

Vision:

All Nova Scotians can access integrated, culturally competent, quality palliative care in a setting of their choice.

Executive Summary

The Nova Scotia Provincial Palliative Care Strategy, "Integrated Palliative Care: Planning for Action in Nova Scotia", was released in May 2014. Our vision of integrated palliative care aligns with the strategic direction of the national palliative care framework, *The Way Forward*, as well as the direction of other many other jurisdictions across the country.

The strategy supports changing our attitudes towards palliative care to ensure that everyone facing life-limiting conditions can benefit from the right symptom management and are fully involved in care planning during an illness. This means shifting our understanding of palliative care from an intervention that takes place in the last months of life, to an approach that can be beneficial much earlier. This includes identifying people who are at higher risk of dying, discussing goals and the plan of care, communicating with patients and families along the way and collaborating as health and community providers. It also means addressing the full range of care needs for people facing the end of life, including their physical, emotional, cultural and spiritual needs, and the needs of their families once they have passed away.

The palliative approach is not about prognosis, but about the support patients and their loved ones need. Nova Scotia has palliative care consultation teams that are ideally positioned to support the health system transition to a palliative approach, and there are many community stakeholders that can provide support as well. Putting the Palliative Care Strategy into action will mean working together as a coordinated system to support patient-centered care.

We have taken many positive steps since the strategy was released. We've increased funding to enhance core palliative care consultation teams, helping people access support in a timely manner. A Provincial Palliative Care Coordinator is now in place. The Nova Scotia Hospice Palliative Care Association was able to help increase education and awareness of Advanced Care Planning, with support from the Department of Health and Wellness (DHW). Work has begun to establish partnerships with key stakeholders, including the new Nova Scotia Health Authority (NSHA) and IWK.

A Provincial Palliative Care Advisory Committee has been established and will continue to ensure progress is made. Palliative care teams can now access the Continuing Care SEAscape program, keeping them up to date on care plans for their patients. A Public Engagement Strategy has been developed, ensuring patients and caregivers are involved at all stages of implementation planning. A palliative care resource for patients and caregivers, "Planning for End of Life" was updated with the support of Cancer Care Nova Scotia and other community partners, and is available both in a booklet and online. A Palliative Care Evaluation and Monitoring Working group will soon begin meeting to develop a palliative care report card, allowing us to monitor the quality of our palliative care system and highlight areas of improvement. Another working group has been established to look at standardizing education and practice support for health care providers and volunteers.

There is still a lot of work to be done, but we are slowly paving the road so that "all Nova Scotians can access integrated, culturally competent, quality palliative care in a setting of their choice".

Pillar 1: Integrated Service Delivery

Strategy highlights

The palliative approach will be rooted in primary care, where there is an established relationship between the patient and their health provider. Services will cross the continuum of care, providing access to a palliative approach for individuals dealing with life limiting conditions as well as those needing end-of-life care. Integrated and seamless, this system will allow for ease of movement across sites of care, including home, long-term and residential care, hospice and/or acute care. Awareness of community resources, including specialized consult teams, will help individuals, their loved ones and health providers ensure that a full range of services are available and accessible to those who need them.

Highlights from 2014/2015

1. Palliative care teams enhanced

With dedicated ongoing DHW funding, palliative care consultation teams were enhanced in areas of highest identified need in the province. The vast majority of Nova Scotians can now receive a home outreach visit from a palliative care clinician. By early 2016, this service will be available across the province.

Team enhanced	Position
Lunenburg and Queens Counties	1 FTE Nurse 0.7 Social Worker
Digby, Shelburne and Yarmouth Counties	1 FTE Nurse
Annapolis and Kings Counties	1 FTE Nurse
Guysborough, Antigonish and Richmond Counties and the southern portion of Inverness County	1 FTE Social Worker (2 x 0.5 positions shared seniors health)
Cape Breton County, Northern and Central Inverness County and Victoria County	1 FTE Nurse (Nurse Practitioner hired, NSHA funding balance)
Halifax area (not including IWK Health Centre) and West Hants	1 FTE Nurse (start date June 1/15)

Palliative care teams authorized to access seascape

While three palliative care teams in the province had access to the Continuing Care case management database, SEAscape, other teams did not. This database provides valuable information to the team as it outlines a service plan, health services currently being provided, assessments that have been completed and contact information. At this time, all of the teams have received approval to access this database. Once teams have a comfort level with this system and Continuing Care assessments, we will continue to look at how to include a standardized Palliative Care Assessment.

3. Palliative home drug program sustainability committee established

The Palliative Home Drug Program, launched in 2012, helps cover the cost of medications for people in their last months of life. While the program was intended to relieve financial burden from those who chose end-of-life care at home, it has experienced some challenges. The program was reviewed, and a new Palliative Home Drug Program Sustainability Committee was formed. The first meeting was held on June 23, 2015 to review the current program and suggest opportunities for improvement. If you would like to reach members of this committee, contact co-chair Cheryl Tschupruk at Cheryl.tschupruk@novascotia.ca.

4. Paramedics providing palliative care in the home

With funding support from the Canadian Partnership Against Cancer, Emergency Health Services (EHS) paramedics in Nova Scotia are now better able to provide palliative care support in the home. By establishing special care protocols, paramedics will be able to respond to calls from those receiving palliative care and provide interventions within their scope of practice, without requiring transportation to a hospital when possible and so desired. Patients receiving palliative care may enroll through discussions with their health care providers in the EHS Special Patient program. Enrolling patients in the program has the added benefit of aligning the care provided to the Care Plan developed by the patient and their health team. This may increase the ability of the patient to remain at home. Health care providers may access enrolment forms at: http://novascotia.ca/dhw/ehs/palliative-care.asp. Paramedics have received additional training in palliative care, with an education session designed specifically for this initiative. This initiative is being co-led by EHS and Cancer Care Nova Scotia. To find out more about this program, contact the project manager, Michelle Harrison, at michelle.harrison@nshealth.ca.

A provincial hospice framework is being developed

The Provincial Palliative Care Strategy supports patients having the choice of four sites of care, including: home, long-term and residential care, acute care and hospice. The focus of the strategy is to support more people to die in the location of their choice, which is usually home. Nova Scotia currently does not have the fourth setting of care, hospices. It is well recognized that a comprehensive palliative care system includes hospice as a setting of care for those who can no longer remain at home but do not need acute hospital care. DHW is currently exploring this policy change with the Nova Scotia Health Authority and updates will be shared as soon as they are available.

6. Palliative care policy and planning being integrated across DHW

Just as the Palliative Care Strategy promotes integration at the service delivery level, it has become clear that policies at the Department of Health and Wellness need to integrate palliative care needs as well. Ensuring that work is aligned, coordinated and complementary allows us to reach further, entrenching palliative care into more policies and work plans rather than only focusing on palliative care in isolation. Building capacity for more people to die in the setting of their choice means working together with many services and programs offered in our healthcare system, such as home and long-term care, 811, and EHS. Other government initiatives, such as the dementia strategy, mental health strategy and the electronic medical records project, are all opportunities improve the quality of palliative care and make the best use of our resources.

7. Best practices being identified and shared

Across the province, there are many innovative approaches in palliative care that are being spearheaded by people who have identified system barriers, and explored ways to overcome them. These include:

- Extensive research on the feasibility of an end of life pathway
- Building palliative care capacity among staff in primary care and long-term care
- Development of a database that will help improve data collection and case management
- Integration of palliative care with oncology programs
- Hosting education sessions on palliative and end of life care, and training facilitators across the province

This is only a glimpse of the great work being done across the province. We will continue to examine best practices and see how they may be implemented in other areas.

8. Working with palliative care programs across the province

The Provincial Palliative Care Coordinator will be working with the Palliative Care Managers across the province to improve consistency. Referral forms, admission and discharge policies have been collected to identify commonalities and help provide recommendations to the NSHA. Our hope is that the NSHA will endorse one provincial referral form and look at how to standardize processes across programs. The coordinator has also begun an inventory of the palliative care programs in each area, including team composition, program description, supports provided, other supports in the community and current relationship with local hospice societies and volunteers. This has helped to identify best practices and gaps in support, and has highlighted some duplication that may be occurring. This work has helped to identify ways we can further integrate palliative care teams into the broader health system.

Pillar 2: Accountability

Strategy highlights

An accountable system is one that has a well-defined governance structure, with clearly outlined roles and responsibilities. Shared accountability is critical to overall success. To ensure the strategy is implemented and continues to move forward, leaders within the department and the health system have been identified to provide oversight. Key indicators to monitor and evaluate system progress and effectiveness will also be identified.

Highlights from 2014/2015

Governance structure established within primary health care

The Provincial Palliative Care Strategy recommends the establishment of a governance structure within the Department of Health and Wellness. The Palliative Care Portfolio is managed within the Primary Health Care Branch, where palliative care policy and planning is provided to all branches of the department. Although the emphasis is to help build capacity in primary health care and in the community, palliative care must be integrated in all settings of care. This means that it must also be prioritized, supported and integrated across the entire department.

Provincial palliative care coordinator hired

This full-time position supports and coordinates the strategic requirements of the strategy implementation. The department has had to manage many emerging palliative care issues this year, including advocacy efforts for residential hospices, the Supreme Court of Canada ruling allowing physician assisted death, and budget issues related to the Palliative Home Drug Program. Having one person responsible for coordinating palliative care policy issues, and related communications, promotes consistency in messaging and alignment with the strategic direction of the Department. With dual reporting to Cancer Care Nova Scotia, the coordinator has been able to work closely with the provincial cancer system to build on linkages between oncology and palliative care. You can contact the Provincial Palliative Care Coordinator, Cheryl Tschupruk, at Cheryl.tschupruk@novascotia.ca.

3. Provincial palliative care advisory committee established

The Palliative Care Strategy also recommended the establishment of a Provincial Palliative Care Advisory Committee, to help ensure ongoing support and progress. The committee is made up of stakeholders from different professions, regions and cultures. Its first meeting was in February 2015 and meetings are held quarterly. The committee also includes three public advisors, who bring personal experience as caregivers and bereaved family members to the discussions.

4. DHW and NSHA roles and responsibilities

With the transition to the Nova Scotia Health Authority and the IWK comes many opportunities for a coordinated provincial approach to palliative care. Discussing roles and responsibilities was an important step in moving the palliative care strategy forward and identifying realistic expectations for the first year of the NSHA mandate. The coordinator will continue to work with the NSHA's Vice-President, Integrated Health Services Program Primary Health Care and Population Health, who is responsible for palliative care. Many provincial palliative care managers have an interest in leading certain areas of work and we will be encouraging others to take on leadership roles related to specific strategy recommendations.

5. Preliminary palliative care quality indicators identified

With the support and expertise of Cancer Care Nova Scotia staff, a shortlist of palliative care quality indicators has been developed. Local experts reviewed the list to ensure indicators met the criteria of being meaningful and important. The indicator list will be provided to the provincial Palliative Care Evaluation and Monitoring Committee to further assess their potential for monitoring palliative care performance. We would like to thank Cancer Care Nova Scotia and the research team for this significant amount of work towards indicator selection.

Pillar 3: Family and caregivers

Strategy highlights

Managing a life-limiting illness and preparing for the end of life is a process that involves more than the patient. Person-centered palliative care recognizes the impact illness has on, and the significant contribution of, the individual's friends and family. This support network is often the glue that holds the care plan together and as a health system, we need to ensure that the individuals who are identified as supports by the patient are involved in decision-making and care planning. This collaboration not only values those in this role but also strengthens the team as a whole. Involvement in decision-making also relates to broader system improvements and the need for public participation.

Highlights from 2014/2015

Public engagement plan developed

We recognize the value of engaging with the public and those who have experienced the palliative care system in helping to improve the system. The Patient Engagement Coordinator at Cancer Care Nova Scotia has provided the expertise and support toward the development of a public engagement plan. This engagement plan will ensure that as we implement the strategy, we include the voices of those with life-limiting illnesses or those who have cared for them. If you are interested in being part of this work, please contact Leslie Hill at leslie.hill@ccns.nshealth.ca.

Caregiver assessment and support explored

The Palliative Care Strategy includes recommendations to develop caregiver assessment and education tools. While caregivers play a vital role in palliative care, the role extends beyond end-of-life care and is a long-term issue for those who have a chronic disease, are frail, or have dementia. This can also apply to parents whose children are living with life-limiting illnesses. To avoid duplication, caregiver related work should be a collaborative effort with a broad stakeholder group that can help confirm a tool and/or processes that can be used by a wide variety of people across health care settings. At this time, caregiver support has been identified as a priority and we will be looking at opportunities to improve this area.

Pillar 4: Capacity Building and **Practice Change**

Strategy highlights

Education, ongoing training and support for staff in all sectors of the health care system, including home support workers, first responders, and volunteers in primary, acute and tertiary care is pivotal to begin a culture shift. We need to enhance capacity in all settings if we are to integrate palliative care across the system. Health care providers have not always felt the need to learn more about palliative care if they did not work on a palliative care team or unit however the philosophical shift we are seeking would mean that anyone who may have contact with someone living with a life-limiting illness should be aware of the benefits of the palliative approach. Education for individuals and families is also critical.

Highlights from 2014/2015

Palliative care training

The Palliative Care Strategy recommends establishing a working group to explore standardized training modules for health care teams. At this time, there are at least three formal palliative care education programs being used in Nova Scotia: LEAP (Learning Essential Approaches to Palliative Care), EPEC-O (Education in Palliative and End of Life Care-Oncology) and the Palliative Care Front Line Education Program. Over the past year, several LEAP, EPEC-O and Frontline education sessions have been provided across the province. As well, more facilitators have been trained to provide LEAP training in their areas. Local teams have also developed specific education sessions to help build capacity in their communities. In one area of the province, the team has surveyed LTC facilities to find out about education needs in that setting of care. Choosing a specific education program and supporting it widely across the province would allow a stronger, more coordinated approach. The Palliative Care Capacity Building and Practice Change Working Group will be looking at whether one standardized education platform should be endorsed for the province and will provide recommendations to the Provincial Palliative Care Advisory Committee.

"Preparing for end of life" resource updated

Developing public education materials will help people better understand palliative and end-oflife care and the type of support that is available across the province. The Department of Health and Wellness had an outdated palliative care information resource which was updated this year. Public advisors and stakeholders are currently reviewing and providing feedback for the next version of this resource. We will also engage the public as we develop more public education materials.

Advance care planning awareness and education enhanced 3.

As part of the 2014 Palliative Care Strategy announcement, funding was allocated to the Nova Scotia Hospice Palliative Care Association to help support advance care planning awareness and education. Over the past year, education sessions have taken place across the province, promoting the national Speak Up! campaign which encourages people to have conversations with loved ones about the type of care they want at the end of life. Campaign materials were also adapted to create a "Speak Up Nova Scotia" resource, reflecting the Personal Directives Act in Nova Scotia. Plans for further advance care planning education and awareness are in the works for the coming year.

Proposed goals for 2015/2016

- 1. Provincial managers leadership group
- Group being co-chaired by Palliative Care Program Manager, Lynette Sawchuk and Provincial Palliative Care Coordinator, Cheryl Tschupruk
- · Group will focus on streamlining service delivery and access.
- 2. Education, capacity building and practice support
- Working group being co-chaired by Palliative Care Managers Janet Carver and Fern Brydon
- Group will focus on standardized education and decision support tools.
- 3. Evaluation and monitoring
- Working group being chaired by Palliative Care Manager Mark Scales
- Group will focus on palliative care quality indicators and developing a palliative care report card.
- 4. Streamline policies to reflect palliative care needs
- Provincial Palliative Care Coordinator will work with DHW branches to update and integrate palliative care needs into existing and future policy.
- 5. Standards to guide health system and service delivery
- Explore the development of provincial palliative care standards that support Strategy implementation, provide system-level direction and consistency in care delivery.
- 6. Confirm caregiver support and education needs
- Work with partners to explore opportunities for collaboration and how health care providers and communities can support caregivers
- Continue to work with public advisors who have experience as caregivers to help quide improvement.
- 7. Increase public awareness of palliative approach and supports available
- Work with the Nova Scotia Hospice Palliative Care Association to provide public information about palliative care, how to access support and the importance of advance care planning.
- 8. Develop a communication strategy
- Raise public awareness of palliative care work, including information sharing, news releases, website enhancement and social media support.