

NOVA SCOTIA  
**Hospice Palliative Care**  
ASSOCIATION



**ANNUAL REPORT**  
**2014-2015**

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## **MESSAGE FROM THE PRESIDENT AND EXECUTIVE DIRECTOR**

We are pleased to introduce this year's annual report. It is an exciting time for hospice palliative care in Nova Scotia and for the Nova Scotia Hospice Palliative Care Association. As we reflect on the last year, it is amazing how much has changed and how much impact the work of members of the NSHPCA has impacted the delivery of hospice palliative care in Nova Scotia.

At last year's annual general meeting, the provincial government had just released the document "Integrated Palliative Care: Planning for Action in Nova Scotia," a plan to guide improving hospice palliative care in Nova Scotia through an integrated palliative approach. Since the announcement, an advisory committee to guide implementation was established, a provincial palliative care coordinator was hired, and additional human resources were provided to palliative care teams in the former South Shore, Annapolis Valley and Capital district health authorities. The Nova Scotia Palliative Care Association has played a key role in the development of the strategy, first as a member of the original steering committee to develop the strategy and then as a partner in its implementation through working on a province wide initiative to improve advance care planning in Nova Scotia.

The last year has also seen an increase in the profile of the NSHPCA and hospice palliative care in general. The Association was featured in media pieces about the provincial strategy, advance care planning, and the recent Supreme Court decision on physician assisted dying. Our Executive Director has travelled from one end of the province to another providing educational sessions on advance care planning and building awareness about the work of the Association.

Outreach and partnership were key focuses of work this year. As you read through this report, you will be provided with details on the NSHPCA Membership survey, a hospice networking day coordinated by the Association, the work of the Quality End of Life Care Coalition of Nova Scotia, and an exciting partnership with the Retired Teachers Organization of Nova Scotia.

New bylaws were passed last year which led to a restructuring of the Board. A transition team worked hard to develop and implement a structure which would increase the breadth and depth of representation of the Board and ensure the Association has the resources needed to continue to be a leader in hospice palliative care in Nova Scotia.

As you read through the report, it is our hope that you will be pleased with the work the Board has undertaken to meet priorities and concerns of the membership. We look forward to continuing to work with you.

Carolyn Marshall  
President, NSHPCA

Colleen Cash  
Executive Director, NSHPCA

## UPDATE FROM THE CHPCA

As president of the NSHPCA, I have the privilege of representing Nova Scotia at the Canadian Hospice Palliative Care Association (CHPCA), as a Board Director. This position provides the opportunity to bring Nova Scotia's perspective to the deliberations about hospice palliative care on a national level. Our continued collaboration strengthens our work provincially through CHPCA's ongoing support of NSHPCA.

CHPCA is continuing to make significant contributions in raising both the public and federal politician's awareness on the importance of quality hospice palliative care services for all Canadian citizens.

### Key achievements to date include:

- Development of a strategic plan for 2015-2018, which will focus on the following key strategies:
  - Promote awareness and integration of hospice palliative and end of life care principles and practices into all community and health settings.
  - Support education of care providers across all settings.
  - Promote evidence informed policy.
  - Promote sustainable partnerships.
  - Build capacity and sustainability of the CHPCA.
- Completion of *The Way Forward Initiative* which has provided lasting resources, directions, and information to move forward with an integrated approach to palliative care.
- Production of a 2015 Federal Election Kit
- Planning the 2015 Provincial Conference
- Development of new "Power of 10" communication materials for Hospice Palliative Care Week 2015
- Educational webinars
- Continued to move forward and enhance advance care planning in Canada through *Speak Up*
- Ongoing efforts to promote the importance of hospice palliative care in light of the recent Supreme Court Decision on physician assisted death.

Carolyn Marshall, NSHPCA President

## **STRATEGIC DIRECTIONS**

In 2013, the Board worked to develop and begin the implementation of a new strategic plan. The following is an overview of the plan and accomplishments to date.

### **Strategic Priorities**

#### **1. Provide leadership to improve hospice palliative care for Nova Scotians.**

- a. Establish the association as leader, expert and knowledge broker for hospice palliative care in the province.
- b. Drive a societal change of hospice palliative care through education and awareness.

### **Key Initiatives:**

- Continue to advocate for and participate in the development of a provincial program for hospice palliative care and ensure hpc is promoted in key provincial policy initiatives.
- Provide mechanisms to support primary care providers to introduce the palliative approach earlier in a disease trajectory.
- Support and promote the broader implementation of advance care planning for patients and families.
- Continue to promote and educate on the need for a palliative approach with a focus on professionals, patients and families.
- Serve as a provincial resource for hospice palliative care - establish a database of credible resources.
- Maintain and enhance partnership and capacity of the Quality End of Life Care Coalition Nova Scotia. (QELCCNS)

### **Accomplishments and Activities for 2014-2015**

- The Executive Director of the NSHPCA has been named a member of the Provincial Palliative Care Advisory Committee which will oversee the implementation of the provincial strategy.
- Worked with members of the Quality End of Life Care Coalition of Nova Scotia to develop a formal response to the provincial palliative care strategy.
- With funding support from the province, the NSHPCA and its partners implemented a public awareness campaign on advance care planning which included the delivery of 14 educational presentations and a province wide media campaign.
- Worked with partners to present a series of educational sessions on hospice palliative care with the College of Registered Nurses of Nova Scotia.
- Conducted focus groups with primary care providers on advance care planning.
- Conducted presentations for health professionals on advance care planning.

- NSHPCA featured in several media pieces regarding ACP, provincial palliative care, and the Supreme Court Decision.
- Developed and delivered our annual conference: *The Future of Dying: Hospice Palliative Care in Nova Scotia over the next 10 years.*

## **2. Strengthen and support membership.**

- a. Be responsive to the needs and priorities of our members.
- b. Engage membership and empower them to have a voice in the NSHPCA.

### **Key Initiatives:**

- Develop a networking/one day session to encourage engagement of hospices around the province. (Develop a list of hospices and contacts)
- Develop mechanisms/supports/ events for professional care providers.
- Conduct a membership survey.
- Facilitate knowledge sharing with our membership through social media, newsletter and website.
- Establish regular communication with membership.

### **Accomplishments and Activities 2014-2015:**

- Membership survey conducted.
- Networking event for hospice societies held.
- Presentations held throughout the province.
- Survey of hospice societies conducted.
- Frequent membership communication via emails.
- Facebook page and twitter page developed and updated on a daily basis.

## **3. Ensure Organizational Sustainability**

- a. Develop the leadership and resources needed to ensure the long term sustainability and growth of the NSHPCA as a leader in HPC.
- b. Provide adequate investments in the sustainability of the organization.

### **Key Initiatives:**

- Develop a fund development plan
- Identify additional sources of funding for the organization.
- Provide and develop the leadership needed to sustain and enhance the NSHPCA.
- Rethink Board membership to ensure a better balance between the clinicians, and the wider community and to retain people with the skills and commitment to implement the strategic priorities.

### **Accomplishment and Activities for 2014-2015:**

- Fund development plan developed and initiatives piloted.

- Board transition team struck to restructure the board to ensure better representation and skill set.
- Staffing resources adjusted to affect budget constraints.
- Grant applications are ongoing with funding secured from the provincial government to help support ACP work.
- Presented first fundraising event on May 10th, 2014.
- Presented first Cash for Christmas Raffle in December 2014.
- Supported Ian's Walk for End of Life Care.
- Nova Scotia Liquor Commission Cash Can Program January 2016.

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## REPORT FROM THE QUALITY END OF LIFE CARE COALITION NOVA SCOTIA



The NSHPCA is the secretariat to the Quality End of Life Care Coalition of Nova Scotia. The Executive Director and NSHPCA Board Member Gael Page are Co-Chairs of the QELCCNS.

QELCCNS Membership November 2014			
<b>Full Membership</b>	Alzheimer's Society of Nova Scotia	Continuing Care Association Nova Scotia	Lung Association Nova Scotia
	Canadian Association for Spiritual Care - Atlantic Region	Cystic Fibrosis Canada, Scotia Chapter	NS League for Equal Opportunities
	Canadian Cancer Society, Nova Scotia	Deafness Advocacy Association NS	NS Hospice Palliative Care Association
	Canadian Red Cross-Nova Scotia Region	Doctors NS	Parkinson Society Maritime Region
	Caregivers Nova Scotia	Health Association Nova Scotia	Prostate Cancer Canada
<b>Affiliates</b>	Always Home Homecare	IWK Pediatric Palliative Care Service- IWK Health Center	L'Arche Atlantic
	Cancer Care Nova Scotia		
	Capital Health Integrated Palliative Care Program	Independent Living NS	NS Palliative Care Physicians

## **Highlights of Activities:**

The QELCCNS continues to work to increase its profile and bring awareness to the wider issues surrounding end of life care in this province. The focus of the QELCCNS over the last 12 months was working with membership to determine how to best ensure that the provincial palliative care strategy moves forward and recognises the priorities and concerns of the Coalition membership; as well as participating in the National Speak Up Campaign.

The QELCCNS held its Annual General Meeting in October 2014 at the Armdale Yacht Club with 17 of the 22 member organizations attending. The main focus of the meeting was to review the coalition's priorities and determine key activities for 2014-2015.

### **Priority: Development of a Provincial Palliative Care Program**

The AGM provided an opportunity for a consultation with the Coalition membership, regarding its current priorities for palliative care in Nova Scotia within the context of the new provincial palliative care strategy. Members were given an opportunity to review the strategy document: *"Integrated Palliative Care: Planning for Action in Nova Scotia"*. The Provincial Palliative Care Coordinator also provided members an overview of the work to date.

In discussing overall system priorities the Coalition members re-confirmed the priorities which were established at their inaugural meeting:

- Better access to hospice palliative care services,
- Improving support for caregivers,
- Enhanced education and information for both health professionals and the public.

The Coalition members then reviewed the provincial strategy, and identified key priorities for action which would be of most importance to the Coalition membership. A detailed written report was developed and will be presented to the Provincial Palliative Care Advisory Committee.

As a provincial organization representing 22 organizations, the QELCCNS, has an important role to play in assisting the provincial government in improving end of life care in Nova Scotia. Fulfilling this role will be led and supported by the NSHPCA as Secretariat and Chair of the QELCCNS. Key roles for the coalition include:

- As an Enabler: Enable partnerships and collaboration for sustainable change.
- As a Voice of the Community: Membership in the QELCCNS currently consists of 22 organizations, representing a wide variety of groups and perspectives all of whom have a vested interest in how the strategy is implemented.
- As a Questioner: Ask policy and research questions to raise public and professional awareness; communicate these to relevant organizations/stakeholders.

- As an Educator: The QELCCNS can provide the expertise as well as a mechanism to roll out educational materials/programs regarding ACP, end of life care issues, family and friend caregivers, and information on end of life issues that are pertinent to specific communities and/or disease groups.
- As an Expert Advisor: Offer wide ranging expertise and perspectives.

### **Priority: Speak Up 2015**

The QELCCNS agreed to participate in the 2015 Speak Up Campaign, a national campaign which encourages people to have the conversation with those closest to them about their wishes at end of life. This participation was supported in part by funding provided by the Nova Scotia Department of Health and Wellness.

Specific activities included:

- Providing support and direction to the overall advance care planning initiative
- Participating and promoting a media campaign.
- Participating in a social media campaign leading up to National Advance Care Planning Day April 2015.
- Distribution of relevant resources to membership and constituents.
- Hosting and coordinating educational events.

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## **ADVANCE CARE PLANNING IN NOVA SCOTIA**

### **Partnership with the Nova Scotia Department of Health and Wellness:**

In November 2014, the NSHPCA was notified by the provincial government that funding support had been received to work with its partners, specifically, the QELCCNS on the following:

- To raise awareness about the importance of advance care planning for the public.
- To better prepare health professionals, specifically those in primary care, to participate and support advance care planning with patients and their families.
- To raise awareness about and improve the tools and supports available to Nova Scotians and their families to conduct advance care planning,

### **Actions and Deliverables to Date:**

- A literature review of ACP in primary care as well as preliminary results of research conducted regarding ACP in medical education will be included in the final report.

- Focus groups with primary care providers have been conducted.
- One of the clinics in the focus group has volunteered to pilot the SpeakUp/ACP information in their diabetes clinic during the month of April.
- Fourteen public presentations- A public presentation based on the Speak Up Campaign has been adapted for Nova Scotia and delivered throughout the province.
- A media campaign to promote public awareness of advance care planning in conjunction with advance care planning day, April 16, 2015.
- Roll out of the 2015 Speak Up Campaign in conjunction with partners in the QELCCNS.
- Targeted educational sessions on ACP for health professionals were conducted for the College of Registered Nurses, the NS Hospice Palliative Care Association Conference 2014-2015, and Cancer Care Nova Scotia.
- Distribution of ACP resources throughout the province.

### **Complimentary Activities:**

#### Department of Senior's Positive Aging Grants Program:

The NSHPCA received funding from the Department of Seniors' Positive Aging Grants Program to provide education and awareness about advance care planning to seniors.

As part of the grant program, the NSHPCA delivered a train the trainer program to members of the Retired Teachers Organization- Nova Scotia with six trainers being given the knowledge and resources to deliver a public presentation on ACP. Trainers have been delivering presentations throughout the province.

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## **MEMBERSHIP REPORT**

For the 2014 membership year, the NSHPCA recorded 134 fully paid members in its database. This number consistent with previous years,.

By means of comparison, the total paid memberships for 2013 was reported as 133.

The NSHPCA continues to work on enhancing its outreach and communication to our members through increased communication, outreach to hospices and a membership survey.

### **NSHPCA Membership Survey:**

The NSHPCA distributed a survey to membership both online and at the 2014 Provincial Palliative Care Conference. The following are a few key highlights of the results:

- A majority of the respondents indicated that they were either very satisfied or somewhat satisfied with their membership in the NSHPCA.
- Respondents would like to see their membership include:
  - Email updates
  - Updates from the Canadian Hospice Palliative Care Association
  - Reduced conference rates
  - Information on upcoming educational events and job announcements.
- Respondents also indicated that they would like more communication from the NSHPCA about the work of the Association.
- It was recommended that the Association work to increase its profile.

In response to the survey, the Association established a Facebook page and began increasing email updates to membership. The board has set membership engagement as a priority going forward and will continue to look for ways to increase membership engagement and awareness.

### **Hospice Networking Day:**

In October 2014, the NSHPCA coordinated a meeting with hospice societies from across Nova Scotia. The meeting was held in Truro and was attended by representatives from 10 of the 13 hospice societies across Nova Scotia.

The meeting provided an opportunity for those attending to network, to share best practices and to discuss how to better engage with the provincial association.

The meeting was deemed to be successful with another event planned for 2015.

Some of the outcomes/recommendations from the gathering included:

- The NSHPCA and the hospice societies develop some joint messaging and information packages/tools regarding what hospice palliative care is and some of the key issues facing Nova Scotians regarding access to care and services.
- The NSHPCA work with the hospice societies to help facilitate better communication and information sharing among the societies, such as providing a portal on the NSHPCA website.
- The NSHPCA and the hospice societies look at a joint fundraising/awareness initiative.

## **NSHPCA BOARD TRANSITION TEAM - FINAL REPORT**

With the hiring of an Executive Director in 2011, the NSHPCA Board of Directors determined that a change of its role from a hands-on, operational Board to a smaller governance Board would allow it to focus on oversight activities, and the ED to focus on operations. It was recognized that Board membership would need to change to add new skill sets related to a governance board. In order to ensure that clinical input was maintained, two Advisory Councils were to be created as a key action to maintain the valued clinical input and to have input from the Hospice Societies. New bylaws were subsequently approved at the June 2014 AGM, that are contemporary and in line with a policy/governance board model.

A Transition Team was established in October, 2014 to aid in the process of moving to a policy board. Key highlights of the transition work include:

- Identification of skill sets/areas of representation desired for the new governance board.
- Identification of risks and strategies to mitigate risk/develop change management.
- Determine term of new Board members and pace/timing of change of membership from old to new.
- Identification and approach possible candidates to populate the new Board,
- Draft Terms of Reference for the Clinical (CAC) and Hospice Societies (HAC) Advisory Councils, which were approved by the Board in January 2015.
- Development of a recruitment strategy and a Call for Nominations for 2015-2016 Board Members
- Development of a recruitment strategy and call for nominations for members of the Clinical Advisory Council
- The ‘Call for Nominations’ included a cover sheet and process for potential candidates to submit their interest, and a 3 page document of ‘Information for Prospective Board Members’. The Call was sent to all members of the Association, placed on NSHPCA website, and on social media outlets.

### Next Steps:

The Transition Team, put forth a proposal to the Board in April 2015, that a Governance Committee be established, as a committee of the Board. This was approved. The Committee will have a mandate to assist the Board to ensure that the Board fulfills its legal and functional responsibilities through adequate governance policy development, recruitment strategies, training programs, monitoring of board activities, and evaluation of board members’ performance.

The Team further identified that the new By-Laws were silent on the Nominations Committee role, and a draft Terms of Reference was developed and presented and approved by the Board in April 2015.

## **NSHPCA BOARD MEMBERS 2014-2015**

With gratitude to those individuals who committed their time, expertise and perspective to serving on the NSHPCA Board of Directors this last year:

Carolyn Marshall - President

Cathrine Yuill, Past President

Dawn Martell, Vice President

Christa Leblanc- Treasurer

Julie Ford- Secretary

Janet Carver - DHA1

Julie Ford - DHA2

Lori Burgess - DHA3

Gerry Helm - DHA5

Patricia MacKay - DHA7

Lynette Sawchuk - DHA8

Aurette Landry - DHA8 - Hospice

Gail Ellsworth - DHA9

Judy Simpson - DHA9- Hospice

Grace MacConnell - IWK

Gael Page - Member at Large

Angus Campbell- Member at Large

Marianne Arab - Member at Large

Dianne Vaughan - Member at Large

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