

DOCTORS NOVA SCOTIA
2018 Position Paper

SUPPORTING THE PALLIATIVE CARE APPROACH:

**RECOMMENDATIONS FOR
NOVA SCOTIANS**

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SUPPORTING THE PALLIATIVE CARE APPROACH: RECOMMENDATIONS FOR NOVA SCOTIANS

EXECUTIVE SUMMARY

Palliative care is evolving and is no longer reserved for those close to death. Health professionals across the globe recognize that when introduced early in the trajectory of a life-limiting or life-threatening illness, a palliative approach to care can improve quality of life, reduce suffering and lower health-care costs. Nova Scotia doctors support an integrated, multi-disciplinary approach to palliative care that will enhance the quality of living and dying for patients and assist in creating a financially sustainable health-care system.

With the increasing prevalence of chronic disease, aging populations and extended life expectancies, palliative care has been identified as an area of priority in medicine. According to a 2016 report from the Canadian Society of Palliative Care Physicians (CSPCP), Canada will need to double the number of palliative care professionals to meet the increased demand. In addition to improving the quality of life for patients and their families, a palliative care approach has the potential to ease increasing fiscal demands on an already overwhelmed health-care system.

Doctors Nova Scotia supports the Integrated Palliative Care Strategy introduced by the Nova Scotia government in May 2014, which aligns with the national framework, *The Way Forward*. The vision of the strategy is that “All Nova Scotians can access integrated, culturally competent, quality palliative care in a setting of their choice” (Nova Scotia Government, 2014). All physicians play a critical role in creating and sustaining a palliative care system that honours this vision. Several factors require consideration if we are to be successful in implementing a palliative care approach to care in Nova Scotia, including:

- Palliative care services need to be available to those dealing with life-limiting illnesses regardless of age, area of residence or proximity to end of life.
- The provincial palliative care framework must identify workforce requirements, educational needs and fee structure changes and define roles and responsibilities of all health-care professionals providing care within the palliative care system.

- A successful transition to the new integrated approach will need to include consideration of how the practices and providers of chronic disease management and palliative care work in conjunction with each other in order to create an efficient, robust health-care system and avoid duplication or gaps in services.
- A successful transition will also require health-care providers currently providing palliative care in the traditional system to recognize the value of working with the specialty palliative care team and embrace a shared-care model when appropriate.
- The transition to the new, integrated system must include a thorough assessment of current palliative care services, including clarification of credentialing for palliative medicine consultants and physicians who have acquired expertise and experience through both formal and informal training, as well as practical learning through working with ailing patients over many years.
- Palliative care training needs to be consistent and accessible for medical students, primary care physicians and specialists.
- Compensation models must evolve to reflect the complex care physicians provide in palliative medicine and support an effective palliative care system.
- As the new palliative care approach is adopted, the provision of services needs to be monitored to ensure equitable distribution across Nova Scotia, recognizing both the size and demographics of the population.

The purpose of this position paper is to identify the actions needed to improve palliative care in Nova Scotia.



CARE FOR PATIENTS AND THEIR FAMILIES

As the Canadian population ages, the importance of palliative care grows. A palliative care approach not only helps improve the patient and family's quality of life, it can also reduce health-care costs.

BACKGROUND

With the number of Canadians aged 65 years and older expected to increase by 25 percent in the next 30 years, the number of deaths per year in Canada is projected to double (Conference Board of Canada, 2015a; Fowler and Hammer, 2013). It is estimated that within 10 years, nearly two-thirds of Canadians who die will have been living with two or more chronic diseases (Nova Scotia Government, 2014). This will result in increasing demand on the health-care system, and on palliative care in particular.

What differentiates palliative care from traditional chronic disease management is its focus on the whole person, using a collaborative team approach that includes spiritual and psychosocial support, advanced care planning and support to family members (Canadian Hospice Palliative Care Association, 2012).

With approximately 90 percent of the population potentially benefiting from quality end-of-life care (Carstairs, 2010) and a growing appreciation of the many benefits palliative care offers, palliative care is an emerging priority in health care. Research demonstrates that patients who receive palliative care benefit in many ways, including improved emotional wellness, less suffering and sometimes greater

longevity (Bakitas, 2009).

The palliative care approach has been widely adopted by countries across the globe, including Canada. This multidisciplinary approach recognizes the importance of a patient-centred, early intervention that shifts focus from providing palliative care only to those facing imminent risk of death to those with life-limiting illnesses who can benefit from comprehensive care and planning. This approach can and should be delivered by all physicians caring for people with life-threatening conditions, with speciality palliative care teams available to help support the primary care teams with more complicated cases (Canadian Hospice Palliative Care Association, 2015).

A palliative care approach can not only improve patient care, but also result in a reduction in health-care costs (Canadian Society of Palliative Care Physicians, 2017; Ravakhah, Chideme-Munodawafa, and Nakagawa 2010). According to the Canadian Society of Palliative Care Physicians (CSPCP), palliative care supports efficient and appropriate use of health-care resources and can result in approximately 30 percent reduction in spending. These savings are possible due to a reduction in the

number of emergency room/intensive care unit visits and hospital admissions, shorter stays, and the elimination of some unnecessary diagnostics and interventions (Bakitas, 2009; CSPCP, 2017).

Despite the increased need for palliative care and the proven benefits it can provide, recent evidence indicates only one in three Canadians has access to this specialized care (CSPCP, 2016).

DEFINITION OF PALLIATIVE CARE

The World Health Organization's (WHO) definition of palliative care is broadly accepted and provides a foundation for those working to improve its delivery. The definition reads:

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- *Provides relief from pain and other distressing symptoms*
- *Affirms life and regards dying as a normal process*
- *Intends neither to hasten or postpone death*
- *Integrates the psychological and spiritual aspects of patient care*
- *Offers a support system to help patients live as actively as possible until death*
- *Offers a support system to help the family cope during the patient's illness and in their own bereavement*
- *Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated*
- *Enhances quality of life, and may also positively influence the course of illness*
- *Is applicable early in the course of illness, in conjunction with other therapies that*

Medical assistance in dying (MAID) is an emerging field and its relationship to palliative care is under discussion across Canada. MAID and its relationship to palliative care are not the subject of this position paper.

are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications (World Health Organization, 2013)

As defined by the WHO, a palliative care approach can and should be implemented throughout the full trajectory of disease, from diagnosis to end of life and beyond, to support grieving family members. Early intervention is crucial with palliative care to ensure patients and their families receive the full benefit this specialized care can provide.

According to the Canadian Hospice and Palliative Care Association (2015), palliative care is a holistic approach that provides benefits to individuals, their families and communities and the health-care system as a whole. Potential benefits to patients include a greater sense of autonomy and control over their lives, better symptom and pain management, psychosocial and spiritual support, greater longevity and a care plan that can adjust as their illness progresses. Loved ones and family members can also benefit from a palliative care approach as they struggle alongside patients dealing with life-limiting conditions. The multidisciplinary palliative care team can include physicians, nurses, social workers, psychologists and home care providers who support patients and their families at all stages of illness and in various settings.

While hospital-based end-of-life care is shown to be the most costly, and the majority of patients dealing with life-threatening illnesses indicate a preference to be treated at home, non-institutional deaths account for less than 20 percent of deaths in Canada (Fowler and Hammer, 2013). Although the majority of costs are incurred by the public health system, families also experience significant expenses. A palliative care approach can ease the financial burden for patients, families and the health-care system.

The palliative care approach focuses on both person and family, and on their quality of life throughout the illness, not just at the end of life. It reinforces the person's autonomy and right to be actively involved in his or her own care, and strives to give patients and families a greater sense of control. Palliative care is viewed less as a discrete service offered to dying persons when treatment is no longer effective, and more as an approach to care that can enhance quality of life throughout their illness (Canadian Hospice and Palliative Care Association, 2015).

PEDIATRIC PALLIATIVE CARE

Just as with other forms of medicine, pediatric palliative care is not simply providing care to “mini-adults.” The foundation of pediatric palliative care is built on the same foundation of relieving suffering and improving quality of life for patients facing life-threatening conditions and their families, but providing that care to a child or youth is unique and complex. Like palliative care for adults, pediatric palliative care is provided by a multidisciplinary team.

The WHO recognizes that young palliative care patients have distinct needs, which are reflected in the following definition:

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease
- Health providers must evaluate and alleviate a child's physical, psychological and social distress
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited
- It can be provided in tertiary care facilities, in community health centres and even in children's homes (WHO, 2013)

Despite support for the many benefits palliative care has to offer and the majority of Canadian pediatricians indicating they have access to pediatric palliative care (Widger et al. 2016), it is believed that only a small percentage of children and youth diagnosed with progressive, life-threatening conditions receive this specialized care (Cyr and Maisonneuve, 2013; Widger et al., 2016).

The number of pediatric palliative care patients is small relative to adult cases, but their care is complex and often involves multiple family and community members. In most cases, the emotional, social and financial impact is extraordinary (Canadian Network of Palliative Care for Children [CNPCC], 2006). Some of the factors unique to pediatric palliative care include limitations in understanding and communication in young patients; unpredictable and often lengthy illness prognoses and trajectories; a large proportion of patients diagnosed with distinct illnesses and as a result, difficulty in developing evidence-based guidelines; and the devastating, far-reaching impact the death of a child has on the entire family and community (CNPCC, 2006). According to the CSPCC (2014), pediatric palliative care in Canada needs further attention to ensure that sufficient services are available for children, youth and their families in the future.

THE ROLE OF THE PHYSICIAN IN PALLIATIVE CARE

The palliative care team consists of a number of professionals, including general practice and specialist physicians, nurses, physiotherapists, social workers and home-care providers. This team is in place to support patients and their families in terms of pain and symptom management, emotional and spiritual support, and home-based care, with the goal of improving quality of life. A Canadian study conducted by the CSPCP (2015) indicated that 86 to 97 percent of physicians providing palliative care are family practitioners.

Both family physicians and specialists play an integral role in the provision of a palliative approach, ranging from initial diagnosis and

identification of the need for palliative care to adjusting medications required to reduce pain and improve quality of life as illnesses progress. The general practitioner is naturally positioned to play a critical and ongoing role in connecting and coordinating a palliative care approach for individuals and their families, while the palliative care physician assumes more of a consultative role, providing expert knowledge, specifically related to medical needs of patients facing life-limiting or life-threatening conditions. Most physicians providing palliative care spend a significant amount of time providing phone consultation, on-call duties and home visits.

NOVA SCOTIA CONTEXT

Nova Scotia experiences some of the highest rates of chronic disease in Canada (Conference Board of Canada, 2015b) and has a higher proportion of its population in the senior age group than most other provinces (Statistics Canada, 2012). As the number of individuals living longer increases, so too does the number of those experiencing chronic disease and frailty. This will result in exceptionally high demands on the health-care system in general, but palliative care in particular.

In Nova Scotia it is family physicians who most often provide palliative care to patients (CSPCP, 2015). It is difficult to determine the number of family practitioners in Nova Scotia who are providing palliative care as many do so within the context of providing chronic disease management, which is not reflected in billings specific to palliative care. Consultation with general practitioners is needed to create an accurate assessment of the degree of palliative care being provided in this way in order to determine workforce requirements in developing a robust palliative care system.

Current specialized palliative care services were established and are administered

according to the geographic regions of the nine former District Health Authorities. Approximately 14 physicians (mostly family physicians), have acquired the necessary expertise, competencies and training to be designated as palliative care specialists in Nova Scotia. The distribution of these specialists does not reflect population size or demographics and varies by region, ranging from none to 0.7/20,000 residents (Nova Scotia Health Authority, 2016). Each palliative care program evolved in terms of team complement, administration and provision of services based on its unique circumstances.

Specialized pediatric palliative care is provided by the IWK Health Centre multi-disciplinary team in Halifax, and includes the equivalent of 1.5 full-time palliative care specialists shared between two physicians. As the IWK is a regional health centre, these services are shared with New Brunswick and Prince Edward Island. It is worth noting that this 1.5 FTE position designated for pediatric palliative care includes not only clinical (patient) time, but also research and educational responsibilities.

In the future, Nova Scotia will experience

increased demands for palliative care. In addition to demographics, earlier intervention and an expanded definition that includes individuals diagnosed with not only life-threatening but also life-limiting conditions, will result in a significant increase in the number of patients requiring palliative care.

With most palliative care in Nova Scotia being provided by general practitioners, it is reasonable to project an additional pressure

being placed on the palliative care system when those physicians become more aware of the integrated palliative care approach and begin making referrals.

As the province works on developing standards for providing palliative care services, it will be important to monitor the service delivery system to ensure it is nimble enough and adequately resourced to respond to the anticipated increasing demands described above.

NOVA SCOTIA PALLIATIVE CARE STRATEGY

In May 2014, the Nova Scotia Department of Health and Wellness introduced a provincial strategy for integrated palliative care with a vision to ensure that all residents have access to comprehensive, culturally competent, quality care in a setting of their choosing. The strategy, which aligns with the national strategy for palliative care, *The Way Forward*, evolved out of a growing appreciation for the broad benefits an integrated approach can provide and the identification of a gap in services that results from a system utilizing the traditional definition of palliative care (Nova Scotia Government, 2014).

The Nova Scotia palliative care strategy is built on four pillars: providing integrated services tailored to the province's unique circumstances; ensuring accountability; including and supporting patients' families and caregivers; and building capacity across professions and settings. The strategy aligns with the move toward more collaborative practice in the province, recognizing the importance of a multidisciplinary, integrated approach that offers a wide range of services within a number of settings, including primary, secondary and tertiary care, as well as those which are community- and home-based.

PRINCIPLES OF PALLIATIVE CARE IN NOVA SCOTIA

PROVINCIAL FRAMEWORK

The provincial palliative care strategy provides a platform for creating and sustaining an integrated palliative care system for Nova Scotia.

The Nova Scotia Department of Health and Wellness has introduced a Palliative Care Competency Framework. This framework provides a plan for multidisciplinary teams to function to-

gether to provide comprehensive palliative care to Nova Scotians. If the framework is to be successful, it is crucial that minimum standards for resource distribution are set, taking into account population size, health demographics and barriers for accessing services, such as geographic distance from service providers.

DNS RECOMMENDATION #1

Define the roles and core competencies of all health professionals providing palliative care, determine workforce needs, and ensure the system is robust and responsive to changes in demand.

DNS RECOMMENDATION #2

Ensure all primary care physicians have access to a multidisciplinary palliative care team including palliative care specialists for support, consultation and/or shared care, if and when required.

One of the challenges that will arise with the expanded definition and reach of palliative care will be how to transition from existing practices to the new approach. In the beginning, palliative care services were initiated when a patient's condition was terminal and they were nearing death. However, evidence demonstrates that the earlier the intervention, the more both patients and the health-care system benefit from the palliative care approach.

DNS RECOMMENDATION #3

Develop guidelines to help identify patients who would benefit from a palliative care approach earlier. These guidelines will assist physicians in determining when and how to transition from chronic care management to a coordinated approach with palliative care.

DNS RECOMMENDATION #4

Provide ongoing support to providers providing care to people with life-limiting illnesses, including most of the chronic diseases, helping them to recognize and transition to a palliative care approach when appropriate.

PALLIATIVE CARE RECOMMENDATIONS

ACCESS TO CARE

Doctors Nova Scotia supports the vision of the provincial palliative care strategy introduced in 2014. All Nova Scotians dealing with life-limiting or life-ending conditions, and their families, need access to a full complement of palliative care services in a variety of settings provided by a multidisciplinary team to improve their quality of life. Palliative care services should be available in a variety of

settings, including the home, long-term care facilities, residential hospice and specialized palliative care units for people who have complex end-of-life care needs that cannot be met in other settings. One of the key learnings from the CSPCP 2015 report on palliative care in Canada was that access to care was highly variable depending on age, area of residence and type of condition.

DNS RECOMMENDATION #5

Ensure that palliative care services are distributed equitably and can adjust to meet the changing needs of the population.

DNS RECOMMENDATION #6

Expand access to residential hospice facilities in areas large enough to support them, and to palliative care or hospice beds to provide an alternative to hospitalization for people whose end-of-life care needs cannot be met at home.

TRAINING

The majority of physicians providing palliative care in Canada are family physicians, most of whom report not having core training in palliative medicine (CSPCP, 2015). Successful implementation of an integrated palliative care strategy in Nova Scotia is dependent on all members of the health-care system acquiring the necessary core knowledge, skills and competencies. Physicians interested in becoming palliative care consultants now have two options for training: the Year of Added Competency through the College of Family Physicians, which leads to a Certificate of Added Competency (CAC), or the Royal College Subspecialty in Palliative Care (new in 2017).

While the Nova Scotia health-care system has developed a document outlining multidisciplinary guidelines for palliative care core competencies and identified educational

strategies for achieving them, it will be equally important to gather a comprehensive understanding of the skill set, expertise and knowledge of physicians currently providing palliative care in Nova Scotia and ensure they are adequately compensated. This will not only support better patient care, but also safeguard the health-care system by assisting with the recruitment and retention of physicians.

The province has trained facilitators across Nova Scotia to teach Learning Essential Approaches to Palliative Care (LEAP) Core, a case-based, inter-professional, adult education, course designed specifically to meet the demand for further education on palliative care. It is a two-day program that is cost effective, provides core palliative care education and is certified for 26.5 Mainpro+ credits.

PALLIATIVE CARE RECOMMENDATIONS

DNS RECOMMENDATION #7

Provide adequate multidisciplinary training to ensure the provision of excellent palliative care and support for patients and physicians.

DNS RECOMMENDATION #8

Palliative care education needs to be supported, enhanced and incorporated at all levels, including:

- *Ongoing development and integration of palliative care curricula at the undergraduate level using the CanMEDS framework*
- *Implementation of a mandatory four-week palliative care rotation in family medicine residency programs*
- *Education for primary care providers and specialists who care for people with life-limiting conditions, regarding the integrated palliative care approach and existing services within Nova Scotia*
- *Providing opportunities for primary care providers to enhance their skills through various levels of training, including those provided within Nova Scotia, by the College of Family Physicians and by other nationally standardized programs*
- *Introduction of the palliative medicine certification by the Royal College of Physicians and Surgeons of Canada, expected to produce qualified specialists in 2019*

COMPENSATION

If the implementation of the provincial palliative care strategy is to be successful in Nova Scotia, many changes need to occur in the health-care system, including compensation models for physicians. In order to ensure that comprehensive services are provided and to support the recruitment and retention of physicians providing palliative care, adequate compensation codes for all payment plans need to be established. In principle, Doctors Nova Scotia expects payment models/fees that:

- Recognize physicians currently providing palliative care to their patients, who have acquired varied formal, informal and prac-

tical experience, expertise and skills

- Recognize consultative and shared care roles of palliative care specialists as they provide the leadership and mentorship required to develop capacity in primary care as well as providing quality care to more complex patients
- Recognize the complexity of palliative care, which includes working on multidisciplinary teams and within multiple settings, and providing significant amounts of after-hours and on-call support, as well as home visits and visits to community-based facilities

DNS RECOMMENDATION #9

Implement physician compensation models that reflect the complex care physicians provide in palliative medicine and support an effective palliative care system.

PALLIATIVE CARE RECOMMENDATIONS

PHYSICIAN RESOURCING

Physician resourcing in Nova Scotia is established, measured and assigned by the Department of Health and Wellness Physician Resource Plan (PRP). Doctors Nova Scotia believes that because the majority of palliative care is being provided by general practitioners not captured in the PRP, additional assess-

ment is required to determine actual system workforce requirements. To be comprehensive, this assessment must include not only patient care requirements, but also workforce needs related to physician leadership, education and replacement of retiring physicians.

DNS RECOMMENDATION #10

Consult physicians about the monitoring of the PRP to ensure palliative care resources are distributed equitably, based on population demographics and increased need. The allotment of FTEs within the PRP needs to reflect the role that palliative care specialists play in providing education and mentorship to support palliative care provision in Nova Scotia.

CONCLUSION

The doctors of this province are committed to providing exceptional, innovative and comprehensive medical care to all Nova Scotians. Doctors Nova Scotia supports the Nova Scotia Integrated Palliative Care Strategy and, along with its members, is positioned to play a critical role in its implementation. With an aging population, high rates of chronic disease and an expanded

definition of those who can benefit from a palliative care approach, the demand for palliative care services provided by general practitioners and specialists will increase significantly. If we are to be successful in providing palliative care to all those requiring it, we must work together to ensure resources are adequately distributed and responsive to increasing need.

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