



Quality End-of-Life
Care Coalition of Canada
La Coalition pour des soins
de fin de vie de qualité de Can

A PROGRESS REPORT

Blueprint for
ACTION
2020-2025



Introduction to the Quality End-of-Life Care Coalition of Canada

The Quality End-of-Life Care Coalition of Canada (QELCCC) is a group of over 36 national organizations dedicated to advocating that “all Canadians have the right to die with dignity, free of pain, in a setting of their choice and surrounded by their loved ones” (QELCCC, 2015). The Coalition believes that to achieve quality end-of-life care for all Canadians there must be a well-funded, sustainable national strategy for hospice palliative care. It is the mission of the QELCCC to work together in partnership to achieve this goal.

During the last 10 years, the QELCCC has been involved with some remarkable successes, (listed chronologically)

- » Canadian Institutes of Health Research (CIHR) Palliative and End-of-Life Care Initiative (2009): This targeted research investment started building clinical research capacity and partnerships with stakeholders and the community, including decision-makers and patients.
- » Canadian Partnership Against Cancer (CPAC) Advance Care Planning Initiative (2013): This initiative raised the awareness of Canadians about the importance of Advance Care Planning (ACP) and equipped them with the tools they need to effectively engage in the process through the Speak Up! Campaign.
- » In response to the continuing increase of the seniors population and caregivers receiving the Compassionate Care Benefits (CCB), the Coalition sent a letter to the Minister of Employment and Social Development of Canada (ESDC) inquiring about how and when the update to CCB will be applied by the government. The Coalition asserted that the implementation of the benefit must be done in a way that will fully inform Canadian citizens of their rights. The Liberal government announced the extension of the CCB to 26 weeks effective January 2016. A social media initiative was completed in January 2016 that resulted in increased awareness amongst Canadians.
- » Quality End-of-Life Care Coalition of Canada (QELCCC) The Way Forward National Framework: A Roadmap for an Integrated Palliative Approach to Care Project (2016), funded by Health Canada: This roadmap for an integrated palliative approach to care highlighted community effort and information on the current hospice palliative care landscape in Canada. A number of discussion papers were developed for this initiative, including a thorough description of the palliative approach to care, a review of health economics, considerations for caregivers, and best practice models from within Canada and internationally.
- » Health Canada established the Framework on Palliative Care in Canada (2018) and Action Plan on Palliative Care (2019) which serve as a blueprint to help shape planning, decision making and organizing change related to hospice palliative care in Canada. This framework recognized the Coalition as an ‘expert’ in the field of hospice palliative care due to the work it had accomplished, and lists the QELCCC in the resource section.

The QELCCC also recognizes and celebrates other milestones in hospice palliative care:

- » Health Canada’s A Common Statement of Principles on Shared Health Priorities (2018): A federal commitment of \$11 billion over ten years to provinces and territories specifically targeted to improve home and community care (including hospice palliative care) and mental health and addiction services.
- » An investment of \$1.9 million over three years (2019-2022) to the Canadian Hospice Palliative Care Association (CHPCA) to help Canadians prepare for their future health care needs, including through public education and awareness, community workshops, and a renewed strategy to promote Advance Care Planning (ACP). Further funding of QELCCC membership organizations toward community-based and grief and bereavement care initiatives.

Executive Summary

Where We Have Been, Where We Are Going

Within the last ten years, Canadians have seen some remarkable milestones in the realm of hospice palliative care. Most recently, Health Canada's tabled Framework on Palliative Care in Canada (2018) and Action Plan on Palliative Care (2019) were released and serve as a blueprint to help shape planning, decision making and organizing change related to hospice palliative care in Canada.

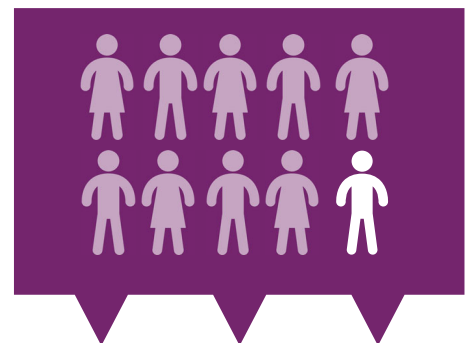
Challenges to access hospice palliative care may exist for every person living in Canada, whether they live in a dense urban community, or a remote rural region. Among these challenges are system capacity issues, lack of understanding of the benefits of hospice palliative care among health care professionals and the public, geography and demographic diversity of care (Canadian Institute for Health Information (CIHI), 2018)). Holistic, regional and culturally-relevant hospice palliative care will address some of these challenges, improving access across the country. Many Canadian jurisdictions name 'community palliative care' as a priority, but few Canadians receive formal hospice palliative care outside of hospitals and residential hospices (CIHI, 2018). Furthermore, CIHI reports that Canadians are living longer, but they are not always living better (CIHI, 2018). For many people, living longer means a struggle with poor health caused by chronic conditions, degenerative diseases or cancer (CIHI, 2018).

Other barriers many Canadians face while seeking hospice palliative care include access to essential medications at the time they are required. Access requires ensuring the appropriate funding is in place, and that supports are there to ensure that the medications can be accessed and administered at the time they are required. Difficulties are also experienced when transitioning between provinces and territories as this brings interruption in coverage. Finally, the need for culturally safe and culturally aware hospice palliative care continues to gain more importance as we strive to respect the culture of current and new Canadians.

The Government of Canada has shown leadership in engaging with provinces and territories to address key health care priorities with the release of their document A Common Statement of Principles on Shared Health Priorities, 2017. This document confirmed an investment of \$11 billion over ten years to provinces and territories specifically targeted to improve home and community care (including hospice palliative care) and mental health and addiction services. With respect to hospice palliative care, the two (2) areas of priority include enhancing access to hospice palliative care at home or in hospices, and increasing support for caregivers. Health Canada established the Framework on Palliative Care in Canada (2018) and Action Plan on Palliative Care (2019) which serve as a blueprint to help shape planning, decision making and organizing change related to hospice palliative care in Canada.

Underserved Groups / People experiencing discrimination

Underserved populations including those in long term care homes or homecare, those who experience discrimination, LGBTQIA+, Canada's Indigenous peoples, incarcerated and ex-offenders, people living with disabilities, those with pediatric needs, people experiencing poverty and homelessness and rural populations require additional consideration and care for developing resources and programs that cater and respect their needs and worldview. Furthermore, support and assistance to new Canadians creates a need to integrate cultural competence into care contexts and policy in a way that fits with constitutional principles of equity and respect for minorities.



Of the **over 270,000 Canadians who die each year, 90% die of chronic illness such as cancer, heart disease, organ failure, dementia or frailty.**

Many of these individuals could benefit from hospice palliative care (Framework on Palliative Care in Canada, 2018)

Caregivers / 'carers'

Caregivers can experience significant emotional, physical and mental exhaustion linked to providing care.

"A 'Carer' (also referred to as caregiver or family caregiver) is a person who takes on an unpaid caring role for someone who needs help because of a physical or cognitive condition, an injury or a chronic life-limiting illness" (Carers Canada, 2019). Caregivers usually have no formal training. While they are expected to follow certain ethical norms, they are not accountable to professional standards of conduct or practice. (Alternatively, "health care provider" describes a provider who is a member of an organization and accountable to norms of conduct and standards of practice. They may be professionals, support workers or volunteers). Data from a 2011 CIHI report indicates that 80% of care is most often provided by informal caregivers (family, friends and neighbours) which creates emotional, physical and financial burdens, and presents severe psychosocial and spiritual impacts, such as isolation and loneliness, on caregiver health (Fast, 2009).

A recent publication from the Canadian Institute for Health Information (CIHI) reports that 33% of caregivers experience signs of distress and burnout (CIHI, 2018). As the time they spend providing care increases, so does the distress they experience (CIHI, 2011). Thirty-two percent of caregivers who provide more than 21 hours of care per week report distress in their role—four times the proportion of distressed caregivers who provide less than ten hours of informal care per week (CIHI, 2011). This signals a need for enhanced respite and bereavement care to support carers.

Advance Care Planning (ACP)

Under access to Advance Care Planning (ACP), the lack of engagement with future care planning is underscored. A Canadian national poll found that "a small proportion (10%) of adults reported ever having discussed ACP with a health care provider (Howard, Bernard, Klein et al., 2018). When identifying contributing factors for this lack of ACP, five main themes emerged: public engagement, health care provider attitudes, creating capacity for primary care providers, integration of ACP into the work flow, and system and policy supports (Howard, Bernard, Klein et al., 2018). These areas will need to be addressed in order for Canadians to understand and participate in advance care planning.

The weight of uncertainty placed on patients, underserved groups, health care professionals and the Canadian health care system(s) points to the need for an effective integrated palliative approach to care across all settings. A Canadian Palliative Care Implementation Collaborative as part of the Framework on Palliative Care in Canada (2018) will enable a fully engaged strategy with a patient-centric approach to hospice palliative care. This approach will improve communication and collaboration among stakeholders and governments, establish standards for hospice palliative care services across the country, and identify supports for patients and family caregivers.

Moving Forward - The Next 5 Years

Of the over 270,000 Canadians who die each year, 90% die of chronic illness such as cancer, heart disease, organ failure, dementia or frailty. Many of these individuals could benefit from hospice palliative care (Framework on Palliative Care in Canada, 2018). By 2026, the number of deaths is projected to increase to 330,000 and to 425,000 by 2036 (Statistics Canada, 2009). These statistics suggest that the need for hospice palliative care in Canada will continue to grow. As part of this growth, the importance of supporting Canadians through grief and bereavement is becoming more evident. An integrated approach to palliative care that is multifaceted in nature and includes support to those who are grieving and bereaving will continue to be an essential component for care for Canadians.

The QELCCC 2020-2025 Priorities

Our Priorities

Over the next five years, the QELCCC will focus on four priorities. The priorities are listed in no particular order:

- 1 Increasing public awareness around hospice palliative care's benefits, issues and areas needing improvement, including support for caregivers and those experiencing grief and bereavement.**
- 2 Ensuring health care providers, volunteers, communities, caregivers and others have access to education and training to ensure they possess the required competencies to provide optimal care.**
- 3 Contributing to research and systematic, standardized data collection on hospice palliative care with special interest including formal and informal caregivers, and grief and bereavement.**
- 4 Advocating for universally accessible and culturally safe access to hospice palliative care for under-served populations and those who provide caregiving and experience grief and bereavement.**

Priority #1: Increasing public awareness around hospice palliative care's benefits, issues and areas needing improvement, including support for caregivers and those experiencing grief and bereavement.

Canadians across the country encounter unique challenges when facing a loved one's illness, whether experiencing illness or bereavement, acting as a 'carer' or a health care professional, awareness helps empower and improve hospice palliative care.

What do we hope to see more of?

- ✓ Caregivers who are better supported, informed and empowered (Source: QELCCC – Key Messages Document)
- ✓ Knowledgeable health care providers with core competencies in hospice palliative care, working in integrated inter-professional care teams which could include, but are not limited to primary care providers, home and community care providers, specialists, paramedics and specialty hospice palliative care providers (Source: QELCCC – Key Messages document)
- ✓ Pediatric hospice palliative care which is available to all infants, children and young adults regardless of their level of medical complexity, and that includes recognition of the need for dedicated medical and psychosocial supports to family members who provide care for them
- ✓ Extended federal/provincial/territorial Compassionate Care Benefit program (CCB) to include a 2-week period for bereavement (Source: The Way Forward National Framework: A Roadmap for an Integrated Palliative Approach to Care document)
- ✓ Identification of the unmet needs of Canadians including caregivers, immigrants and refugees, rural, remote and Indigenous communities, children, adolescents and young adults, incarcerated individuals and ex-offenders, people living with disabilities, those in long term care homes or those in the community requiring care and experiencing poverty and homelessness, LGBTQIA+ communities and other underserved groups (Source: The Way Forward National Framework: A Roadmap for an Integrated Palliative Approach to Care document, adapted to include others)
- ✓ Expanded and improved access to information, tools, education and supports including online supports that are readily available to all caregivers to assist in the delivery of quality care and to reduce feelings of isolation (Source: The Way Forward National Framework: A Roadmap for an Integrated Palliative Approach to Care document)
- ✓ Implementation of a targeted education and awareness campaign about the availability of resources for caregivers and health care providers (Source: The Way Forward National Framework: A Roadmap for an Integrated Palliative Approach to Care document)
- ✓ A routine expectation that health care providers assess caregiver quality of life as a part of routine practice, and to make caregivers aware of tools and resources to support them (Source: The Way Forward National Framework: A Roadmap for an Integrated Palliative Approach to Care document)

Priority #2: Ensuring health care providers, volunteers, communities, formal and informal caregivers and others have access to education and training to ensure they possess the required competencies to provide optimal care.

A skilled health workforce is needed to deliver hospice palliative care services. This workforce includes health care providers, caregivers and volunteers.

What do we hope to see more of?

- ✓ Increase community capacity to provide care, support caregivers and increase access to palliative care services by leveraging the Compassionate Communities movement
- ✓ The implementation of targeted education and awareness campaigns to increase Canadians' understanding of hospice palliative care, appropriate resources, and their options for care during the illness as well as the importance of appropriate advance care planning (ACP) and conversations with health care providers (Source: QELCCC Key Messages document)
- ✓ More inter-professional palliative care training to educate and equip primary – generalist-level health care providers with the essential skills and competencies to provide better palliative care to more Canadians
- ✓ Increased capacity to offer advanced level palliative care training to a larger cadre of physicians, nurses, and social workers. This group is needed to providing training, mentoring and consultative support to their colleagues, and to provide clinical services for complex cases
- ✓ Education for senior health care leaders, administrators and policy makers to provide foundational knowledge on hospice palliative care to help drive systems-level change around better integration of hospice palliative care
- ✓ Sustain a cohesive, efficient and effective Pan-Canadian approach to hospice palliative care, to include public education campaigns
- ✓ The development of entry-to-practice programs for health care professionals, including specific attention to competencies in providing a palliative approach to care
- ✓ Inclusion of hospice palliative care competencies into curricula for inter-professional primary and generalist-level health care professionals
- ✓ A shift in attitudes within the health care system(s) to educate and support health care providers to integrate self-care practices into work routines and overcome their own fear of loss, dying, and death (Source: The Way Forward National Framework: A Roadmap for an Integrated Palliative Approach to Care document)

- ✓ Expansion and improved access to information, tools, education and supports, including online supports, available to all caregivers to assist in the delivery of quality care and to reduce feelings of isolation (Source: QELCCC Key Messages document)
- ✓ Tools to increase knowledge and understanding of medical and spiritual aspects of dying, death and grieving and build capacity within faith groups to support compassionate care within and beyond the faith community for individuals with a grave illness
- ✓ Methods to provide employers, managers, and employees with practical tools, resources and activities to help increase awareness and to reduce stigma related to caregiving, death, dying and grieving in the workplaces, and help increase the comfort level and ability of managers and colleagues to better support employees in need and to help them stay productively engaged in the workplace
- ✓ The Inclusion of educational accreditation standards relating to hospice palliative care in entry-to-practice accreditation programs
- ✓ The inclusion of accreditation standards requiring home- and community-based health care services to provide hospice palliative care to nationally-accepted standards

Priority #3: Contributing to research and systematic, standardized data collection on hospice palliative care with special interest including formal and informal caregivers, and grief and bereavement.

Improved data collection, research, and knowledge translation (KT) will enhance the quality of life for all Canadians living with life-limiting illnesses by providing data and evidence to inform on improvements and develop new models and tools for care.

What do we hope to see more of?

- ✓ Systematic, standardized data collection and accountable funding models which include pediatric data (Source: The Way Forward National Framework: A Roadmap for an Integrated Palliative Approach to Care document)
- ✓ The development of national performance indicators and reporting systems to measure the integrated palliative approach to care that includes community-based care and patient and caregiver experience
- ✓ Continued investment into hospice palliative care research including seed funding to enable research teams to demonstrate proof-of-concept (Source: QELCCC Research and KT Committee Key Messages document)
- ✓ Targeted research funding to address priority areas such as caregiver burden, grief and bereavement (Source: QELCCC Research and KT Committee)
- ✓ The inclusion of individuals with hospice palliative care expertise on grant review committees, such as the Canadian Institutes of Health Research's (CIHR) new College of Reviewers (Source: QELCCC Research and KT Committee Key Messages document)
- ✓ Best practices and innovative approaches to service delivery – including telehealth (Source: Palliative Care Australia document)

Priority #4: Advocating for universally accessible and culturally safe access to hospice palliative care for under-served populations and those who provide caregiving and experience grief and bereavement.

Underserved populations have limited access to hospice palliative care that is linked to a variety of factors, including Canada's vast geography, health care system capacity issues, a lack of understanding benefits of hospice palliative care, demographic and cultural diversity.

What do we hope to see more of?

- ✓ The provision of appropriate resources and supports for Indigenous communities to ensure community members receive hospice palliative care where and how they wish to receive it
- ✓ Flexible service delivery approaches that optimize resources (Source: QELCCC Key Messages document)
- ✓ More developed pediatric hospice palliative care. Advances in technology have meant that children with more and more complex medical conditions are surviving infancy and living into adolescence and adulthood. Alongside acute care, pediatric hospice palliative care offers support with decision making about interventions, management of complex symptoms, and support with care planning and sources of respite
- ✓ Access to essential medications for all Canadians when required. This includes ensuring the appropriate funding is in place, and that supports are there to ensure that the medications can be accessed and administered at the time they are required, even if this is outside of regular office or clinic hours (Source: Palliative Care Australia document)
- ✓ Better transitioning between provinces and territories (to ensure that there is no interruption in the provision of optimal hospice palliative care)
- ✓ Culturally safe and culturally aware hospice palliative care (Source: Palliative Care Australia document)

Conclusion

One of the key challenges over the next five years will be informing Canadians that hospice palliative care is an essential service that should be provided to everyone. To achieve this goal, the QELCCC has identified four priorities areas:

- ✓ increasing public awareness around hospice palliative care's benefits, issues and areas needing improvement, including support for caregivers and those experiencing grief and bereavement;
- ✓ ensuring health care providers, volunteers, communities, formal and informal caregivers and others have access to education and training to ensure they possess the required competencies to provide optimal care;
- ✓ contributing to systematic, standardized research and data collection on hospice palliative care with special interest including formal and informal caregivers, and grief and bereavement, and
- ✓ advocating for universally accessible and culturally safe access to hospice palliative care for under-served populations and those who provide caregiving and experience grief and bereavement.

The QELCCC will advocate for the creation of a Canadian Hospice Palliative Care Implementation Collaborative as part of the Framework on Palliative Care in Canada (2018) that will enable a fully engaged strategy with a patient-centric approach to hospice palliative care.

References

- Australia, Government of Western Australia, Department of Health. (2018) Retrieved March 2, 2019 from [https://ww2.health.wa.gov.au/~media/Files/Corporate/general_documents/Health Networks/Palliative care/WA End-of-life and Palliative Care Strategy 2018-2028.pdf](https://ww2.health.wa.gov.au/~media/Files/Corporate/general_documents/Health_Networks/Palliative_care/WA_End-of-life_and_Palliative_Care_Strategy_2018-2028.pdf)
- Canadian Hospice Palliative Care Association (CHPCA). The Way Forward National Framework: A Roadmap for an Integrated Palliative Approach to Care Initiative: An Integrated Palliative Approach to Care, 2014.
- Canadian Institute for Health Information (CIHI). Access to Palliative Care in Canada. Ottawa, Ontario: 2018. Retrieved from <https://www.cihi.ca/sites/default/files/document/access-palliative-care-2018-en-web.pdf>
- Canadian Institute for Health Information (CIHI). Health Care in Canada, A Focus on Seniors and Aging. Ottawa, Ontario: 2011. Retrieved March 2, 2019 from https://secure.cihi.ca/free_products/HCIC_2011_seniors_report_en.pdf
- Carers Canada (n.d.). Carer Facts. Retrieved June 18, 2019, from <https://www.carerscanada.ca/carer-facts/>
- Compassionate caregiving searching. (n.d.). Retrieved April 22, 2019, from <http://www.tiwebsite.com/search/compassionate-caregiving>
- Fast, J. (2009). Impact on health of Seniors caring for Seniors. University of Alberta Research on Aging, Policies and Practice. Retrieved May 15, 2019 from https://rapp.ualberta.ca/wp-content/uploads/sites/49/2018/04/Impact_on_Health_of_Seniors_Caring_for_Seniors_2009Mar.pdf
- Government of Canada. Framework on Palliative Care in Canada / Cadre sur les soins palliatifs au Canada. December 2018. <https://www.canada.ca/en/health-canada/services/health-care-system/reports-publications/palliative-care/framework-palliative-care-canada.html>
- Government of Canada. Action Plan on Palliative Care / Plan d'action sur les soins palliatifs. August 2019. <https://www.canada.ca/en/health-canada/services/health-care-system/reports-publications/palliative-care/action-plan-palliative-care.html>
- Government of Canada. (2017). Shared Health Priorities. Retrieved June 18, 2019 from <https://www.canada.ca/en/health-canada/corporate/transparency/health-agreements/shared-health-priorities.html>
- Howard, M., Bernard, C., Klein, D., Elston, D., Tan, A., Slaven, M., . . . Heyland, D. K. (2018). Barriers to and enablers of advance care planning with patients in primary care. *Canadian Family Physician*, 64(4), E190-E198. Retrieved May 16, 2019 from <http://www.cfp.ca/content/64/4/e190#ref-14>
- Statistics Canada. Population Projections for Canada, Provinces and Territories: 2000-2026. Ottawa, Ontario. Catalogue #91-520
- Public Health Palliative Care International (PHPCI). The Public Health Approach to Palliative Care, Retrieved from <http://www.phpci.info>
- Puchalski, C. M., Vitillo, R., Hull, S. K., & Reller, N. (2014). Improving the spiritual dimension of whole person care: reaching national and international consensus. *Journal of Palliative Medicine*, 17(6), 642–656. doi:10.1089/jpm.2014.9427
- Quality-End-of-Life Care Coalition of Canada (QELCCC). Key Messages Document, 2018.
- Widger, K. (2012). Pediatric Palliative Care in Canada in 2012: A cross-sectional descriptive study. *CMAJ Open*. Retrieved from <http://www.phpci.info/public-health-approach>
- Widger, K., Davies, D., & Drouin, D. J. (2007). Pediatric Patients Receiving Palliative Care in Canada Results of a Multicenter Review. *JAMA Network*. doi:doi:10.1001/archpedi.161.6.597

Lexicon of Terms Related

Lexicon taken from *The Way Forward National Framework: A Roadmap for an Integrated Palliative Approach to Care (2016)*

Like all health care practices, hospice palliative care has its own language and terminology. This lexicon of terms is designed to help those interested in implementing an integrated palliative approach to care develop a common language and understanding.

Advance Care Planning (ACP)

A process people can use to: think about their values and what is important to them with regard to their health care choices; explore medical information that is relevant to their health; communicate their wishes and values to their loved ones, substitute decision-maker and health care team; and record their health care choices and decisions in the event they can no longer speak for themselves. The process may involve discussions with their health care providers and people who are significant in their lives. Advance care planning may result in the creation of an advance directive or “living will”, which is a person’s formal or informal instructions about their future care and choice of treatment options.

Aging

Aging is a natural process that happens to all living things. In people, the process of aging has an effect on the body and mind, and can affect health and quality of life. For example, as people age, their hearts become slower, their blood vessels and arteries become stiffer, their bones shrink in size and are more likely to break, their muscles lose strength, they may become less coordinated or have trouble balancing, and their memory becomes less efficient. The changes that occur with aging affect quality of life and increase the risk of dying. See “Frailty”.

Autonomy

The capacity for self-determination, and one of the rights associated with liberty. Respect for autonomy means acknowledging the person’s right to make choices and take actions based on their own values and belief system and not interfering with the person when they exercise that right.

Care

All interventions, treatments and assistance provided to the person and family to treat disease and enhance health and well-being.

Care plan

See “Plan of Care”

Caregiver

Anyone who provides care. Formal caregivers are members of an organization and accountable to defined norms and professional standards of practice. They may be professionals, support workers, or volunteers. They are sometimes called “providers.” Family caregivers are not members of an organization. They are family members and other significant people (as identified by the care recipient) who provide unpaid care and assistance to individuals living with a debilitating physical, mental or cognitive condition. Family caregivers usually have no formal training. While they are expected to follow certain ethical norms, they are not accountable to professional standards or practice.

Chronic disease

A chronic disease is one that may develop slowly, last a long time, be incurable, and be progressive and/or life-limiting. Examples of life-limiting chronic diseases include cardiovascular disease,

chronic kidney disease, congestive heart failure, diabetes, dementia, emphysema, multiple sclerosis, amyotrophic lateral sclerosis and some forms of cancer. The disease and its treatment may cause symptoms such as fatigue, pain and sleep problems; they can also limit people's activities, cause them psychological distress and have a negative effect on their quality of life. A chronic disease can't be cured but its symptoms can be managed.

Expectations

Issues, hopes and fears identified by the person and/or family that require attention in the plan of care.

Family

Those closest to the patient in knowledge, care and affection. The person defines their "family" and who will be involved in their care and/or present at the bedside. May include:

- » the biological family
- » the family of acquisition (related by marriage/contract)
- » the family of choice and friends (including pets).

Frailty

Frailty is a nonspecific state of vulnerability caused by changes to a number of physiological systems (see "Aging"), which may be related to a variety of physical, psychological, cognitive and social factors. Together, these changes lead to reduced function and strength, and affect the person's resilience and ability to cope with any stress, such as an infection or disease or personal loss. Frailty is most commonly seen in the elderly but can also occur in adults and children who are seriously or chronically ill. Someone who is frail is at high risk of physical and cognitive decline, disability and death. Frailty can cause pain and discomfort. It can also limit people's activities, cause them psychological distress and have a negative effect on their quality of life.

Goals of care

Describes people's goals for their care and should include treatment of the disease and/or symptom management. In some cases, it includes limits on the interventions that people want, such as "do not resuscitate" orders.

Home care

Home care includes an array of services for people of all ages, provided in the home and community setting, that encompasses health promotion and teaching, curative intervention, rehabilitation, support and maintenance, social adaptation and integration, and support for family caregivers.

Hospice palliative care

Care that aims to relieve suffering and improve the quality of life.

Illness

Absence of wellness due to disease, other conditions, or aging.

- » An acute illness is one that is recent in onset and likely to be time-limited. If severe, it could be life threatening.
- » A chronic illness is likely to persist for months to years. If it progresses, it may become life threatening.
- » An advanced illness is likely to be progressive and life threatening.

- » A life-limiting illness is one that affects health and quality of life, and can lead to death in the near future.
- » A life-threatening illness is one that is likely to cause death in the immediate future.

Integrated palliative approach to care/community-integrated palliative care

Care that focuses on meeting a person's and family's full range of needs – physical, psychosocial and spiritual – at all stages of a chronic progressive illness. It reinforces the person's autonomy and right to be actively involved in their own care – and strives to give individuals and families a greater sense of control. It sees palliative care as less of a discrete service offered to dying persons when treatment is no longer effective and more of an approach to care that can enhance their quality of life throughout the course of their illness or the process of aging. It provides key aspects of palliative care at appropriate times during the person's illness, focusing particularly on open and sensitive communication about the person's prognosis and illness, advance care planning, psychosocial and spiritual support and pain/symptom management. As the person's illness progresses, it includes regular opportunities to review the person's goals and plan of care and referrals, if required, to expert palliative care services.

Interdisciplinary, multidisciplinary or interprofessional team

Caregivers with different training and skills who work together to develop a team and implement a person's plan of care. Membership varies depending on the services required to address the person's and family's identified issues, expectations, needs and opportunities. An interdisciplinary team typically includes one or more physicians, nurses, social workers, psychologists, spiritual care practitioners, pharmacists, personal support workers, and volunteers. Other disciplines may be part of the team if resources permit.

Outcome

A measurable end result or consequence of a specific action, usually related to the person's health or overall well-being.

Palliative approach to care

See "Integrated palliative approach to care"

Pain and symptom management

Pain and other symptoms that cause discomfort (e.g., shortness of breath, fatigue, changes in mood or functional ability, psychosocial or spiritual distress) can be caused by underlying diseases. They can also be caused by the treatments for those diseases, the side effects of treatments and the process of aging. An integrated palliative approach to care focuses on helping people manage pain and other symptoms as a way to reduce discomfort and improve quality of life. Many different techniques can be used to manage symptoms, including medication, exercise (physiotherapy), breathing, meditation, the use of heat and cold, biofeedback processes, diet, repositioning, counselling and psychosocial and spiritual support.

Person

Someone living with a chronic progressive illness. Based on the person's preferences and wishes, the person directs and guides their own care plan as far as possible, and is a contributing member of the interdisciplinary team.

Plan of care

The written plan that describes the person's assessed health needs and goals, and the care that will be provided to meet those needs and goals.

Performance indicators

A statistical compilation of standardized measures/metrics used to evaluate specific parameters of a health service, such as access and quality.

Provider

A formal caregiver who is a member of an organization and accountable to norms of conduct and standards of practice. They may be professionals, support workers or volunteers.

Quality care

The continuous striving by an interdisciplinary team/organization to meet the expectations and needs of the people and families it serves and the standards established by the organization, health authority, profession and accreditation bodies.

Quality of life

Well-being as defined by each individual. Quality of life relates both to experiences that are meaningful and valuable to the person, and their capacity to have such experiences.

Regional health programs or authorities

Health planning organizations responsibilities for setting policies, allocating resources to support care and approving organizational plans to deliver services.

Regional team

Regional teams are functional units designed to provide oversight and expert support for formal caregivers and multiple care teams within a given population/region/setting of care.

Setting of care

The location where care is provided. Settings of care may include the person's home, primary care settings (e.g., a doctor's office, nursing station, community clinic), an acute, chronic, or long-term care facility, a hospice or palliative care unit, a jail or prison or in the case of homeless individuals, the street.

Spirituality

Spirituality is a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices (Puchalski et al., 2014).

Substitute decision-maker

A person or agency chosen by the person or appointed by the jurisdiction to act on his or her behalf. Substitute decision-makers are normally held to substituted judgment or best interest standards.

Suffering

A state of distress associated with events that threaten the intactness of a person. It may be accompanied by a perceived lack of options for coping.

Value

Something that is morally desirable and/or a fundamental belief on which spirituality and/or a practice is based. A value can be intrinsic — perceived as worthy or treasured in and for itself (e.g., liberty) — or a value can be instrumental perceived as worthwhile for pragmatic purposes (e.g., money to obtain goods or services).

Quality End-of-Life Care Coalition of Canada Members endorsing this document:

ALS Society of Canada (ALS Canada)
Alzheimer Society of Canada
Canadian AIDS Society (CAS)
Canadian Association for Spiritual Care (CASC)
Canadian Association of Occupational Therapists (CAOT)
Canadian Association of Psychosocial Oncology (CAPO)
Canadian Association of Social Workers (CASW)
Canadian Breast Cancer Network (CBCN)
Canadian Cancer Society (CCS)
Canadian Frailty Network (CFN)
Canadian Home Care Association (CHCA)
Canadian Hospice Palliative Care Association (CHPCA)
Canadian Network of Palliative Care for Children (CNPCC)
Canadian Nurses Association (CNA)
Canadian Society of Palliative Care Physicians (CSPCP)
Canadian Society of Respiratory Therapists (CSRT)
Canadian Virtual Hospice (CVH)
Carers Canada
College of Family Physicians of Canada (CFPC)
HealthCareCAN
Heart and Stroke Foundation of Canada (Heart & Stroke)
Huntington Society of Canada
Kidney Foundation of Canada
Mental Health Commission of Canada (MHCC)
National Initiative for the Care of the Elderly (NICE)
Ovarian Cancer Canada
Pallium Canada
Realize
SE Health