ages
2. people who are aging, frail and/or have chronic illnesses will receive hospice palliative care services integrated with their other care in the setting of their choice
3. people who are aging, frail and/or have chronic illnesses will receive consistent, seamless integrated care if/when they must change care settings (CHPCA 2015, p. 7)

In the fall of 2021 in a response to election questions regarding palliative hospice care, the Liberal party affirmed its support of integrated palliative care with an allocation of $6 billion over 10 years to provinces and territories, and $184.6 million over five years for home and palliative care for Indigenous communities." (Liberal Party of Canada, Sept 2021). In addition, the government committed the following:

- $1.9 million for the Canadian Hospice Palliative Care Association to improve advance care planning;
- $2 million for the Canadian Virtual Hospice to expand virtual services and resources;
- $600,000 for the Canadian Home Care Association to improve delivery of care at home; and
- $6 million to Pallium Canada in order to expand palliative care training across the country so that health professionals are fully able to support Canadians and their families during palliative care
- a new $9 billion plan to improve long-term care in Canada

## Provincial – British Columbia

In 2013 the BC Ministry of Health released the *Provincial End-of-Life Care Action Plan for British Columbia: Priorities and Actions for Health System and Service Redesign*. Some features of the plan include:

- adoption of a population-needs-based model of palliative/hospice care as exemplified by Australia
- this model is based on "the principle that palliative care services must be effective, efficient and ethically delivered at the medically appropriate time." It also recognizes the needs of family members and the importance of volunteers and community. (BC Ministry of Health 2013, p. 8)
- emphasis is on early identification of palliative needs, discussion of patient wishes, recognition of changing needs as health condition changes, promotion of collaboration between primary care GPs and hospice/PC specialists

BC Ministry of Health actions that have addressed goals of the action plan:

- support of practices that reflect a shift from unplanned hospital deaths to planned, expected natural deaths at home
- created Palliative Care Benefits Program providing access to the same drugs and palliative supplies and equipment at home as if the person were in hospital, in the last six months of life

- instituted provincial physician fee codes GP Palliative Care (2009) and PC specialist services (2012)
- increased hospice beds provincially
- updated advance care planning legislation
- provided after hours PC nursing support phone line province-wide (for Home and Community Care nurses)
- all health authorities have developed palliative care teams with training (Ministry of Health and BCMA)
- University of Victoria & Fraser Health authority project (Michael Smith Foundation) on palliative approach to nursing has provided learning and training
- four of the five regional health authorities use the continuing care information management system (CCIM) to collect data (CHPCA 2013, p. 23)

## Equal access

As the demand for palliative and hospice care grows, decision makers are also focused on how to provide quality services that are consistent and equally accessible throughout the country (CIHI, 2018). Canada's 2018 *Framework on Palliative Care* indicates that "according to the Economist Intelligence Unit's 2015 Quality of Death Index, Canada has slipped from 9th to 11th out of 80 countries based on the availability, affordability and quality of palliative care. While the provision of palliative care has improved since its inception in the 1970's, a number of reports have identified ongoing gaps in access and quality of palliative care across Canada."

A CIHI study of end-of-life use of health care services during the last two years of life found that 79% of deaths in Canada were those aged 65 and over, and the majority of those deaths were caused by life-limiting illness but only 15% of those patients received palliative care (BC Ministry of Health, 2013, p. 7).

As the Provincial Hospice Working Group reported in 2020, BC is in the early stages of addressing equitable access. Practice norms and training for hospice care vary throughout the province, funding is inconsistent, and evaluation systems for palliative and hospice care vary considerably (Provincial Hospice Working Group 2020; CHPCA 2013; see also David May on Urban/Rural discrepancies in palliative care, Aug 2021).

# Appendix C – Documents reviewed

BC Centre for Palliative Care. October 2019. *Hospice Care in British Columbia*. PowerPoint summary of hospice survey.

BC Government, BCStats, British Columbia Population Projections. https://bcstats.shinyapps.io/popProjApp/

BC Ministry of Health. November 2020. *In Plain Sight: Addressing Indigenous-specific Racism and Discrimination in B.C. Health Care, Summary Report*. https://engage.gov.bc.ca/app/uploads/sites/613/2020/11/In-Plain-Sight-Summary-Report.pdf

BC Ministry of Health. March 2013. *Provincial End-of-Life Care Action Plan for British Columbia: Priorities and Actions for Health System and Service Redesign*. https://www.health.gov.bc.ca/library/publications/year/2013/end-of-life-care-action-plan.pdf

BC Ministry of Health. 2006. *Provincial Framework for End-of-Life Care in British Columbia*.

BC Ministry of Health, Health Sector Information, Analysis and Reporting Division. October 2020. *Local Health Area Profile – Sunshine Coast – 2018/19* (*LHAP 2018/19*)

Canadian Hospice Palliative Care Association (CHPCA). 2015. *The Way Forward National Framework: A Roadmap for an Integrated Palliative Approach to Care*. (In partnership with Quality End-of-Life Care Coalition of Canada (QELCCC) and Government of Canada.) http://www.hpcintegration.ca/media/60044/TWF-framework-doc-Eng-2015-final-April1.pdf

Canadian Hospice Palliative Care Association. 2013a. *Innovative Models of Integrated Hospice Palliative Care, The Way Forward Initiative: An Integrated Palliative Approach to Care*. http://www.hpcintegration.ca/media/40546/TWF-innovative-models-report-Eng-webfinal-2.pdf

Canadian Hospice Palliative Care Association. 2013b. *Palliative Care in the Community: An Environmental Scan of Frameworks and Indicators, The Way Forward initiative: An Integrated Palliative Approach to Care*. http://www.hpcintegration.ca/media/43475/TWF-Environmental%20Scan%20Report%20EN%20FINAL.pdf

Canadian Institute for Health Information (CIHI). 2018. *Access to Palliative Care in Canada*.

CBC News. October 6, 2021. BC's seniors advocate calls for paid sick leave, more staff in long-term care to prevent COVID-19 deaths. https://www.cbc.ca/news/canada/british-columbia/long-term-care-covid19-bc-seniors-advocate-report-1.6201448

Cohen, SR; MacKinnon, CJ; N Kogan, N; Dewitte, M; Penner, JL; Parmar, MP; Khadoury, A; Feindel, A. 2015. *Guiding Family Caregivers of People at the End of Life: A Handbook*.

District of Sechelt, Town of Gibsons, Sunshine Coast Regional District. February 2020. *Sunshine Coast Child Care Action Plan*. https://www.sechelt.ca/Portals/0/flash/Sunshine%20Coast%20Child%20Care%20Action%20Plan(1).pdf

Government of Canada. 2020. *Second Annual Report on Medical Assistance in Dying in Canada 2020.* https://www.canada.ca/en/health-canada/services/medical-assistance-dying/annual-report-2020.html#3_1_table

Health Canada. 2019. *Action Plan on Palliative Care.* Health Canada. 2018. *Framework on Palliative Care in Canada. (*Blueprint to help shape planning, decision making and organizing change related to hospice palliative care in Canada.) https://www.canada.ca/en/health-canada/services/health-care-system/reports-publications/palliative-care/framework-palliative-care-canada.html

Health Canada. 2018. A *Common Statement of Principles on Shared Health Priorities.* (Agreement between federal government and provinces and territories)

Liberal Party of Canada. September 2021. *Fully Commit to funding and implementing the Framework on Palliative Care in Canada.* Response to election questionnaire from Quality End-of-Life Care Coalition of Canada. https://www.chpca.ca/wp-content/uploads/2021/09/LPC-2021-Survey-Response-QELCCC.pdf

Luta et al. 2021. Evidence on the economic value of end-of-life and palliative care interventions: A narrative review of reviews. *BMC Palliative Care* (2021) 20:89. https://doi.org/10.1186/s12904-021-00782-7

May, David. 2021. Rural-Urban inequities in palliative care. *BC Medical Journal* vol. 63 no. 6 (July/August 2021): 255.

Provincial Hospice Working Group. August 2020. *Hospice Care in BC – The Path Forward.* https://secureservercdn.net/198.12.144.78/amb.9a6.myftpupload.com/wp-content/uploads/2020/08/PHWG-Report-August-20200824a.pdf

Quality End-of-Life Care Coalition of Canada (QELCCC). 2020. *Blueprint for Action* 2020-2025. www.chpca.ca/wp-content/uploads/2020/03/QELCCC-Blueprint-for-Action-2020-2025-H.pdf

Quality End-of-Life Care Coalition of Canada (QELCCC), Canadian Hospice Palliative Care Association, & Govt of Canada. n.d. (2013?) *Cost effectiveness of palliative care: A Review of the Literature.*

Sunshine Coast Resource Centre (Baxter, B. & Feindel, P.), 2021. *A Strategic Framework for Action on Poverty Reduction.* https://resourcecentre.ca/our-projects/poverty-reduction-strategy

Urban Matters CCC. November 2020. *Sunshine Coast Housing Needs Report.* https://gibsons.ca/wp-content/uploads/2020/11/2020-11-17_SUNSHINECOAST_HNR-FINAL.pdf

Vancouver Island Health Authority. 2008. *As death approaches.* (caregiver pamphlet)

Vancouver Coastal Health, Home and Community Care, Home Care Services. 2008. *Home Care Services – Service Summary List.*

# Appendix D – Acronyms

| | |
|---|---|
| ACP | Advance Care Planning |
| ACSC | Ambulatory care sensitive conditions |
| ALC | Alternate Level of Care |
| BC | British Columbia |
| BCEHS | British Columbia Emergency Health Services |
| CHPCA | Canadian Hospice Palliative Care Association |
| CIHI | Canadian Institute for Health Information |
| ER | Emergency Room |
| LEAP | Learning Essential Approaches to Palliative Care |
| LHAP | Local Health Area Profile |
| LTC | Long-term care |
| MAiD | Medical Assistance in Dying |
| MOST | Medical Orders for Scope of Treatment |
| PCWG | Palliative Care Working Group (SCDoFP) |
| PHWG | Provincial Hospice Working Group |
| SCDoFP | Sunshine Coast Division of Family Practice |
| SCHS | Sunshine Coast Hospice Society |
| VCH | Vancouver Coastal Health |