A Charter for End-of-Life Care

How we treat those who are dying in our community reflects who we are as a society. All Ontarians have the right to die with dignity, to have access to physical, psychological, bereavement and spiritual care, and to be granted the respect consistent with other phases of life.

As professional, volunteer and family representatives of Ontario’s hospice palliative care community, we are committed to providing the best possible quality end-of-life care to Ontario residents and their families. Our goal is to optimize their quality of life and to minimize the physical and emotional suffering associated with this phase of life.

We endorse an integrated approach focused on the individual and their family and caregivers, accessible through hospice palliative care services in the local community and tailored to individual needs.

Our efforts to increase awareness and availability of quality and integrated end-of-life care run parallel to our collaboration with government, social agencies and other decision makers to develop innovative clinical, community and public policy strategies.

On behalf of the residents of Ontario whom we serve, we speak with a unified and cohesive voice, share information and resources, and work through a coordinated network of partners from the voluntary, public and professional sectors.

This Charter was created collaboratively during a 2004 province-wide consultation to develop a provincial strategy for end-of-life care.

All hospice palliative care programs and care settings in Ontario were represented.

The Charter reflects our shared philosophy.

Our Mandate
The Hospice Association’s mission is to ensure that our members consistently deliver the finest end-of-life care possible to individuals, their families and friends, with life-threatening conditions.

Our Vision
That every person and family in the province of Ontario can quickly and easily access the finest end-of-life care when required.

Our Values
Caring, compassion, collaboration, sincerity and responsibility serve as our core values, guiding our decisions and actions.
Navigating Change

Change continues to be the only constant in Ontario’s evolving health care system. As with all change, it creates both opportunities and obstacles. Adapting to new structures, fundraising in a difficult economy, increased reporting demands, and the ever growing population in need of hospice care all present stressful challenges. Ever resilient, many hospices looked for creative opportunities for positive change and growth. Partnerships with each other, with hospitals and community support organizations, innovations in training models, exploring voluntary integration, and staff-sharing are a few examples of how hospices are adapting to provide the best possible hospice palliative care for the people of Ontario.

Last year was also a time of refocus for HAO. Building on internal changes that expanded the association’s capacity, our focus this year was three fold: increasing our public policy dialogue; strengthening relationships with our members; and expanding our standards and accreditation program. On the public policy front, your staff and board have been in ongoing discussions with the Ministry of Health and Long-Term Care. Our key messages continue to stress the need for adequate funding for community and residential hospices and the need for a provincial hospice palliative care policy. We believe the Ministry has an increasingly stronger sense of the hospice movement and the need for sustainable funding.

The changing healthcare environment makes unifying our voices an imperative. HAO collaborated with the Provincial End-of-Life Care Network, the Ontario Palliative Care Association and the Ontario College of Family Physicians to provide leadership in the adoption of a provincial systems design framework. The framework, set for release in November 2010 provides for a full continuum of care settings and services, ensures there is a clearly defined hospice palliative care program in each care setting where people die, and calls for funding models and policy direction that support an integrated hospice palliative care system.

We also entered formal discussions with the Ontario Palliative Care Association (OPCA) bringing the two organizations closer to becoming one provincial association. A survey of HAO membership in March 2010 indicated overwhelming support for integration with 92 per cent of hospice members in favour. The board formed a joint working group with the OPCA board with the goal of bringing a motion for integration before the memberships in April 2011. Integration will combine the strength of the hospice community and the dedication of professionals, practitioners and volunteers to create a strong unified voice for hospice palliative care and the people we serve.

The next year will continue to present new opportunities and we are committed to ensuring an association that works with our members and supports the care they provide. We thank our members for their continued support and faith in the HAO as we move forward in 2010-2011.

John Crean  
Chair, Board of Directors

Rick Firth  
Executive Director
Our History

The Hospice Association of Ontario began with eight members in 1989. Since then, the association’s membership has grown to be Canada’s largest volunteer hospice organization and the largest direct service provider within Ontario’s voluntary health care sector. In addition to visiting volunteer hospices, Ontario now has the largest number of residential hospice homes in Canada with 23 in operation and more in planning.

From a grass roots movement with hospices developed around kitchen tables and church basements, Ontario’s hospices have evolved into multi-program community based organizations. While structures have become more sophisticated in response to the rapid growth, the heart of the movement has not changed. People in time of great need remain the focus of all we do.

To support the rapid expansion of hospice over the last 20 years, HAO led the way with the development of a standardized volunteer training, residential hospice standards, and visiting volunteer standards. With support from our members, HAO also developed a made in Ontario accreditation process for visiting volunteer hospices.

The Hospice Association of Ontario continues to adapt and respond to the changing needs of our members and the people they serve. As the demand for hospice palliative care continues to grow in the coming years, the volunteer sector is positioned to play a key role in meeting the demand for care.

Quality of life, family wellness, community involvement and living in dignity are all part of hospice’s compassionate vision.

Canadian Firsts by HAO

- Standards and accreditation model for Visiting Home Hospice Volunteer programs
- Standards for Community Residential Hospices
- Standardized, comprehensive volunteer training process and manual
- Multi-cultural strategy and corresponding guide for hospice palliative care
- A manual and tool kit for developing a residential hospice
- Facilitation of unprecedented pledge of provincial government funding for more than 30 community residential hospices

HAO Quick Facts

- Largest hospice organization in Canada
- Over 13,500 volunteers
- Caring for 12,500 people each year
- Serving 450 communities
- Over 700,000 hours annually
- One of the largest volunteer service contribution in Ontario
  - 98 Hospices
  - 23 Residential Hospices
- Service provision to over 23,000 consumers seeking information on hospice palliative care programs and services
- Provided hospice palliative care education and training for 323 staff in long-term care homes and community support services
Provincial Hospice Palliative Care Conference

The first joint conference ever to be hosted by the Hospice Association of Ontario and the Ontario Palliative Care Association was a stunning success! Close to 500 people who work or volunteer in hospice palliative care attended. The conference theme "One Vision One Voice", reflected the historic collaboration of the two associations. Many thanks to the delegates, presenters, sponsors and volunteers who made it happen.

The academic calibre of the speakers, the inter-professional approach of many of the presentations and the numerous opportunities for reflection and rejuvenation provided an exceptional experience and a unique learning opportunity for delegates. Highlights included a keynote presentation on the hospice palliative care community’s response to legalization of assisted suicide by Dr. José Pereira: Lessons from the Swiss Experience, and a provocative panel debate on the same topic.

Delegates could choose from more than 70 presentations and workshops. On the social side, the delegates enjoyed a night in Paris at the gala dinner, complete with entertainment by a troupe of circus performers.

Special thanks to the joint organizing committee for putting together an amazing conference:

From the Hospice Association of Ontario
Beth Ellis, (Co-Chair) 
Executive Director 
Dr. Bob Kemp Hospice Foundation Inc.
Brent Charette 
Executive Director 
Hospice Wellington
Maureen Talbot 
Director, Spirituality and Bereavement 
Dr. Bob Kemp Centre for Hospice Palliative Care

From the Ontario Palliative Care Association
Dr. Lesia Wynnychuk, MD. (Co-Chair) 
Assistant Professor, University of Toronto 
Consultant, Palliative Medicine 
Sunnybrook Health Sciences Centre
Karen Fisher 
Palliative Services and Wellness Coordinator 
Hospice Wellington
Amanda MacLennan 
Palliative Care Nurse Clinician 
Brampton Civic Hospital
One Vision One Voice Sponsors in 2009

Gold Level Sponsors

Silver Level Sponsors

Wyeth

Bronze Level Sponsors

Refreshment Break Sponsors

Exhibitor Sponsors
June Callwood Awards

The June Callwood Award was established by the Hospice Association of Ontario to acknowledge and thank outstanding hospice volunteers throughout Ontario. Established in 1994, the award was named in honour of the late June Callwood, a patron and long-time advocate of hospice. June never missed the awards presentation ceremony and considered it a highlight of each year. Recipients received their medals at the provincial hospice palliative care conference in April 2009.

Words from June Callwood

I was raised in a village of a few hundred people, mostly related to one another and all members of one congregation—so we were close knit. Everyone was poor and the way the village worked was that we had to help one another. If something bad happened to anyone, it was our collective responsibility to come to the rescue. All the children were safe because all of the adults watched over us, and all of the children, in turn, had to run errands for any adult who asked. I grew up thinking that is the way the world works, that we have responsibility for one another, be they kin folk or not. We are dependent on one another, and could not stand alone for very long. Joseph Conrad said, “We exist only so long as we hang together.” And that is the way the hospice movement works; people hanging together. It is a noble sight. It is an ennobling practice.

2009 June Callwood Circle of Outstanding Hospice Volunteers


The Order of St. Lazarus

HAO gratefully acknowledges the generous support of the June Callwood Awards by The Order of St. Lazarus, Toronto Commandery.
Public Policy

Public policy was our primary focus in 2009-2010. Staff and Board members held numerous meetings with the Ministry of Health and Long-Term care on issues ranging from funding to hospice palliative care systems design. Our key messages to government are:

- Hospice care is a compassionate and cost effective alternative to hospitalization
- Community based visiting hospices care for more than 12,500 people each year. Quality in-home care reduces emergency room visits
- Quality in-home reduces caregiver stress and burnout
- Residential hospice is essential for people living with the challenges of a life-threatening illness and who can no longer be cared for in their own home, yet do not require the expensive and highly technical care of an acute care hospital
- A provincial hospice palliative care policy is essential in addressing the fragmentation and inconsistency in hospice palliative care across Ontario

As a member of the steering committee of the Quality Hospice Palliative Care Coalition of Ontario, HAO has been successful in obtaining the coalitions endorsement of the funding model in the residential hospice business case and recognition of the key role hospice volunteers play in community based care.

HAO’s communications working group developed and issued a response to the provincial budget in March expressing disappointment that no additional hospice funding was announced in the budget. The Hospice Association of Ontario understands the government is in a difficult financial position but believes that, especially in a time of fiscal challenge, investing in more cost effective services is most prudent.

In the midst of a system change that focuses on integration HAO will continue to represent the interests of our members through participation at various provincial tables.
Standards and Accreditation

HAO has developed standards to support members in the delivery of service based on best practice. Two standards are available: Client Service Standards for the Volunteer Visiting and Residential Hospice Standards. Our standards are based on the Canadian Hospice Palliative Care Association’s A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice (2002).

HAO Standards reflect a commitment to continuous quality improvement, acknowledge the desire of the individuals to remain at home or in a home-like environment, illustrate the need to support informal caregivers, demonstrate accountability and transparency and support continuity of care.

Visiting Home Hospice Accreditation

HAO offers members accreditation to the Client Service Standards for the Volunteer Hospice. The goal of the Hospice Association of Ontario’s Visiting Home Hospice Volunteer Accreditation Program is to ensure the delivery of consistent, high-quality, home-based volunteer hospice palliative care throughout Ontario.

Accreditation is an efficient and effective means of continuous learning and improvement—a provincial benchmark for Ontario hospices. The program is intended to assist each HAO member in quality improvement efforts as they relate to visiting hospice volunteer client services.

Accreditation improves risk management, provides outcome measurement for funders, supports quality improvement, validates the role of the volunteers as members of the hospice care team, and focuses on client-centred care with increased organizational confidence.

To date 44 of our 98 member hospices have achieved accreditation. 14 have obtained Level I Accreditation and 30 have Level II accreditation.

“The Standards are a lovely demonstration of the application of the Canadian Hospice Palliative Care Association’s Model! I can imagine that they will be very useful to Hospices and Long-Term Care Facilities around the world.” Dr. Frank Ferris, Medical Director, Palliative Care Standards/Outcome Measures, San Diego Hospice and Palliative Care and co-author of A Model to Guide Hospice Palliative Care

“Implementing the HAO Standards gave us the opportunity to institute consistent practices which in turn enhanced our organizational confidence and credibility.” Maryann Lepage, Executive Director, Sudbury Regional Palliative Care Association
Expansion of Standards and Accreditation

In February 2010, HAO began exploring the options for expanding the standards used by Ontario’s hospices. This project is in response to requests from our members to expand accreditation beyond the client service standards for visiting volunteer programs. To achieve expansion, standards for all areas of operation are needed. This includes governance, financial management, human resources, fundraising, and other client service related programs such as complementary therapies, day hospices, and psychosocial/spiritual programs.

To avoid duplicating the costly process of developing a set of standards of this scope, HAO has joined the Ensuring Excellence initiative as a founding member. Ensuring Excellence is a pan-Canadian initiative led by Imagine Canada in partnership with Volunteer Canada and the HR Council to develop a set of standards and codes of conduct specific to the non-profit sector.

Ensuring Excellence (EE) will provide standards applicable to most non-profit organizations including hospices. The EE standards will be the foundation to which we add existing HAO technical standards for visiting volunteer and residential hospices, and emerging standards for complementary therapy and other programs.

Through 2010 and early 2011 the accreditation working group will review the EE documents and provide advice to HAO on the implementation of the EE standards as they become available.

Complementary Therapy Standards

Marianne Tavares is leading the HAO Complementary Therapies Working Group in the development of standards for the use of complementary therapies (CT) in hospice care. Prior to coming to Canada in 2009, Marianne was a nurse for over 20 years in England before moving to Leeds to develop the complementary therapy service at St. Gemma’s Hospice in 1999. Marianne practiced massage, aromatherapy, Reiki and hypnotherapy, and managed a team of paid and volunteer therapists. Marianne developed the National Guidelines for the Use of Complementary Therapies in Supportive and Palliative Care. A survey of HAO members on the use of complementary therapies was done in January 2010 and the working group formed in March. The working group is comprised of eight individuals from member hospices across Ontario that provide complementary therapies in the hospice.
In member services, we focused on increasing member participation in planning and development through the formation of working groups for residential hospice, community hospice, complementary therapy, communications, and standards.

The association is developing new relationships with corporate partners to provide fundraising opportunities for our member hospices. The opportunities will emerge in the first half of 2010 and will continue to evolve. HAO is committed to leveraging relationships and the association's provincial presence to provide member hospices with opportunities to raise funds in their local community.

To support the centralization of residential hospice statistics, HAO developed a simplified online statistics reporting process for residential hospices.

HAO is currently testing an online donor management system for use by our member hospices on a subscription basis. Testing will be complete in late fall 2010.

HAO held an advocacy training seminar in January 2010 attended by 30 hospice people from around the province. The seminar focused on understanding the effective advocacy strategies, developing key messages and coaching on how to advocate in person.

The HAO insurance program through preferred insurance broker Canada Brokerlink, provides members with access to insurance products designed specifically for the hospice sector. One of the unique insurance coverages offered is a professional liability policy which insures the hospices for the work of complementary therapists who may not have their own insurance.

Interested in joining a working group? Please contact Rick Firth by email: rfirth@hospice.on.ca
Public Awareness

HAO partnered with TAXI Advertising and Design to develop a public awareness poster campaign. The innovative and thought provoking posters ran in Toronto bus shelters in January and in two Ontario wide editions of the National Post. The posters were targeted at the 20 to 30 year old population and purposely avoided the use of traditional hospice imagery. We are working on our second campaign for late 2010 to early 2011. The campaign will be an awareness poster about the role and importance of hospice.

HAO produced our first ever televised public services announcements. This project was done with significant support from Pat Mills at Alliance Hospice. The announcements are 30 second volunteer recruitment commercials and originally ran on the Rogers TV network throughout January 2010. The commercial was voiced by hospice volunteers in English and French and subtitled in Chinese, Spanish, Tagalog, and Punjabi. The commercials direct people interested in volunteering to the HAO website or our province-wide toll free number. HAO continues to seek air time to televise these public service announcements.

All of the public services announcements and posters may been viewed on HAO's website at www.hospice.on.ca/hospiceontario.php.

HAO received over 50 volunteer enquires in early 2010. Each volunteer was referred to the hospice servicing their local areas.

HAO is supporting the development of an online volunteer training system as a partner in a Trillium Foundation grant. Under the leadership of Doane House Hospice in Newmarket and working with George Brown College in Toronto the project will build a media rich e-learning training module using new communication technologies. It will introduce and orient the non-profit sector to the use of technologies like wikis, blogs, pod cast producer and a user friendly content management system. This technology will help bridge the gap between experts and technology, providing sector wide opportunities for non-profit’s capacity building through e-learning. HAO will maintain ownership of all intellectual property rights of the final product and its components on behalf of the hospice sector.
Financial Review

The Hospice Association of Ontario ended the year on March 31, 2010 with a current year surplus in the operating fund of $11,785 (2008 = -$30,982).

The audited financial statements are available upon request.

Revenue by Source (total revenue: $753,649)

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<tr>
<th>Source</th>
<th>Amount</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Gov’t Grants</td>
<td>$258,343</td>
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<tr>
<td>Conference</td>
<td>$251,343</td>
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<tr>
<td>Donations and Fundraising</td>
<td>$181,995</td>
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<td>Membership Fees and other income</td>
<td>$61,473</td>
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Expenditures by Service (total expenditures: $741,864)

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<tr>
<th>Service</th>
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<td>Palliative Education</td>
<td>$146,789</td>
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<tr>
<td>End-of-Life Info Service</td>
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<tr>
<td>HAO Member Services</td>
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The Hospice Association of Ontario gratefully acknowledges the financial support of the Ontario Ministry of Health and Long-Term Care and the Toronto Central Local Health Integration Network.
We don't know if there is life after death. But we do know there is life before death.

Help us be there to the very end.

Hospice Association of Ontario

Visit hospice.on.ca to volunteer.