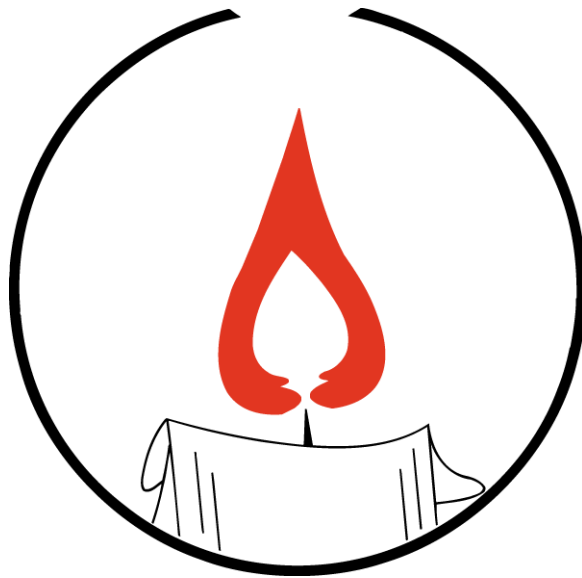


**ONTARIO PALLIATIVE CARE  
ASSOCIATION**



**ANNUAL REPORT**

**January 1, 2006 to December 31, 2006**

## **2006 Executive and Board of Directors**

### **Executive**

<b>PRESIDENT</b>	Patricia Van Den Elzen, Executive Director, PalCare Network for York Region
<b>VICE PRESIDENT</b>	Chris Sherwood, Palliative Pain & Symptom Management
<b>TREASURER</b>	Liliane Locke, Director, Care of the Elderly, Rehabilitation & Palliative Care Programs, SCO Health Services
<b>MEMBERS AT LARGE</b>	Barb Linkewich, VP Health Services, Meno Ya Win Health Centre Marsha Wolowich, Pain & Symptom Management Coordinator of Wellington Dufferin

### **Regional Representatives**

#### **Central South Region**

Judy Ball  
Chris Sherwood, Palliative Pain & Symptom Management

#### **South West Region**

Sharon Allen, Hotel Dieu Grace Hospital  
Marie Palmer, Pain & Symptom Consultant/Educator, Grey Bruce PC Hospice Association Inc.

#### **Central West Region**

Diane Reid, Halton Peel Palliative Care Initiatives  
Marsha Wolowich, Pain & Symptom Management Coordinator of Wellington Dufferin

#### **Toronto Region**

Deborah Lavender, Executive Director, Toronto Palliative Care Network  
Vicki LeJambe, Oncology & Palliative Care Clinical Consultant

#### **Central East Region**

Carol Ford, Regional Clinical Programs Coordinator, PalCare Network for York Region  
Theresa Morris, PC Nurse Consultant/Manager, Peterborough Regional Health Centre

#### **East Region**

Liliane Locke, Director, Care of the Elderly, Rehabilitation & Palliative Care Programs, SCO Health Services  
Sharon Preston, Project Coordinator/Educator, Palliative Care Integration Project

#### **North Region**

Barb Linkewich, Program Manager, Pain & Symptom Management Team  
Marg Poling, Palliative Care Advisor, Victorian Order of Nurses  
Vanessa Williams

### **Liaison Representatives**

**OMA Palliative Care Section...Lesia Wynnychuk, Consultant, Palliative Medicine, Sunnybrook Hospital**



## REPORT FROM THE PRESIDENT

### *“Continuing the Momentum”*

The theme of the 17<sup>th</sup> Annual Ontario Provincial Conference on Palliative and End-of-Life Care *“The Quest for Quality”* is a natural progression in the ‘new era’ of hospice palliative care across Ontario.

We have witnessed phenomenal changes in the health care system this past year. April 1, 2007 marked the official transition of knowledge, power and responsibility from the Ministry of Health to the 14 Local Health Integration Networks.

We received approval from the membership to realign our Board of Directors and our regional structure to line up with the LHIN’s. Ensuring close contact with the LHIN’s and the End-of-Life Care Networks is key to enabling us to influence policy decision-making on end-of-life care in Ontario.

OPCA continued to focus on our key strategic directions to improve our ability to meet our mandate to provide *“a strong voice for quality end-of-life care in Ontario”*.

During this past year, we have actively sought feedback from our members on the key issues, improved our communications with members and key stakeholders, and have strengthened our partnerships within the hospice palliative care community.

Our partnership with Humber College continues to produce an ever evolving and improved conference each year. Some of the innovations introduced at the 2006 Conference were:

- development of workshop streams to assist delegates in making their workshop selections;
- introduction of an Administrative Stream as a follow-up to the 2005 Network Symposium with topics of key interest to program administrators and policy makers;

- continuation of the Special Interest Groups networking sessions launched in 2004 which provide a focus for colleagues to discuss key issues and common interests;
- an inaugural physicians networking session which provided an opportunity for meeting and discussing new developments and challenges and was warmly received.

Feedback from our members has indicated a strong interest in holding our Annual Provincial Conference in a location other than Toronto. The Board of Directors responded to this feedback and laid the groundwork to move the 2007 Conference to London. The outcome of the evaluation of this change in location will determine the feasibility of holding the conference in various locations throughout the province in the future.

We are also pleased with the decision to hold our Annual General Meeting during the Awards Luncheon at this year’s Conference. This will allow all Conference delegates to witness our accomplishments and our on-going commitment to improving end-of-life care in Ontario.

We were honoured to welcome Vida Vaitonis, Director, Home Care and Community Support Branch, Ministry of Health and Long-Term Care as our guest speaker at our 2006 Annual General Meeting. Ms Vaitonis spoke passionately of the need for fair and equitable end-of-life care across our province and in all sizes and types of communities—from the large urban centres with multi-cultural populations to the small rural communities with limited access to resources.

The response to our first membership survey clearly indicated the importance and value of keeping connected with our organization’s membership. The majority of respondents viewed OPCA as a strong advocate and supported the association working jointly with organizations such as the Hospice Association of Ontario to improve patient access to palliative

and end-of-life care. We plan to continue to use the survey tool to establish an on-going dialogue with our members to ensure we stay focused and responsive to the changing needs of our membership.

OPCA-sponsored task forces have addressed key issues of concern to providers of end-of-life care. Chris Sherwood, OPCA Vice President has chaired two groups addressing Do Not Resuscitate Orders and Certification of Expected Death. Chris reports positive progress, with the Do Not Resuscitate Orders being close to implementation. We owe much to Chris and the dedicated team that have worked diligently to bring about changes in areas that cross many boundaries and have a major impact on the quality of end-of-life care. OPCA is committed to allocating resources to address issues of this nature in the future.

Liliane Locke, OPCA Treasurer, is OPCA's representative on the planning committee for the Canadian Hospice Palliative Care Association National Conference to be held in Toronto in 2007 and we are looking forward to an outstanding event.

We joined our voice to that of the Canadian Hospice Palliative Care Association and the Quality End-of-Life Care Coalition of Canada in helping to focus attention on the Federal funding cut to the Secretariat on Palliative and End-of-Life Care. We sent a letter to all Ontario Members of Parliament and Members of the Provincial Parliament informing them of our concerns. We closed our letter with Harvey Chocinov's quote "*Unfortunately, in end-of-life care, we do not have a vocal constituency: The dead are no longer here to speak, the dying often cannot speak, and the bereaved are often too overcome by their loss to speak.*" We then stated: "*The Ontario Palliative Care Association and our members speak for this silent constituency: we ask that you hear our voice and help us speak for them.*" We have had responses from a number of MP's and MPP's thanking us for the input and expressing their willingness to support our actions.

Chris Sherwood, OPCA Vice President, and Beth Ellis, Hospice Association of Ontario Board Member, made a joint presentation at the Ontario

Hospital Association Conference. Chris' topic was *'Interpreting our Model of Hospice Palliative Care'*. We thank Chris for representing OPCA and the work we do in a positive, professional manner.

We continue to recognize excellence in hospice palliative care with the Dorothy Ley Award of Excellence, awarded each year to an individual recognized by their peers for outstanding contributions to end-of-life care. This award was established in 1996 and we now have nine individuals on our honour roll. In addition to honouring the individual selected by our Awards Committee, we also present a framed certificate of recognition to each individual nominated.

We were pleased to be asked to help promote the Marilyn Lundy Hospice Palliative Care Award this year. This award, sponsored by the Temmy Latner Centre for Palliative Care, is presented each year to a nurse in Ontario who has demonstrated excellence in knowledge and skills in palliative care nursing.

As I prepare to hand over the President's gavel to Chris Sherwood, I have been reviewing my feelings about my experience with the Ontario Palliative Care Association over the past dozen years. Overwhelmingly, these feelings are ones of pleasure and gratitude to have had the opportunity to work with so many individuals with a passionate commitment to ensuring "quality end-of-life care for all Ontarians". We have worked hard, but we've also had the opportunity for personal growth, to develop strong personal ties, and to make a difference! I thank each and every person who has contributed to my own growth and development and I wish all of you much success and happiness in the future. I also would like to extend a special thank to Ellen Power our Administrative Manager and to Barry Ashpole, Communications Consultant; their commitment and dedication have made many of our achievements possible.

I look forward to continuing my involvement as your Past President and to working closely with Chris and the incoming Board members.

Sincerely,



## History of the Ontario Palliative Care Association

On November 12, 1980, the Palliative Care Work Group, Toronto chairman Dr. Larry Librach, chaired the first informal meeting of representatives from all parts of Ontario. The enthusiasm generated by this meeting led to the formation of the Ontario Palliative Care Association and our first official meeting was held May 11, 1981 at Toronto Grace Hospital with 27 in attendance. The first executive elected were Dr. Larry Librach, Sister Judith Souliere, Dr. John Scott, and Dr. Ann Thomas. The initial tasks taken on by the executive were:

- affiliation with the Ontario Hospital Association (accomplished November 1981)
- funding of palliative care (on-going)
- educational events (on-going)
- assisting in the development of Guidelines and Standard for Palliative Care in Ontario (on-going)
- development of a manual of palliative care programs and members (on-going)
- development of a newsletter (established in 1982 and on-going)

During 1984/85, the Regional Groups were developed to expand our provincial representation. We currently have 7 Regions across Ontario and two representatives from each Region (three representatives from the North Region) sit on our Board of Directors.

In 1989, we received our Letters Patent and were incorporated as a registered charitable organization.

Our membership has grown from 57 at our first Annual General Meeting in 1982, to over 300 currently and includes the full spectrum of individuals involved with and committed to palliative care in Ontario.

## Definition of Hospice Palliative Care

Hospice palliative care aims to relieve suffering and improve the quality of living and dying.

Hospice palliative care strives to help patients and families:

- address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears
- prepare for and manage self-determined life closure and the dying process
- cope with loss and grief during the illness and bereavement.

Hospice palliative care aims to:

- treat all active issues
- prevent new issues from occurring
- promote opportunities for meaningful and valuable experiences, personal and spiritual growth, and self-actualization.

Hospice palliative care is appropriate for any patient and/or family living with, or at risk of developing, a life-threatening illness due to any diagnosis, with any prognosis, regardless of age, and at any time they have unmet expectations and/or needs, and are prepared to accept care.

*Source: A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice, Canadian Hospice Palliative Care Association, March 2002, page 17*

## Guiding Principles

**Patient/Family Focused** – As patients are typically part of a family, when care is provided the patient and family are treated as a unit. All aspects of care are provided in a manner that is sensitive to the patient's and family's personal, cultural, and religious values, beliefs and practices, their developmental state and preparedness to deal with the dying process.

**High Quality** – All hospice palliative care activities are guided by:

- the ethical principles of autonomy, beneficence, nonmaleficence, justice, truth-telling and confidentiality
- standards of practice that are based on nationally-accepted principles and norms of practice, and standards of professional conduct for each discipline
- policies and procedures that are based on the best available evidence or opinion-based preferred practice guidelines
- data collection documentation guidelines that are based on validated measurement tools.

**Safe and Effective** – All hospice palliative care activities are conducted in a manner that:

- is collaborative
- ensures confidentiality and privacy
- is without coercion, discrimination, harassment or prejudice
- ensures safety and security for all participants
- ensures continuity and accountability
- aims to minimize unnecessary duplication and repetition
- complies with laws, regulations and policies in effect within the jurisdiction, host and hospice palliative care organizations.

**Accessible** – All patients and families have equal access to hospice palliative care services:

- wherever they live
- at home, or within a reasonable distance from their home
- in a timely manner.

**Adequately Resourced** – The financial, human, information, physical and community resources are sufficient to sustain the organization's activities, and its strategic and business plans. Sufficient resources are allocated to each of the organization's activities.

**Collaborative** – Each community's needs for hospice palliative care are assessed and addressed through the collaborative efforts of available organizations and services in partnership.

**Knowledge-Based** – Ongoing education of all patients, families, caregivers, staff and stakeholders is integral to the provision and advancement of quality hospice palliative care.

**Advocacy-Based** – Regular interaction with legislators, regulators, policy makers, healthcare funders, other hospice palliative care providers, professional societies and association, and the public is essential to increase awareness about, and develop hospice palliative care activities and the resources that support them. All advocacy is based on the Canadian Hospice Palliative Care Association's model to guide hospice palliative care.

**Research-Based** – The development, dissemination, and integration of new knowledge are critical to the advancement of quality hospice palliative care. Where possible, all activities are based on the best available evidence. All research protocols comply with legislation and regulations governing research and the involvement of human subjects in effect within the jurisdiction.

*Source: A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice, Canadian Hospice Palliative Care Association, March 2002, page 19, 20*

## **Role of the Ontario Palliative Care Association**

**Advocacy** - We present a strong, proactive voice on issues specific to the provision and delivery of quality end-of-life care – professional education, standards of practice, government policy development and funding, and public awareness.

**Education** - We promote professional education of hospice palliative care providers through our support of an annual provincial hospice palliative care conference and offering educational bursaries.

**Recognition** – We recognize excellence in hospice palliative care with the annual Dorothy Ley Award of Excellence in Hospice Palliative Care, and support of hospice palliative care with the Outstanding Philanthropist Award.

**Communication** - Our newsletter is published three times per year and is distributed to our full membership plus organizations and individuals with an interest in hospice palliative care issues.

**Partnerships** – We maintain a close partnership with the Canadian Hospice Palliative Care Association and develop partnerships with other organizations to address specific issues as they arise.

## **Mandate**

Our mandate is to further the provision of high quality, timely, and effective hospice palliative care to all Ontario residents through our activities in advocacy, education, awareness, communication, and partnerships.

## **Goals**

To support our members by:

- Providing education development opportunities to facilitate communication
- Being a central resource for information
- Being a link between local, regional, provincial and national palliative care

To encourage the development and expansion of palliative care in Ontario by:

- Advocating the importance of palliative care through influencing government policy and funding
- Promoting standards in palliative care
- Participating in the evolution and implementation of standards
- Enhancing the work of OPCA
- Maintaining financial stability

## **The Provincial 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.

### **OPCA Position Paper: Regional Home Palliative Care for Ontario**

The Ontario Palliative Care Association (OPCA) strongly supports government initiatives to develop regional home palliative care programs throughout Ontario. We would like to bring forward a number of principles that we feel should govern the development of these programs:

1. The planning and implementation of these programs should follow the Model to Guide Hospice Palliative Care Based on Principles and Norms of Practice as identified by the Canadian Hospice Palliative Care Association. Since these standards are being used by the Canadian Council of Health Services Accreditation to accredit institutions and agencies including home care programs and by the Hospice Association of Ontario to set standards, the norms of practice will introduce a consistency in programming and make evaluation of programs consistent.
2. Wherever possible, interdisciplinary teams of health care professionals and volunteers should form the core of services. The nature of home palliative care requires a variety of skills and maximum support to patients and their families to stay at home as long as possible. The Community Care Access Centres should be provided with funding to support advance practice nurses, social workers with specialized palliative care skills and primary palliative care nurses. The funding for palliative medicine physicians to work with these teams should be through alternate payments programs and special consideration be given to models for rural and northern practices. Volunteer hospices should receive sufficient funding to support the training of volunteers to work as part of the regional teams.
3. Regional services should not consist of a loose coalition of institutions and agencies. These institutions and agencies should be bound by legal agreements to participate actively in the regional programs and be bound by service deliverables. In the best of all models, regional teams of secondary experts should stand on their own with clear lines of responsibility back to a management group that includes members of the public. In the best of all models, personnel on the teams would be hired by or seconded to the teams and be responsible to the teams for their clinical services.
4. There should be a single focus of access for services in each region although referrals may come from many sources.
5. A common chart in the home is required in order to standardize record keeping.
6. Common data must be collected in each region so that outcomes can be monitored effectively.
7. Specialized hospice palliative care teams must be present in each institution/hospital.
8. Specialized hospice palliative care teams must be available to support patients/residents in long term care facilities and community supportive housing.

## **Annual Ontario Provincial Conference**

The Ontario Palliative Care Association has a partnership agreement with the Humber Institute of Technology & Advanced Learning to produce the Annual Ontario Provincial Conference on Palliative & End-of-Life Care. This agreement details the responsibility of each of the partners and the financial specifics.

The Conference goals and objectives are:

- To provide the highest quality in education for practitioners involved in palliative and end-of-life care
- To provide a forum for the exchange of scientific information
- To provide opportunities for interdisciplinary education and networking
- To provide recognition of OPCA and Humber as leaders in the field of Palliative and End-of-Life Care Education
- To provide increased awareness of palliative and end-of-life care services among other care providers, government and the general public
- OPCA and Humber to engage other related Associations and individual experts to participate in a planning committee

## **Educational Bursaries**

Educational Bursaries are awarded, usually to the Annual Ontario Provincial Conference, as determined by the Board of Directors and as our financial position allows. Applications are accepted from individuals working in a palliative care program or enrolled as a student in a palliative care field. Membership in OPCA is not a requirement. The applications are reviewed by the Awards Committee and winners selected according to a predetermined criteria.

## **Palliative Care Outstanding Philanthropist Award**

This award is designed to recognize and show our appreciation for those individuals, families, corporations, foundations, and community and service organizations who best exemplify vision, financial support and dedication towards fostering the true spirit of palliative care in Ontario.

While the financial support offered by these philanthropists is important to our cause, it is the encouragement and validation of our efforts that means so much to us as individuals. They are truly the “unsung heroes” of palliative care in Ontario.

### ***Honour Roll Recipients of the Palliative Care Outstanding Philanthropist Award***

Knoll Pharma Inc. (1997)  
Glaxo Wellcome (1998)  
Saint Elizabeth Health Care Foundation (1999)  
Parkwood Hospital (2000)  
Peterborough Festival of Trees (2000)  
Barrie Rose (2001)  
Purdue Pharma Inc. (2003)  
Care for Kids (Toronto) (2004)  
Albert Latner (2004)  
Stuart and Irene Lunn (2004)

*Note: No award presented for 2002 and 2005.*

## **Dorothy Ley Award of Excellence in Hospice Palliative Care**

The late Dorothy Ley was one of Canada's first champions for quality care at the end of life. She brought a unique individuality to the field of hospice and palliative care, and maintained a highly visible and vocal presence during her distinguished career until her death in 1994. Dr. Ley was a pioneer and she broke new ground in fields of medicine and in health care in general.

The Dorothy Ley Award of Excellence, established in 1996, is a perennial reminder of her truly great legacy. Presented by OPCA, the Dorothy Ley Award of Excellence is awarded annually in recognition of an individual or team effort to advance and improve the quality of palliative and end-of-life care.

Nominations are made and endorsed by three individuals, one of who must be a current member of OPCA. The nominee is not required to be a member of OPCA. The Board appoints a Selection Committee to review the nominations and select the recipient based on predetermined criteria.

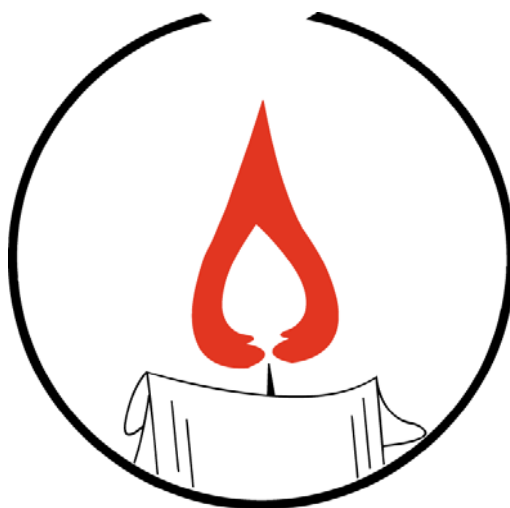
### *Honour Roll Recipients of the Dorothy Ley Award of Excellence In Hospice Palliative Care*

Mary Vachon, RN, PhD (1996)  
Reena McDermott, RN (1997)  
Shari Douglas, RN (1998)  
Frank Ferris, MD (1999)  
Linda Bowring, MD (2000)  
Ivan Stewart, MD (2001)  
John Flannery, RN (2002)  
Deborah Dudgeon, MD (2003)  
Jean Echlin, RN, MScN (2004)  
Maryse Bouvette, RN, BScN, MEd, CON(C),  
CHPCN(C) (2005)



*Maryse Bouvette accepting the 2005 award from Chris Sherwood, OPCA Vice President*

# ONTARIO PALLIATIVE CARE ASSOCIATION



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